RESEARCH PAPER

Trends in Government-Initiated Public Engagement in Canadian Health Policy From 2000 to 2021

Tendances dans les activité initiées par le gouvernement pour la participation du public aux politiques canadiennes de la santé de 2000 à 2021

ROMA DHAMANASKAR, MBE
PhD Candidate
Health Policy Program
Faculty of Health Sciences
Department of Health Research Methods, Evidence and Impact
McMaster University
Hamilton, ON

KATHERINE BOOTHE, PhD
Associate Professor
Department of Political Science
Centre for Health Economics and Policy Analysis
McMaster University
Hamilton, ON

JOANNA MASSIE, MA
PhD Candidate
Department of Political Science
McMaster University
Hamilton, ON

JEONGHWA YOU, PhD
Research Fellow
Department of Health Research Methods, Evidence and Impact
McMaster University
Hamilton, ON

DANIELLE JUST, PhD
Lead,
Performance, Funding and Capacity
Ontario Health
Toronto, ON

GRACE KUANG, BHSc
MD Student
Temerty Faculty of Medicine
University of Toronto
Toronto, ON

JULIA ABELSON, PhD
Professor
Department of Health Research Methods, Evidence and Impact
Centre for Health Economics and Policy Analysis
McMaster University
Hamilton, ON

Abstract

Introduction: Canada has a rich history of public engagement in health policy; however, shifts in engagement practices over time have not been critically examined.
Methodology: We searched for cases of government-initiated public engagement in Canadian health policy from 2000 to 2021 at the federal, provincial (Ontario, British Columbia, Nova Scotia) and pan-Canadian levels. Government databases, portals and platforms for engagement were searched, followed by academic and grey literature using relevant search terms. A coding scheme was iteratively developed to categorize cases by target population, recruitment method and type of engagement.
Results: We identified 132 cases of government-initiated public engagement. We found a predominance of feedback and consultation engagement types and self-selection recruitment, especially at the federal level from 2016 onward. Engagements that targeted multiple populations (patients, public and other stakeholders) were favoured overall and over time. Just over 10% of cases in our survey mentioned efforts to engage with equity-deserving groups.
Conclusion: Overall, our results identify a heavy reliance over time on more passive, indirect engagement approaches, which limit opportunities for collaborative problem solving and fail to include equity-deserving populations. Those overseeing the design and implementation of government-initiated public engagement will draw valuable lessons from this review to inform the design of engagement initatives.

Résumé

Introduction : Le Canada a une longue histoire de participation du public dans les politiques de la santé; cependant, les changements dans les pratiques de mobilisation au fil du temps n'ont pas été examinés de façon critique.
Méthodologie : Nous avons recherché des cas de participation du public aux politiques canadiennes de la santé initiés par le gouvernement entre 2000 et 2021 aux niveaux fédéral, provincial (Ontario, Colombie-Britannique, Nouvelle-Écosse) et pancanadien. Des recherches ont été effectuées dans les bases de données, les portails et les plateformes gouvernementaux, puis dans la littérature universitaire et grise en utilisant les termes de recherche pertinents. Un système de codage a été mis au point de façon itérative pour catégoriser les cas par population cible, méthode de recrutement et type de mobilisation.
Résultats : Nous avons identifié 132 cas de mobilisation du public à l'initiative du gouvernement. Nous avons constaté une prédominance des types de mobilisation visant la consultation et la rétroaction ainsi que des méthodes d'auto-recrutement, surtout au niveau fédéral à partir de 2016. La mobilisation qui cible plusieurs populations (patients, public et autres intervenants) a été favorisée dans l'ensemble et au fil du temps. Un peu plus de 10 % des cas relevés dans le cadre de notre enquête indiquent des efforts visant à impliquer des groupes qui méritent une attention sur le plan de l'équité.

Conclusion : Dans l'ensemble, nos résultats indiquent une forte dépendance au fil du temps vers des approches de mobilisation plus passives et indirectes, qui limitent les possibilités de résolution collaborative de problèmes et ne tiennent pas compte des populations qui méritent une attention sur le plan de l'équité. Les responsables de la conception et de la mise en œuvre des initiatives de mobilisation du public lancées par le gouvernement tireront de précieuses leçons de cet examen pour éclairer la conception de telles initiatives.

Introduction

If we are going to develop health policies that work for the public, we need to consider what is important to the public when designing these policies. This is the work of the field of public engagement, which seeks to involve individual or groups of citizens, taxpayers, community members and advocates who may be affected by or interested in a wide array of societal issues (Carman et al. 2013; Conklin et al. 2015; Fancott et al. 2018). In the health policy context, engagement roles and activities focus on incorporating public input into various stages and domains of policy decision making (Abelson et al. 2016; Conklin et al. 2015; Gauvin et al. 2010). In the related field of patient engagement, emphasis is placed on the involvement of health service users and caregivers in the design of more patient-centred health systems informed by patients' lived experiences and needs. When well-designed and executed, engagement structures and processes can not only inform and shape policy decisions but also foster an active and vibrant citizenry, build trust among citizens and in their institutions and enhance the legitimacy of policy decisions (Bherer et al. 2016; Davidson 2020).

Struggles over identity and power lie at the heart of the public and patient engagement enterprise. As a result, defining the "who" and the "how" of engagement is not only conceptually challenging but also inherently political (Arnstein 1969; Quick and Feldman 2011). Determining which combination of publics, patients, caregivers and communities should have voice or choice in shaping health policy has been debated for decades. Terms that are often used interchangeably with engagement, such as *consult*, *involve*, *collaborate*, *partner* and *co-design*, send important signals about the level of power and influence wielded over the decision-making process. In this paper, we seek to bring definitional clarity to these terms and trace major trends in Canadian government–initiated public engagement while still appreciating the fundamentally political dimensions of the field.

Canada's history of public engagement: Key policy and institutional shifts

Canada has a rich history of public engagement in the health sector, dating back to the 1964 and 2002 royal commissions on health services led by Justice Emmett Hall and the honourable Roy Romanow (Government of Canada 1964; Government of Canada 2002). As early as the 1970s, various forms of direct public engagement have been recommended or implemented as a means of improving the health system's responsiveness to local health needs.

Early on, this largely took the form of citizen representation on regional health services delivery or administrative boards but was later carried into the more widespread health system decentralization movement of the 1990s, which called for increased public participation and citizen consultation to inform local health decisions (Abelson and Eyles 2002).

Since these early innovations, approaches to the "who" and "how" of public engagement in Canadian health policy can be broadly characterized by two major trends: (1) an emphasis from 2000 to 2010 on citizens and taxpayers as "values consultants" to policy processes; and (2) an emerging role from 2010 onward for patients, families and caregivers as "lived experience" consultants and collaborators in health system design and governance. These eras, while not sharply defined, can be broadly traced to key policy developments and organizational advancements.

Notable innovations in the 2000–2010 era include the development of typologies and frameworks for public engagement (Government of Canada 2000), a series of high-profile provincial and federal government–initiated public engagement processes (Government of Canada 2002; Government of Saskatchewan 2009; Standing Senate Committee on Social Affairs, Science and Technology 2006; White and Nanan 2009) and growing experimentation with deliberative public engagement methods, including the establishment of legislatively mandated, deliberative advisory bodies in Quebec and Ontario (*Act Respecting the Health and Welfare Commissioner* 2005; *Transparent Drug System for Patients Act* 2006). At the time of their introduction, these initiatives represented significant departures from more traditional public consultation approaches in their emphasis on informed, values-based discussions designed to find common ground around tangible policy solutions (Abelson et al. 2007; Blacksher et al. 2012; Bombard et al. 2011; Maxwell et al. 2003).

A shifting emphasis toward a more patient-focused engagement agenda can be traced back to 2010, catalyzed by quality-of-care concerns and the landmark Institute of Medicine report in the US, *Crossing the Quality Chasm* (Institute of Medicine [US] Committee on Quality of Health Care in America 2001). In Canada, this led to the establishment of new institutional players, such as the Canadian Patient Safety Institute and the Canadian Foundation for Healthcare Improvement (now amalgamated into a single organization, Healthcare Excellence Canada), a "patient-focused" legislative agenda (*Excellent Care for All Act* 2010; Ministère de la Santé et des Services sociaux 2018; *Patients First Act* 2016) and the introduction of new structures called Patient and Family Advisory Councils (PFACs) designed to embed patient and family caregiver voices and experiences within healthcare organizations (Government of Canada 2022; Government of Ontario 2020). These institutional changes shifted the engagement discourse from citizens and taxpayers to patients and caregivers (Gauvin et al. 2009) and formalized a new set of health system players with interests and agendas (Abelson et al. 2016; Carman et al. 2013; Patient Voices Network 2018).

Institutional shifts in the Canadian health policy landscape have continued. Provincial governments are continuously experimenting with different organizational structures for the planning and delivery of care that define, and identify roles for, different constituencies of the public (Government of Ontario 2020; Health Quality Ontario 2019). There is more mixing of *public* and *patient* in organizational governance structures and patient advisor and partner roles are expanding, perhaps suggesting increased legitimacy of a wider range of experience and expertise in the work of health systems (CADTH 2022, 2023; Health Quality Ontario 2019).

Provincial and national organizations of citizens and patients have also emerged, with explicit missions to improve health systems and contribute to policy (Imagine Citizens Network 2023; Patient Advisors Network 2023; Patients for Patient Safety Canada n.d.). This highlights the increased mobilization of citizens and patients as organized interests in the health system and their more advocacy-focused activity around health system improvement goals (as compared to prior roles as lived experience or values consultants). Recent efforts to more clearly identify the personal, organizational and health system level impacts of public engagement reinforce this shift (Abelson et al. 2023; Boivin et al. 2018).

The emergence of co-design, and the related practices of co-creation and co-production, have also entered the engagement lexicon (Greenhalgh et al. 2016; Loeffler and Bovaird 2016; Moll et al.2020; Mulvale et al. 2019). Co-design, whether applied as a philosophy or a method, broadly refers to the application of user-centred approaches to solve service or system-level challenges, with an emphasis on partnership and reducing power differentials (Moll et al. 2020). The rapid uptake of co-design (if not the practice, the language) reflects underlying tensions about power sharing and influence over decision making. These tensions have led to normative interpretations and hierarchies of *good engagement* in which passive consultation is viewed as less desirable than collaborative or patient leader models. The level of influence the public has in decision making, most prominently depicted in Arnstein's famous ladder of citizen participation (Arnstein 1969), has been a persisting focus of attention. Of recent concern is not only the *degree* of influence a person or group might have, but a critical examination of *who* has the privilege to have any influence at all. Long-standing issues of equity in public engagement (and the health system more generally) have come to a head since COVID-19, with calls for greater and more meaningful engagement with equity-seeking groups (Abebe and George 2022; McGrail et al. 2022; Sayani et al. 2021).

Common criticisms of public engagement

While the shifts outlined above can be distinguished by tracing major policy and institutional developments in public engagement over the last two decades, how well they mirror the practices of actual public engagement initiatives has not been investigated. As approaches to public engagement in Canadian health policy continue to evolve, determining shifts in day-to-day engagement practices seems important. Of particular interest is whether government-initiated public engagement has adapted favourably to respond to early criticisms of the field.

In their review of public engagement in health policy decision making, Abelson and Eyles (2002) identified key criticisms of the field: the dominance of powerful interest groups, engagement with only the most educated publics and a lack of legitimacy and accountability in engagement processes. They also offered a number of suggestions to restore the initial value and potential of public engagement as an important democratic input to health policy reform. These include providing accessible and easily identifiable opportunities for engagement, improving transparency and accountability through more ongoing and sustained engagement and using engagement approaches that complement the issues and publics being engaged. It is unclear whether the concerns and proposed solutions raised in their report have been meaningfully addressed, especially as public engagement in Canadian health policy has become more institutionalized.

We aimed to address this knowledge gap by examining broad trends in public engagement in Canadian health policy through the collection of cases of government-initiated engagement from 2000 to 2021 ("case survey"). Our aim was to track shifts that might signal changes in engagement approaches and responses to long-standing critiques, by collecting a mix of broad (health system–wide) and specific (topics and decisions) engagement activities initiated at the federal, provincial and pan-Canadian levels of government. To our knowledge, no such repository of public engagement activities for the health sector exists.

Framework and Methods

We searched for cases of government-initiated public engagement in Canadian health policy since 2000. This time frame was chosen to assess the degree to which democratic innovations over the last 20 years have addressed the criticisms of public engagement in Canadian health policy raised around the time of the Commission on the Future of Health Care in Canada (Government of Canada 2002). These criticisms highlighted issues pertaining to the representativeness, legitimacy and responsiveness of public engagement processes. Our search was limited to identifying cases at the federal, provincial, regional and pan-Canadian levels, keeping our focus on engagement in health policy decisions. Purely local engagement activities, such as those initiated at the municipal level or by healthcare facilities, were excluded. Engagement activities initiated by researchers were also excluded. The case survey was intended to be a comprehensive but not all-encompassing collection of engagement activities. Our goal was to describe trends in public engagement since 2000, rather than to capture every instance of engagement.

Search strategy

Our search was limited to the following jurisdictions: federal, provincial (British Columbia [BC], Ontario [ON], and Nova Scotia [NS]) and pan-Canadian. The selection of BC, ON and NS as provincial jurisdictions was motivated by our goal of capturing geographical diversity and team member knowledge of the history and supporting provincial structures for engagement in these provinces. Federal and provincial cases were those that were initiated by the federal or provincial government. Pan-Canadian cases were initiated by one or more pan-Canadian health agencies funded by, but at an arm's length to, federal and provincial governments. For example, the Canadian Agency for Drugs and Technologies in Health[1] (CADTH) is an independent organization that was created by and receives funding from the Canadian federal, provincial and territorial governments (excluding Quebec) to conduct health technology assessments.

Team members were assigned to collect cases from the different jurisdictions (federal, provincial [ON, BC, NS], pan-Canadian) and time periods (2000–2010, 2011–2021) using a similar approach. Government databases and platforms for engagement were searched first; these were available for at least some time period for all jurisdictions, except pan-Canadian. This was followed by a search of the academic and grey literature, most commonly using Google Scholar and Google web search respectively. Team members searched for cases not captured in, or years not captured by, the databases. A combination of search terms was used, including *health policy, health reform, policy development, government, public engagement, public involvement, patient engagement, patient involvement, feedback, deliberation, consultation, co-design, [jurisdiction]*, and *[year]*.

We continued to collect cases until either new cases could not be found or the team determined there was enough variation captured. Sufficient variation was determined by a combination of the number of cases, distribution of cases across time periods, variety in the engagement approaches and target populations and ability to find additional cases. For example, we chose to stop collecting federal-level cases when we had collected a large number of cases across time periods, additional cases were concentrated in the more recent time period (2011–2021) and we were not finding any more variation in engagement approaches and target populations in newer cases.

Framework for analysis

We developed an organizing framework to describe and categorize the range of public engagement initiatives in the health policy sector, which was then used to code and analyze all identified cases of public engagement. The team identified an initial categorizing scheme to describe engagement activities according to who was engaged and how they were engaged. Two aggregator sources of cases – Participedia (https://participedia.net/) and the *CIHR's Citizen Engagement in Health Casebook* (CIHR 2012) – were used to identify *typical* cases and to trial and refine the framework. The final framework is presented in Table 1 and key elements are elaborated upon below.

Who was engaged?

TARGET POPULATION

Our case survey captured engagement activities targeting the general public and/or patient populations. Here, "patient" refers to individuals and caregivers who have experiences of living with (or caring for someone with) a particular illness and managing their care in the Canadian health system. Engagement activities that *only* involved experts, policy makers, government officials or other stakeholders were not collected. Cases were classified as

TABLE 1. Coding framework for public engagement cases

General information	
Date	Year(s)
Jurisdiction	Federal, provincial (BC, ON, NS), pan-Canadian
Who was engaged?	
Target population	Patient, public, multiple
Recruitment method	Self-selection, targeted invitation, appointment, multiple
Priority given to equity-deserving populations	Yes/no
How were they engaged?	
Ongoing or one-time?	Ongoing, one-time
Type of engagement	Feedback, consultation, deliberation, co-design, multiple

BC = British Columbia, NS = Nova Scotia, ON = Ontario.

"multiple" if they engaged with a combination of target populations, namely, public, patient, stakeholder or expert groups.

RECRUITMENT METHOD

Recruitment method describes how prospective participants were invited to take part in the activity. "Self-selection" engagements are those for which individuals had to learn about or locate the engagement activity and choose to participate on their own. "Targeted invitation" involves the identification and recruitment of specific individuals or groups to participate, who then choose whether or not to engage. "Appointment" applies to situations in which an engagement opportunity is available (e.g., advisory council membership) and individuals are recruited through open advertisements and/or invitations to apply for the position, then are selected to engage. This differs from a targeted invitation to participate in that it sometimes involves an element of self-selection (e.g., a newspaper advertisement inviting individuals to apply) *and* because it implies an assessment process after individuals apply to ensure some criteria for participation are met. Finally, "multiple" refers to any combination of the other recruitment methods.

PRIORITIZING EQUITY-DESERVING POPULATIONS

Cases that explicitly mentioned prioritizing or engaging with equity-deserving groups were flagged as such. Whether the engagement or related outreach activity achieved this goal was not assessed.

How were they engaged?

ONGOING OR ONE-TIME

Cases were defined as "one-time" if they were only occurring at one instance or in relation to a specific policy initiative, even if this spanned multiple years. "Ongoing" activities were those that were embedded and recurring within organizations (e.g., advisory committees).

TYPE OF ENGAGEMENT

Cases were described according to the engagement approaches employed and their distinguishing features (i.e., feedback, consultation, deliberation, co-design, or multiple methods of engagement). Activities for which participants provided their opinions on policy proposals and health services, such as via surveys and comment periods, were classified as "feedback." Consultation-style engagement included open public forums where the public could provide their opinion on policy problems, solutions, and principles; these consultations were usually broad and open-ended compared to more narrowly framed feedback opportunities. Deliberative engagement activities were those where citizens engaged on a policy issue through in-depth discussion and value-based reasoning that informed judgements about how to proceed on a particular issue. This could include, for example, roundtable discussions. Finally, co-design activities involved partnerships between key stakeholders and service users with the aim of collaboratively designing solutions. Where possible, engagement activities were described according to the publicly available documentation of the case, unless self-description varied significantly from the definitions outlined.

Data analysis

Cases were collected and collated into a master Excel file. To cross-check the initial coding, two categories (type and target population) were coded independently by a second team member. The cross-check was completed for approximately 20% of the initially coded cases for each jurisdiction. Each team member cross-checked a jurisdiction and time period they were not initially assigned. Of the 46 cases that were cross-checked, there were 10 discrepancies for type of engagement (78% agreement) and 12 discrepancies for target population (73% agreement). Coding discrepancies were resolved through discussion and reconciliation among team members. As a last step, one team member categorized cases by topic areas (e.g., health sector or issue) to allow for further analysis by topic. All analyses were conducted in Excel (version 16.53).

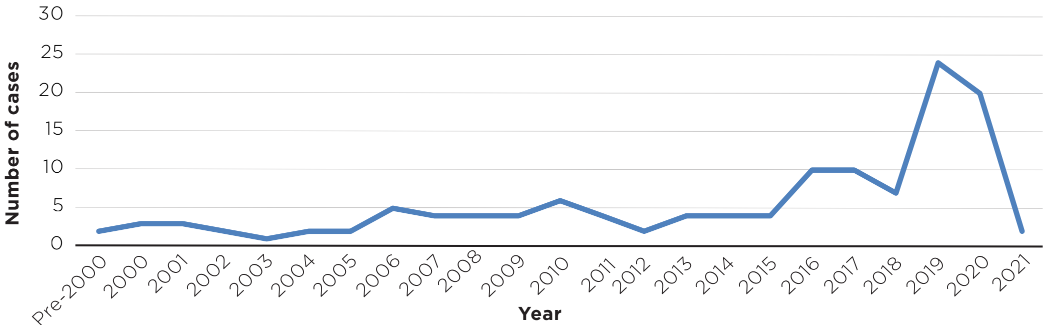
Results

Of the 136 unique cases that were collected for the case survey, four cases were removed that did not meet our inclusion criteria after further review, leaving us with 132 for analysis.

Overall, we collected 45 cases at the federal level (34%), 74 cases at the provincial level (58%; 41 cases from ON [33%], 17 from BC [13%] and 16 from NS [12%]) and 11 cases at the pan-Canadian level (8%). Of the 132 cases, information regarding the start date and end date could not be found for two cases. Notably, two cases from our sample begin in 1996 and 1999, respectively, but extend past the year 2000, hence their inclusion in the final analysis.

The number of engagement activities over time for the 130 cases for which we had year data is visualized in Figure 1. The number of cases per year is relatively stable over time, with a slight increase in 2016 and 2017 and then a sharp spike in 2019 and 2020, explained by an increase in the number of federal cases collected during this period.

FIGURE 1. Number of cases over time



Two cases did not have time data.

Of the 132 cases, 96 (73%) were one-time activities and 36 (27%) were ongoing. All cases at the federal level were one-time activities only. One-time cases were favoured in all jurisdictions except at the pan-Canadian level. Only a small number of cases (18 [14%]) mentioned prioritizing or engaging with equity-deserving populations.

While not the focus of analysis in this paper, the sectors and topics covered by the largest proportion of cases, accounting for close to 70% of cases (91 of 132), were health technology, tobacco and vaping, health reform, mental health, aging and long-term care, public health and infectious diseases and COVID-19.[2]

Below, we compare public engagement in health policy across jurisdictions (federal, provincial and pan-Canadian) and across two time periods (2000–2010 and 2011–2021) as well as for the following engagement elements: target population, recruitment method and type of engagement.

Target population

Results for target population are reported by jurisdiction (Table 2) and by time period (Figure 2). Target audience was categorized as "multiple" in half the cases (65 of 130). A third of cases (33%) were categorized as targeting the public and 22 of 130 (17%) were listed as targeting patients only. It is important to note that these categories were infrequently defined or elaborated on, so it was not possible to determine who actually participated in these engagement activities or who the organizers were seeking to recruit. Some calls for *public* participation may in fact have recruited or otherwise engaged individuals who might be more accurately labelled stakeholders, patients or others with relevant involvement in the health system.

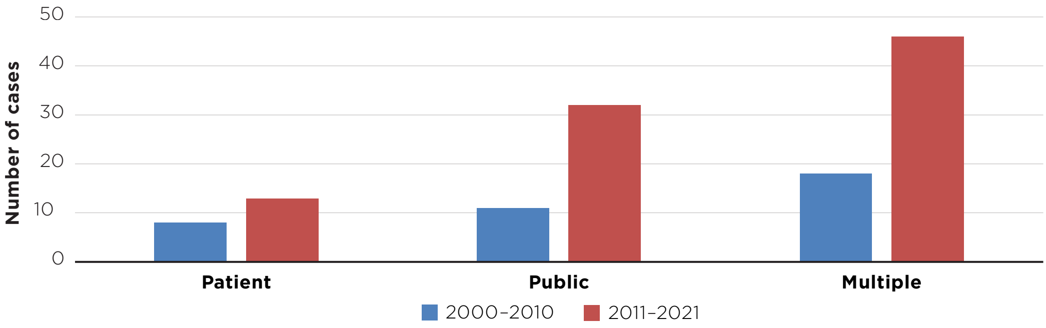
Overall, federal activities heavily favoured engagement with multiple populations, with more than 67% of activities being classified this way. Public-only activities were rare at the federal level and relatively less common at the provincial level. Conversely, pan-Canadian activities had a relatively equal distribution across categories. Looking between time periods, we can see an overall increase in engagement with all population types and a significant increase (18 to 46) in the number of cases with multiple target audiences.

TABLE 2. Number of cases for each target population, by jurisdiction

	Target population			
	Target population	**Provincial**	**Pan-Canadian**	**Total**
Multiple	30	31	4	**65**
Patient	13	27	3	**43**
Public	2	16	4	**22**
Total	**45**	**74**	**11**	**130**

Two cases did not have information about target population.

FIGURE 2. Number of cases for each target population, by time period



Recruitment method

Recruitment method results are reported by jurisdiction (Table 3) and by time period (Figure 3). Self-selection was the most commonly categorized recruitment method, representing 55% of cases overall and 78% of federal cases. Self-selection was also favoured at the provincial level, representing almost half of all cases (46%). Appointment was dominant among pan-Canadian cases (54%) but was notably absent at the federal level. Over time, the use of self-selection clearly began to overshadow the use of all other recruitment methods, as evidenced by its dominant use at the federal level in recent times. Although few in number overall, targeted approaches that provide the opportunity to prioritize specific populations have seen a notable decline in recent years, with only three cases after 2010.

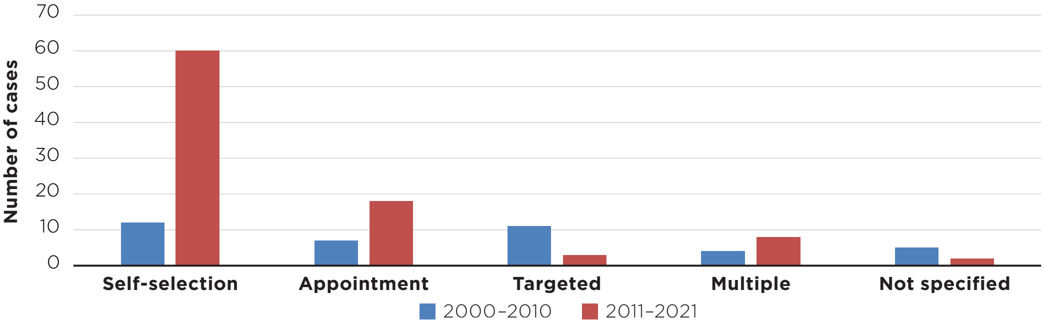
Type of engagement

Results for type of engagement are reported by jurisdiction (Table 4) and by time period (Figure 4). Feedback and consultation were the most popular forms of engagement used, together representing 86 out of 130 (66%) of cases. Deliberation was used to a lesser degree in the cases reviewed (in 22% of cases) and co-design was represented in only 2 cases (0.01%) both at the provincial level.

TABLE 3. Number of cases for each recruitment method, by jurisdiction

	Recruitment method (absolute)			
	Federal	**Provincial**	**Pan-Canadian**	**Total**
Self-selection	35	35	3	**73**
Appointment	0	19	6	**25**
Targeted	5	8	2	**15**
Multiple	4	8	0	**12**
Not specified	1	6	0	**7**
Total	**45**	**76**	**11**	**132**

FIGURE 3. Number of cases for each recruitment method, by time period



Feedback was the preferred engagement type used at the federal level, representing just over half (53%) of the federal cases. Together, feedback and consultation made up nearly 60% of provincial engagement efforts. Deliberation was favoured at the pan-Canadian level with 5 out of 11 activities (45%) using this type of engagement. Across eras we can see a significant jump in the number of cases using feedback post-2010. This is largely explained by the increase in the number of federal cases as a proportion of the total. Consultation-based activities also see a modest increase over time from 13 activities prior to 2010 to 24 activities post-2011. Deliberative activities are relatively constant across both periods.

Discussion

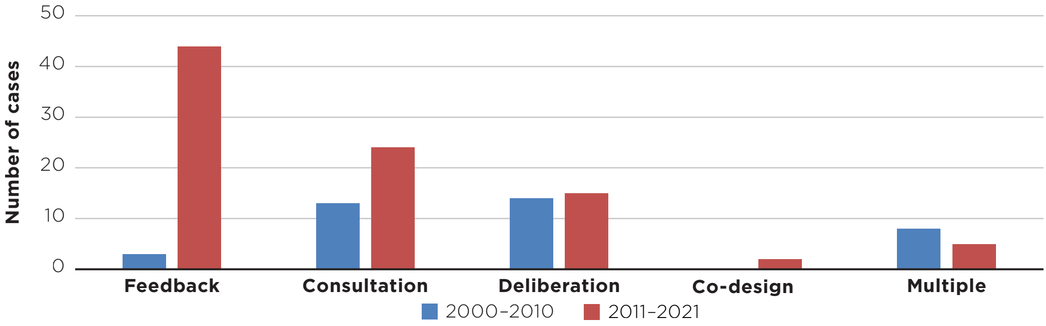
Our review of more than 100 cases of government-initiated public engagement at the federal, provincial and pan-Canadian levels has highlighted several broad trends that appear to reinforce some long-standing critiques noted in the public engagement literature. A large proportion of the health-related public engagement initiatives we reviewed are characterized by: (1) an emphasis on feedback and consultation activities that provide limited opportunities for more collaborative problem solving; (2) a reliance on self-selection and appointment methods for recruiting citizens that systematically favour more privileged individuals who are able to proactively seek out engagement opportunities; and (3) minimal attention given to the design of inclusive engagement opportunities that prioritize equity-deserving populations.

TABLE 4. Number of cases for each type of engagement, by jurisdiction

	Type of engagement			
	Federal	**Provincial**	**Pan-Canadian**	**Total**
Feedback	24	21	2	**47**
Consultation	13	23	3	**39**
Deliberation	4	20	5	**29**
Multiple	4	8	1	**13**
Co-design	0	2	0	**2**
Total	**45**	**74**	**11**	**130**

Two cases did not have information about type of engagement.

FIGURE 4. Number of cases for each type of engagement, by time period



The predominance of feedback and consultation-style activities in our case survey reflect the federal government's decision in 2016 to track and publicize its health-related public engagement activities, which primarily consist of self-selected feedback. The Consulting with Canadians portal allows the government to passively seek public comments on a variety of issues such as health, immigration and food and drug safety (Government of Canada 2023). While the portal potentially increases access to and visibility of engagement opportunities, allowing for broader engagement, the predominance of self-selected feedback suggests a shallower style of engaging with the public. This is also corroborated by the few deliberative activities and absence of co-design used at the federal level.

A reliance on self-selection and appointment methods for recruitment has important implications for the accessibility of public engagement activities. The self-selected feedback style activities, which dominate our case survey, require members of the public and patients to initiate engagement and, therefore, may be less accessible to individuals and groups who are not well connected or aware of how to seek out engagement opportunities (Fung 2003; Massie and Boothe 2024). This disproportionately affects equity-deserving populations who are already underrepresented in public and patient engagement networks and face barriers to access, and substantiates common equity concerns about public engagement efforts that only engage the most well-resourced members of the public (Abebe and George 2022; Sayani et al. 2021; Snow et al. 2018). The lack of attention being directed to more inclusive and targeted approaches to engagement mirrors the extremely low number of cases that mention prioritizing equity-deserving populations in our case survey.

While more intentional approaches to recruitment, such as targeted recruitment, may be warranted to support equitable engagement, it is essential not to fall into the trap of "recruitmentology" where disproportionate attention is given to perfecting recruitment at the detriment of other factors that could make engagement more accessible. For example, appropriate compensation of engaged individuals and fostering safe and inclusive spaces for engagement can play an important role in making engagement desirable (Armos 2020; Epstein 2008; Massie and Boothe 2024; Snow et al. 2018). Members of structurally equity-deserving communities often have justified mistrust in the health system and may be skeptical of public engagement initiatives, which take time and effort and are led by institutions that have perpetuated harms (Abebe and George 2022; Snow et al. 2018). Furthermore, a lack of tangible change resulting from public engagement can lead to unfulfilled expectations and further mistrust, highlighting the importance of accountability and transparency in engagement processes.

Two findings from our case survey challenge the description of eras offered in the introduction. First, the overrepresentation of "one-time" versus "ongoing" engagement activities suggests that engagement is still commonly structured as one-time opportunities to gather input on a specific issue, rather than as ongoing, recurring activities embedded in organizations. This seems to contradict key efforts to include patients within advisory bodies and may partially explain the lack of engagement with equity-deserving populations due to a reliance on self-selection recruitment methods. It is important to note, however, that ongoing activities using deliberative and co-design methods may still produce exclusionary effects, especially if participation requires investment of personal resources (time, money), in-depth understanding of the health system or experience navigating institutional norms and expectations for engagement. Dissenting voices that are critical of the status quo may end up being silenced, excluded or choose to stop engaging and institutionally embedded advisory boards may struggle to retain diverse membership (Glimmerveen et al. 2021).

Second, rather than seeing a clearly delineated shift from public-centred to patient-centred activities, after 2010 we found a dramatic increase in the number of activities engaging "multiple" publics, denoting a greater mixing of "public," "patient," and "other" (e.g., industry, expert) interests. We also see a substantial increase in the number of "public"-only cases between the two time points but fail to see a notable increase in "patient"-only activities. The mixing of target populations may indicate an important ideological gap in engagement practices and assumptions of consistency between public and patient engagement. While the patient engagement and public engagement movements are interrelated and patients are of course members of the public, we believe there are important distinctions to be considered. McCoy and colleagues (2019) identify patient engagement as a pragmatic exercise to develop health policies and services aligned with patient experiences and needs, and public engagement as a democratic tool to improve the representation, transparency and accountability of policy decisions. Appreciating these distinct rationales for patient and public engagement may encourage more purpose-driven activities that consider *why* engagement with a *specific population* is necessary within a given policy context. Overall, our case survey suggests that shifts in institutional arrangements have not translated as neatly to the practice level, at least not within the scope of the government-initiated engagement cases we reviewed.

Limitations and Conclusion

Our case survey provided a unique opportunity to bridge key trends in policy discourse and institutional developments with on-the-ground engagement practice during a period of considerable growth in the field of public engagement in Canadian health policy. There are several limitations to our analysis. First, in focusing on government-initiated activities from 2000 to 2021, the case survey findings do not speak to engagement trends in the health research community or at the regional and local health system levels, where significant developments in public and patient engagement were also happening (CIHR 2011; The Change Foundation 2014). Second, while the number of cases collected and reviewed is substantial, it is not encompassing of all government-initiated engagement activities. Finally, our analysis is limited to documenting and describing what we found from publicly available case reports, which limited our ability to explore cases in more depth and for explanatory purposes.

The results of this case survey provide a helpful baseline of key trends in Canadian government-initiated health policy engagement from 2000 to 2021. We offer a novel descriptive framework that may prove useful to both scholars and practitioners working in the engagement field. Our findings provide an important foundation for responding to growing calls for more inclusive and transformative engagement that prioritizes groups that have been historically excluded from the design of health policies that affect them. In particular, policy makers should note the limitations of self-selected feedback activities and consider dedicating engagement resources toward supporting equitable, community-informed approaches to hear those voices that would otherwise be excluded. This could take the form of redirecting resources to community-based organizations to conduct engagement with their own communities, increasing the time dedicated for engagement activities to allow for relationship-building and trust with equity-deserving groups or adding accountability and evaluation mechanisms to engagement plans so that individuals feel they are making a difference through their engagement activities. Those overseeing the design and implementation of government-initiated public engagement can draw valuable lessons from this case survey to inform the design of future engagement initiatives.

Correspondence may be directed to Julia Abelson by e-mail at abelsonj@mcmaster.ca.

Notes

[1] This organization's name has now changed to Canada's Drug Agency (CDA).

[2] For more detail on engagement by topic, see the full report: https://ppe.mcmaster.ca/wp-content/uploads/2024/09/pehp-public-engagement-trends-in-canadian-health-policy.pdf.

References

Abebe, A. and R. George. 2022, April 5. Failure to Include Black Communities in Health Policy Public Engagement Perpetuates Health Disparities. *The Conversation*. Retrieved August 21, 2023. <https://theconversation.com/failure-to-include-black-communities-in-health-policy-public-engagement-perpetuates-health-disparities-180383>.

Abelson, J. and J. Eyles. 2002, July. *Public Participation and Citizen Governance in the Canadian Health System.* Discussion Paper No. 7. Commission on the Future of Health Care in Canada. Retrieved August 21, 2023. <https://publications.gc.ca/site/eng/9.558203/publication.html>.

Abelson, J., M. Giacomini, P. Lehoux, F.-P. Gauvin. 2007. Bringing 'the Public' into Health Technology Assessment and Coverage Policy Decisions: From Principles to Practice. *Health Policy* 82(1): 37–50. doi: 10.1016/j.healthpol.2006.07.009.

Abelson, J., L. Tripp, M. MacNeil, A. Lang, C. Fancott, R. Ganann et al. 2023. Development of the Engage with Impact Toolkit: A Comprehensive Resource to Support the Evaluation of Patient, Family and Caregiver Engagement in Health Systems. *Health Expectations* 26(3): 1255–65. doi:10.1111/hex.13742.

Abelson J., F. Wagner, D. DeJean, S. Boesveld, F-P. Gauvin, S. Bean et al. 2016. Public and Patient Involvement in HTA: Framework for Action. *International Journal of Technology Assessment in Health Care* 32(4): 256–64. doi:10.1017/S0266462316000362.

Act Respecting the Health and Welfare Commissioner, CQLR c C-32.1.1. 2005. Government of Quebec. Retrieved August 12, 2024. <https://www.canlii.org/en/qc/laws/stat/cqlr-c-c-32.1.1/95401/cqlr-c-c-32.1.1.html>.

Armos N. 2020. *Beyond Inclusion: Equity in Public Engagement.* SFU Morris J. Wosk Centre for Dialogue. Retrieved August 21, 2023. <https://www.sfu.ca/content/dam/sfu/dialogue/ImagesAndFiles/ProgramsPage/EDI/BeyondInclusion/Beyond%20Inclusion%20-%20Equity%20in%20Public%20Engagement.pdf>.

Arnstein, S.R. 1969. A Ladder of Citizen Participation. *Journal of the American Institute of Planners* 35(4): 216–24. doi:10.1080/01944366908977225.

Bherer, L., P. Dufour and F. Montambeault. 2016. The Participatory Democracy Turn: An Introduction. *Journal of Civil Society* 12(3): 225–30. doi:10.1080/17448689.2016.1216383.

Blacksher, E., A. Diebel, P.-G. Forest, S.D. Goold and J. Abelson. 2012. What is Public Deliberation? *Hastings Center Report* 42(2): 14–17. doi:10.1002/hast.26.

Boivin, A., A. L'Espérance, F.-P. Gauvin, V. Dumez, A.C. Macaulay, P. Lehoux et al. 2018. Patient and Public Engagement in Research and Health System Decision Making: A Systematic Review of Evaluation Tools. *Health Expectations* 21(6): 1075–84. doi:10.1111/hex.12804.

Bombard, Y., J. Abelson, D. Simeonov and F.-P. Gauvin. 2011. Eliciting Ethical and Social Values in Health Technology Assessment: A Participatory Approach. *Social Science and Medicine* 73(1): 135–44. doi:10.1016/j.socscimed.2011.04.017.

Canadian Agency for Drugs and Technologies in Health (CADTH). 2022. Patient and Community Advisory Committee. Retrieved August 21, 2023. <https://www.cadth.ca/patient-and-community-advisory-committee>.

Canadian Agency for Drugs and Technologies in Health (CADTH). 2023. The pCODR Expert Review Committee (pERC). Retrieved August 21, 2023. https://www.cadth.ca/pcodr-expert-review-committee-perc-0

Canadian Institutes of Health Research (CIHR). 2011. *Canada's Strategy for Patient-Oriented Research.* Retrieved August 21, 2023. <https://cihr-irsc.gc.ca/e/44000.html>.

Canadian Institutes of Health Research (CIHR). 2012. *CIHR's Citizen Engagement in Health Casebook*. Retrieved August 12, 2024. <https://publications.gc.ca/collections/collection_2012/irsc-cihr/MR4-12-2012-eng.pdf>.

Carman, K.L., P. Dardess, M. Maurer, S. Sofaer, K. Adams, C. Bechtel et al. 2013. Patient and Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies. *Health Affairs* 32: 223–31. doi:10.1377/hlthaff.2012.1133.

Conklin, A., Z. Morris and E. Nolte. 2015. What is the Evidence Base for Public Involvement in Health-Care Policy? Results of a Systematic Scoping Review. *Health Expectations* 18: 153–65. doi:10.1111/hex.12038.

Davidson, A. 2020 April 4. Building Trust Means Letting the Public Be Part Of COVID-19 Decisions. *Policy Options*. Retrieved August 21, 2023. <https://policyoptions.irpp.org/magazines/april-2020/building-trust-means-letting-the-public-be-part-of-covid-19-decisions/>.

Epstein, S. 2008. The Rise of "Recruitmentology": Clinical Research, Racial Knowledge, and the Politics of Inclusion and Difference. *Social Studies of Science* 38(5): 801–32. doi:10.1177/0306312708091930.

Excellent Care For All Act. 2010. Government of Ontario. Retrieved July 15, 2024. <https://www.ola.org/en/legislative-business/bills/parliament-39/session-2/bill-46>.

Fancott, C., G.R. Baker, M. Judd, A. Humphrey and A. Morin. 2018. Supporting Patient and Family Engagement for Healthcare Improvement: Reflections on "Engagement-Capable Environments" in Pan-Canadian Learning Collaboratives. *Healthcare Quarterly* 21: 12–30. doi:10.12927/hcq.2018.25642.

Fung, A. 2003. Recipes for Public Spheres: Eight Institutional Design Choices and Their Consequences. *Journal of Political Philosophy* 11(3): 338–67. doi:10.1111/1467-9760.00181.

Gauvin, F.-P., J. Abelson, M. Giacomini, J. Eyles and J. Lavis. 2010. "It all Depends": Conceptualizing Public Involvement in the Context of Health Technology Assessment Agencies. *Social Science and Medicine* 70: 1518–26. doi:10.1016/j.socscimed.2010.01.036.

Gauvin, F.-P., E. Martin, P.-G. Forest and J. Abelson. 2009. L'expérience citoyenne et le système de santé au Québec. In A.-P. Contandriopoulos, Z. Hartz, M. Gerbier and A. Nguyen, eds., *Santé et citoyenneté: les expériences du Brésil et du Québec* (pp. 45–70). Les Presses de l'Université de Montréal.

Glimmerveen, L., S. Ybema and H. Nies. 2021. Who Participates in Public Participation? The Exclusionary Effects of Inclusionary Efforts. *Administration and Society* 54(4): 543–74. doi:10.1177/00953997211034137.

Government of Canada. 1964. Royal Commission on Health Services, 1961 to 1964. Retrieved August 21, 2023. <https://www.canada.ca/en/health-canada/services/health-care-system/commissions-inquiries/federal-commissions-health-care/royal-commission-health-services.html>.

Government of Canada. 2000. *The Health Canada Policy Toolkit for Public Involvement in Decision Making*. Retrieved August August 12, 2024. <https://www.canada.ca/content/dam/hc-sc/migration/hc-sc/ahc-asc/alt_formats/pacrb-dgapcr/pdf/public-consult/2000decision-eng.pdf>.

Government of Canada. 2002. *Building on Values: The Future of Health Care in Canada*. Commission on the Future of Health Care in Canada. Retrieved August 21, 2023. <https://publications.gc.ca/collections/Collection/CP32-85-2002E.pdf>.

Government of Canada. 2022. Patient and Family Advisory Committee. Canadian Forces Health Services Centre Ottawa. Retrieved August 21, 2023. <https://www.canada.ca/en/department-national-defence/services/bases-support-units/cf-health-services-centre-ottawa/pfac.html>.

Government of Canada. 2023. Consulting with Canadians. Retrieved August 21, 2023. <https://www.canada.ca/en/government/system/consultations/consultingcanadians.html>.

Government of Ontario. 2020, June 23. Ontario Appoints New Chair for the Minister's Patient and Family Advisory Council [News release]. Retrieved July 15, 2024. <https://news.ontario.ca/en/release/57337/ontario-appoints-new-chair-for-the-ministers-patient-and-family-advisory-council>.

Government of Saskatchewan. 2009. Patient First Review. Retrieved August 21, 2023. <https://www.saskatchewan.ca/government/health-care-administration-and-provider-resources/saskatchewan-health-initiatives/patient-first-review>.

Greenhalgh, T., C. Jackson, S. Shaw and T. Janamian. 2016. Achieving Research Impact Through Co-Creation in Community-Based Health Services: Literature Review and Case Study. *The Milbank Quarterly* 94(2): 392–429. doi:10.1111/1468-0009.12197.

Health Quality Ontario. 2019. Health Quality Ontario's Patient, Family and Public Advisor's Council, 2019. RetrievedAugust21,2023. <https://www.hqontario.ca/Patient-Partnering/Health-Quality-Ontarios-Patient-Family-and-Public-Advisors-Council>.

Imagine Citizens Network. 2023. *Annual Report 2022–2023*. Retrieved August 21, 2023. <https://imaginecitizens.ca/wp-content/uploads/2023/06/ImagineCitizensNetwork_AnnualReport202223-2.pdf>.

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

Loeffler, E. and T. Bovaird. 2016. User and Community Co-Production of Public Services: What Does the Evidence Tell Us? *International Journal of Public Administration* 39(13): 1006–19. doi:10.1080/01900692.2016.1250559.

Massie, J. and K. Boothe. 2024. Recruiting for Engagement in Health Policy. *Healthcare Policy* 20(Special Issue): 36–47. doi:10.12927/hcpol.2024.27415.

Maxwell, J., S. Rosell and P.-G. Forest. 2003. Giving Citizens a Voice in Healthcare Policy in Canada. *British Medical Journal* 326: 1031–33. doi:10.1136/bmj.326.7397.1031.

McCoy, M.S., J. Warsh, L. Rand, M. Parker and M. Sheehan. 2019. Patient and Public Involvement: Two Sides of the Same Coin or Different Coins Altogether? *Bioethics* 33: 708–15. doi:10.1111/bioe.12584.

McGrail, K., J. Morgan and A. Siddiqi. 2022. Looking Back and Moving Forward: Addressing Health Inequities after COVID-19. *The Lancet Regional Health–Americas* 9: 100232. doi:0.1016/j.lana.2022.100232

Ministère de la Santé et des Services sociaux. 2018. *Cadre de référence de l'approche de partenariat entre les usagers, leurs proches et les acteurs en santé et en services sociaux Québec*. Retrieved July 15, 2024. <https://publications.msss.gouv.qc.ca/msss/fichiers/2018/18-727-01W.pdf>.

Moll, S., M. Wyndham-West, G. Mulvale, S. Park, A. Buettgen, M. Phoenix et al. 2020. Are You Really Doing "Codesign"? Critical Reflections When Working With Vulnerable Populations. *BMJ Open* 10(11): e038339. doi:10.1136/bmjopen-2020-038339.

Mulvale, G., S. Moll, A. Miatello, G. Robert, M. Larkin, V.J. Palmer et al. 2019. Codesigning Health and Other Public Services with Vulnerable and Disadvantaged Populations: Insights from an International Collaboration. *Health Expectations* 22(3): 284–97. doi:10.1111/hex.12864.

Patient Advisors Network. 2023. *PAN Annual Report 2022-2023*. Retrieved August 21, 2023. <https://drive.google.com/file/d/1rurIWTH4HX1DcZOqSq5ouzmiohyNP5FY/view?pli=1>.

Patients First Act. 2016. Government of Ontario. Retrieved July 15, 2024. <https://www.ola.org/en/legislative-business/bills/parliament-41/session-1/bill-210>.

Patients for Patient Safety Canada. n.d. Patients for Patient Safety Canada. Retrieved August 12, 2024. <https://www.patients4safety.ca/>.

Patient Voices Network. 2018. *Patient Voices Network 2017/18 Annual Report*. Retrieved August 21, 2023. <https://patientvoicesbc.ca/wp-content/uploads/2018/12/PVN-2017-2018-Annual-Report-Final-1.pdf>.

Quick, K.S. and M.S. Feldman. 2011. Distinguishing Participation and Inclusion. *Journal of Planning Education and Research* 31(3): 272–90. doi:10.1177/0739456X11410979.

Sayani, A., A. Maybee, J. Manthorne, E. Nicholson, G. Bloch, J.A. Parsons et al. 2021. Building Equitable Patient Partnerships During the COVID-19 Pandemic: Challenges and Key Considerations for Research and Policy. *Healthcare Policy* 17(1): 17. doi:10.12927/hcpol.2021.26582.

Snow, M.E., K. Tweedie and A. Pederson. 2018. Heard and Valued: The Development of a Model to Meaningfully Engage Marginalized Populations in Health Services Planning. *BMC Health Services Research* 18(1): 181. doi:10.1186/s12913-018-2969-1.

Standing Senate Committee on Social Affairs, Science and Technology. 2006, May. *Out of the Shadows At Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada*. The Senate of Canada. Retrieved August 21, 2023. <https://mentalhealthcommission.ca/wp-content/uploads/2021/09/out_of_the_shadows_at_last_-_full_0_0.pdf>.

The Change Foundation. 2014. *Patient/Family Advisory Councils in Ontario Hospitals. At Work, in Play.* Retrieved August 12, 2024. <https://canadacommons.ca/artifacts/1223002/patientfamily-advisory-councils-in-ontario-hospitals/1776080/>.

Transparent Drug System for Patients Act, 2006, S.O. 2006, c. 14 - Bill 102. Government of Ontario. Retrieved July 15, 2024. <https://www.ola.org/en/legislative-business/bills/parliament-38/session-2/bill-102>.

White, F. and D. Nanan. 2009. A Conversation on Health in Canada: Revisiting Universality and the Centrality of Primary Healthcare. *The Journal of Ambulatory Care Management* 32(2): 141–49. doi: 10.1097/JAC.0b013e31819941f3.