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Services de santé, gestion et recherche de politique

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Participation du public aux politiques canadiennes de la santé

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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.

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EDITORIAL

Engaging Canadians in Health Policy Is no Trivial Matter

There are many challenges with stewarding a public healthcare delivery system in Canada. The system is a beast with its own momentum. The public shares sad experiences with accessing emergency departments or securing a primary care physician on a daily basis. Provinces, territories and the federal government are all acutely aware that their delivery systems perform poorly in contrast with other countries.

These challenges have spurred governments, ministries of health and local delivery system leaders to seek engagement with the public and community-based organizations in order to solicit their input on a range of important healthcare issues. This is not as simple as it seems; there is no magic or a *right* way to identify, recruit and sustain engagement with people and organizations' representatives that reflects inclusive and equitable perspectives regarding the direction of provinces' and territories' health systems.

In this special issue of *Healthcare Policy*, a team of researchers, fellows, trainees and community leaders focused their efforts on describing and tackling the complex problem of charting a path for meaningful public engagement in healthcare. Their efforts culminated in three valuable accomplishments, including an equity-centred engagement guide that serves as a resource for engagement practitioners, delivering a community fellowship program that supported community-based organizations' engagement projects and supporting a cohort of trainees to assume leadership roles in engagement activities.

The editorial team of *Healthcare Policy* supports the McMaster University team's efforts to present their findings in an accessible format since the issue of representative and inclusive engagement is critical for informing and supporting provinces' and territories' future healthcare delivery system reforms.

There are six research manuscripts and two reflection papers in this special issue, each written by highly motivated researchers, fellows, trainees and community leaders with deep or growing experience in public engagement. The special issue's contents aim to describe the elements of purposeful and equitable public engagement, the pitfalls to avoid while engaging with stakeholders and the public and how to sustain interest in purposeful engagement with the public.

Addressing underrepresentation through purposeful inclusiveness and equitable representation is critically important for sustained and effective public engagement. A transformation of public engagement practices is overdue and the contributions from this special issue should be integral to policy makers and health system leaders' efforts in this domain. I believe the contents of this special issue are meaningful and replete with valuable advice.

JASON M. SUTHERLAND, PhD
Editor-in-Chief

ÉDITORIAL

La participation des Canadiens aux politiques de santé n'est pas une mince affaire

La gestion d'un système de prestation des soins de santé au Canada présente de nombreux défis, et le système est une véritable bête qui suit son propre élan. Chaque jour, le public vit de tristes expériences quant à l'accès aux services d'urgence ou quant à la recherche d'un médecin de première ligne. Les provinces, les territoires et le gouvernement fédéral sont tous très conscients du fait que le rendement de leurs systèmes de santé est médiocre par rapport à celui d'autres pays.

Ces défis ont incité les gouvernements, les ministères de la Santé et les responsables des systèmes de santé à solliciter le public et les organisations communautaires afin de connaître leur avis sur une série de questions importantes touchant aux soins de santé. Cela n'est pas aussi simple qu'il y paraît; il n'existe aucune formule magique ni aucune *bonne façon* de déterminer, recruter et maintenir la mobilisation des personnes et des représentants d'organisations, tout en reflétant les questions d'inclusion et d'équité, pour assurer l'orientation des systèmes de santé provinciaux et territoriaux.

Dans ce numéro spécial de *Politiques de Santé*, une équipe de chercheurs, de boursiers, de stagiaires et de dirigeants communautaires décrivent et examinent le problème complexe que pose le tracé d'un chemin pour la participation significative du public aux soins de santé. Leurs efforts ont abouti à trois réalisations importantes, notamment un guide de mobilisation axé sur l'équité qui sert de ressource et propose un programme communautaire pour soutenir les projets de mobilisation des organisations et pour épauler un groupe de stagiaires afin qu'ils assument des rôles de leadership dans les activités de mobilisation.

L'équipe de rédaction de *Politiques de Santé* a appuyé les efforts de l'équipe de l'Université McMaster afin d'en présenter les conclusions dans un format accessible, car la question de la participation représentative et inclusive est essentielle pour informer et soutenir les réformes des systèmes de santé des provinces et territoires.

Ce numéro spécial présente six manuscrits de recherche et deux articles de réflexion, rédigés par des chercheurs, des boursiers, des stagiaires et des leaders communautaires très motivés qui ont une expérience approfondie ou croissante de la mobilisation du public. Le contenu de ce numéro spécial vise à décrire les éléments d'une participation publique ciblée et équitable, les pièges à éviter au moment de s'engager auprès des intervenants et du public ainsi que la façon de maintenir l'intérêt du public pour la participation ciblée.

Il est essentiel de s'attaquer à la question de la sous-représentation grâce à une participation ciblée et équitable du public afin d'assurer une mobilisation durable et efficace. Il est grand temps de transformer les pratiques de mobilisation du public et la contribution de ce numéro spécial devrait faire partie intégrante des efforts des décideurs et des dirigeants du système de santé dans ce sens. J'estime que le contenu de ce numéro spécial est important et riche en précieux conseils.

JASON M. SUTHERLAND, PhD
Rédacteur en chef

INTRODUCTION

Public Engagement in Canadian Health Policy: Looking Back, Taking Stock and Charting the Future

Participation du public aux politiques canadiennes de la santé : rétrospective, bilan et tracé de l'avenir

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Abstract

Canada has a rich history of public engagement in the health policy sector. However, current political, economic and social challenges call for critical reflection on this history, to assess whether current approaches to engaging Canadian *publics* are up to the task, and what adaptations or new approaches might be needed. If the persisting inequities in health systems across Canada are going to be addressed, it is imperative that those designing, developing and implementing policies find ways to reflect the needs and preferences of the communities and populations most adversely affected by these inequities in their decisions. The purpose of this special issue is to address this important topic through a series of research papers and commentaries. Our work is targeted to health policy makers across Canada who are seeking

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*On behalf of the Public Engagement in Health Policy Project Team, McMaster University.

to engage with various publics on a wide array of health policy issues. We offer key insights into what more purposeful and equitable public engagement might look like, as well as common pitfalls in public engagement practices and how they can be avoided.

Résumé

Le Canada a une longue histoire de participation du public dans le secteur des politiques de santé. Cependant, les défis politiques, économiques et sociaux actuels exigent une réflexion critique sur cette histoire afin d'évaluer si les approches actuelles pour mobiliser le *public* canadien sont à la hauteur de la tâche et pour savoir quelles adaptations ou nouvelles approches pourraient s'avérer nécessaires. Si on veut s'attaquer aux inégalités persistantes dans les systèmes de santé au Canada, il est impératif que ceux qui conçoivent, élaborent et mettent en œuvre les politiques puissent trouver des moyens de refléter dans leurs décisions les besoins et préférences des communautés et des populations les plus touchées par ces inégalités. Le présent numéro spécial a comme objectif d'aborder cet important sujet grâce à une série de commentaires et d'articles de recherche. Notre travail s'adresse aux décideurs canadiens en matière de santé qui cherchent à engager la discussion avec divers publics sur un large éventail d'enjeux en matière de politiques de la santé. Nous offrons des renseignements clés sur ce que pourrait être une participation plus ciblée et équitable du public, ainsi que sur les pièges courants et la façon de les éviter.

Introduction

Canada has a rich history of public engagement in the health policy sector. However, current political, economic and social challenges call for critical reflection on this history, to assess whether current approaches to engaging Canadian *publics* are up to the task, and what adaptations or new approaches might be needed.

The purpose of this special issue is to address this important topic through a series of research papers and commentaries. Our work is targeted to health policy makers across Canada – both federally and at the provincial and territorial levels – who are seeking to engage with various publics about a wide array of health policy issues relating to the governance, funding, organization and delivery of health services, programs and technologies. We offer key insights into what more purposeful and equitable public engagement might look like as well as common pitfalls in public engagement practices and how they can be avoided. If the numerous and persisting inequities in health systems across Canada are going to be addressed, it is imperative that those designing, developing and implementing policies find ways to reflect the needs and preferences of the communities and populations most adversely affected by these inequities in these decisions.

The contributions in this special issue are the culmination of a three-year Public Engagement in Health Policy (PEHP) project (hereafter "the Project") led by an interdisciplinary team of scholars and practitioners who have wrestled with key concepts fundamental to addressing calls for more inclusive and transformative public engagement processes (Public Engagement in Health Policy Project n.d.). We have done this through descriptive, conceptual and empirical research, enhanced by opportunities for exchange with leading engagement scholars, practitioners and community partners.

In this introductory article, we present the work in the special issue and briefly describe some of our other project activities and outputs, including an equity-centred guide to public engagement resources for practitioners and community groups, a community fellowship program that supported innovative public engagement projects and a series of research fellowships that allowed an outstanding group of trainees to take a leadership role in designing and implementing various project activities. These fellowships were foundational to the Project, and so we turn to them first.

Research Fellowships, Community Leadership and Tools for Practitioners

A key aim of the Project was to build leadership and capacity in the field of public engagement in health policy. To achieve this goal, we funded six project fellowships for a mix of graduate and undergraduate students from McMaster University in Hamilton, ON. Project fellows conducted their own research activities mentored by senior faculty, while supporting the overarching objectives of the Project and learning more about public engagement. Several papers in the special issue are outputs of these activities, led by research fellows Roma Dhamanaskar, Joanna Massie and Jeonghwa You.

The Project also funded 11 fellowships to help community-based organizations conduct their own public engagement activities in the health and social care sector. Community-based organizations are uniquely poised to directly serve community needs and tackle policy problems at the local level, but they often operate with limited funds and resources. Our fellowships helped accelerate work that was already happening in community settings and prioritized front-line engagement activities that advanced the goals of inclusivity with a diverse range of populations. We see untapped potential here for relationship-building between community-based organizations, which have connections to equity-deserving groups, and policy makers looking to enhance the impact of public engagement processes on policy outcomes.[1]

Throughout our work, we found that public engagement practitioners in government and community-based organizations alike were grappling with calls for more inclusive and equitable approaches to engagement. This prompted us to do an environmental scan of the resources currently available on the topic. We found many resources covering a variety of topics, ranging from defining principles and key concepts (like equity, diversity and inclusion) to making plans for equitable engagement to implementing strategies when conducting and facilitating engagement. Rather than recycling the ideas and approaches from the resources we found, we developed an equity-centred engagement guide (Ul Haq et al. 2023) that collected and organized existing resources into an actionable roadmap for engagement practitioners and those in policy advisory roles.

We discuss these non-traditional outputs here to highlight the potential for university-based research groups to conduct unique and meaningful activities that generate impact beyond convential academic research activities. Through our fellowships, we were able to directly support the next generation of engagement scholars as well as community-based organizations that are actively doing this work on the ground. Our equity-centred engagement guide (Ul Haq et al. 2023), as well as our Project blog and health policy podcast series through Matters of Engagement (2024), have helped make public engagement scholarship more accessible and disseminate our Project learnings outside academic settings and into policy making spaces.

Next, we delve more into our research contributions through this special issue.

Research Contributions

The contributions in this issue are structured around three phases of *looking back, taking stock* and *moving forward* in public engagement in Canadian health policy. The papers are intentionally diverse in their jurisdictional focus (pan-Canadian, Ontario), their form (empirical research, commentaries and oral histories), the populations they attend to (older adults, Black communities) and the issues they tackle (representation, recruitment, equity). They challenge prevailing understandings of public engagement and bring underrepresented communities to the foreground. They imagine a future for more ethical and reflexive engagement and propose public engagement as a tool for addressing ethically contentious policy problems facing Canadian health policy makers today. We hope these papers combined with our other Project outputs serve to inform discussion and debate about how more robust, equitable approaches to public engagement can strengthen current and future health policy decision making in Canada.

In the issue's lead article, Roma Dhamanaskar and colleagues trace the history and key trends in public engagement in Canadian health policy from 2000 to 2021, providing a reference point for subsequent papers (Dhamanaskar et al. 2024). From their review of more than 100 cases of government-initiated public engagement at the federal, pan-Canadian and provincial government levels, several broad trends emerge that reinforce long-standing critiques noted in the public engagement literature. Most notably, government-initiated public engagement activities were dominated by self-selection recruitment methods and feedback-style engagement, limiting opportunities for more sustained and thoughtful engagement with the public. This potentially explains another troubling finding from the review – only about 1 in 10 activities mentioned prioritizing equity-deserving populations.

The next three papers examine these critiques in greater depth. Joanna Massie and Katherine Boothe tackle the topic of recruitment for public engagement, reflecting on the Project's own public engagement workshop with community members, engagement practitioners and researchers (Massie and Boothe 2024). They echo other scholars' critiques of "recruitmentology" (Massie and Boothe 2024: 38) where disproportionate attention is given to the technical aspects of recruitment to the detriment of other factors that shape engagement, like trust, community building and power relations, and grapple with the practical challenges of applying these critiques to an actual recruitment process. They describe important trade-offs and key lessons when making decisions about recruitment that will be especially helpful for those attempting to foster inclusive and equitable engagement.

Jeonghwa You and colleagues explore the theme of representation and the role of intermediaries who are seeking to represent the interests of others, particularly those who are unable to advocate for themselves (You et al. 2024). Drawing on a set of interviews with residents or family members of residents in long-term care facilities in Ontario, this paper offers important insights about who can and should represent this group in policy making, what contributes to their legitimacy as representatives for others and how this might help to build public trust and support for policy making in a sector that relies heavily on intermediaries. Although the research was carried out in Ontario, the insights shared in this work will be relevant to other provincial and territorial jurisdictions engaged in policy development work in the long-term and community care sectors.

Rhonda C. George and Alpha Abebe centre Black communities in their exploration of how Black community leaders and advocates influenced policy before, during and since the COVID-19 pandemic, often through community-led, bottom-up initiatives (George and Abebe 2024). This challenges the prevailing narrative of top-down, government-led and formalized public engagement structures that many in the field have become familiar with, opening the door to more community-driven approaches. The paper describes the sense of responsibility and collectivist leadership approaches that Black leaders embody, allowing them to influence policy change despite structural barriers.

The last two papers in the issue look ahead to the transformative potential of public engagement. Roma Dhamanaskar and Julia Abelson propose public deliberation – a type of engagement that emphasizes sustained dialogue between members of the public – as an essential strategy for ethical policy making for medical assistance in dying (MAiD) (Dhamanaskar and Abelson 2024). They describe how Canada can use its rich history and leadership in public engagement in tandem with key lessons from other countries to engage the public about ethically complex MAiD policies.

Finally, Jamila Michener brings researchers into the fold in her description of "scholarly public engagement" (Michener 2024: 94). She calls for more reflexive and values-driven approaches to public engagement led by researchers who want to make a change in the world. She describes four pitfalls that limit the potential for transformative public engagement and brings her own lived experiences as a public engagement scholar to discuss how these pitfalls may be avoided and addressed.

This special issue is enriched by two oral histories by community leaders, Camille Orridge and Lanre Tunji-Ajayi, who share their perspectives as health advocates from and for communities that are often underrepresented in public engagement initiatives (Orridge 2024; Tunji-Ajayi 2024). Camille Orridge details her 50-year history as an advocate for Black communities and offers important lessons for designing equitable health systems through collaborative efforts. She calls for caution and reflection when using increasingly popular public engagement methods, like co-design, which may produce exclusionary effects. Lanre Tunji-Ajayi describes her advocacy for patients with sickle cell anemia, a condition that disproportionately impacts Black communities. She identifies persistence as a hallmark for success when engaging policy makers while also discussing the personal toll this can take when compounded with structural forms of anti-Black racism.

Overall, this special issue explores the potentials and pitfalls for Canadian public engagement in the health policy sector. We engage with questions that the public engagement field has been grappling with for years – inclusivity, equity, recruitment and representation. We find a sustained interest from health policy makers in engaging the public over the past 20 years; however, we also note some important deficiencies in current practices. As approaches to engaging the public continue to evolve to meet current needs, we hope that some key messages from this special issue can help shape future practices. These include moving beyond recruitment when designing inclusive engagement activities, appreciating communities that engage with policy makers outside formalized engagement structures and ensuring engagement is rooted in core values like democracy and equity. Transformation takes time; this special issues offers some next steps toward more purposeful public engagement in Canadian health policy.

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Note

[1] You can read more about the community fellowships and related events that we hosted here: https://ppe.mcmaster.ca/research/public-engagement/leadership-and-capacity-building/community-fellowships/.

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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

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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).

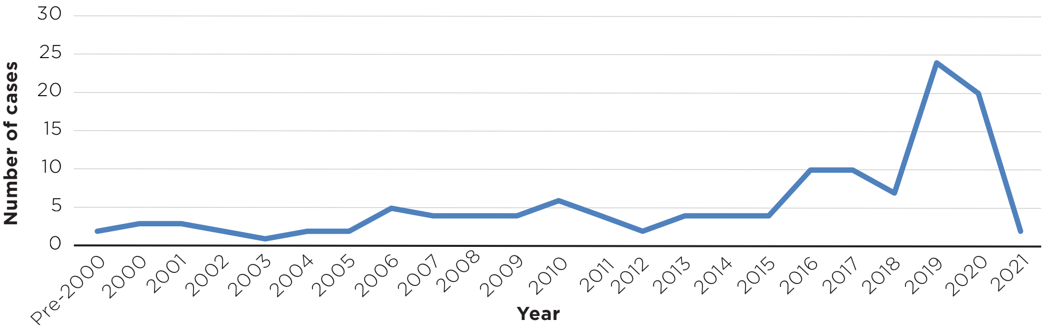
Results

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.

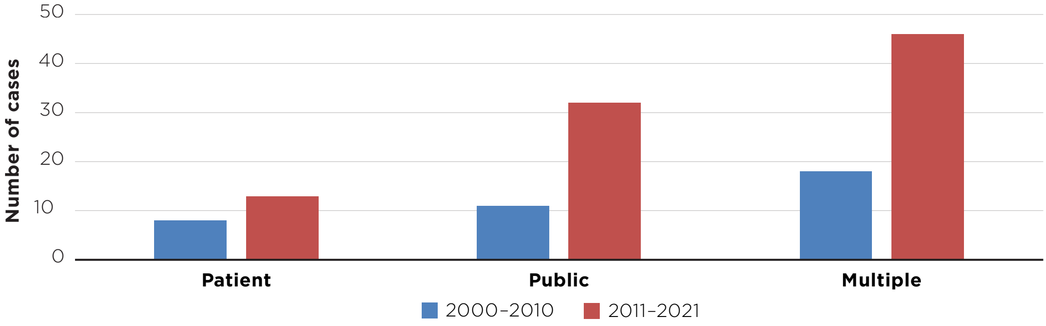
Overall, federal activities heavily favoured engagement with multiple populations, with more than 67% of activities being classified this way. Public-only activities were rare at the federal level and relatively less common at the provincial level. Conversely, pan-Canadian activities had a relatively 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.

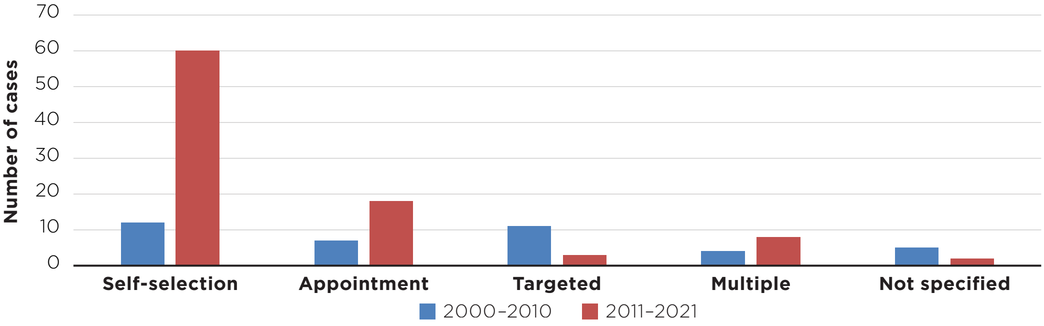
Type of engagement

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

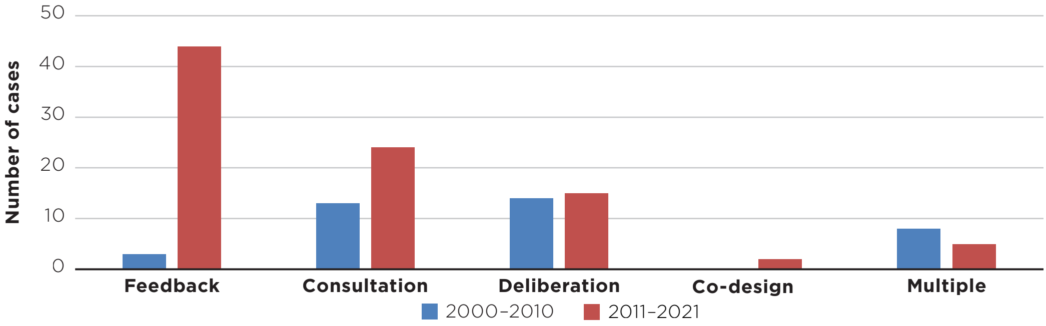
Our review of more than 100 cases of government-initiated public engagement at the federal, provincial and pan-Canadian levels has highlighted several broad trends that appear to reinforce some long-standing critiques noted in the public engagement literature. A large proportion of the health-related 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.

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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.

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RESEARCH PAPER

Recruiting for Engagement in Health Policy

Recrutement pour la participation aux politiques de la santé

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Abstract

Background: Who participates in public and patient engagement processes, and in what capacity they participate, matters. The strategies employed to recruit participants shape the outcomes and legitimacy of engagement processes. We explore these issues through a case study of workshop recruitment.
Methods: We conducted a mixed-methods study drawing on literature about existing theories of engagement, and integrated findings from the research team's own public engagement workshop in September 2022. We sought to align theoretical frameworks with practical approaches to recruiting for engagement.
Results: There are inherent trade-offs in recruitment methods. While the theory of recruitment is valuable, practical implementation is complex and highly context-dependent. Engaging existing partners and fostering relationships beyond specific events is crucial. Hybrid workshops and low-barrier honoraria promote participation; however, decisions about location and time create barriers. Finally, balancing trusting relationships with critical perspectives can create tension.
Discussion: Recruitment is foundational for the engagement process, and requires flexibility, responsiveness and a realistic understanding of barriers. Our study suggests that there is no universal formula for ideal participant makeup or event format. Meaningful engagement

requires ongoing dialogue and constant adjustment based on practice. Policy makers can use these insights to align recruitment and engagement strategies with their goals in order to move beyond quick, technocratic fixes.

Résumé

Contexte et objectifs de l'étude : Il importe de savoir qui participe aux processus de mobilisation du public et des patients, et à quel titre. Les stratégies utilisées pour recruter des participants déterminent les résultats et la légitimité des processus de mobilisation. Nous explorons ces questions à travers une étude de cas sur le recrutement en atelier.
Méthodes : Nous avons mené une étude mixte en nous appuyant sur la littérature concernant les théories existantes sur la mobilisation et les résultats intégrés de l'atelier de mobilisation publique de l'équipe de recherche en septembre 2022. Nous avons cherché à aligner les cadres théoriques avec les approches pratiques du recrutement.
Résultats : Les méthodes de recrutement comportent des compromis inhérents. Bien que la théorie du recrutement soit précieuse, sa mise en œuvre pratique est complexe et dépend fortement du contexte. Il est crucial de mobiliser les partenaires existants et d'entretenir des relations au-delà des événements spécifiques. Les ateliers hybrides et la facilité d'accès favorisent la participation; cependant, les décisions concernant le lieu et le temps créent des obstacles. Enfin, l'équilibre entre les relations de confiance et les perspectives critiques peut donner lieu à des tensions.
Discussion : Le recrutement est fondamental pour les processus de mobilisation et exige de la souplesse, une réactivité et une compréhension réaliste des obstacles. Notre étude suggère qu'il n'existe pas de formule universelle pour le format idéal des participants ou des événements. Pour bien fonctionner, la mobilisation demande un dialogue continu et des ajustements constants fondés sur la pratique. Les décideurs peuvent utiliser ces renseignements pour aligner leurs stratégies de recrutement et de mobilisation sur les objectifs visés, afin de dépasser les solutions rapides et technocratiques.

◆

Introduction

Public and patient engagement is a broad term that describes the act of involving citizens and patients in health system decision making (Abelson et al. 2016).[1] Who participates, and in what capacity they participate, matters. Are participants contributing from the perspective of their lived experience with the health system or from the perspective of their public values? Are participants from a diverse range of perspectives given meaningful opportunities to participate? The process of recruiting participants for public engagement critically shapes the outcomes and legitimacy of the engagement. In this article, we review the recent literature on recruiting and design for public engagement to understand how theory and practice align and reflect on the process of recruiting participants to the *Reimagining Public Engagement* workshop organized by McMaster University's Public Engagement in Health Policy Project team in September 2022 (Massie et al. 2022).

Our survey of public engagement in Canadian health policy over the last 20 years found limited evidence of efforts designed to include marginalized or underrepresented groups in public engagement for health policy (Dhamanaskar et al. 2024). Our colleagues' research on Black community-led engagement also demonstrates crucial gaps in who is engaged in Canadian health policy (George and Abebe 2024). These gaps have implications for the legitimacy of public engagement projects: the systematic exclusion of certain individuals and groups means these processes fail to meet democratic goals of representation and inclusion and deprive policy makers of necessary information.

Faced with these challenges, researchers and engagement professionals often turn to "better" recruitment and the adoption of technical fixes to "reach the hard-to-reach." However, labels such as "hard to reach" blame communities for their lack of participation when, in fact, these activities are often difficult to access for reasons including and beyond faulty recruitment. Epstein (2008) argues that "recruitmentology," a study of "the efficacy of various social, cultural, psychological, technological, and economic means of convincing people" to participate in health research and health policy, falls short, and advocates for researchers and practitioners to instead "focus attention on issues of trust, collective memory, and power relations" (Epstein 2008: 823). Many communities justifiably mistrust the health system. Engagement, especially government- and researcher-led engagement, will not meet their needs and may indeed perpetuate further harms. Rowland and Kumagai (2018) note a lack of clarity about precisely *what* patients are being asked to represent, affecting both the patient experience and process outcomes. Dr. Nav Persaud warns against equating diversity with equity when it comes to recruiting public and patient participants without addressing wider, systemic barriers to equity and diversity in the health system (Johannesen and Angl 2021).

This paper integrates theories of recruitment with practical experiences of organizing a workshop. Our goal is to facilitate more nuanced conversations about recruitment for public engagement and prompt new research about the relationship between participant recruitment and engagement outcomes. We purposely interweave existing literature with data and reflections from our workshop to emulate the dynamic nature of making recruitment decisions – moving between theories and methods, engagement goals, organizational constraints and participant preferences.

Recruiting for the *Reimagining Public Engagement in a Changing World* Workshop

The Public Engagement in Health Policy Project (September 2020 to December 2023) aimed to deepen understanding of, and make recommendations for, public and patient engagement in health policy and planning. The project's interdisciplinary team, primarily from McMaster University in Hamilton, Ontario, consisted of academic faculty and trainees from the departments of Health Research Methods, Evidence, and Impact and Political

Science and the Faculty of Humanities. Team members brought diverse expertise in areas such as health system financing, elder care, drug assessments, Black community engagement and democratic innovations. As the project entered its final year, the team hoped to showcase project findings and seek input about the project's final stages. The team planned an event, *Reimagining Public Engagement in a Changing World*, held in September 2022. Our goal was to engage individuals and groups who are affected by or interested in our work, referred to as consumers or the affected public (Degeling et al. 2015).

The workshop aimed to share insights about possible directions for change in Canadian public and patient engagement, gather participant and practitioner perspectives on challenges in engagement and co-create practical resources to navigate public engagement more effectively. We hoped that participants with more engagement experience would reflect on successes, gain new insights into challenges of existing structures and explore potential directions for change. We hoped that participants with less engagement experience would gain insights into existing structures to help them navigate engagement more effectively and provide critical insights that may change and improve those structures.

As our team was interested in both the theoretical and practical dimensions of recruitment, we kept detailed notes about recruitment decision making and implementation processes throughout the workshop. We used primarily targeted recruitment, with limited self-selection opportunities as the workshop drew near. The next sections provide an overview of recent literature about these recruitment approaches, and why we chose them, and reflect on how the recruitment strategies and event design shaped the workshop outcomes. We conclude by identifying key lessons for future recruitment efforts while balancing practical constraints, namely time, resources, space and networks. We report briefly on post-workshop feedback from participants. Research was approved by the McMaster Research Ethics Board (project no. 5482).

Recruitment Methods, Costs and Benefits

Our approach to recruiting workshop participants combined targeted recruitment and self-selection. While these are only two of many approaches to recruitment (see Rowe and Frewer [2005] for an overview of approaches, and Rowland and Kumagai [2018] for types of representation), they are frequently used in health policy engagement activities, particularly when specialist firms are not employed to assist with more complex methods like stratified random sampling. We draw on recent research highlighting significant risks and trade-offs associated with these popular approaches and describe how these trade-offs shaped our workshop planning decisions.

Self-selection

Self-selection, in which individuals learn about the engagement activity and choose to participate on their own, was the most common method of recruitment in our team's survey (Dhamanaskar et al. 2024). While self-selection theoretically "promotes a kind of universal opportunity for participation that ostensibly ignores social circumstances" and is praised for its ease of implementation (Beauvais 2018: 149), social circumstances strongly influence who is able to self-select. When participants self-select, the resulting groups "are frequently quite unrepresentative of any larger public. Individuals who are wealthier and better educated tend to participate more than those who lack these advantages, as do those who have special interests or stronger views" (Fung 2006: 67) (see also Fung 2003; Ryfe and Stalsburg 2012). In the worst-case scenario, self-selection uses the guise of "openness" to absolve organizers from making concerted efforts to reach and incorporate the views of specific groups and individuals, often to the detriment of those who have less resources to engage.

Targeted recruitment and appointment

Targeted recruitment involves inviting individuals to participate based on expertise or knowledge. Appointment includes an additional step, during which applicants are assessed against preset criteria (Dhamanaskar et al. 2024). These methods may involve selectively recruiting from groups that are less likely to engage or setting criteria for the skills, experiences, and characteristics participants should have (El Enany et al. 2013; Fung 2006). For example, the Ontario Government's *Roadmap to Wellness: A Plan to Build Ontario's Mental Health and Addictions System* included input from health system leaders, community organizations and other governmental actors, and also specifically sought input from "people with lived experience of mental health and addiction issues, their families and caregivers" (Government of Ontario 2020).

There is a risk that targeted recruitment and appointment replicate the problems of self-selection if they privilege familiar groups – people with whom organizers have an existing relationship and/or those who have previous experience with patient engagement. In such cases, targeted recruitment can lead to professionalization of participants and their loss of legitimacy with the group they purport to represent (El Enany et al. 2013). While an existing relationship with organizers can promote trust in the engagement process, it risks excluding dissenting voices and privileging those who have proven to be agreeable, especially if the relationship is predicated on organizers having power over outcomes that are important to participants. Where recruitment is shaped by narrow eligibility criteria and norms of engagement, targeted recruitment risks having the participants fit the process rather than the other way around. Glimmerveen et al.'s (2021) study of community engagement in a long-term care organization in the Netherlands finds that critical voices were excluded from the engagement process by organizers and more supportive participants because they violated the norm of "constructive engagement." Participants who were critical of the process were characterized by organizers and other participants as "too loud," "not saying anything substantial" or not really looking for solutions, and thus their participation was deemed illegitimate (Glimmerveen et al. 2021: Table 2).

The problem of replicating issues of self-selection may be relatively obvious and therefore easy to avoid by dedicating additional resources; however, problems of participant professionalization leading to a loss of credibility and an informal exclusion of critical voices are more subtle, and may require fundamental changes to the design and implementation of an engagement process. Meaningful participation is not just "recruiting better" – it is also ensuring that the engagement process is able to accommodate and metabolize the contributions of a wider range of participants.

Whom to Engage and How to Reach Them?

Early in planning, we knew we wanted a participant composition that balanced researchers, government, healthcare organizations and community members – patients, caregivers and members of the public who have lived experience of illness/with the health system or who are affected by health policy planning, either directly or indirectly. Realizing that we wanted participant diversity and a balance among target groups, we decided to use targeted recruitment. Leveraging our existing networks, we sent invitations in rounds to specific individuals, assessing attendee composition at regular intervals. We used snowball sampling to expand the list of invitees, which generated further invitees. Finally, as the event date approached, we used a self-selection approach and sent open invitations to organizations, groups and listservs we thought might be interested.

We intended for the majority of community members who participated would be people who are not well-served by existing structures for public engagement. To reach these communities, we relied on our existing networks and reached out directly to organizations working in health services, policy and Black advocacy. While we took steps to lower participation barriers for these audiences, all patient advisor participants were part of well-established engagement programs (see Appendix 1, available online at longwoods.com/content/27415). The participation of these attendees was very valuable, although we reflect below on possible barriers to broader participation.

Our team, with rich interdisciplinary networks within the target groups we wanted to engage with, assumed that these strong, pre-existing networks would be a benefit, as existing trust provides a valuable foundation for communication. While these networks produced a diverse invitee list, comparing the list of initial invitees to that of attendees suggests that uptake across team members' networks was variable in ways we should have better anticipated and accounted for. (Please note that we did not collect detailed demographic data from participants, so cannot quantify the diversity of participants in terms of race, gender or age.)

We knew that using our existing networks also risked biasing participant composition, relying too heavily on partners who have been "professionalized" (El Enany et al. 2013), excluding negative contributors (Glimmerveen et al. 2021) or working with people who were too familiar to be able to provide novel perspectives (Greenhalgh et al. 2011). Yet we were reasonably confident that contributors with critical feedback would have space to share their reflections, for three key reasons. First, the diversity of our networks meant that some invitees were newer to the space. Second, the established collaborative relationships many invitees had with one or more project team members was expected to mitigate power imbalances, as being empowered to critique processes requires a certain amount of trust that there will be no personal or professional repercussions. Finally, the workshop goals were relatively low stakes: the project team was not making policy decisions, but rather seeking to share and improve its research practices and results. Participant feedback during and after the workshop suggested that there was space for critical reflection, although biases may have persisted.

Beyond Recruitment: Accessibility and Compensation

Once we had decided on targeted and self-selection recruitment methods, we knew we had to design our workshop in a way that allowed those we recruited to participate according to their preferences while also meeting the goals of engagement. We sought to balance in-person, discussion-based small group sessions with the knowledge that participants may be better able to participate if they could join remotely, particularly those not in academia or with caregiving responsibilities (e.g., Abelson et al. 2022 Tripp et al. 2022). We ultimately decided to break the day into two components. In the morning, we showcased new and emerging research, and participants were able to engage both online and in person. The afternoon session was designed to further our collective understanding of engagement in health policy and help develop resources to aid engagement, and as such, was in person and interactive.

We held the event on campus at McMaster University in Hamilton, ON, which enabled us to use campus resources to host online participation; it reduced logistical barriers (e.g., we were easily able to provide parking passes) and it was accessible. However, this decision runs counter to the engagement principle of meeting people where they are at. This critique was picked up in a post-event survey, where one respondent commented that "meaningful inclusion is hard when activities always take place on researchers' 'turf'". A subsequent event organized by the team was held at an off-site satellite campus of McMaster, and in future we would consider the possibility of other accessible public spaces, like the Art Gallery of Hamilton.

We had decided early on to offer compensation to acknowledge the contributions of articipants (Fox et al. 2024; Greenhalgh et al. 2011), but we did not anticipate the complexity of university policies. For example, we could reimburse travel expenses, but could not offer a per diem since the workshop included lunch. We also recognized that a burdensome reimbursement process may in itself be a disincentive. We therefore offered an opt-in honorarium with a low barrier to apply – all participants received an expense claim form (see Appendix 2, available online at longwoods.com/content/27415) that allowed them to opt into the honorarium, which did not have minimum participation requirements. We ensured information about compensation was easily accessible in all workshop communications.

We were also navigating the ongoing effects of COVID-19 during event planning. We held the event in person on the McMaster campus, although we were prepared to pivot to a virtual event if necessary. Workshop communications outlined specific health measures being taken, including offering high-quality masks, which we strongly encouraged (but did not require) participants to wear. We also ensured that there was accessible outdoor space during refreshment breaks. Still, we recognize that barriers may have persisted, especially as the afternoon sessions were held in smaller rooms and mask-wearing was not mandated.

Evaluating Recruitment: Tracking Participation and Promoting Reflection

As we did not track demographic details of participants (race, gender), we cannot know whether groups were underrepresented or overrepresented. We faced a tension common to researchers seeking to conduct meaningful engagement. On the one hand, collecting demographic data is critical for understanding who is under- or overrepresented. However, collecting these data may act as a disincentive to participation; it risks exacerbating the perception of participants as research "test subjects." Such feelings may be amplified for groups who have been harmed through historical and ongoing research practices, justifying our decision not to track demographic details.

While we were not planning a workshop that was statistically representative of the wider population, we recognize that choosing not to track demographic details hindered our ability to gauge the success of our outreach efforts. Rather than avoiding demographic data entirely, we would recommend collecting basic data and openly communicating the goals of the engagement activity and intended use of the data.

While we did not collect demographic information, we do have some information about attendees, such as organization type and role (Appendix 2). The morning session was hybrid, and 57 participants joined the discussion via Zoom. The majority of participants identified were either researchers or engagement professionals. Online participation allowed multiple people to attend from the same organization, and also meant broad geographic participation, including attendees from other provinces (British Columbia) and cities (Ottawa).

Afternoon workshop participants were asked to complete a consent log indicating how they would like to be identified. This allowed participants to identify their role in relation to engagement. Participants were primarily patient advisors, students, researchers or engagement practitioners. However, we note that although participants may have indicated their *primary* attribution, participants may bring experience from multiple perspectives. All in-person community participants were patient advisors associated with two organizations, both of which have existing relationships with research team members and/or the university. These existing relationships were likely important in individuals' decision to participate, reiterating the importance of networks. Our experience suggests that more organization-specific outreach is important early in the recruitment process to ensure that prospective participants find both the "ask" and the "offer" of the engagement activity acceptable, and to ensure sufficient flexibility to respond to participants' needs and interests.

Lessons and Recommendations

We finish by reflecting on lessons from the literature, and the challenges and trade-offs that come from applying them in practice. This is not to critique the theories of recruitment and engagement listed above, but rather to highlight the barriers to real-world application of such theories.

We chose two methods of recruitment, self-selection and targeted recruitment, both of which carry inherent biases. However, we were confident that these methods matched our engagement goals and took steps to mitigate common pitfalls.

Recognizing that self-selection may lead to an over-representation of certain groups, we limited the first tranche of invites, being intentional about the composition of researchers, practitioners and community members. We offered low-barrier compensation, which was clearly communicated to partners. We sought to mitigate concerns about COVID-19 by outlining the safety measures we were taking and going beyond the minimum required by the university.

Our conservative and iterative recruitment process allowed us to balance representation of various groups and respond to participant needs to ensure the agenda reflected their priorities. However, this iterative approach also limited broad recruitment and promotion. In hindsight, promoting the event widely from the outset may have attracted more diverse voices. While ensuring a balance of participants was important, it came at the expense of attracting a broad audience and potentially reaching individuals who were not familiar with our research project. Likewise, our decision to not collect demographic data limited our ability to reflect on the diversity of our participant composition. Requesting this information, and communicating its purpose clearly, would be beneficial for people seeking to improve their own recruitment processes as long as this aligns with participant preferences.

Our recruitment strategy leveraged existing networks and relationships branching from the research team. A key lesson here is that building rich, trust-based networks is essential for designing responsive and meaningful engagement. However, building these networks requires significant time and investment. Policy makers and researchers should allocate time to foster relationships well in advance of, and outside the purpose of, engagement. For managers, we suggest that this time investing in relationships should be recognized and valued, even if there are no immediate tangible benefits. This long-term relationship building is especially essential when making "asks" of time-constrained, overworked and under-resourced community organizations, who must see engagement as a worthwhile investment before they decide to participate. Finally, we recommend recognizing the boundaries of one's networks and consider how to include voices that lie outside networks or those voices that may be excluded from formalized networks. There are tools available to help with this work; we recommend in particular the Public Engagement in Health Policy Project's step-by-step guide to equity-centred engagement (Ul Haq et al. 2023).

Hybrid events, or at least some hybrid components, are largely expected now. We recommend that event organizers consider their goals and understand the trade-offs when deciding to host events online versus in person. Although it requires more logistical planning, hybrid components can help promote accessibility, especially as we adjust to post-pandemic life.

Event organizers may find it helpful to consider the geography of their potential audiences, the format of the event and what technological supports would be required. Finally, we suggest that online participants are not treated as secondary participants; small steps, like having an online question-and-answer moderator, may help to build online inclusion. The field of engagement would also benefit from more research that investigates the implications of online versus in-person participation.

We also recognize that a single event is unlikely to facilitate the full range of input and voices needed to make informed decisions and will systematically exclude those who have other responsibilities during the day. We suggest considering how to garner different perspectives from different places (e.g., offering shorter evening meetups or changing the location to a community centre) and, where possible, engaging in more personalized outreach to meet the preferences of the communities and organizations being engaged. This diversity of approaches would also help to create conditions in which participants with "fresh eyes" can be critical, while also working with partners with whom there are trusting relationships. This mosaic approach is present in work by Rowland et al. (2021) who advocate for incorporating different activities and participants based on the objectives of the engagement. We recommend being up front and honest about the limitations of the event format; a single event is unlikely to achieve all goals of engagement. Relatedly, we suggest that managers set reasonable expectations of engagement activities and dedicate resources for multiple points of engagement where possible.

It is clear that there is no formula or process that organizers can use to fulfill all goals of engagement. Organizers have to be flexible, responsive and willing to invest time to engage diverse communities. This means carefully considering the location and timing of the event, planning opportunities for satisfying online participation and considering the possibility of multiple points of engagement in different formats. It also means devoting time and resources to "engagement about engagement": how researchers and practitioners can get feedback on the engagement activity itself and incorporate those lessons into future work.

Conclusion: A Call for Reflexive Recruitment

Through our workshop, we were able to apply theories of recruitment in practice. We now offer some directions for the future. For researchers, we suggest more comparative research that explores the ways in which recruitment affects both the process of the engagement itself and the outcomes that follow. Few comparative studies explore this question, which has led to a lack of understanding of the impact that different recruitment methods have on engagement. For practitioners, we suggest thoughtful reflection about the goals of engagement and how recruitment may shape their ability to realize these goals. We urge practitioners to be reflexive, and regularly consider how design decisions may produce exclusionary effects. Exclusion can be complex and requires frank conversations, not only with participants but also invitees who chose not to participate. It requires asking about experiences with engagement, and what voices or perspectives are missing. It also requires recognition that barriers to participation go beyond logistical issues such as costs, location and time and extend to experiential elements such as how safe, welcoming and inclusive the space feels and whether the institution has the capacity to hear different perspectives and respond to calls for change.

Key lessons from our own experience include setting aside time to build relationships outside of specific engagement activities; ensuring that the event design allows for critical reflection; providing online participation options if relevant; having strategies in place to evaluate the success of recruitment strategies; and, where possible, hosting multiple engagement opportunities. Where it may not be feasible or desirable for some prospective participants to come to a full- or part-day workshop, pursue other opportunities to work with communities who might find value in the work. Finally, in some instances, the best solution may not be a marginal adjustment to standard recruitment methods, but instead a process of public engagement that turns *recruitment* on its head by seeking out community-led engagement so that affected groups determine the terms on which they contribute to the policy process (George and Abebe 2022).

The first step to improved engagement, whether for a researcher or for a practitioner, is understanding what the potential pitfalls are; to address them requires reflexivity, honesty and a commitment to balance trade-offs and adapt to participants' needs.

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Note

[1] For more on these terms, see the McMaster University Public Engagement in Health Policy Project's key terms and concepts: https://ppe.mcmaster.ca/research/public-engagement/key-terms/.

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RESEARCH PAPER

Whom Do I Trust to Represent Me? Long-Term Care Resident and Family Perspectives on Legitimate Representation

En qui puis-je faire confiance pour me représenter? Point de vue des résidents en soins de longue durée et de leurs familles sur la représentation légitime

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Abstract

Introduction: Public engagement in long-term care policy making in Canada has primarily focused on "intermediary agents" who speak on behalf of long-term care (LTC) residents and their family caregivers. Yet the legitimacy of these intermediaries, as perceived by those they represent, has gone largely unexplored. This study examines LTC resident and family perspectives on who can legitimately represent them in LTC policy making.

Methodology: We used an interpretive description design, drawing on semi-structured interviews with LTC residents and family caregivers in Ontario, Canada. Data were analyzed using inductive thematic analysis.
Results: Eighteen interviews were conducted with 19 participants. Three key characteristics of legitimate representatives were identified: (1) willingness to act in the best interests of residents and families, (2) having the necessary skills and capacity to participate in LTC policy making and (3) engaging directly with residents and families.
Conclusion: Governments and civil society organizations seeking to establish and maintain legitimacy in the eyes of LTC residents and family members can pursue this goal by supporting intermediaries who mirror the identities or experiences of those they represent, who are dedicated to serving their interests and who routinely and directly engage with them to understand the realities of LTC.

Résumé

Introduction : La participation du public à l'élaboration des politiques de soins de longue durée au Canada a surtout été axée sur les « agents intermédiaires » qui parlent au nom des résidents en soins de longue durée (SLD) et de leurs proches aidants. Pourtant, la légitimité de ces intermédiaires, telle qu'elle est perçue par ceux qu'ils représentent, demeure largement inexplorée. Cette étude examine le point de vue des résidents en SLD et de leurs familles quant à savoir qui peut légitimement les représenter dans l'élaboration des politiques.
Méthodologie : Nous avons utilisé un modèle de description interprétative, en nous appuyant sur des entrevues semi-structurées avec des résidents en SLD et leurs proches aidants en Ontario, au Canada. Les données ont été analysées à l'aide d'une analyse thématique inductive.
Résultats : Dix-huit entrevues ont été menées auprès de 19 participants. Trois caractéristiques clés des représentants légitimes ont été identifiées : (1) la volonté d'agir dans l'intérêt supérieur des résidents et de leurs familles, (2) avoir les compétences et la capacité nécessaires pour participer à l'élaboration des politiques en matière de SLD et (3) s'engager directement avec les résidents et les familles.
Conclusion : Les gouvernements et les organisations de la société civile qui cherchent à établir et maintenir leur légitimité aux yeux des résidents en SLD et de leurs familles peuvent poursuivre cet objectif en soutenant des intermédiaires qui reflètent l'identité ou les expériences de ceux qu'ils représentent, qui se consacrent à servir leurs intérêts et qui communiquent régulièrement et directement avec eux pour comprendre les réalités des SLD.

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Introduction

Governments across Canada have recognized public engagement (PE) as an integral part of health policy making (Abelson and Eyles 2004). Compared to traditional approaches to policy making, where the public remains a passive beneficiary of policy decisions, PE has various anticipated benefits, including developing better-informed policies and enhancing the perceived legitimacy of those decisions (OECD 2009). In Ontario, the *Patients First Act* (2016) and the establishment of Ontario Health Teams align with the active engagement of patients and communities in health system planning, design and governance (Government of Ontario 2024). The value of public input has also been recognized in Ontario's long-term care (LTC) sector, although the direct involvement of LTC residents and families is in its infancy (Frank et al. 2023).

Residents and families can join a residents' or family council in their individual home to advocate for their needs; however, their roles are generally limited to the personal care or facility level, such as care conversations, planning social activities and meal and laundry services, and do not extend to policy making (Hylmar 2016). Instead, various individuals or organizations are often observed proposing policy solutions for the health and well-being of LTC residents (Barbieri and Ghibelli 2017; You and Abelson 2022). These entities, which can be referred to as "intermediary agents," act as a bridge between policy makers and LTC residents and families, representing the interests of residents and families in policy making (Falanga et al. 2021; Keogh et al. 2021). Intermediary agents are not limited to a single type of role or profession within the sector and may hold multiple identities, including LTC residents (e.g., a resident who also serves as an organizational representative of seniors) or family members (e.g., a family member who is a geriatrician) (Barbieri and Ghibelli 2017).

The reliance on intermediaries in LTC policy making can be attributed to the prevailing regulatory environment prioritizing safety concerns over residents' autonomy (Frank et al. 2023). Additionally, challenges faced by LTC residents, such as physical and cognitive frailty (Holroyd-Leduc et al. 2016), constrain their ability and willingness to contribute directly to policy making (Mattila et al. 2017). These unique factors in the LTC sector provide self-claimed representatives with active and expanding roles in policy making, often without a formal authorization process (e.g., elections) (Leardini et al. 2019). While the engagement of intermediaries can ideally yield similar benefits as PE (Martinez and Kohler 2016), it does not automatically legitimize their representation (Montanaro 2012).

Political representation and related concepts of legitimacy and authorization are complex concepts with a wide range of interpretations (Arnesen and Peters 2018; Rehfeld 2011). For instance, descriptive representation, where representatives mirror the social identity or experiences of those they represent (e.g., female representatives representing female constituents) (Mansbridge 1999) may compromise substantive representation, which focuses on actual policy alignment with constituents' interests (Arnesen and Peters 2015). Furthermore, the debate extends to whether substantive representatives should act as delegates, following constituents' preference, or as trustees, using their own judgement to determine the best action (Dovi 2018). Given these multiple meanings of representation, this study adopts Suchman's (1995) view of legitimacy: "a generalized perception or assumption that the actions of an entity are desirable, proper, or appropriate within some socially constructed system of norms, values, beliefs, and definitions" (p. 574). Legitimacy is subjectively constructed (Arnesen and Peters 2018) and the perspectives of those represented serve as the baseline for assessing the legitimacy of representation (Leardini et al. 2019).

Despite the active role of intermediary agents in LTC policy making in Ontario, their legitimacy, as perceived by those they represent, remains largely unexplored. This research examines the perspectives of LTC residents and their families on who they believe can or should represent their interests in policy making.

Methodology

Design

This study uses an interpretive description design (Thorne 2016). This approach is commonly used to develop knowledge relevant to clinical and other applied health contexts. Interpretive description recognizes that understanding of realities is co-constructed between the researcher and participants (Hunt 2009).

Sampling and recruitment

Purposive sampling was used based on the following criteria: (1) age 18 years or older, (2) personal experience as a resident or a family caregiver of a resident in LTC facilities in Ontario and (3) English fluency. Participants were recruited through e-mail outreach to organizations across Ontario that closely collaborate with or advocate for LTC residents and family caregivers, online advertisements on Twitter (now X) and LinkedIn and snowball sampling through participant referrals. The online advertisements generated numerous potentially bogus responses (e.g., brief e-mails lacking detail about respondent experience with LTC and directed inquiries about the study honorarium) and this recruitment approach was stopped immediately. The recruitment focus shifted to direct contacts with organizations known to collaborate with LTC residents and family caregivers, asking them to share the recruitment information through their networks. By employing this approach, we were aware of the possibility that these organizations, which themselves can be considered intermediaries, may have shaped our results.

To appreciate participants' time, an honorarium of $25 was provided in the form of a gift card or mailed cheque. Recruitment and data collection ceased when the lead investigator (JY) determined that the study had reached a point where data analysis had the potential to provide new knowledge to extend existing evidence and adequate information power was established. Ethics approval of the study was obtained in November 2022 from Hamilton Integrated Research Ethics Board (reference no. 2022-15150-GRA).

Data collection

One-on-one semi-structured interviews were conducted, except for two family caregivers who requested to participate together. Interviews were conducted in English via Zoom, digitally recorded and transcribed verbatim. Reflective notes were taken during and shortly after the interviews. The interview transcripts and reflective notes were stored in the NVivo data analysis software.

The interview guide included general questions, enabling interviewees to freely discuss characteristics of good intermediary agents in policy making. Probes were used to elicit and clarify the interviewees' responses. The concept of "intermediaries" was introduced at the beginning of each interview as those who speak on behalf of LTC residents and families in Ontario's LTC policy making. The interviewer provided examples (e.g., "they can be professional groups, labour unions, charities, business associations or academic experts") without referring to specific organizations. When asked for examples, the interviewer named some active intermediary agents in Ontario and continued to discuss their characteristics.

Data analysis

Interview data were analyzed using inductive thematic analysis procedures (Maguire and Delahunt 2017). The method of constant comparison was used, which encourages researchers to remain skeptical and continuously question the initial conceptualizations of the collected data to obtain a coherent and rich interpretation about the phenomenon of interest (Hunt 2009; Thorne et al. 2004).

Results

Eighteen interviews were conducted with 19 participants. The interviews lasted 45 to 70 minutes. Participants included 17 family caregivers and two LTC residents with experience in Ontario LTC facilities.

Three unifying themes were identified describing the core characteristics of trustworthy intermediaries. Each theme is discussed below, with illustrative quotes attributed to different types of respondents (i.e., R for resident or FM for family member + participant number).

Before delving into core characteristics, participants discussed the role of intermediaries. They acknowledged the importance of representation for LTC residents and their families, particularly when self-advocacy is challenging. They noted various barriers to advocating on their own behalf, including residents' cognitive impairment and family members' commitments, such as day-to-day caregiving for the residents, jobs and childcare.

One participant explained:

> The average length of stay for residents in long-term care is 18 months. They're so much more physically and medically compromised when they move in. So as a result … they're turning over so quickly that you don't – you know, they certainly can't organize and get together and do anything …. So we need to have someone that speaks for us. (FM8)

Participants also frequently mentioned the fear of repercussion when voicing their concerns, underscoring the need for others to speak for them. One participant described "see[ing] it in the family council when people will complain about something and they're like, 'But don't say I said it'" (FM5).

Despite acknowledging the importance of intermediaries' role, participants expressed uncertainty about the alignment of intermediaries' interests with their own, prompting questions such as "whose interests are they acting on?" (FM1).

Theme #1: Trustworthy intermediaries are willing to act in the interests of LTC residents and families

Participants emphasized the importance of intermediaries' sincere willingness to improve LTC policies and systems. One participant described this as, "you have to have that passion about it to say, you know what, I'm going to be in this place too at some point, hopefully, and I want to make sure I'm taken care of" (FM5). Participants differentiated this dedication from that of intermediaries who consider their roles as a "stepping stone" to future careers (FM2) or who would "walk away" when offered better terms and pay (FM10).

Participants also emphasized the importance of intermediaries who share the social identity of residents and/or family members, suggesting that intermediary groups include LTC residents or their families "[in] some proportionality of the representatives on a committee" (FM17) to provide important perspectives of "those who are actually living [in LTC environments]" (FM15). To this end, some participants proposed a form of "direct engagement" (FM1), for which governments "empower" them (FM3) and host government-led "direct engagement with a representative of every resident of a long-term care facility to provide annual feedback" (FM11).

Concerns were expressed over intermediaries who primarily support the interests of different groups rather than the interests of LTC residents and their families (e.g., health professionals, researchers or LTC home operators). This misalignment was worrisome, as the priorities of these intermediaries may deviate from those of residents and families. For instance, one participant mentioned that intermediaries with a labour perspective might be "too narrowly focused" on financial investments, increased staff and training as opposed to the care outcomes for LTC residents (FM17). In this regard, some participants viewed intermediaries' past actions and accomplishments as important indicators of their genuine passion and dedication to represent them, as described by this participant:

> They can say that they represent the seniors or long-term care resident, but if I want to see if an individual or an organization, whether they can truly represent [us] or do what they say, I will look at their credentials …. What have they done in the past? (FM16)

Notably, participants want intermediaries to be more engaged in advocacy efforts with a "rock the boat" stance (FM8), rather than merely behaving like a liaison. These perspectives were prominently voiced in relation to government-funded intermediaries who may feel limited in speaking out or challenging the government, therefore inhibiting policy change. As one participant described:

> [Anonymized] are into gradual, easy steps, trying to be gentle and positive and not antagonize. There are situations where they seem to want to tone things down so that you don't get confrontational questions or confrontational statements being made …. [T]here's no way that the [anonymized] can become self-supporting to be truly independent of government [or] other voices. (R2)

Intermediaries taking on a "middleman" or "liaison" role (FM8) rather than being LTC advocates generated concerns among participants who perceived that their voices are "purposely ignored" (FM10), "filter[ed]" (FM4) or "stifle[d] in the wilderness" (FM10) by intermediaries. Participants felt that some intermediaries intentionally avoided welcoming and listening to their concerns by not clearly communicating the existence of family council meetings to family members (FM12), or by directing family members to "talk" about their complaints rather than "write" them down (FM9). Accordingly, many participants identified the importance of intermediaries being free from potential conflicts of interest and hidden motives. This emphasis was prominent when discussing the for-profit industry:

> [For-profit industry actors are] motivated by their bottom line … [and] some of the things that they do are based on economies and efficiencies … . Their opportunities were there to eliminate costs [for] them: maybe it's in the cleaning and painting, the maintenance, things like that, that they don't end up spending the money. (R2)

Finally, participants identified the provision of accurate and balanced information and perspectives as a sign of information not being "compromised … to fit the political reality" (FM1). The need for transparency in conveying information was also stressed to ensure their interests are accurately represented with "a great deal of integrity … [rather than] interpret[ing] it the way they wish" (FM4).

Theme #2: Trustworthy intermediaries have the necessary skills and capacity to participate in LTC policy making

Participants underscored the importance of intermediaries having the necessary knowledge, skills and capacity to be able to contribute effectively to policy making. One participant described the importance in this way:

> Politicians do not listen to individuals … . [Y]ou need to have someone who represents a larger group … being communicated with on a regular basis, sending those weekly information bulletins, responding positively to personal enquiry, leading workshops, organizing – that is the person that has a better chance of being actually heard. (FM2)

Participants valued a range of professional knowledge and expertise, such as geriatrics, nursing, dietetics, pharmacy, human rights and disability laws, space design and change management. One participant stated, "I can accept when people with learned backgrounds, who have studied epidemiology, who have studied medicine, who know about healthcare in terms of, you know, they are legitimate professionals, right." (FM10).

Participants also perceived the lived experience of LTC residents and their families, as well as the first-hand knowledge of front-line workers, as an important form of knowledge that reflects the realities of LTC, ensuring intermediaries have an "accurate picture of what should happen" (FM13). This knowledge was perceived as essential compared with "findings from other reports that may not have the true understanding" (FM16). Most believed that the LTC policies and programs do not accurately reflect "the current realities" (FM1), including "the daily frustrations [of residents]" (R2) and "the boots-on-the-ground" perspectives (FM6). In this regard, some participants explicitly valued lived experience over professional knowledge. As one participant stated, "We treat the doctor as God, we listen to everything they say. Right. But then the doctor may not be aware of … very small things that family members know about the residents that the doctors don't" (FM16). While valuing lived experience, participants emphasized the importance of intermediaries being able to differentiate "the personal story with the overall message" (FM2) and address the shared needs and concerns common to all individuals in LTC homes.

Participants perceived adequate resources and skills as key enablers in making their voices "visible to public" and being able to "put a bit of heat on decision makers" (FM11). This was described as having effective communication skills to deliver clear and concise messages that can be understood by both the public and government officials (FM2), "understanding of all the factors at play there [bureaucracy of the health system]" (FM11) and "networking with people [key LTC stakeholders]" (FM17). Adequate "operating funds" (FM12) were identified as important support for this work, rather than relying solely on volunteers.

Participants who emphasized the importance of lived experience favoured intermediaries with this experience over those trying to attain the level of policy resources and capacity of other well-resourced entities (e.g., LTC industry). As one participant articulated:

> I don't expect … their job … to work magic and come up with a lot of change overnight. If they put forth 50 things in front of government and two things were truly addressed, I would think, "OK, that that's good progress," because I know it's not realistic to think you get 100 percent. (FM14)

Theme #3: Trustworthy intermediaries effectively engage with LTC residents and families

Participants emphasized the importance of engaging with intermediaries through regular, two-way dialogue as a crucial aspect of their trustworthiness. As one participant stated, "I could communicate my personal opinion, I could say – have you considered this? As long as I am not dismissed, then that person still has my respect and I trust that that person is speaking on behalf of the greater good" (FM2). Conversely, participants reported distrust in intermediaries who display a lack of interest in hearing from residents and families, describing experiences in which two-way communication was absent:

> They were in a communicating or telling mode, not asking mode … . I'm not asking for direct access to the policy decision maker, but there has to exist some kind of a vehicle through which voices are heard. (FM10)

Participants found that two-way communication helps intermediaries to accurately represent their interests. As one participant stated:

> These people should be in communication directly with residents. So that they're coming from that, and they can go ahead and say, "These are what the residents' opinions are, and these are what the residents would like to see happen." And be able to speak forthrightly on that. (R2)

Even with available opportunities for interaction, participants want intermediaries to gather input from a wide range of individuals. Participants emphasized the diverse and heterogenous care needs of LTC residents and felt that intermediaries communicating only with specific segments (e.g., those who are frail) are not effective representatives. One participant stated, "I'd mainly worry about them speaking, because they all make assumptions about your level of cognition… . [O]ne person cannot just represent someone like me with cognitive skills and then someone who needs a feeding tube" (R1). Another participant echoed this perspective:

> If the government assumes long-term care is for people who are physically and mentally compromised to the point of not being able to speak for themselves, they go to organizations that represent only those groups. And they will get the perspective of only those groups …. So if there were an association that very proactively reached out and made a point of getting the perspectives of underserved … I would trust them. (FM15)

Regarding the pursuit of diversity, participants emphasized the importance of intermediaries' proactive outreach to those who may be less inclined to speak up, including "the silent majority" (FM10) and "the perspectives of underserved" (FM15). One participant explained:

> You get the people [who] complain because they're angry enough to make the effort … . [Y]ou've turned off a lot of people who might have really good ideas and want

> to move things forward or whatever. So, you've got to really encourage everyone and meet them where they're at and really try and bring them out. (FM8)

Participants also highlighted their preferences for particular methods of engaging with intermediaries. One participant noted, "I don't find questionnaires that fulfilling, I like the one-on-one Zoom calls … because I think that's when people really listen to you." (R1). Another participant reaffirmed this idea: "If we were to try to write this in the e-mail format to have our discussion, you'd probably spend two weeks putting it together to write it back-and-forth …. It's not as efficient as everybody claims." (FM1). Other participants emphasized the need for a safe way of communicating, "They have meetings with residents and goes[sic] over issues, so there's a system in place. But when it comes to something that, what's the word, controversial as what I raised, I'm inclined to think I might do something more anonymous" (FM4).

Discussion

Discussion of the findings in relation to relevant literature

Our results have implications for common PE practices in current LTC policy making. The importance of having intermediaries who can represent the interests of LTC residents and families in situations where they are unable to speak for themselves is recognized, although concerns arise regarding the alignment of intermediaries' interests with those of LTC residents and families, which in turn affect the level of trust in their representation. The emphasis on trust in our findings is unsurprising, as trust forms the basis for constituents' willingness to endorse the legitimacy of their representatives (Hegtvedt 2015; Moreno-Luzon et al. 2018).

Our findings prominently highlight the value of intermediaries who either mirror the identity of or possess experience as LTC residents or family members. On the surface, this resonates with the concept of descriptive representation, frequently linked to perceived legitimacy within politically disadvantaged populations (Arnesen and Peters 2018). However, our findings also offer insights into substantive representation, which is often observed together with descriptive representation but brings a stronger focus to the policy outcomes that arise from representation (Hayes and Hibbing 2017). Our study participants connected the characteristics of substantive representation with intermediaries' willingness and capacity to act in their best interests as a means to drive actual benefits, rather than the characteristics of descriptive representation, in which intermediaries' identities merely matched those they were representing (e.g., average or randomly selected entities that have the identity or experience of LTC residents or family members).

Study participants' emphasis on intermediaries' identities and experiences partially echo tensions observed in previous studies between professionals' and LTC residents' views regarding what is best for residents (Nelson et al. 2005) and perceived conflicts between residents, families, staff and institutions regarding residents' safety and quality of life (Armstrong

2018). However, with the exception of entities closely associated with the for-profit industry, participants regarded the lived experience of LTC residents and families as complementary rather than contradictory to the expertise of other stakeholders (e.g., medical professionals).

Participants perceived that effective two-way communication between intermediaries and LTC residents and families can function to enable and facilitate the desired characteristics for trust. This finding aligns with literature on "consucrats" – individuals who themselves are consumers and have become professional advocates, representing a specific group or community. Consucrats often encounter credibility challenges as consumers' representatives, as they become too professionalized and entrenched in the health system, leading to a loss of effectiveness and authenticity over time (de Leeuw 2020). To ensure their effectiveness and authenticity, broadening their engagement efforts to connect with those they represent is critical. This allows representatives to convey a wide range of real-world concerns beyond their personal views and their efforts gain support from the voices they represent (DeCamp et al. 2021; Yamashita 2013).

Interestingly, our study participants emphasized factors related to input legitimacy (i.e., ensuring fair and inclusive policy making process) over output legitimacy (i.e., producing acceptable policy outcomes) (Boedeltje and Cornips 2004; Strebel et al. 2019). This could be attributed to the study's focus on intermediaries' characteristics connecting more with input rather than output. However, several participants explicitly recognized intermediaries' constraints in being able to influence policy change while still valuing desired characteristics (e.g., lived experience and shared identity as a LTC resident or a family member or caregiver). This may indicate that participants recognize the legitimacy deficiencies existing within the procedural elements of current LTC policy making environments, while also understanding the dynamics associated with achieving policy change.

Implications for policy and practice

While many intermediaries have represented and advocated for the interests of residents and families, there is a lack of understanding regarding which intermediaries are perceived as legitimate from the perspectives of those they represent. Our findings reveal the perspectives of LTC residents and families on who they believe can and should represent them in policy making, which has direct implications on LTC policy making in Ontario and other jurisdictions with similar LTC arrangements.

Ontario's *Fixing Long-Term Care Act* (2021) mandates annual consultations between the Minister of Long-Term Care and organizations representing residents' and family councils. However, it does not specify which organizations should be consulted, raising concerns about representation in the context of the varied intermediaries within the LTC sector – concerns that were emphasized by our study participants. Governments can address these limitations by disclosing the criteria for selecting organizations and regularly updating the list of organizations chosen, based on feedback from LTC residents and families to better reflect their views. In addition to consulting intermediaries, the government can facilitate direct input from a diverse range of LTC residents and families while considering the resource constraints of intermediaries, which was also highlighted by our study participants. This requires establishing safe channels to protect those who voice concerns and employing accessible and effective engagement methods for diverse populations. By implementing these measures, the government will take important steps toward ensuring legitimacy of their policy making approaches in the eyes of LTC residents and family members. If other jurisdictions similarly recognize the active roles of intermediaries representing LTC residents and families in various PE initiatives, these recommendations could be valuable for government entities in enhancing the legitimacy of their policy making approaches.

Intermediaries in Ontario and other jurisdictions aiming to enhance their legitimacy should regularly engage with LTC residents and families to gather comprehensive first-hand knowledge. Such engagement will demonstrate their commitment to their representative roles. Furthermore, they can develop competencies to be effective in the policy making arena, including advocacy, political entrepreneurship and communication skills. Publishing summaries of their engagements and detailing how engagement input influenced their activities could also foster transparency, an important enabler to increasing perceived legitimacy.

Implications for future research

This study purposefully used a broad definition of intermediaries without differentiating between the various types (e.g., individuals, small-scale organizations, large-scale organizations). Future research could explore how perceptions of legitimacy might vary by the distinct types of intermediaries, as their responsibilities, memberships, organizational structures and resources inherently shape their characteristics and activities. Additionally, with participants prioritizing input legitimacy over output legitimacy, further research can investigate the empirical and perceived connections between the two. Lastly, it is crucial to investigate the perceived legitimacy of intermediaries' representation and desired characteristics across different contexts, considering the necessity of intermediaries for other populations who cannot advocate themselves.

Conclusion

This study has uncovered three essential characteristics of intermediaries closely related to their legitimacy in representing LTC residents and families, as perceived by them. Our findings offer valuable insights for government and non-government organizations endeavouring to enhance or maintain legitimacy within the long-term care policy making process, particularly where intermediaries play an active role.

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RESEARCH PAPER

Black Community Health Advocates in Ontario: A Look at Health Policy Engagement From the Ground Up

Défenseurs de la santé de la communauté noire en Ontario : regard de fond en comble sur la mobilisation des politiques de santé

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Abstract

Study objectives: Disproportionately negative pandemic outcomes, lack of race-based data collection and poor engagement of Black communities in policy decision making have been widely documented for Black Canadians. We examine this to understand how formal public engagement processes might be more inclusive of Black peoples to inform more responsive policies.
Methods: The study employed an asset-based lens to examine how Black communities have engaged in health policy and advocacy in Ontario. In-depth interviews were conducted with eight participants who self-identify as Black, recruited using purposive and intensity sampling to (1) identify *information-rich* cases, including people who have been at the forefront of high-impact work in this space and (2) participants whose mission and mandates represented diverse approaches and sub-populations.
Results: Our findings suggest that while Black community advocates face systemic and contextual barriers, they also embody deep and multifaceted knowledge, training and experience, which inform the rich ways that they approach advocacy.

Discussion: Despite its Ontario focus, this study adds breadth and depth to the existing literature on health policy and historically marginalized populations, offering broader lessons for policy makers across jurisdictions. Our findings encourage policy makers to better recognize, make space for and cultivate fertile advocacy foundations, cultural knowledge and community-driven systems already present in Black communities.

Résumé

Objectifs de l'étude : Les résultats disproportionnés négatifs de la pandémie, le manque de collecte de données fondées sur la race et la faible participation des communautés noires à la prise de décisions politiques ont été largement documentés pour les Canadiens noirs. Nous examinons cette question pour comprendre comment les processus officiels de participation du public pourraient être plus inclusifs pour les personnes noires afin d'éclairer des politiques plus réactives.
Méthodes : L'étude a fait appel à une approche fondée sur les atouts pour examiner la façon dont les communautés noires se sont mobilisées dans les politiques de santé et la défense des droits en Ontario. Des entrevues approfondies ont été menées auprès de huit participants qui se sont identifiés comme étant noirs, recrutés à l'aide d'un échantillonnage ciblé et intensif pour (1) identifier des cas riches en information, notamment des personnes qui ont été à la pointe d'un travail à fort impact dans ce domaine et (2) des participants dont les missions et mandats représentaient une diversité d'approches et de sous-populations.
Résultats : Nos constatations suggèrent que, bien qu'ils soient confrontés à des obstacles systémiques et contextuels, les défenseurs des droits des communautés noires incarnent également une connaissance, une formation et une expérience approfondies et multiformes, lesquelles façonnent la richesse de leurs approches pour la défense des droits.
Discussion : Malgré sa focalisation sur l'Ontario, cette étude ajoute de la profondeur et de l'ampleur à la littérature existante sur les politiques en matière de santé et les populations historiquement marginalisées, offrant des leçons plus larges aux décideurs de toutes les provinces et territoires. Nos constatations encouragent les décideurs à mieux reconnaître, à faire de la place et à cultiver la base de la défense des droits, les connaissances culturelles et les systèmes communautaires déjà en place dans les communautés noires.

Introduction

The COVID-19 pandemic illuminated the disproportionately negative health outcomes experienced by Black Canadians in both ordinary and emergency situations. This includes increased risk of contracting COVID-19, higher death rates and greater negative economic impacts as a result of pre-existing health disparities (African-Canadian Civic Engagement Council and the Innovative Research Group 2020; Amin and Bond 2020; Dei and Lewis 2020; Derfel 2021; Etowa et al. 2021; Etowa and Hyman 2021; Knight et al. 2021).

The alarm and high-profile nature surrounding the global pandemic converged with the global protests following the police killings of George Floyd and Breonna Taylor, expanding the appetite for engagement with Black communities across sectors and institutions – including the health policy sector. It is important to note that several critical conversations and important advancements have been made as a result of this season of increased engagement (Harris and Marcucci 2023; Thomas et al. 2024; Yeo and Jeon 2023). However, many of the underlying issues are yet to be adequately addressed, including a broader failure to address the social determinants of health in Black communities (Datta et al. 2021; Iroanyah and Cyr 2020; McKenzie 2020; Mensah and Williams 2022; Siddiqi et al. 2021), a historically poor track record of meaningfully engaging Black communities in health policy decision-making processes and a broader lack of disaggregated race-based data collection at all levels (municipal, provincial and federal) (Dhamanaskar et al. 2024; Glimmerveen et al. 2019; Polletta 2016). Among these underlying issues includes a lack of awareness and/or attention within the literature to the unique ways in which Black communities mobilize, advocate and lead change processes. These insights, however, are critical to the success of any aims to ethically and meaningfully engage Black communities in health policy decision making and change processes.

As such, in this paper, we examine how health policy makers might refine and reform their public engagement processes to increase the representation of Black people. In so doing, we take a ground-up approach and focus on the narratives of individual Black community leaders in Ontario, with the aim of understanding how they have engaged with and impacted health policy processes. These narratives highlight a plethora of issues; however, in this paper we focus specifically on 1) the personal and professional pathways that led these Black leaders to this work; 2) the nature of their leadership styles and approaches to advocacy; and 3) experiences and challenges while engaging with policy and decision makers. We conclude this paper with a discussion about the policy implications of our analysis, including the need for health policy decision makers to transform their public engagement efforts with the unique capabilities, approaches and needs of Black community leaders in mind.

Methodology

The theoretical and methodological choices for this work were driven by a desire to centre Black community voices in policy discussions and, by extension, challenge the circular and reductionist narratives about gaps and deficits in the Black community that often prevail in public discourse. We took a "critical qualitative inquiry" approach to this work (Denzin 2017: 8), and our data collection methods included semi-structured in-depth interviews with eight participants who self-identified as Black and engaged in public-facing work as health leaders and advocates in Black communities in Ontario. As Denzin (2017) describes, a critical qualitative inquiry approach involves unsettling traditional research by centring marginalized voices, using inquiry to reveal sites for change and activism and acting as a bridge between academic critique and policy change. In line with this scholarly tradition, our work aims to "celebrate community, to experiment with traditional and new methodologies [and] with new technologies of representation" (Denzin 2017: 15). The theoretical framework that has guided our research is informed by Yosso's (2005) conceptualization of "community cultural wealth" (p. 69), which challenges epistemological norms and assumptions to amplify community-based ways of knowing and doing. Yosso's (2005) approach draws upon the counternarratives of historically marginalized communities to challenge deficit narratives by highlighting the cultural wealth, strengths and skill sets that often go unrecognized. These forms of cultural wealth (i.e., aspirational, social, navigational, resistant, familial and linguistic capital) emerge from wells of knowledge that are filled by intergenerational and community-based transfers, contemporary lived experiences and determination in the face of hostile systems and environments (Yosso 2005). This framework underpinned our analytic approach, which leans upon asset-based theoretical models that move us toward an appreciative approach to understanding Black issues, communities and leaders (Lamm et al. 2017; Yosso 2005).

For our data collection, we employed a purposive and intensity sampling strategy (Patton 2001) to recruit research participants for this study. This involved directly recruiting a focused set of "information-rich" cases that manifest the phenomenon in question "intensely" (Marshall and Rossman 2010: 105, 111), including people who have been at the forefront of high-impact work in this space. We also made an effort to recruit participants whose organizations/networks represented a diversity of approaches and sub-populations served. Our inclusion criteria required that the participants self-identified as Black and engaged in public-facing work as grassroots or organizational leaders in Black communities and/or health advocacy spaces in Ontario. As such, most participants were already known to us because of their public profile garnered through doing this work. Our semi-structured interviews were 60 to 90 minutes in length and took place in the summer and fall of 2021. These interviews were recorded, transcribed and analyzed thematically using an interpretive analytical approach (Denzin 2017). The project was approved by the McMaster University Research Ethics Board (Project no. 5482).

As critical and interpretive scholars, we recognize the importance of making note of our positionality in relation to the identities and experiences of our research participants and the overall focus and orientation of our research. Both authors of this paper identify as Black-Canadian women, with ancestral connections to the Southern Caribbean and East Africa. We both have past and continuing connections to African/Black community organizations and seek ways of bridging academia and community through our work. Being an *insider* in relation to our respondents came with many advantages in the interview process (e.g., ease of access, trust, racial and cultural concordance). However, we recognize that as academic researchers, we are still implicated in and affected by enduring power imbalances that exist between academia and historically marginalized communities, and worked to acknowledge and navigate this relational and ethical in-betweenness (Razack 2022) throughout the research process.

Results

Personal and professional pathways into this work

Many of the Black community advocates and leaders in our study were quite diverse, not only in their organizational mandates as it pertains to whom they serve, but also in their backgrounds. As such, they embodied cross-sector and interdisciplinary roots in areas spanning fields like medicine, natural sciences, community development, economics, creative arts, manufacturing and psychology. When we asked our participants to define the population that they serve, most were quite emphatic about centring the Black community. However, it should be noted that all of the participants were keenly aware of the fact that Ontario's Black communities were not monolithic and were quite diverse in culture, ethnicity, language, origins and, thus, needs. As one community leader noted:

> I serve those who are oppressed in similar ways to me, but I don't think we're necessarily of one community. So, when we're sitting here in the Canadian context – I think we serve diverse Black communities who because we look the same, we're oppressed by the same anti-Black racism; and so, the work that I do helps them. I am definitely learning about each of our communities.

As such, some of the leaders also chose to focus their advocacy efforts on sub-populations based on particular intersections, such as age, ethnic group or health profile (e.g., specific chronic or genetic diseases). At the centre of their areas of focus was always a deep commitment to getting at the roots of health disparities and addressing systemic gaps.

How our participants came to the work of community health advocacy also varied greatly. As one participant stated, their interest in advocacy work came from their lived experience as a Black person. This participant came from a natural sciences background but studied at an institution that emphasized a critical and Black-centred approach. As such, they were able to adopt a nuanced and interdisciplinary approach to thinking about health disparities at the intersection of race. Another health leader was inspired to advocate for the health of Black communities through a convergence of factors, including an interest in understanding how social planning can inform responses to acute and ongoing social problems. As they developed more expertise, they began to see the ways in which race would intersect with various social determinants of health and was intrinsically linked to disproportionate outcomes for Black communities. Moreover, they observed both the redundancy in various interventionist programming and the inefficiencies of existing top-down approaches. This inspired them to find new and more efficacious ways to address these structural problems.

For others, their entry point into the health advocacy space was rooted in personal experiences in healthcare institutions. These experiences often included bearing witness to traumatic events where themselves, a loved one, or community member did not have their medical, physical or mental needs adequately met. This exposed the structural nature of racial gaps and power dynamics in the healthcare system, which inspired their interest in serving others through advocacy. As one participant shared, they had often observed racially disparate treatment in their capacity as a healthcare worker, stating that "healthcare was [currently] designed to serve White Canadians." In these ways, the participants were often driven to become advocates through lived experiences that provided them with a critical, deeper and more intimate understanding of systemic gaps beyond their academic training.

Many of our participants "fell into" or came to the work of community advocacy organically, building relationships with like-minded people committed to instituting systemic changes that would disrupt the healthcare space. In so doing, they combined their passion with their cross-sector and interdisciplinary educational training and experiences to "build and grow on the job," united in the goal to, as one participant described, "secure the lives of Black people."

Community-based leadership approaches to health advocacy

In our discussions with participants, they also outlined some central ways they engaged with their advocacy work. First, many described that their advocacy approaches were rooted in Afro-centric principles that were grounded in African/Black ways of knowing – a collectivistic and humanistic leadership style that is anchored in service to and building trust with the broader community (Airhihenbuwa 1995; Penceliah and Mathe 2007). This included a deep engagement with communities to closely listen to their needs and working *with them* to create intervention strategies. As one participant stated:

> What we do is essentially listen very, very closely to what community is saying and identifying its challenges and then work with community to build a vision for how we address those situations, whether it be mental health, chronic disease, or how to address [broader] social determinants of health. And then our job is to mobilize the skills, tools, and resources to work with [the] community to implement interventions and do it at scale.

Second, integral to the nature of this advocacy work is a deep sense of respect and accountability to the communities that they serve, which have entrusted them with their stories and needs. This accountability also included working diligently to hold formal institutions accountable when they would make promises or aim to partner with Black community organizations. Third, we found that the nature of the work that these health leaders and advocates engaged in was quite diverse and complex. At the time of interviewing, much of the work called for these leaders and their organizations to support Black communities in more acute and emergent situations, such as the global pandemic. Advocacy in that case could include but was not limited to addressing pandemic-induced challenges, such as food and housing insecurity, or providing and connecting community to mental health services.

This work was in addition to the administrative labour required to keep these organizations running – often on shoestring budgets. As such, the work of these community advocates was quite onerous. One participant described the multifaceted nature of their advocacy work as "triaging," juggling and prioritizing efforts between acute, urgent needs in emergency situations and those that were organizational, programmatic and long-term.

> My day-to-day looks different. Every day is different. A lot of our work right now is focused on mental health for children and youth. And then, a lot of it is focused on COVID, so my personal day-to-day is filled with trying to think strategy, it's trying to deal with operational things – whether it be HR things or budgeting, as well as trying to move forward on our programmatic commitments and getting work done. So, my brain is often kind of split amongst those three kinds of things, all at the same time and trying to make it work … That's exactly what we have to do; triage it, every day.

At other times, advocacy work was shaped by broader goals that were more systemic and political in nature and were aimed at addressing the broader social determinants of health that contribute to racial health disparities. In addition to maintaining existing administrative duties and acute needs, this kind of advocacy aimed to achieve systems change and often required engaging in various forms of research and liaising with formal policy channels. Engaging with formal policy makers often involved encountering additional barriers and the need to navigate inequitable power dynamics and structures. This tension was captured by one of our participants who expressed the following:

> Look, nobody is going to come to rescue us, so we have a responsibility to do something about it. And it's challenging because the power lies somewhere else, and the responsibility lies somewhere else.

This participant went on to explain that they saw their policy engagement work as an effort to try to close the gap between those who have power and those who take responsibility to take action on these issues.

Experiences engaging with policy and decision makers

The Black community leaders we spoke with explained how the ways in which they interfaced with health policy and systems leaders were multidimensional and quite varied in terms of initiation, process and outcome. One participant described their organization's experiences with health policy makers by expressing, "sometimes we convene or sometimes we get convened." Leaders spoke about systems-level work as something that required skill and savvy, including an understanding of where the levers of change were and how best to mobilize community voices and resources to push against these levers.

> You can't just jump into a meeting with politicians you know? We really have to have those spaces of organizing and sharing ideas and coming to a consensus about what our approach is and making sure that we're creating space for dissenting voices.

The navigational capital (to borrow from Yosso's 2005 model) demonstrated by the respondent above is one that was described by multiple participants as a form of knowledge that was built and passed down through intracommunity and intergenerational transfers and mentorship.

While many of the leaders we spoke with displayed an adeptness and effectiveness in navigating health advocacy processes, they also spoke at length about the wear and tear and the obstinate challenges they encountered while doing this work. For example, participants described the ways in which they would have to perform arduous educational labour in their efforts to engage with policy makers to achieve changes like improving systemic access to medical care for Black communities. As one health leader articulated,

> I find that this role, we call it advocacy but it's also education because there's this narrative in Canada that racism doesn't exist here, and we've been accused over and over that [engaging in work that addresses the issue of race in health] is racist and divisive in [and] of itself. So, the work sometimes becomes, first of all, proving why we're having this conversation, and then forcing people to acknowledge anti-Black racism in the healthcare system and take accountability for that and change it.

In these ways, the advocacy work of the participants often pulled them in many different directions, summoning them to draw on their varied expertise, experiences, training and members of their organizational teams to manage the array of demands. While this speaks to their effectiveness and ingenuity as leaders, the gymnastics involved in this line of work also takes a psychic and physical toll – especially on people who are already stretched and experiencing these same structural barriers in their personal lives.

It is also important to note that the participants' advocacy was often outside of traditional or mainstream institutions, pathways and organizations. This means that their labour was more often than not offered voluntarily in an unpaid or marginally paid capacity. As a result, participants shared that they often lacked the mental, physical and particularly financial resources to carry out their policy advocacy to its fullest extent. As one participant described, the advocacy work they engaged in was most often "off the side of their desk" in addition to other personal and work commitments. Therefore, many of our participants were often stretched quite thin and this impacted their ability to engage in policy conversations and processes to the extent that they would like. One participant stated:

> Other groups who are more established will have staff and resources that just monitor policy, keep ahead of policy, get input into policy. We sometimes don't even have

> the time to go to the meetings when they call a meeting to talk about policy. So, the very structure of [agencies serving Black communities] always start at a disadvantage because [we don't have the] time and the [infrastructural capacity or access] to get engaged before the policy actually gets written.

It is important to acknowledge and examine the systemic challenges and barriers like the ones described above by Black community leaders. However, it is also critical that we do not let this focus ensnare us in a trap that reinforces the framing of Black peoples and communities as perpetually lacking or without capital. Instead, we should be inspired by their ingenuity, rich skill set and the lengths that these Black community leaders have reached *in spite of* these challenges. Further, we should be motivated by the transformative possibilities if these barriers were to be removed.

Discussion

The narratives shared by Black community health advocates in Ontario provide a powerful call to action for health policy makers. One central implication is the pressing need to recognize the strengths, assets and capacities embedded within these community leaders. Their interdisciplinary perspectives, diverse personal pathways and cultural and community intelligence contribute a rich tapestry of insights that can significantly inform policy formulation. The leaders we spoke with shared a deep sense of responsibility and accountability toward their communities, but also a recognition of and frustration with the inequitable distribution of power that mitigates their capacities to drive the change their communities need. By acknowledging the deep understanding these leaders possess about their communities and cultures, and the participatory processes and systems of accountability that they call upon in their work, policy makers are better positioned to access this expertise to create policies that are culturally responsive, relevant and impactful.

The narratives of these advocates also shed light on the structural barriers that impede their meaningful engagement in policy processes. Not only do these barriers negatively impact the leaders, the implications also extend to less effective policies, poorer community health outcomes and ultimately detriments to broader public health. Providing adequate financial resources, sustained institutional support and meaningful pathways for engagement better position Black community leaders, and the communities they represent, to contribute critical insights to policy discussions and processes. Addressing these systemic obstacles not only amplifies the voices of these leaders, but also acknowledges their vital role in shaping policies that address health disparities and promote equity.

Perhaps the most critical policy implication drawn from this study is the imperative for health policy makers to learn from and equitably partner with Black community leaders in ways that demonstrate true knowledge of and respect for the cultural wealth and assets they bring to the table. These advocates have been able to foster trust and strong and responsive networks by employing community-based and collectivist leadership approaches. As such, policy makers at all levels of government (municipal, provincial and federal) can refine and reform existing formal public engagement processes to increase the representation of Black perspectives and peoples. They can embrace the principles of deep community engagement, active listening and collaboration modelled by these leaders to develop more inclusive and impactful health policies. However, given the deeply entrenched and long historical processes that have created current structural inequalities, we contend that a paradigm shift is also necessary, as resolution requires policy responses that are specific, targeted and contextual. Benchmarks must also be established and monitored in partnership with, if not led by, Black community organizations who are already experts of the constituencies they serve. Nevertheless, critical to this is recognizing and valuing the work and expertise these leaders and groups already have and providing the sustained support, investment and platforms that clear the path for the work that they do.

Frameworks like "critical qualitative inquiry" (Denzin 2017: 8) and "community cultural wealth" (Yosso 2005: 69) are also important in shifting the attention of researchers and policy makers toward community-based skills and assets that might have otherwise been buried beneath a deficit framing and a hyperfocus on challenges, needs and gaps. This reframing challenges mainstream notions of public and community engagement that rely upon fragile foundations, such as moral or bureaucratic imperatives (e.g., equity, diversity and inclusion [EDI] mandates). Instead, it offers a more accurate representation of this work and its capacity to be a rich source of critical technical policy expertise. This is an opportunity for mutual benefit all around, as leaders benefit from greater support, policy makers benefit from technical expertise and communities benefit from policies that reflect their lived experiences and needs.

Conclusion

In this paper, we elucidated the narratives of Black community health advocates in Ontario, paying attention to insights that hold vital implications for health policy makers interested in meaningfully engaging Black communities in policy processes. Our exploration has also illuminated the structural barriers that hinder meaningful policy engagement for these advocates without losing sight of all they have managed to accomplish despite these barriers. Based on our findings, we posit that there is an urgent need for health policy makers to recognize, leverage and amplify the strengths, assets and capacities of Black community leaders to appropriately and effectively engage Black communities, reduce harm and begin to address health policy gaps. Central to this call to action is a need for race-based data collection and policy engagement that is Black-led and centred at the municipal, provincial and federal levels to facilitate targeted, effective and data-driven interventions that are reflective of the distinct ways that Black community leaders approach their health advocacy work. In order to ensure stability and sustainability, Black-led health organizations also need core operational funding rather than relying on the existing contingent and project-based funding models.

While our study underscores the transformational potential of equitably partnering with Black community leaders, we also challenge traditional forms of community partnerships and engagement that does so without addressing existing community assets and structurally produced resource constraints. By shifting from deficit-based approaches to a framework that recognizes community capital and wealth, these collaborations can drive equitable health policies that truly reflect the voices and needs of the communities they aim to serve. Ultimately, we affirm that centring Black community leaders in the policy making process is more than just a checkbox in an equity mandate. Rather, such work is invaluable for decision makers interested in critical insights that might help to break the vicious cycle of unresponsive health policies and poor health outcomes for Black communities.

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COMMENTARY

"Whatever Job I'm In, I'm Going to Find a Way to Make a Difference" – A Black Community Leader's Perspective on Engagement and Advocacy

« Quel que soit le travail que je fais, je trouverai un moyen d'apporter des changements » – Point de vue d'une leader communautaire noire sur la mobilisation et le plaidoyer

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Abstract

Camille Orridge is a patient and community-focused healthcare leader who has passionately and tirelessly worked for more than 50 years to address systemic barriers in the healthcare system, creating innovative equitable health solutions for underserved populations. She has founded a number of key initiatives, including Pathways to Education, the Canadian Home Care Association and the Black Coalition for AIDS Prevention (Black CAP) and has served on numerous boards, as a volunteer and in her capacity as the CEO of the Toronto Central Local Health Integration Network. In this oral history narrative, Camille reflects on her extensive 50-year journey as a healthcare advocate, identifying victories but also areas that continue to be barriers for historically marginalized communities, such as Black communities. In so doing, she discusses the complexities that she has encountered while pushing boundaries and reimagining a more equitable healthcare system in Ontario and reveals key historical touchpoints in the health equity and advocacy space.

Résumé

Camille Orridge est une dirigeante des soins de santé axée sur les patients et la communauté qui travaille avec passion et sans relâche depuis plus de 50 ans pour éliminer les obstacles systémiques dans le système de santé, créant des solutions de santé équitables innovantes pour les populations mal desservies. Elle a fondé un certain nombre d'initiatives clés, dont

Passeport pour ma réussite, l'Association canadienne de soins et services à domicile et Black CAP (une coalition de personnes noires pour la prévention du SIDA) et elle a siégé à de nombreux conseils d'administration en tant que bénévole et à titre de PDG du réseau local d'intégration des services de santé (RLISS) du Centre-Toronto. Dans ce récit, Camille évoque son vaste parcours d'un demi siècle en tant que défenseure des soins de santé, s'arrêtant sur les victoires mais aussi sur les secteurs où on observe encore des obstacles pour les groupes historiquement marginalisés, comme les communautés noires. Ce faisant, elle aborde la question des situations complexes qu'elle a rencontrées, en repoussant les limites et en réimaginant un système de santé plus équitable en Ontario, et elle révèle les principaux points historiques dans les domaines de l'équité en santé et de la défense des droits.

Doors, Suits and Hoops: Being Black in the Workforce

I was often the only person of colour and the only woman of colour in a group. In these settings, our voices get erased. For your voice not to be erased, you have to get more aggressive and more forceful. Then you become the "angry Black woman" very quickly. I did a lot of stuff to jump through hoops: I made sure I wore the right suit, all the stuff you do in order to enter and belong. But I was blessed in a way that many of us are – especially when you come from countries that are Black countries, you have a different sense of self. But also, I have a family network, and although my mom did not have a lot of money, I was always secure because she'd always say, "You can come home."

I never felt the need to be liked. You see people in spaces that feel the need to be liked, so they turn themselves into a pretzel to be liked. I had more of a need to be respected, and that allowed me to do the work I needed to do. So, for government and for policy folks, they knew that I delivered, I got work done. It was hard for them to dismiss me when I was a good worker that they could rely on.

I learned from others – I saw people who dedicated their lives to community and activism, but got burnt out, and then became mean and destructive to the very same community. I knew I did not want to do that. So as difficult as it was for me, I always had my friends, colleagues, like-minded staff, who I could call up and say, "You can't believe the shit that has happened." And I had my family. And in my family, we do not talk about work. We eat, we laugh, we talk. And striking that balance was always important for me.

Whatever job I am in, they are going to pay me and I need to feed my kid. But whatever job I'm in, I'm going to find a way to make a difference. I do not always have to promote or talk about making a difference, I just need to find a way to use that job to make that difference.

Working Toward Big Wins: Collaborating on Policy Change

It is a known fact that your best chance of influencing policy is before policy gets made and it's harder to change policy once it is done. But that sets up significant barriers. The Black- or minority-focused organizations doing the work are usually so stretched and so underfunded that they do not have the time or resources to be doing this policy and advocacy work ahead of time. Other more established groups have staff and resources that monitor, keep ahead of and provide input into policy; we sometimes do not even have the time to go to the meetings to talk about the policy. So Black organizations or community-based agencies serving their communities are at a disadvantage from the outset.

If there is any inkling that what you are advocating for takes money or services away from mainstream communities, policy makers do not like to go there. There is a sense that the pie is small, and that by asking for something, it takes resources away from other people (from people who vote, or from people who have a voice). It is a way of thinking, "We don't have enough for people who currently need services, but you're asking to extend the policy for more people." And I have to say, "Yes, because the people who are not getting care are people of colour. We need to talk about how nobody has enough resources, but we cannot continue to leave people of colour out because there isn't enough money."

The people who are writing policy usually come from particular perspectives – an educational background or training – and are often disconnected themselves from communities. Even when you get Black people doing policy, their education and life trajectory removes them from being continually integrated in communities. This disconnect means that, often, steps to ensure the impact is consistent across communities are missing from policies.

For example, when I was at the Toronto Central Local Health Integration Network (LHIN), some partners from Toronto Public Health and I formed a group called the Toronto Health Indigenous Advisory Committee, which we funded as a side project. We wanted to focus on St. James Town [in Toronto, ON] – it was dense, with no park, no healthcare, nothing. It is a city by itself, without all the amenities of a city. We hired a community-based firm that then hired community members – a lot of whom were unemployed or on social assistance – and paid and trained them. These community members did all the interviews with the community – essentially a needs assessment for the community. What came out as their number one need was dental care for children. The LHIN did not do dental care for children, but we could not walk away from that community need. So, we focused on what else was needed. We found it – Health Commons needed a space in the community where the health providers could come together. Ten years later, Health Commons is still going and because Toronto Public Health is a partner, we could ask them what we could do about the dental care. Toronto Public Health was able to use what they were already doing and adjust it to this community. Making change is not always about brand-new programming; it can be about adjusting existing delivery methods to meet the needs of people not being served. I consistently got around policy barriers by creating pilots and using existing resources in order to gather the data to inform and push policy forward.

Pilot research was the way I found to do a lot of policy shifts: every time we were told we could not do something, I would find another way to gather the data, and evaluate it, to show our approach was more efficient. Policy does not change without hard data. Sometimes you can make the argument for good care, but very rarely do you get the policy change you want if you ignore the economic argument. When we started Pathways to Education, a stay-in-school program for high school students, we got a consulting firm to do the economic analysis about why we should work hard to get our kids graduated from school. We argued that otherwise the workforce in the future will not be available for our businesses, and if these businesses do not have students taking jobs, they will lose business on the international front. Those kinds of arguments held up.

When I was on the AIDS Advisory Committee to the Minister of Health, the AIDS medication was really expensive. The committee wanted to go to the minister to ask for money to support people with AIDS. And I said, "I am not going to the minister to ask them to fund AIDS that way." Instead, I said, "Let's talk about other catastrophic illnesses with expensive medications, let's join up with heart and lungs organizations." That was hard, because then we encountered homophobia in those groups. But we could not walk away because the ultimate goal was too big. We will walk into spaces where we experience anti-Black racism, but you still stay in that space to do the work, to get where you want to go. You do not always have the privilege of walking away if the goal is what drives you. Together, we reframed the ask to, "Let's say $200 is a reasonable amount anybody should pay for drugs. And anybody whose drug bill is above $200 will get government support, regardless of the medical condition that requires that drug." That policy went through, and that is how we have Trillium drug support. Because it was the cost of drugs that the government was supporting in this policy; it included AIDS drugs, but it was not limited to AIDS. Sometimes you need to work together with others to get policy change for your people.

Co-Designing and Advisory Committees: Who Is at the Table and Who Is Missing?

Co-design drives me crazy. When people talk about wanting people with experience on their committees, it usually means having one or two people there. These people with lived experience are usually highly educated, and it is one dimensional. I do not have a problem with co-design, I have a problem about how it really is only always focused on the people who are at the table who invariably come from a particular race or class. Sometimes this is because other voices are not sought out, other times it is because there are too many barriers to participate. People living in poverty often do not have time to come sit down in meetings for hours. So, it is not that I'm objecting to co-design, I'm objecting to co-design as it is currently structured. Because we are left out, other people are left out, poor people are left out.

Everybody in healthcare wants advisory committees, they want to hear patient voices. Well, most of the people who participate – even if they are people of colour – have status and education. You are not really hearing from the other half of the people who are not in the room. I sit on the advisory committee for arthritis because I have bad arthritis, and I'm really clear: I do not represent poor people or all Black people with arthritis, you need to go hear from them. I can tell you what my experience is, and my experience comes with privilege and knowledge. Anything I'm bringing has nothing to do with the immigrant experience now. I can no longer fulfil that role as an immigrant, I'm too far removed. I cannot speak for that community and I will not. I will say, let us form a focus group and let us reach out so we can connect with people from those communities so that you can hear their voices.

COVID-19: Lessons in Designing Systems for Equity

I think COVID-19 has exposed for the mainstream what Black and Indigenous communities have always known. Nothing about COVID-19 should have been a surprise because we knew from SARS who is at risk from every infectious disease that comes. I'm always a bit cautious about making health outcomes a Black community issue, as if it is because of your skin colour that this happens. It is not. Our health outcomes have a direct relationship to anti-Black racism, which then puts us in certain living conditions, in certain jobs, under certain working conditions. We are the people who work in places like community care where you do not get full time jobs, where you do not get benefits, where even if you are sick, you have to go to work or else you do not get paid. Those jobs are what exposed us to COVID-19; it is racism that put us in those jobs, in communities where we cannot afford housing. It is not a surprise because given that combination, we were prime candidates to get sick.

We are left in the same place post COVID-19 if we, as a society, do not do anything about community care, about benefits, about employment, about housing. Any new dollar should have conditions attached to it: we need to see that you now address the needs of the people you are not serving. That is where the opportunities are. So that is my hope for the post–COVID-19 era: taking a funding and equity approach to making sure that people who are not currently getting care, get care. Attach conditions to money. Do that analysis as to who will be negatively impacted and put strategies in place to address that.

This is a time where we have to stay strident and firm on change.

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COMMENTARY

"You Can't Let Go" – A Black Community Leader's Perspective on Engagement and Advocacy

« Vous ne pouvez pas laisser tomber » – Point de vue d'une dirigeante de la communauté noire sur la mobilisation et le plaidoyer

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Abstract

Lanre Tunji-Ajayi is president and CEO of the Sickle Cell Awareness Group of Ontario (SCAGO). This charitable organization focuses on ameliorating the lives of those living with sickle cell disease by providing evidence-based support to patients and supporting clinical and psychosocial research, health promotion and the development of best practice guidelines. Lanre's passion for this work is personal. Following the death of her brother Sunday Afolabi from preventable and treatable complications of sickle cell disease, Lanre immersed herself in advocacy for community health and quality patient care. In this oral history narrative, Lanre reflects on her decades-long journey advocating for those living with sickle cell disease – a disease which disproportionately affects Black people. Her reflections focus acutely on the challenges she has faced in raising awareness and visibility, including through formal public engagement policy processes. Lanre also speaks to the personal costs she has encountered engaging in this advocacy work and the subtle and institutionalized forms of anti-Black racism that have punctuated this already difficult effort to bring about change.

Résumé

Lanre Tunji-Ajayi est présidente et chef de la direction du Groupe de sensibilisation à la drépanocytose de l'Ontario (SCAGO). Cet organisme de bienfaisance vise à améliorer la vie des personnes atteintes de drépanocytose en offrant un soutien fondé sur les données probantes aux patients et en appuyant la recherche clinique et psychosociale, la promotion de la santé et l'élaboration de lignes directrices sur les pratiques exemplaires. La passion de Lanre pour ce travail prend racine dans sa vie personnelle. Après le décès de son frère Sunday Afolabi, à la suite de complications évitables et traitables de la drépanocytose, Lanre s'est engagée dans la défense des droits de la communauté en matière de santé et de soins aux patients. Dans ce récit, Lanre réfléchit sur son parcours de plusieurs décennies en faveur des personnes atteintes de drépanocytose - une maladie qui touche les personnes noires de façon disproportionnée. Ses réflexions portent essentiellement sur les défis qu'elle a dû relever pour sensibiliser et accroître sa visibilité, notamment par le biais des processus officiels des politiques de mobilisation du public. Lanre parle également des coûts personnels qu'elle a dû supporter en s'engageant dans ce travail et des formes subtiles et institutionnalisées de racisme anti-Noir qui ont ponctué l'effort déjà difficile pour amener le changement.

Engaging with Policy Makers: Be Persistent and Proactive

The intersection of race and chronic disease, that Is where we are.

The government is not going to come and say, "Oh, we know there's sickle cell somewhere, we want to help you." We have to be proactive; we have to go and knock on their door. We have been knocking on this door for years. Most of the time you find that the needs of the community fall on sympathetic ears, but that does not mean that they are going to do anything about it. So, it calls for intense advocacy. It calls for persistent advocacy to ensure that the patients and families will have access to care similar to that of all the people in the province who may not be of their race or who may not have sickle cell disease. I have held advocacy meetings at the seats of power in Toronto, Saskatoon and Ottawa to get policy makers to understand that we are not leaving. I always say persistence in advocacy is the key to success.

However, the happenings in 2020 with the killing of George Floyd brought to light the racism that is deeply rooted in the western world, and that helped us in a way. As sad as it is, it had some positives because it helped people wake up and realize that there are things we need to look at in our own environment in Canada. There is racism, and we need to address it. I think that opened a new way of looking at things for everybody, even at the ministry level. We continue to proactively knock on policy doors; as one goal is achieved, we need to work on the next one, and the next one.

They want to brush you off because there are so many people who are coming at them and they are thinking, "Well, it's very small, this population, money should be going to this and that," and that's why you have to be more proactive. Sickle cell only affects about 6,500 people across the country, with about 3,500 in Ontario. So, it may make logical sense to a politician to think, "Why am I putting money here when I could put money in something that affects way more people?" But then why is the funding trajectory for cystic fibrosis and hemophilia very different even though there are fewer people with those diseases than with sickle cell disease? Cystic fibrosis affects a total of 4,200 hundred people in Canada and the annual budget is close to 20 million. Until recently, there has been no sickle cell organization with an annual budget of more than $200,000 in the country.

You cannot let it go. You cannot relax.

Even though we have some promises from ministries for funding, I'm still consistently asking, "Where are we on it? Who is reviewing it now?" You have got to be on top of it, you cannot sit aside. Otherwise, another election will come by and they will say, "Oh yeah, that's gone with the election. Let's move on." We do not know who is going to be in the next government and if they are going to support us.

You cannot waste time while people are dying and suffering. And so, working with policy makers is something that you must be persistent about and that you cannot let go of – you know, you cannot lose sight of them. There is a way to do policy advocacy, which I had to learn. It was not taught to me, but I learned from working in advocacy over the last 19 years that persistence is the key to the win.

Strategic Engagement and Purposeful Collaboration: The Art of Bringing People Together

One of the things we have done is create the Patient Advisory Advocacy Council within the Sickle Cell Awareness Group of Ontario (SCAGO). This is a nine-member council comprising individuals with sickle cell disease, their caregivers, family members, a medical doctor and myself as CEO as an *ex-officio* member. The members of the council sit on hospital working groups and provide advice for protocols for care. We are empowering and bringing the voice of sickle cell disease across the hospital. We are shifting the conversation to bring visibility to the patients as spokespeople and researchers in their own disease areas because no one knows their disease more than them.

We are seeing a shift in that we are engaged from the get-go more than ever, and we also initiate engagement on an as-needed basis. Based on what we need to accomplish, we will engage with the right people who will make it happen. So that is strictly how we have been working. If I want the hospital to do something for a program in the hospital, I reach out to the administrators of the hospital. If I want to do something that has to do with newborns, I reach out to Newborn Screening Ontario. I strategically pick who I need to reach out to and who I need to speak with based on the work that we are trying to do. We will reach out to policy makers at different levels who will help to ensure that we are successful in our aspirations and can make the impact that is needed. In addition, collaboration, collaboration, collaboration! Collaboration is important. We have to look for collaborators who will help us advance what we want – so you have to call the Black Health Alliance to the table, you have to call Council of Agencies Serving South Asians to the table, you have to look for the appropriate collaborators and engage and work with them to achieve your goal.

"Sickle Cell Disease is a Family Affair": The Personal Motivations and Sacrifices of Advocacy Work

The sickle cell work is a lot. I work from 5:00 am in the morning until 7:00, 8:00 pm, minimum, and it is all sickle cell. That is my schedule most days. So there has to be passion. I am not salaried, so it has to be passion. My passion for this work is rooted in my family. I am a sibling of individuals that have sickle cell disease, but I am not a parent and I do not have the trait myself. So, if you ask me, "Why do you put so much energy and time into this when you're not directly affected by the disease?" then I am going to say, "it's [the] love of siblings," and I always say sickle cell disease is a family affair. Being a sibling is what is pushing me and propelling me to keep going because I know how much my brother suffered before he died and I'm grateful to God my sister is still alive. I know what it could be living with sickle cell disease, and I want to ensure that we do not have to lose another young person to preventable complications.

Sometimes it gets to be too much because I'm so overwhelmed and have so much to do, and I'm like, "OK. Hold on. Let's put this in perspective, why am I doing this?" When it gets like that, it is funny sometimes, somebody will send me a text to say, "Ms. Lanre, I just want to appreciate you for all you do." Or sometimes it is somebody in need in the hospital and I think, "Well, this is why I'm doing what I'm doing." Somebody has to speak on their behalf. So that is why I do what I do. It is not because I have enough funding and resources, because there is little of that. I sometimes use my own money to support this work at the Ontario or global level. But when a 20-year-old says to me, "I don't want to live. I want to die. It's more peaceful. It's better for me. I'm in pain all the time. I don't want to be here anymore," that is deep. That is deep. That is deep. These people are what keep me going. Everything we do is to bring visibility to sickle cell disease and amplify the voices of the people and families living with this disease.

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RESEARCH PAPER

Public Deliberation for Ethically Complex Policies: The Case of Medical Assistance in Dying in Canada

Délibération publique pour des politiques complexes sur le plan éthique : l’aide médicale à mourir au Canada

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Abstract

Almost 50,000 people in Canada have had a medically assisted death since federal legislation was passed in 2016. Still, the debate about the permissibility of medical assistance in dying (MAiD) continues to rage. The central role of shared values and ethics in public policy making emphasizes the importance of engaging the public, particularly around heavily value-laden issues such as MAiD. Public deliberation, a mode of engagement that fosters sustained and reasoned discussion between participants, is well-suited to addressing such ethically contentious policy issues. In this paper, we review recent efforts to engage the public on assisted dying within and outside Canada and explain how public deliberation could contribute substantively to MAiD policy making.

Résumé

Près de 50 000 personnes au Canada ont eu une mort par assistance médicale depuis l'adoption de la loi fédérale en 2016. Néanmoins, le débat sur la permissibilité de l'aide médicale à mourir (AMM) est toujours en cours. Le rôle central des valeurs et de l'éthique dans la formulation des politiques publiques souligne l'importance de la participation du public, particulièrement en ce qui concerne les questions fortement liées aux valeurs comme l'AMM. La délibération publique, un mode de participation qui favorise une discussion soutenue et raisonnée entre les participants, est bien adaptée pour aborder ce type de politiques controversées sur le plan éthique. Dans ce document, nous examinons les efforts récents pour mobiliser le public sur l'aide à mourir au Canada et à l'étranger et nous expliquons comment la délibération publique pourrait contribuer de façon substantielle à l'élaboration des politiques de l'AMM.

Background

Medical Assistance in Dying (MAiD) legislation has seen swift and significant change since the landmark *Carter v. Canada* decision (2015), which struck down the Criminal Code prohibitions on assisted dying (Downie 2022). The unanimous Supreme Court decision led to the passing of federal Bill C-14 in 2016, which allowed MAiD for those with a grievous and irremediable medical condition and a reasonably foreseeable natural death. Since then, we have seen amendments to remove the "reasonably foreseeable natural death" requirement for MAiD eligibility (i.e., in 2021 through Bill C-7), with expectations for those with mental illness as their sole underlying condition to become eligible for MAiD in 2027 (Department of Justice 2021; Health Canada 2024). Despite these notable policy evolutions, the general public has had little opportunity to deliberate about the state of MAiD in Canada, the profound social implications that changes in MAiD policies have on Canadians and the shared values that underlie these contentious issues.

Values such as compassion, autonomy, equity, fairness and protection of vulnerable persons are at the centre of the MAiD debate and need to be brought to the surface and directly questioned in conversations around assisted dying (Buchman 2019; Fontalis et al. 2018; Herx et al. 2019; Schüklenk et al. 2011). The ethical acceptability of MAiD policies should be judged by how well they reflect commitments to these underlying values in their design and execution. Engagement with the public is needed to determine the full range of these values, how they may be appropriately balanced against one another and how they can inform MAiD policy making. MAiD is a unique health policy issue; rather than focusing on standardized indicators for health policy success like improved health outcomes, assisted dying policies require values-based reasoning to determine whether a policy truly reduces suffering, improves autonomy or reflects compassion. Discussion of the values that underpin MAiD, potential trade-offs between them and how they are operationalized into policies have been relegated to the courtroom and Parliament to date but would be better served by directly engaging the individuals who will be impacted by MAiD policies.

There are numerous aspects of MAiD policy making that could benefit from public deliberation. Most pressing is the eligibility of individuals with mental illness as the sole underlying condition. While the sunset clause to include this eligibility criteria was to come into effect in March 2024, the federal government has been granted an extension until 2027 (Health Canada 2024). This extension period is an opportunity for federal and provincial governments to seriously engage with the public about whether eligibility for persons with mental illnesses still aligns with Canadian values. This could include questions such as these: Should people with mental illnesses as their sole underlying condition be eligible for MAiD? Would all mental illnesses qualify for eligibility and if not, how would we fairly decide which ones would be eligible? Would additional safeguards be needed for those who fall under this eligibility criterion? Other issues include how healthcare providers should discuss MAiD with their patients (i.e., whether this conversation should be initiated by the patient or the provider) (Bryden 2020), the ethical acceptability for organ donation after MAiD (Middleton 2019; Mulder 2019) and how to handle access issues emerging due to a lack of willing providers, especially for cases where death is not reasonably foreseeable (Frolic and Oliphant 2022).

We argue in this paper that public deliberation is a particularly fruitful approach to engaging Canadians about MAiD. We start by outlining the recent history of public engagement on assisted dying policies in Canada, then address the question "Why deliberation?" before describing Canadian and international experiences with deliberation on assisted dying. We argue that such engagement is imperative due to the value-laden nature of assisted dying policies, as well as the constantly evolving nature of Canada's MAiD regime. We discuss potential pitfalls of using deliberation for ethically contentious health policies like MAiD and how they can be avoided. While we do not take a stance on the ethical permissibility of MAiD in this paper, we do believe that approaches to public engagement thus far have been insufficient and that public deliberation can improve the ethical acceptability, transparency and trustworthiness of MAiD policy decisions.

Government-Initiated Public Engagement for MAiD in Canada

The evolution of MAiD in Canada has been marked by government-initiated expert panels, parliamentary committees and public consultations. The earliest example is the 2010 public consultation headed by the National Assembly of Québec's Select Committee on Dying with Dignity (2012). Following the release of a consultation paper, individuals and organizations could submit briefs, attend public hearings or answer an online questionnaire. More than 6,500 responses to the online questionnaire were received and 239 individuals and organizations contributed to the public hearings. The consultation covered all end-of-life policies, not only assisted dying, and the culminating report paved the way for the *Act Respecting End-of-Life Care* in Quebec (Downie 2022).

The federal government first engaged with Canadians about MAiD in 2015 after the Supreme Court decision that removed Criminal Code prohibitions on assisted dying (Downie 2022). The federal government responded by establishing an external panel mandated to consult Canadians and key stakeholders to inform its legislative response (External Panel on Options for a Legislative Response to *Carter v. Canada* 2015). Over a three-month period, almost 15,000 responses were received on their online consultation tool, *The Issue Book*, which sought to educate respondents on issues around assisted dying while also eliciting their perspectives on key issues such as eligibility and safeguards (External Panel on Options for a Legislative Response to *Carter v. Canada* 2015). The panel's final report noted that particularly complex issues such as advance directives for MAiD or eligibility for mature minors are issues for which "there is no known consensus and where debate can be expected to emerge over time" (External Panel on Options for a Legislative Response to *Carter v. Canada* 2015: 12).

Also in 2015, the provincial and territorial governments appointed an expert advisory group to advise the ministers of health and justice who would be responsible for implementing the federal legislation (Provincial–Territorial Expert Advisory Group on Physician-Assisted Dying 2015). This group engaged in consultations with stakeholder groups, including patient advocacy groups, but not with the public or individual patients. In the same year, the House of Commons and Senate created a special joint committee to "consult with Canadians, experts and stakeholders, and make recommendations on the framework of a federal response on physician-assisted dying that respects the Constitution" (Special Joint Committee on Physician-Assisted Dying 2016: 2). The committee received briefs from a number of organizations and individuals and met with witnesses across their meetings.

Despite these initial opportunities, Canada's most extensive public consultation on MAiD did not occur until 2020, after a Quebec Superior Court ruling struck down the "reasonably foreseeable natural death" requirement for MAiD (Department of Justice 2021; Government of Canada 2020). The two-week public consultation consisting of a short questionnaire received more than 300,000 responses, and elicited Canadians' perspectives on establishing additional procedural safeguards for non-terminally ill patients seeking MAiD. In 2021, Bill C-7 was passed that removed the eligibility criterion of a "reasonably foreseeable natural death" and enacted a sunset cause wherein people with mental illness as their sole underlying condition would automatically become eligible for MAiD in March 2023 (now extended to 2027) (Department of Justice 2021; Health Canada 2024). This new controversial issue led to the creation of the Expert Panel on MAiD and Mental Illness (2022), which did not engage in public consultations.

Critiques of Current Public Engagement Efforts for MAiD Policy Making

The federal and provincial governments have clearly initiated efforts to engage the public on MAiD policy, most commonly through public consultations. These engagements have used short surveys, comment periods, or public hearings to elicit the views of the already-interested public. However, these engagement methods fall short when trying to ascertain public views on such ethically complex issues. One-time surveys can only garner the immediate views of the public, which may not reflect well-informed or reasoned perspectives (Solomon and Abelson 2012). Further, survey questions may be phrased to reflect the policy priorities and vision of policy makers, and closed-ended response categories (e.g., Likert scales, multiple choice) limit opportunities for respondents to share nuanced perspectives. This is in tension with the inherent complexity of the MAiD debates, which necessitate deeper engagement.

Feedback-style activities like surveys and submitted briefs require members of the public to initiate engagement. This skews participation to those individuals who are already interested in a policy issue and have the personal resources to be engaged (e.g., time, internet access) (Dhamanaskar et al. 2024). It may also lead to the overrepresentation of organized interests, such as nonprofits and professional organizations that have the resources to mobilize their membership and/or engage on their behalf. Importantly, self-selection into engagement can inadvertently lead to the exclusion of certain groups, often vulnerable groups, from participation. This becomes problematic as MAiD uniquely impacts certain vulnerable populations, like disabled persons and individuals who lack access to social support (e.g., housing).

Finally, surveys, comment periods and public hearings often resemble a one-way dialogue between decision makers and the public, giving little room for members of the public to actively engage in the policy making process (Dhamanaskar et al. 2024). Such engagements do not give the public the opportunity to imagine what a policy may look like in practice and to deal with the consequences and trade-offs that emerge when implementing policy in the real world. While hundreds of Canadians have been engaged through consultation methods so far, it is unclear how public views have been factored into MAiD policy decisions, potentially indicating a lack of transparency and accountability mechanisms to report on the impact of engagement.

The Role of Public Deliberation in MAiD Policy Making

An extensive literature supports the use of public engagement to foster public trust and approval of political institutions and design policies attentive to public needs (Bherer et al. 2016). Deliberative forms of public engagement offer an alternative and possibly more meaningful approach to public engagement on MAiD. While feedback-style engagement elicits the public's immediate and pre-conceived ideas, deliberation gives participants the opportunity to be informed about a policy issue, consider and share differing perspectives and possibly even transform their own thinking (Blacksher et al. 2012). This encourages participants to not only consider the values at stake in various MAiD policies, but to also imagine what those values look like when actualized into policy. Deliberative activities tend to avoid recruitment through self-selection, instead opting to invite individuals directly and possibly reaching individuals who may not have chosen or known how to engage otherwise (Longstaff and Burgess

2010). Interestingly, the external panel, expert panel and special joint committee on MAiD all call their committee meetings (among committee members) "deliberations," suggesting that they see the value in reasoned discussion to form policy recommendations.

Policy making for MAiD has four features that make it well-suited for deliberative public engagement: (1) it reflects conflicting values about the public good, (2) it is an inherently controversial and divisive topic, (3) it combines technical and real-world knowledge and (4) it is a policy area where trust can be easily eroded (Solomon and Abelson 2012). First, MAiD policy making obviously deals with conflicting public values, including compassion, autonomy, protecting vulnerable persons and justice. Many disability activists argue that Canada's increasingly permissive MAiD system reveals a lack of respect and value for disabled lives, which are made inherently vulnerable due to ableist systems (Coelho et al. 2022; Herx et al. 2019). Conversely, MAiD supporters argue that people with disabilities should have the autonomy to choose a dignified death and MAiD should be seen as a compassionate response to intolerable suffering (Adams et al. 2017; Buchman 2019). Ultimately, the appropriate balance between these values to form a MAiD regime that is ethically acceptable to Canadians is of profound public concern. Deliberation is particularly useful as it allows participants to consider how policy decisions impact not only themselves but large communities, understand the underlying values that produce divergent opinions and meaningfully engage with opposing viewpoints (Solomon and Abelson 2012).

Policy making for MAiD also combines technical expert knowledge and real-world experience. While consultation with experts, such as healthcare professionals, lawmakers, policy makers and bioethicists, is obviously important and has been the mandate of many government panels and committees, the lived experiences of patients, disabled persons and other individuals cannot be undermined. Many disability activists argue that general support for MAiD may reflect a misunderstanding about the difficulties of living with a disability, which many attribute not to the disability itself but to the lack of social supports to live *with* the disability (Lemmens and Krakowitz-Broker 2020). Public deliberation can help bridge the gaps between these important and sometimes contrasting views of experts and persons with lived experience, giving the public access to a broad range of experiences and evidence to inform perspectives on MAiD.

Finally, MAiD policy making, by virtue of its inherently value-laden and controversial nature, can erode public trust in the MAiD regime and even the healthcare system more broadly. There has been rising concern about unethical practices within Canada's MAiD administration. These include individuals seeking and becoming eligible for MAiD due to a lack of social supports like housing and medical care (Mulligan and Bond 2022). Individuals with disabilities also report being offered MAID by their healthcare providers, noting this as a harmful sign of ableism in the healthcare system (CTV News 2018). Public deliberation can be an important avenue for policy makers to hear and consider public concerns, while also increasing transparency and accountability for complex policy decisions.

As MAiD policy making continues to evolve in Canada, the need for public deliberation is apparent. The eligibility of mental illness as the sole underlying condition has now been delayed three times, suggesting that federal and provincial governments do not feel ready to move forward with this eligibility criterion (Osman 2024). Public deliberation can help policy makers engage members of the public in deeper conversations about MAiD and mental illness and test out different policy outcomes on a smaller scale. This can help increase confidence in policy decisions that have been deliberated by the public. Lack of public awareness about MAiD and end-of-life care in Canada also calls into question the value of consultations that may be eliciting the misinformed or underinformed views of the public (Ipsos 2016). The information-giving aspect of deliberation can ensure that public perspectives are shaped by trustworthy information about what death and dying look like in Canada. Without good-faith discussions between individuals who share different viewpoints, MAiD debates risk becoming even more polarized over time. Recognizing that values like equity and compassion are shared, regardless of support for MAiD, can help the public and policy makers see the merit in opposing perspectives.

Promising Examples and Potential Pitfalls: Lessons from Canada and Beyond

While federal and provincial governments have yet to engage Canadians in deliberations about MAiD, the use of deliberation is not new to Canada nor to the issue of MAiD. Public deliberation has been used in Canada to address ethically complex policy issues like biobanking and childhood vaccination (Burgess et al. 2008; O'Doherty et al. 2021). Researchers from Quebec have used deliberative methods to engage the public and healthcare professionals about informational needs about MAiD (Boivin et al. 2019). Leveraging a strong history of leadership in the public deliberation field, Canadian policy makers have existing structures and rich experiences to draw on when designing deliberative activities to engage the public on MAiD (Bentley et al. 2018; MAP Centre for Urban Heatlh Solutions 2024).

International experiences also provide key teachings for Canada. In 2018, the Minister for Health and Social Services in Jersey established a citizens' jury on assisted dying (Jersey Assisted Dying Citizens' Jury 2021). The jury, consisting of 23 demographically representative residents, were asked to answer the question, "Should assisted dying be permitted in Jersey and, if so, under what circumstances?" They heard from a wide variety of experts and persons with lived experience on both sides of the issue across 10 deliberative sessions. Some important reflections by jury members were that the issue was "a lot more complicated than [they] first thought," that they were "now in a better position to take an informed position [on assisted dying]" and that they "[became] more accepting of opposing views" (Jersey Assisted Dying Citizens' Jury 2021, pp. 30–31).

However, participants in the Jersey citizens' jury felt that the voting process at the end of the deliberation (which sided with permitting assisted dying) may have alienated participants on the opposing side. A key lesson for policy makers here is that perceptions about the fairness and success of deliberative activities depends on how they are designed. While policy makers might prefer the conclusiveness of voting-based deliberations, especially in cases where deliberations directly shape policy making, the voting process may interfere with good-faith discussions by arranging participants as winners and losers. Building consensus, through voting or other methods, is not always the outcome of deliberations. This was the case for a researcher-initiated citizens' jury in New Zealand on the ethical permissibility of assisted dying, which saw the deliberative group become more polarized in their views after deliberation (Walker et al. 2020).

Lack of consensus or even increased polarization after deliberations may be a sign of the inherent complexity of MAiD debates rather than cause for concern. The New Zealand citizen's jury was useful in uncovering disagreement, improving understanding between conflicting views, and clarifying rationales for differing viewpoints. Many participants changed their views during the process, demonstrating the power of deliberation's information-giving and discussion-based features to shift and potentially shape more informed positions. While policy makers may feel wary of initiating deliberations that do not produce clear findings, individual disagreement can still lead to viable policy solutions through greater acceptance of divergent viewpoints and discussions about the broader public good (Solomon and Abelson 2012).

Increasing polarization during or after deliberations can also hint at design flaws in deliberative processes that require attention. For example, the information-giving portions of deliberations about MAiD policies may be a source of mistrust if the expert viewpoints or lived experiences shared are perceived as biased or skewed toward one perspective. Initial malleability to new arguments and information may shift to more rigid positioning as a result of this mistrust. Allocating enough time and attention to selecting experts and persons with lived experience on both sides of the issue, with neutral perspectives if possible, will be particularly important for MAiD deliberations.

Designing inclusive activities is also an important consideration that can challenge current norms in deliberative practice. Deliberative activities tend to invite individuals to engage using a stratified random sample to reproduce the demographic diversity of a particular region (Longstaff and Burgess 2010). However, demographic representation can lead to the domination of majority interests, which may not sufficiently consider how MAiD disproportionately affects groups such as disabled persons and individuals lacking access to social supports (Ott and Knopf 2019). In such cases, deliberations may warrant the "overrepresentation" of certain perspectives; for example, deliberations about mental illness may want to prioritize engagement with individuals with mental illness.

Finally, the capacity for deliberation to increase trust in MAiD policy decisions depends on whether participants feel their contributions made a difference; engagement that is perceived to be tokenistic or just for show can undermine public trust in the process (Solomon and Abelson 2012). For highly contentious policy issues like MAiD, policy makers may be reluctant to clearly state whether public viewpoints will influence policy decisions, increasing the risk of tokenistic engagement. Accountability and transparency are key tenets of meaningful engagement, where individuals are informed about the potential impact of their engagement on the policy making process (Li et al. 2015). When assurances of policy impact are not possible, transparency is essential to clarify goals and set the terms of engagement.

Conclusion

As assisted dying policies continue to evolve in Canada, governments have a responsibility to meaningfully engage Canadians on the design and implementation of our MAiD regime. While public consultations have been interspersed with key legal and policy developments, opportunities for deep and sustained reflection are notably lacking. Deliberation offers an alternative and essential route for Canadians to critically reflect on the values and tensions underlying MAiD and for policy makers to seek the informed perspectives of the public. Policy makers who plan to conduct and learn from such deliberations would benefit from collaborations with researchers in Canada who have expertise with such methods and trusted community organizations that represent key target populations for engagement. Truly transformative engagement on MAiD requires policy makers to create opportunities for deliberation that are responsive to issues of polarization and mistrust that can arise in these ethically complex discussions and attentive to the communities commonly excluded from them that may be uniquely affected by changes in MAiD policies.

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RESEARCH PAPER

Ethical and Transformative Scholarly Public Engagement: Pitfalls, Possibilities and Promises

Engagement éthique et transformateur du public scientifique : pièges, possibilités et promesses

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Abstract

At its core, public engagement is geared toward transformative ends – to change the world for the better. Yet, the means are also critical. Scholars who engage communities and public processes should do so ethically, in ways that comport with core values. Despite good intentions, however, researchers seeking to engage the public face substantial challenges. This paper highlights the pitfalls and perils associated with scholarly public engagement and points to the promise of ethical and transformative engagement – that is, engagement for sound reasons carried out in effective ways. I make the case that ethical and transformative public engagement requires that researchers remain aware of their position, attentive to who is being engaged and discerning about how to engage.

Résumé

Dans son essence, la mobilisation du public est axée sur des fins transformationnelles – changer le monde pour le mieux. Pourtant, les moyens employés pour ce faire sont également importants. Les chercheurs qui s'engagent auprès des communautés et dans les processus publics devraient le faire de façon éthique, en respectant les valeurs fondamentales. Malgré leurs bonnes intentions, les chercheurs qui cherchent à mobiliser le public se heurtent toutefois à des défis considérables. Cet article met en évidence les pièges et les dangers associés à la participation du public aux travaux des universitaires et souligne la promesse d'une participation éthique et transformatrice, c'est-à-dire une participation pour de bonnes raisons et réalisée de manière efficace. Je soutiens qu'une mobilisation publique éthique et transformatrice exige que les chercheurs demeurent conscients de leur position, qu'ils soient attentifs aux personnes mobilisées et qu'ils fassent preuve de discernement quant à la façon de les mobiliser.

Introduction

Policy makers, bureaucrats, media and even community organizations all rely on researchers (academic and non-academic) for purposes that range from relatively minimal (e.g., explaining research findings) to quite significant (e.g., co-producing collaborative research). Given researchers' specialized knowledge, they are capable of supporting policy and practice in ways that advance the common good. The pivotal role research scholars can play was apparent during the COVID-19 pandemic (Ball 2021; Yin et al. 2021). Nevertheless, researchers face significant barriers to producing useful and effective engaged scholarship (Calice et al. 2022; Sdvizhkov et al. 2022). To expand and leverage the possibilities of research to contribute to positive social change, these and other obstacles must be continually articulated and grappled with. This article does so by elaborating four common pitfalls that undermine ethical, transformative public engagement among scholars. None of the challenges outlined here are surprising, nor is the discussion of them novel. Still, the task of ethical and transformative public engagement among scholars is perennial and enduring. It is new to scholars who are first encountering it and presents ever-evolving trials to experienced scholars. This is why reiterating the difficulties of ethical scholarly engagement through a different lens (as I do in this paper) is a useful contribution, even if the insights offered are not innovative. Indeed, it is in recurring rearticulation of vital principles that we forge a shared culture of ethical and transformative scholarly public engagement (SPE).

Defining, Conceptualizing and Motivating Scholarly Public Engagement

I define SPE as "the involvement of researchers in institutional processes that have direct relevance to the public good, with the aim of informing, enriching, or influencing those processes to produce public benefit."[1] This definition sensitizes us to two key elements of scholarly engagement. First, SPE must be oriented toward public processes (e.g., conducting research to support community organizations, enriching public knowledge via media, developing evidence useful for policy making and more). The point here is to differentiate between individualized engagement disconnected from larger institutional processes (e.g., a researcher volunteering at a local food bank to help distribute food) and public engagement embedded within such processes (e.g., a researcher working collaboratively with a food bank to study and promote building community power in food insecure locales). Second, SPE must be for the purpose of producing public benefit. This point distinguishes between engagement that yields private benefits (e.g., a researcher collaborating with a corporate or nonprofit entity to help improve internal workplace practices) and engagement that generates public benefit (e.g., a researcher collaborating with a state administrative agency to understand and address the administrative burdens placed on social policy beneficiaries).

It is worth noting that SPE as defined above encompasses related scholarly practices, including community-engaged research and community-based participatory research (Barkin et al. 2013; Kantamneni et al. 2019). Community-engaged research (CER) is "a research paradigm that creates space for communities, community members, and community-based organizations to work in collaborative partnerships with academic researchers" (Kantamneni et al. 2019: 65). Community-based participatory research (CBPR) is a related but more intensive approach in which members of communities are "equal participants in the development and conduct of the research" and for which "the research has direct benefits for the people involved" (Hacker 2013: xi). If CER and CBPR can be thought of as distinct approaches on a shared continuum "ranging from research in the community setting to research that fully engages community partners," then SPE is a broader umbrella than both (Hacker 2013: 2). Though SPE is always in relation to the public good, it is not always conducted directly in communities and does not always fully engage communities. Some scholars may engage from outside of communities (e.g., by partnering with government agencies that are trying to solve community problems) or may not involve communities until a middle or latter stage of research (thus not fully engaging them). These other choices are part of the calculus of how to ethically engage as a scholar, and are often contingent on context, constraints, resources or the specifics of the research being conducted. I focus (intentionally) on the broader concept of SPE (rather than more specific approaches, like CER and CBPR) to make the insights shared here applicable to a wider range of scholars who may be at different levels and/or stages of experience with engaging with processes relevant to public actors and institutions.

A broad throughline that applies to CER, CPBR and other forms of SPE is that researchers must be able to identify the public purpose of their engagement and connect their efforts to a larger understanding of how to make change in the world (i.e., a feasible theory of change). In the absence of such clarity, SPE can too easily be motivated by aims that are divorced from public good. Researchers can engage to build their own status, elevate the profile of their academic institutions or appease university donors. None of these motives capture the core impetus of public engagement. Put most simply, the point is to change the world. Public engagement should be designed to facilitate some degree of social transformation. The goal of social transformation is lofty. Such ambition may seem like the artifact of naiveté or hubris. Yet, scholars invested in public engagement must push beyond skepticism to cultivate possibilities of ethical and transformative public engagement. Transformative engagement is that which unreservedly seeks to change the world. Ethical engagement is that which does so in ways consistent with core principles of equity, democracy and transparency.

Laying a foundation for ethical and transformative SPE requires confronting four potential pitfalls: (1) failing to interrogate one's positioning and motives, (2) failing to co-produce clear values and expectations around the processes of engagement, (3) having myopic or exclusionary perspectives on who and how to engage and (4) ignoring or underestimating power dynamics. These are hardly the only pitfalls possible. Other scholars have considered these and many more (Downey 2018; Kantamneni et al. 2019; Salmon et al. 2017). Below, I draw on concrete examples from my own experience to demonstrate the risks of each pitfall. I do not provide neat resolutions. Instead, I instructively describe critical challenges that scholars must continually confront as they traverse uneasy paths toward ethical and transformative engagement.

Pitfall #1: Failure to Self-Interrogate

I grew up in working-class neighbourhoods in New York City as a Black American woman and the daughter of immigrant parents. Throughout my youth, I experienced the systems of economic and racial inequality that would eventually become the centerpiece of my scholarship and teaching. Even as I found my way to an economically stable life as an academic researcher, I remained tethered (through relationships, moral commitments and personal experiences) to race–class subjugated communities like those where I spent my formative years. Working with those communities is an essential aspect of my scholarly purpose. For this reason, I view public engagement as both an opportunity and obligation.

I am now a tenured professor at an Ivy League institution. In this capacity, I have benefitted considerably from institutional funding to facilitate community-engaged teaching and learning. At the same time, being at a top research institution has downsides. Because my commitment to public engagement predated my tenure and promotion, I ran the risk of overinvesting in that domain to the detriment of my research (the latter of which was more pivotal to my tenure case). What is more is that I am located within an organization that some community partners (rightly) view as an engine of privilege, distant from and unaccountable to less advantaged people and communities. That makes building trust an uphill climb, and moving at the speed of trust already requires time, a scarce resource. There is no easy solution to these dilemmas. They require choice after uncomfortable choice. Being sober about such choices and willing to decentre our personal interests in making them are most crucial.

Though pursuing public engagement in my scholarly life has been challenging, I've always believed – as Black feminist thinkers have long said – that if we change systems in ways that make things better for those who face stark precarity and disadvantage, we will necessarily improve life for everyone (The Combahee River Collective Statement 1977). Still, I have often found myself wondering whether academic institutions are properly equipped to foster such change. On many occasions, I've been unsure of whether the engagement of academics (including myself) was more instrumental and extractive than ethical and transformative. In my current role as Senior Associate Dean of Public Engagement at a school of public policy, part of my work involves grappling with these questions. My approach to this work is more community-centred, capacious, equity-oriented and critical than it would be if I did not bring the specific background and perspectives I do to the role.

Exposing these details about myself is not an exercise in navel-gazing. To the contrary, I started with myself because the first pitfall I want to highlight is the failure to discern one's own positioning or a lack of reflexivity (Salmon et al. 2017). Reflexivity is a precursor to ethical public engagement. As researchers who work within educational institutions, we have a platform and resources that can be deployed for both good and ill. Acknowledging the contours of our own power and positions (even as we work within constraints) is necessary for acting with intentionality and integrity. Moreover, each of us inevitably bring a personal history to bear on our work engaging government, policy makers, media and communities. Those histories make us more (or less) comfortable with certain people, places, actions and strategies. Such histories structure our ability to build relationships, our understandings of policy problems and our outlook on the world. Understanding ourselves, our motives and our limits is essential for SPE.

Pitfall #2: Failure to Establish Clear Values and Expectations

Ethical public engagement requires committing to a set of core values to which scholars can hold themselves accountable and be held accountable. I will offer an example.

One of the first public engagement efforts I undertook involved working with a local community organization. The organization wanted to understand whether a policy spearheaded by officials in their city had successfully reduced poverty. I was keen to help them assess this so that they could develop an advocacy plan to benefit low-income communities in the city. I had positive initial conversations with the partner organization. I employed a small team of student researchers to assist with the poverty assessment. My team collected a wide range of quantitative and qualitative data. The results did not yield what my community partner expected. It was clear from early on that my partner was critical of the policy under study. However, our analysis revealed a complicated picture. My team's quantitative assessments registered appreciable reductions in the local poverty rate and our qualitative exploration revealed that some people were helped by the policy (even while others were not). Our conclusion was that the policy was partially successful, with much room for improvement. This was not what my community partner wanted to hear. Anticipating tension, I procrastinated and did not clearly communicate. The partner became frustrated and hesitated to communicate with me as well. Altogether, the partnership was not fruitful.

One of my biggest mistakes was failing to clarify and co-produce the values driving our work and the expectations we could have of one another. This is something we should have settled before embarking on a partnership – either informally through intensive conversations, formally through a memorandum of understanding or both. Unfortunately, I approached the project as a research activity: a one-off process of answering an empirical question (was the antipoverty initiative effective). I also viewed it as an opportunity (I wanted to do more engaged work and had received funding to do it). But I did not understand it as a relationship and a commitment that I was accountable for following through on.

If I could do it over today, I would ground my engagement in shared values and transparent expectations. One value I would emphasize is integrity, which dictates that I faithfully convey the findings of research without altering the results to satisfy either myself or my partners. Another value would be equity. It is only through equitable practice (i.e., involving a representative range of actors affected by and involved with the processes we study) that we produce sound findings. If I had established these values at the onset and worked to come into alignment with my community partner, we might have had a successful collaboration. While each researcher must determine which values are priorities, the practice of co-establishing and clarifying some set of principles is of foremost importance.

Pitfall #3: Myopic, Exclusionary Perspectives

Having a capacious vision of SPE means critically assessing which actors to engage, what counts as engagement and how to engage. As public engagement is not part of the formal training of most researchers, we can too easily come to espouse narrow conceptions of engagement (e.g., those that primarily centre elite political actors), myopic understandings of what counts as engagement (e.g., writing op-eds or legislative testimony) or exclusionary approaches to the practices of engagement (e.g., engaging easy-to-reach actors while ignoring those we are less familiar or comfortable with). But transformative engagement necessitates the inclusion of a wide range of actors and partners in engagement practices, embracing forms of engagement that are not only elite-facing but also grounded in communities and pushing beyond our comfort zones in terms of whom and how we engage.

In my own work, the SPE I get the most attention for is not the work that reflects this inclusionary vision. For example, I have gotten accolades on the several occasions I have testified before the US House of Representatives or directly engaged federal policy makers. While these activities are worthwhile, they are also episodic and indeterminate in terms of outcomes. Alternatively, my work over the last two years with a local tenant organization has been much more meaningful. That work is rooted in a specific community of people. My academic partner and I obtained grant funding to help the tenant union hire an additional organizer and conduct informative focus groups (allowing us to ensure that our community partner receives direct support). This work has gotten comparatively little notice, but it has been predominantly community facing and has involved forms of engagement that I never would have considered were it not for a genuine partnership with directly affected people. For example, we are currently working to make a short film that the tenant union will use as an organizing and advocacy tool. The film will likely not generate much interest beyond the specific communities we engage with. However, within those communities, it can be leveraged to inform and mobilize the people who experience the predatory excesses of the US housing market.

Our aim is for this work to bring marginalized tenants into deeper relationship with governing bodies and to facilitate their influence on policy. Yet, we cannot shortsightedly assume that policy influence is only (or even optimally) possible through direct engagement with policy makers or other elite power brokers. An ethical attitude toward engagement requires that we think carefully about how change happens, and that we push beyond tendencies of engaging the most accessible, prominent or reputable people through the most traditional practices.

Pitfall #4: Ignoring or Underestimating Power

The fourth pitfall concerns power. Power is often unacknowledged in approaches to public engagement. Even while "voice" and "lived experience" gain ascendency among many scholars committed to public engagement, power remains underattended. Yet, voice without power is tokenism. Bringing people with lived experience to the table without a recognition of power dynamics is hollow symbolism. Where are peopled with "lived experience" sitting at the tables we invite them to? Who else is at those tables? What are the rules structuring who gets to have influence over the decisions made at the tables? Unless there is real path between sitting at such tables and influencing the processes that unfold there, people with lived experience are being instrumentalized for purposes that do not benefit them. To be fair, this is usually unintentional. Regardless, once inclusion expands the circle of participants in a policy process, we must chart a feasible path to power for those with the most at stake in policy decisions. Given the status quo of many political institutions, we cannot expect marginalized actors to fall seamlessly into ongoing processes. Instead, their presence requires power analyses that reveal ways to restructure processes to build power in otherwise marginalized communities (Michener 2022a, 2022b; Michener and Ford 2022; Michener and Ford 2023).

One thing worth noting is that public engagement does not involve giving anybody power. Power is not something that can be conferred as such. Empowering communities is not as much the goal as is building power. The difference may be subtle, but it suggests that power already exists in marginalized communities, but institutional and other barriers hinder its effective exercise. SPE should be part and parcel of eroding such barriers (e.g., by providing access to knowledge, financial resources and other forms of support) and certainly has a mandate to never reinforce them.

Conclusion

The pitfalls elaborated above point to affirmative possibilities. SPE is not an ordeal rife with risks, it is a landscape filled with potential. The pitfalls detailed thus far threaten to diminish those positive prospects if not sufficiently mitigated. Yet, approaching engagement with reflexive intentionality holds promise for the kind of public engagement that brings meaning to research and enables it to be a mechanism of social transformation. The possibilities underlying the four perils noted above are fourfold. First, a commitment to ethical public engagement presupposes thoughtful introspection to assess our motives and positionality.

Second, effective engagement requires co-producing values and negotiating expectations that equip us to work respectfully with our partners in the work. Third, transformative public engagement entails cultivating a capacious, inclusionary vision of what counts as engagement, who should be involved in it and how to implement engagement practices. Finally, identifying and acknowledging and taking steps to redistribute power points us toward engagement approaches that build power in the places it has been unduly eroded. Taken together, these possibilities light a path forward for public engagement that might change the world for the better.

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Note

[1] This definition leaves room for interpretation. Who counts as a researcher? Which institutional processes have direct relevance to the public good? What constitutes public benefit? The answers to such inquiries are contingent on specificities of context. They cannot be determined in the abstract but must be actively grappled with by scholars and those they work alongside.

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