

# Unpacking the ‘Public’ in Public Engagement In Search of Black Communities

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Public engagement in health policy encompasses several visions, mandates, frameworks, and approaches, which are aimed at including the broader public in health policy decision-making processes. This includes models that offer tools and methods (e.g., hearings, focus groups, citizen panels, etc.) for consulting and partnering with communities to facilitate their participation in policy decision-making. This kind of public engagement is often described as integral to policy decision-making and the quality of health services (Gauvin & Abelson, 2006; Ham, 2001, 85; Health Canada, 2000; Polletta, 2016). These approaches signal an openness to hearing the diverse views of Canadians and suggests a shift away from the more top-down approaches to health policy decision-making that governments have traditionally employed.

However, closer examination of these public engagement practices reveal gaps that call the true depth and breadth of these initiatives into question, therefore chipping away at their legitimacy and efficacy. Some scholars have argued that public engagement in health policy practices are often performative in nature, described by Polletta (2016) as “spectacles of public participation”. They can also be prone to political interference, are often inadequately resourced, can result in unfulfilled expectations (Gauvin & Abelson, 2006; Polletta, 2016; Shore & Williams, 2018), and can be self-selecting and designed in ways that make inclusive engagement difficult (Dhamanaskar et al., 2022). Other critical scholars have also pointed to a systemic privileging of amenable and acquiescent perspectives that do not disrupt the status quo, in addition to a devaluation, cooptation, and delegitimization of dissenting and critical voices (Glimmerveen, 2019).

In seeking out or privileging more agreeable voices, the gaps, inequities, and problems within health care systems can be left inadequately addressed. As a result, populations that are already marginalized and vulnerable, including those with lay expertise (i.e. lived experience with chronic health conditions),

are further silenced and invisibilized (Tritter, 2006). There is also evidence to suggest that there are many community voices missing from these conversations when they do take place, such as Indigenous, racialized, and Black perspectives (Balkissoon, 2020; Datta et al., 2021; Dhamanaskar et al., 2022; Grant & Balkissoon, 2019; Lau, 2021; McKenzie, 2020). For example, in Dhamanaskar et al.'s (2022) recent review of government-initiated public and patient engagement activities in health policy from 2001-2021, only 8/132 (14%) of the cases mentioned prioritizing or engaging with marginalized populations, and it is difficult to assess the efficacy of even these few efforts to be inclusive.

This raises the question, who really is 'the public' in public engagement--and how legitimate and effective can these processes be with such critical gaps in representation? To be truly transformative, public engagement in health policy must reflect the agency, diversity, and interconnectivity present within communities (Hendricks, 2006). However, it appears to fall short when it comes to meaningfully engaging the diverse communities of Canada and shifting power dynamics in ways that can inform systemic changes within the health care system. These are not simply technical or design challenges, but deeply political issues and barriers that need to be clearly identified and acknowledged in order to be tackled head on.

### **Black Community Engagement in Health Policy: Some Critical Questions**

The current context of the global pandemic has brought these issues of systemic exclusion from health policy engagement into greater focus (Sayani et al., 2021). We have known for some time that social determinants such as race, social class, education, and environment impact health outcomes in both ordinary and emergency situations (see Dalsania et al., 2021; Fuchs, 2017; Mikkonen & Raphael, 2010; Palmer et al., 2019; Turner-Musa et al., 2020). The pandemic has crystalized this knowledge, as data consistently demonstrates that marginalized groups, such as Black communities, have been disproportionately impacted by COVID-19.

Black communities in both Canada and the United States are at a higher risk for contracting COVID-19, have been dying at disproportionate and alarming rates, and suffer greater negative economic impacts (Abebe, 2020; ACCEC & INNOVATIVE, 2020; Amin & Bond, 2020; Dei & Lewis, 2020; Derfel, 2021; McKenzie et al., 2021; Siddiqi et al., 2021). What adds to these concerns is the tension between the devastating impact of COVID-19 on Black communities, what appears to be a poor track record of meaningfully engaging Black communities (among other marginalized groups) in health policy decision-making processes (Dhamanaskar et al., 2022), and a lack of a robust race-based data and research across Canada to document and analyze these issues.

Given the incredibly high stakes, there are some critical questions that we should be asking ourselves as researchers, health practitioners, activists, and policymakers. What do we think we know about the needs and desires of Black

communities in Canada as it relates to their health, and where does this knowledge come from? What are the ways we have historically engaged Black communities in health policymaking in Canada? To what extent are Black communities *actually* represented in the ‘public’ portion of the ‘public engagement’ processes we speak about? What are the challenges we have encountered when attempting to engage Black communities in these processes, and what do we attribute these challenges to? What can we learn from the ways that Black communities have self-advocated and mobilized to create their own health-focused solutions and interventions? Finally, can we afford to move forward with the status quo if we are in fact designing health policies and systems that are not adequately informed by and serving the communities who need it most?

By posing these questions, we seek to disrupt the notion that Black community engagement in health policy (or lack thereof) is some tangential technical issue. If we are willing to follow the paths these questions lead us down, we will likely find that these are instead core and existential questions that speak volumes about the efficacy of our health systems and policies, and who these systems traditionally aim to serve. Finally, while there is vital grey literature captured by practitioners and community organizations (as cited in this piece), it is essential that the needs and experiences of Black communities within healthcare be adequately reflected in the academic literature. As such, it is critical that we continue to advocate for the collection of race-based health data across Canada to strengthen these health equity discussions and policy reform efforts (Black Health Leaders, 2020; Pinto, 2020; Rayner et al., 2020).

One of the profound impacts of the #BlackLivesMatter movement, particularly following the murder of George Floyd, has been a collective exasperation with the ways in which politicians and institutions have often feigned ignorance about the systemic barriers and forms of violence Black communities face in their daily lives. Practices of symbolic anti-racism that present a veneer of action rather than substantive structural change only serve to add insult to injury (see George et al., 2020). Therefore, while we continue to collect more data and pursue more research, we also need simultaneous and courageous conversations at policy and practitioner tables that include a radical level of honesty as the starting point. This begins with an acknowledgement that our failures to successfully engage Black communities in health (and other) policy decision making processes: 1) *matter* and are in fact critical failures; 2) reflect a particular history of systemic racism, marginalization, and political indifference; and, 3) needs to be tackled with focus, humility, and imaginative thinking – *what got us here won’t get us there*.

Finally, if we begin any of this work without Black communities at the table and leading these discussions, we have missed the point entirely.

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