# Trends in Public Engagement in Canadian Health Policy from 2000-2021: Results from a Comparative Descriptive Analysis

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#### **Abstract**

Canada has a rich history of public and patient engagement in health policy; however, shifts in engagement practices over time have not been well examined. We aimed to describe trends in engagement approaches in health policy by collecting examples of government-initiated engagement activities from 2000-2021 ("case survey"). Cases were identified through engagement portals, academic literature, and grey literature and were coded according to pre-defined categories including type of engagement, target population, selection method, and whether they took steps to include marginalized populations. We identified 132 cases conducted at the federal and pan-Canadian levels, as well as in Ontario, British Columbia, and Nova Scotia. Our survey found a predominance of feedback-oriented engagement activities, and activities that used self-selection recruitment methods, especially at the federal level from 2016 onwards. Target populations included members of the public, patients, and other stakeholders (such as health professionals or other experts) and varied across jurisdictions; engagements that targeted multiple populations simultaneously were favored overall and over time. Just over 1 in 10 cases in our survey mentioned efforts to engage with marginalized groups. The following sectors accounted for the majority (69%) of collected cases: health technology, tobacco & vaping, health reform, mental health, aging & long-term care, public health & infectious diseases, and COVID-19. Our results identify a heavy reliance over time on more passive, indirect engagement approaches, especially at the federal level. This approach to engagement in theory allows for broad-based contributions, but ultimately falls short in addressing long-standing critiques and recent calls for more transformative, inclusive engagement for equity-seeking groups in particular. Our results provide the foundation for future work that will examine these issues in greater depth, by sector, population and modality, and with the aim of pointing to modernized public engagement approaches.

# **Supplementary Materials**

Supplementary files related to this publication can be found at <a href="mailto:ppe.mcmaster.ca/research/public-engagement">ppe.mcmaster.ca/research/public-engagement</a>.

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### 1.0 Introduction

The Public Engagement in Health Policy project aims to strengthen health policymaking in Canada by providing a platform for interdisciplinary scholarship, education and leadership in public engagement. Through our research, education and leadership opportunities, we seek to address current challenges such as how health policymakers can respond to calls for more inclusive and transformative public engagement processes and how public engagement can be used to improve policy responsiveness, enhance democratic legitimacy, and build trust between governments and citizens.

As part of our scoping work for this project, we examined general trends in public engagement in Canadian health policy since 2000. 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, pan-Canadian and provincial levels of government.

#### 2.0 Methods

We searched for cases of government-initiated public engagement in Canadian health policy since 2000 (herein referred to as the "case survey"). This timeframe was chosen to assess the degree to which democratic innovations over the last twenty 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. These criticisms highlighted issues pertaining to the representativeness, legitimacy and responsiveness of public engagement processes (Abelson and Eyles, 2002). Our search was limited to identifying cases at the federal, provincial, regional, and pan-Canadian levels in keeping with 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.

# 2.1 Search Strategy

Our search was limited to the following jurisdictions: Federal, pan-Canadian, British Columbia (BC), Ontario (ON), and Nova Scotia (NS). The selection of BC, ON and NS as provincial jurisdictions was motivated by our goal of capturing geographical diversity. Team member knowledge of the history and supporting provincial structures for engagement in these provinces also helped with case identification. Federal and provincial cases were those that were initiated by the federal or provincial government. Regional cases may have been initiated by health authorities but often in relation to provincial government initiatives. Pan-Canadian cases were largely initiated by one or more pan-Canadian health agencies funded by, but at an arm's length to, federal and provincial governments.

Team members were assigned to collect cases from different jurisdictions (Federal, pan-Canadian, ON, BC, NS) and time periods (2000–2010 or 2011-2021). Each team member followed a similar approach for collecting cases. 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 literature and grey literature, most commonly using Google Scholar and



Google web search respectively. Team members searched for cases not captured in the databases and for years where databases were not active. A combination of search terms was used, including: "public engagement", "public involvement", "patient engagement", "patient involvement", "feedback", "deliberation", "consultation", "co-design", "[jurisdiction]", and "[year]."

Team members continued to collect cases until new cases could not be found or the team determined there was enough variation captured to move on to the next phase of the project.

## 2.2 Coding of Engagement Activities

The team identified a preliminary set of categories to describe the engagement activities using a generic WHO, WHAT, WHY framework. Two aggregator sources of cases – Participedia (<a href="www.participedia.net">www.participedia.net</a>) and the CIHR Public Engagement case book (2012) – were used to identify 'typical' cases and to trial and refine the preliminary coding categories. A final set of coding categories (Table 1) was applied to all cases.

Table 1. Coding categories for engagement cases
Date (year)
Jurisdiction (federal/provincial/regional/pan-Canadian)
Ongoing or one-time
Type (feedback, consultation, deliberation, co-design, multiple)
Target population (patient, public, multiple)
Recruitment method (self-selection, targeted invitation, appointment, multiple)
Prioritize marginalized populations (Y/N)

## 2.2.1 Ongoing or One-Time

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

# 2.2.2 Type of Engagement

Cases were defined as using feedback, consultation, deliberation, co-design, or multiple methods of engagement. Activities where participants provide their opinion on policy proposals and health services, such as surveys and comment periods, were classified as "feedback." Consultation-style engagement includes open public forums where the public can provide their opinion on policy problems, solutions, and principles; these consultations are usually broad and open-ended compared to more narrowly framed feedback opportunities. Deliberative engagement activities are those where citizens engage on a policy issue through in-depth discussion and value-based reasoning that informs judgements about how to proceed on a particular issue. For example, this could include roundtable discussions. Finally, codesign activities involve partnership between key stakeholders and, most importantly, 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.



## 2.2.3 Target Population

Our case survey captured engagement activities targeting the general public and/or patient populations. Engagement activities that *only* involved experts, policymakers, government officials, or other stakeholders were not collected. Cases were classified as "multiple" if they engaged with a combination of target populations, namely, public, patient, stakeholder, or expert groups.

#### 2.2.4 Recruitment Method

Recruitment method describes how prospective participants were invited to take part in the activity. "Self-selection" engagements are those where 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 where 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, and then are selected to engage. This differs from a targeted invitation to participate in that it sometimes involves an element of self-selection (for example, 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.

## 2.2.5 Prioritizing Marginalized Populations

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

# 2.3 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 ~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.



## 3.0 Results

136 unique cases 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%), 11 cases at the pan-Canadian level (8%), 41 cases from ON (33%), 17 cases from BC (13%), and 16 cases from NS (12%). 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 is 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 which is explained by an increase in the number of federal cases collected during this period.

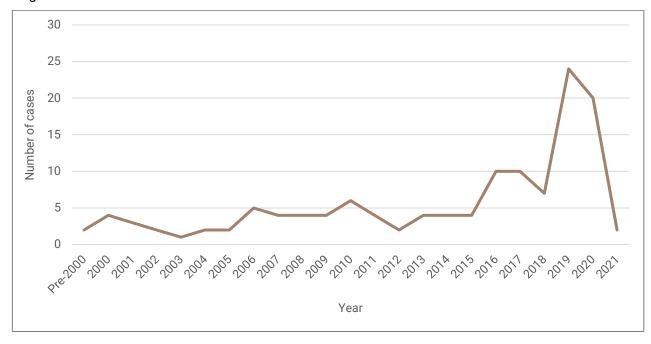


Figure 1. Number of cases over time

Looking again at all 132 cases, 96 (73%) were one-time activities, and 36 (27%) were ongoing. All cases at the federal level were one-time; overall, one-time cases were favoured in all jurisdictions except at the pan-Canadian level. A small number of cases, 18 (14%), mentioned prioritizing or engaging with marginalized populations.

# 3.1 Engagement Type

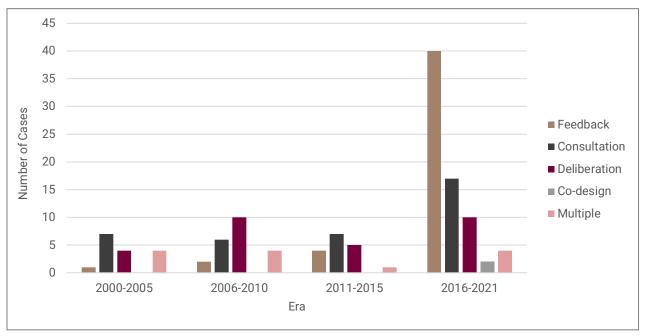
Type of engagement activity was categorized as either feedback, consultation, deliberation, co-design, or multiple. Two cases were missing data for this category. Data for the remaining 130 cases is outlined by jurisdiction (Table 2) and by era (Figure 2). Feedback and consultation were the most popular 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%).

Feedback was the preferred engagement type used at the federal level, representing just over half (53%) of the federal cases. Deliberation was favoured at the pan-Canadian level with 5 out of 11 activities (45%) using this type of engagement. Ontario was the only jurisdiction to include any co-design activities. As discussed earlier, the increase in the overall number of cases from 2016, and the predominant use of feedback and consultation, is largely explained by the increase in the number of federal cases as a proportion of the total. There are no clear trends prior to 2015 other than a fairly consistent use of all approaches across time.

Table 2. Cases by engagement type and jurisdiction							
	BC	Federal	NS	ON	pan-Canadian	TOTAL	
Feedback	7	24	7	7	2	47	
Consultation	6	13	3	14	3	39	
Deliberation	2	4	5	13	5	29	
Multiple	1	4	1	6	1	13	
Co-design	0	0	0	2	0	2	
TOTAL	16	45	16	42	11	130	

Figure 2. Number of cases by type of engagement sorted by eras



# 3.2 Target Population

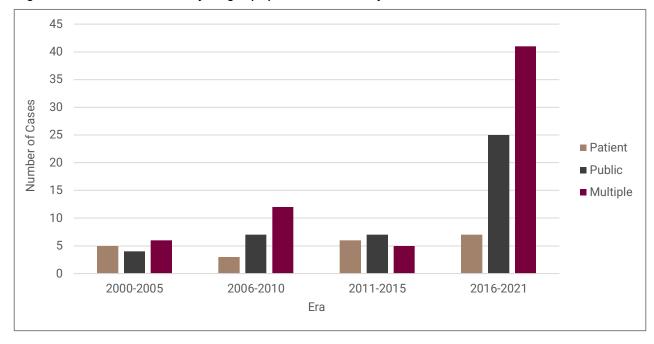
Target population was classified as either public, patient, or multiple. Two cases were missing data for this category. Data for target population is reported by jurisdiction (Table 3), and by era (Figure 3). Target audience was categorized as "multiple" in half the cases (65 out of 130). A third of cases (33%) were categorized as targeting the "public", and 22 out of 130 (17%) listed a patient-only target population. 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 labeled stakeholders, patients, or others with relevant involvement in the health system.

Target population varied widely by jurisdiction, with federal-level and ON favouring "multiple" and NS favouring "public", and pan-Canadian having a relatively equal distribution across categories. Looking across time, the emphasis on multiple target populations relative to others is fairly consistent with the exception of 2011-2015 where it dropped below "public" and "patient".

Table 3. Cases by population and jurisdiction							
	BC	Federal	NS	ON	pan-Canadian	TOTAL	
Multiple	7	30	2	22	4	65	
Public	7	13	9	11	3	43	
Patient	3	2	3	10	4	22	
TOTAL	17	45	14	43	11	130	

Figure 3. Number of cases by target population sorted by eras

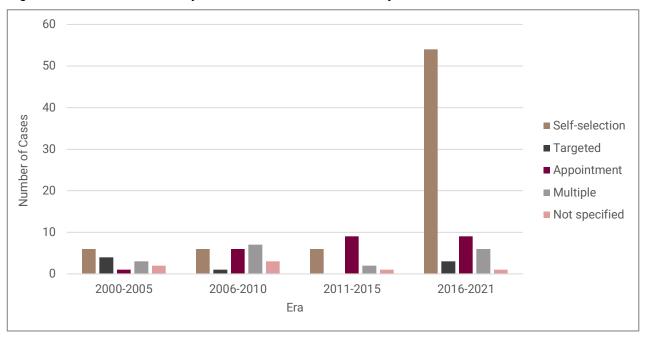


#### 3.3 Recruitment Method

Recruitment method was categorized as using self-selection, targeted invitation, appointment, multiple, or not specified. Recruitment method results are outlined by jurisdiction (Table 4) and by era (Figure 4). Self-selection was the most commonly categorized recruitment method, representing 55% of cases overall, and 78% of federal cases. Self-selection was also favoured in BC, representing 71% of cases in this province. Looking over time, the use of self-selection clearly overshadows the use of all other recruitment methods in recent times, given its dominant use at the federal level. Although few in number overall, targeted approaches that provide the opportunity to prioritize specific populations were used in the early 2000s and more recently but are almost non-existent between 2006 and 2016.

Table 4. Cases by recruitment method and jurisdiction							
	BC	Federal	NS	ON	pan-Canadian	TOTAL	
Self-selection	12	35	8	15	3	73	
Appointment	1	0	3	15	6	25	
Targeted	1	5	1	6	2	15	
Multiple	2	4	2	4	0	12	
Not Specified	1	1	2	3	0	7	
TOTAL	17	45	16	43	11	132	

Figure 4. Number of cases by recruitment method sorted by eras



# 3.4 Engagement by Topic Area

Unique cases were sorted into broad topic areas such as policy sector, disease/condition or population focus (Figure 5). The top seven topics (excluding "general") were subject to further analyses by jurisdiction, type of engagement, target population, and recruitment method (Figures 6-9). Health technology, tobacco & vaping, health reform, mental health, aging & long-term care, public health & infectious diseases, and COVID-19 were the sectors that covered the largest proportion of engagement cases, together accounting for 91 out of 132 (69%) of cases.

Health technology and tobacco & vaping issues comprise most of the engagement at the federal level, in recognition of the federal government's regulatory role in these areas, but there is also considerable engagement work in the health technology sector at the pan-Canadian level, and in Ontario. Engagement on broad health system reform issues, mental health, and aging & long-term care are more concentrated at the provincial level, particularly in Ontario which also likely reflects provincial responsibilities for health care delivery. Public engagement on COVID-19 has been specific to BC and NS (and possibly other provinces not surveyed) while engagement on other public health & infectious disease topics has been more evenly distributed across the surveyed jurisdictions.

When reviewing engagement type by topic, both feedback and deliberation were found to be used extensively in the health technology sector while consultation was more commonly used in the mental health and aging & long-term care sectors. Feedback has also been heavily used in engagement on topics of tobacco & vaping and COVID-19.

Engagement by target population shows a tendency to engage with multiple populations for most topic areas except for health reform and COVID-19. COVID-19 cases favoured engagement with the public. Engagement with patients was more common in health technology and mental health sectors.

Self-selection was the preferred recruitment method for engagement activities for all topics except for mental health. This was especially apparent for topics where the majority of engagement was occurring at the federal level (e.g., tobacco & vaping, health technology). Almost all instances of appointment occurred in health technology cases.

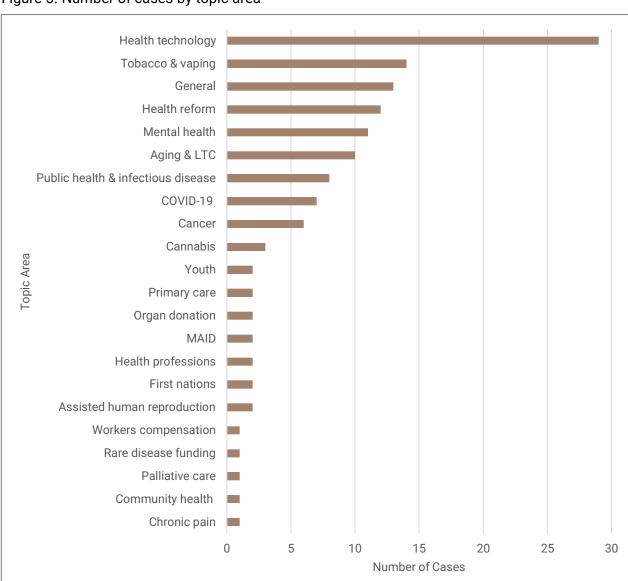


Figure 5. Number of cases by topic area

Figure 6. Number of cases by jurisdiction for most popular topic areas

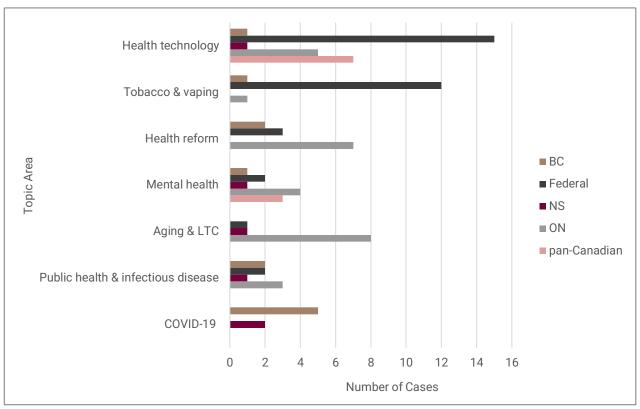


Figure 7. Number of cases by type of engagement for most popular topic areas

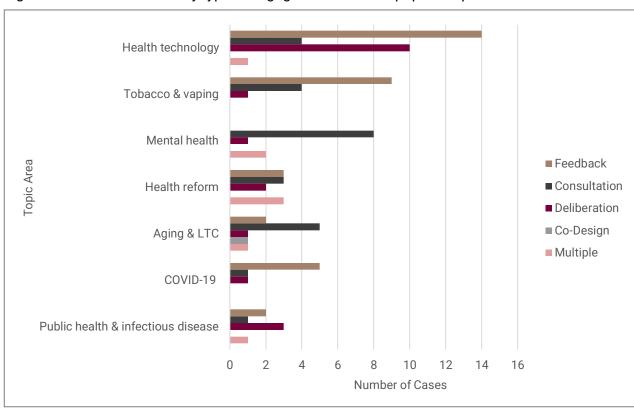


Figure 8. Number of cases by target population for most popular topic areas

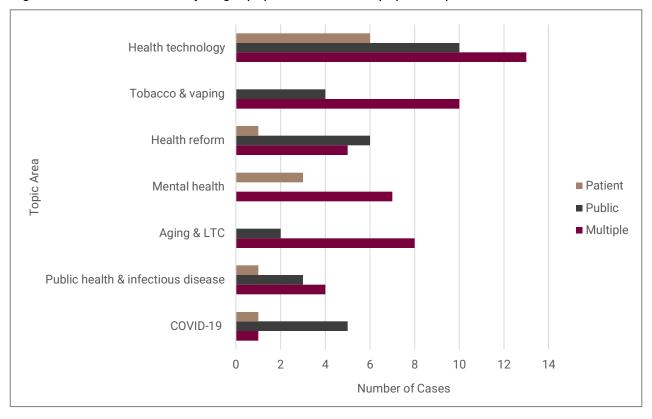
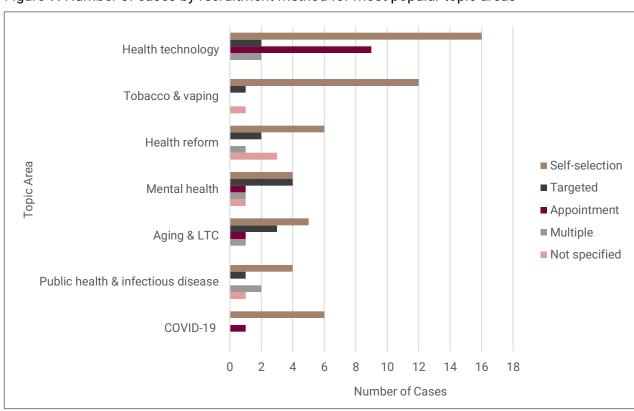


Figure 9. Number of cases by recruitment method for most popular topic areas



#### 4.0 Discussion

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

When looking at our cases over time, there were few notable trends beyond the sharp rise in the number of cases at the federal level from 2016 on, which relied almost exclusively on more narrowly framed feedback and consultation methods. Over the time period reviewed, we found consistency in: i) the use of multiple target populations (i.e., public and patient); ii) emphasis on self-selection and appointment relative to other recruitment methods (with some recent attention being given to targeted approaches); and iii) reliance on one-time versus ongoing engagement activities. The latter result, in particular, suggests that engagement activities are still most commonly structured as "one-off" opportunities to gather input on a specific issue, rather than as ongoing, recurring activities embedded in organizations.

Our results are skewed by the federal government's decision in 2016 to track and publicize its health-related public engagement activities, which primarily include self-selected feedback, and likely point to a broader but shallower style of engagement. We plan to dig deeper into this finding to determine whether this is illustrative of a government that knows the benefit of public engagement but has perhaps fallen short in devoting adequate resources to more inclusive approaches, or whether this reflects the type of engagement that they have chosen to pursue. This is of particular importance since self-selected feedback activities may be less accessible to individuals and communities who are not already well connected and aware of how to seek out engagement opportunities, which appears to be reflected in the low reported levels of engagement with marginalized populations across cases.

Our survey included engagement activities by pan-Canadian agencies at arm's length from government, primarily the Canadian Agency for Drugs and Technologies in Health (CADTH). Interestingly, this is where we see the highest proportion of engagement activities that include some form of deliberation, and where the organizing bodies have well-developed and longstanding deliberative frameworks (see for example the <u>Deliberative Framework</u> for the expert review committee that evaluates oncology drugs). These bodies are also, arguably, where we see the least policy power. CADTH's committees (with their institutionalized public and patient members) make recommendations about the funding of drugs and other health technologies, but do not have direct control over funding or other policy decisions. This concentration of deliberation in venues with less policy power is a topic we plan to investigate further.

Our analysis of cases by topic identified several areas of concentrated engagement activity including health technology, tobacco and vaping, health reform, mental health, aging and long-term care, public health and infectious diseases, and COVID-19 most recently. Together, these topic areas represent more than two-thirds of our total cases and illustrate some interesting patterns to be further analyzed. Despite COVID-19 only emerging as a public health issue in the last two years, it has been the focus of considerable public engagement activity, reflecting the salience of this area to policymakers. However, most of these activities involved seeking feedback from self-selected members of the undefined public. Given the populations most adversely affected by the pandemic, more targeted approaches with a particular focus on equity-seeking groups might have been called for – a theme we intend to explore more fully in this project.



## 5.0 Conclusion

Our case survey has generated numerous insights about trends in engagement practices in Canadian health policy. We are building on this work by examining some of the themes highlighted in this review in greater detail, for example, by looking at public engagement by *sector*, *population* and *modality*. Outputs from this next phase of our work are aimed at generating insights that will support more inclusive and transformative engagement in at least three arenas expected to be in the spotlight over the coming years: i) long-term care policy; ii) addressing health inequities within racialized communities, iii) the use of digital engagement platforms, and iv) the opportunities and challenges posed by a potential deliberative turn in public engagement in health policy.