

What's Involved with Wanting to Be Involved? Comparing Expectations for Public Engagement in Health Policy across Research and Care Contexts

Que signifie « vouloir participer »? Comparaison
des attentes en matière d'engagement public pour les
politiques de santé dans les contextes de la recherche
et des services de santé



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Abstract

Objectives: We explored public preferences for involvement in health policy decisions, across the contexts of medical research and healthcare.

Approach: We e-surveyed a sample of Canadians, categorizing respondents by preferences for decision control: (1) more authority; (2) more input; (3) status quo. Two generalized ordered logistic regressions assessed influences on preferences.

Results: The participation rate was 94%; 1,102 completed responses met quality criteria. The dominant preference was for more input (average = 52.0%), followed by status quo (average = 24.9%) and more authority (average = 21.1%), though preferences for more control were higher in healthcare (57.2%) than medical research (46.8%). Preferences for greater control were associated with constructs related to reduced trust in healthcare systems.

Conclusion: The public expects health policy to account for public views, but not base decisions primarily on these views. More involvement was expected in healthcare than medical research policy. As opportunities for public involvement in health research grow, we anticipate increased desired involvement.

Résumé

Objectifs : Nous avons étudié les préférences de la population quant à la participation aux décisions en matière de politiques de santé dans le contexte de la recherche médicale et dans celui des services de santé.

Démarche : Nous avons effectué un sondage en ligne auprès d'un échantillon de Canadiens, en classant les répondants selon leurs préférences quant au contrôle sur les décisions : (i) plus d'autorité; (ii) plus de suggestions ("input"); (iii) statu quo. Deux analyses de régression logistique généralisée ordonnée ont permis d'évaluer les influences sur les préférences.

Résultats : Le taux de participation était de 94 %; 1 102 questionnaires remplis répondaient aux critères de qualité. La préférence dominante était plus de suggestions (moyenne = 52,0 %), suivi du statu quo (moyenne = 24,9 %) et de plus d'autorité (moyenne = 21,1 %), quoi que les préférences relativement à plus de contrôle étaient plus élevées pour les services de santé (57,2 %) que pour la recherche médicale (46,8 %). Les préférences pour un plus grand contrôle étaient associées à des constructs liés à une baisse de la confiance envers les systèmes de santé.

Conclusion : La population s'attend à ce que les politiques de santé reflètent ses points de vue, mais pas à ce que les décisions se fondent principalement sur ces points de vue. On s'attend à une plus grande implication dans les services de santé que dans les politiques pour la recherche médicale. Alors qu'il y a davantage d'occasions pour la participation de la population dans la recherche sur la santé, nous nous attendons à ce qu'il y ait un plus grand désir de participation.

Introduction

In the last several decades, there has been growing political interest in involving the public in health policy decision-making (Mitton et al. 2009). Many initiatives address public engagement in healthcare, including in resource allocation decision-making (e.g., health technology assessment; Gagnon et al. 2011; Menon and Stafinski 2011), or service design and quality improvement (Barello et al. 2012; CFHI 2011, 2014). As well, a largely distinct body of work explores engagement in the context of health research, including in setting priorities for the allocation of research funds, conducting research, and analyzing and disseminating its findings (Boote et al. 2002, 2010; Domecq et al. 2014; Elberse et al. 2011; O'Donnell and Entwistle 2004). In both the healthcare and health research contexts, the emphasis of recent work is on engaging patients (and informal caregivers), to take advantage of patients' particular expertise and ensure accountability to patients as users of healthcare services and research-based knowledge. Less recent work explores engagement with the general or lay public, who are prospective service users as well as citizens with a broad interest in public investments in generating knowledge or services for the community as a whole. The engagement of the general public in policy development related to health research and healthcare is important for reasons of democratic accountability and legitimacy, given the influence of such policy on the future of health knowledge and health systems.

In Canada, policy efforts related to public involvement have been directed more towards healthcare than health research. On the healthcare side, calls for increased public engagement from various government commissions and public institutions are long-standing (e.g., the Clair Commission [2000], the Fyke report [2001], the Health of Canadians report [Kirby and LeBreton 2002], the Mazankowski report [2001] and the Romanow report [2002]) and engagement activities have proliferated (e.g., citizens' juries, deliberative polling; Abelson et al. 1995, 2003; Maxwell et al. 2003; Menon and Stafinski 2008). Historically, less has been done to engage the public in health research policy – a point highlighted in the 2011 external review of the Canadian Institutes of Health Research (CIHR 2011a). However, the introduction of Canada's Strategy for Patient-Oriented Research by CIHR has created momentum for change in health research policy, though this is not directed at the lay public; rather, it is specific to patient engagement (CIHR 2011b). Moreover, while this work encourages the engagement of patients with the research process, it does not highlight the role of patients or the public in setting priorities in health research.

To date, the bulk of the research on public engagement in healthcare and health research policy has focused on describing these activities (Abelson et al. 1995; Burgess et al. 2008; Godard et al. 2007; Gooberman-Hill et al. 2008; Maxwell et al. 2003; Menon and Stafinski 2008; Oliver et al. 2004) and on determining the effectiveness of different methods of engagement (Abelson et al. 2003; Dolan et al. 1999; Rowe et al. 2005). Some work has also examined whether or not the public wants to be involved in health policy decision-making and the core determinants of these preferences, such as trust. In the healthcare context, this literature shows that, in general, the public expresses interest in being involved in

decision-making (Abelson et al. 1995; Bowling 1996; Broqvist and Garpenby 2015; Dolan et al. 1999; McKie et al. 2008; Richardson et al. 1992; Wiseman et al. 2003). Less has been done regarding the public's desired role in health research policy. One study found that only 40% agreed that "citizens should assume a more important role in decisions on science and technology" (Luján and Todt 2007) but another found that 69% of people believe that "scientists should listen more to what ordinary people think" (Castell et al. 2014).

There are many different forms of engagement or involvement, from consultation without decision authority, to co-production or partnership, ensuring public authority with respect to decision-making (Arnstein 1969; Bovaird 2007). Yet despite the broad range of possibilities, only a small body of work explores how the public wants to be involved in health research and healthcare policy. Where it has been considered, the extent of the public's desired involvement in healthcare decision-making varies, with a distinction based on how much control the public wants to have in the decision-making process (Bowling 1996; Dolan et al. 1999; Richardson et al. 1992; Wiseman et al. 2003). Often, the public would prefer to play a consulting role, rather than being responsible for making final decisions (Castle and Culver 2006; Litva et al. 2002, 2009; Shrimpton et al. 2008). In the research context, some work has explored the factors involved in wanting to have a role in these decisions. For example, Knight and Barnett (2010) found that higher political efficacy, defined as "people's belief that they can make demands of governing systems and get adequate responses from these systems," is associated with preferences that experts make decisions about science governance. There is also a literature examining engagement exercises as a strategy for building public trust, though there is some debate about its effectiveness (Molster et al. 2013; Petts 2008; Wynne 2006). Thus, it remains unclear whether trust is an important influence on preferences for involvement in health policy.

Given the limited Canadian data available on public opinion regarding public engagement in healthcare and health research policy, the objective of this study was to explore preferences and identify factors that may influence desired involvement in health policy decisions among the Canadian "lay public." Specifically, we sought to compare public preferences for public involvement across healthcare and health research, with a particular focus on medical research. We also sought to explore the factors associated with the public's preferred level of involvement.

Methods

Sample and data collection

In January 2013, we administered a bilingual (French, English) survey to a representative sample of Canadians through an Internet panel provided by Survey Sampling International (SSI), which hosts online panels to support market and academic research. Eligible panelists were sent an e-mail inviting them to participate in the survey by following a link to the survey page. Those willing to participate who met targets for a nationally representative sample by age, gender and region of residence, consistent with 2011 Statistics Canada data, were eligible to complete the questionnaire. To recognize time invested, SSI provided incentives to panelists who completed relevant sections of the questionnaire (respondents were able to select rewards points, prize draws or cash).

Questionnaire design

We probed attitudes towards the role of the public in healthcare and medical research policy within a survey study on newborn screening, which included specific items about population screening in newborns (Miller et al. 2015), and research opportunities with leftover blood samples generated through newborn screening (Hayeems et al. 2016), as well as general items regarding healthcare and research policy. Items in the research context used the terminology “medical research” to align with the biomedical nature of some of the items (e.g., references to blood samples and curing disease). The survey also included a training module to familiarize respondents with newborn screening concepts and the types of trade-offs inherent in this type of health policy issue (e.g., identifying infants with disease/false positive results). The items reported in this study were set apart in two sections of a large, 10-section survey, where they were framed as addressing other issues in newborn screening, healthcare and medical research in general. The survey questionnaire was developed by a multidisciplinary team based on a review of the literature (European Commission 2005; Gaskell et al. 2005, 2011; Johri et al. 2009; Kim et al. 2001; Pardo and Calvo 2002; Schwartz et al. 2004; Straten et al. 2002; Willison et al. 2008) pretested through face-to-face cognitive interviews (over three rounds; $n = 16$) and piloted with members of the internet panel ($n = 87$) to assess comprehension, face and content validity. The study was approved by the University of Toronto Health Sciences Research Ethics Board.

Measures

The items that are the focus of this paper were adapted from standardized items used to assess public understanding of science, alongside selected bespoke items. Specifically, we included three sets of items exploring public preferences for involvement in science decision-making modified to be specific to “healthcare programs” or “medical research,” as well as other items assessing trust in healthcare and medical research systems.

The first of the three-item sets assessed preferences for taking account of the public’s views, seeking opinions on the following statement: “To direct [healthcare programs/medical research] in the right way, it would be better to take more account of what the public thinks, in other words people like you and me” (von Roten 2004). These items were assessed using five-point Likerts, from strongly agree through strongly disagree.

The second set assessed preferences related to making decisions contrasting public and expert opinion. Respondents selected whether “Decisions about [healthcare programs/medical research] should be based primarily ...” “... On the advice of experts” or “... On the general public’s views” (European Commission 2005). Finally, the third item set assessed beliefs about the types of knowledge that should be used in health policy decisions, asking whether “Decisions about [healthcare programs/medical research] should be based primarily ...” “... on scientific evidence about the risks and benefits involved” or “... on the moral and ethical issues involved” (European Commission 2005).

Other attitude items were assessed with five-point Likerts, from strongly agree through strongly disagree. Three items assessed trust in healthcare systems (i.e., role in funding [Potter et al. 2012], and assuring quality [Straten et al. 2002]) and three items assessed trust in medical

What's Involved with Wanting to Be Involved? Comparing Expectations for Public Engagement

research systems (i.e., the conduct of researchers [adapted from Pardo and Calvo 2002], the curative potential of its outcomes [adapted from Pardo and Calvo 2002], and protection for participants [*de novo*]). See Table 1 for additional items of solicited demographic information about participants.

TABLE 1. Attitudes towards public involvement in healthcare programs and medical research

Questionnaire items	Total (N = 1,102)	
	n	%
<i>Public expectation for input</i>		
To direct healthcare programs in the right way, it would be better to take more account of what the public thinks, in other words people like you and me		
Strongly agree	401	36.4
Agree	492	44.6
Neutral	158	14.3
Disagree	43	3.9
Strongly disagree	8	0.7
To direct medical research in the right way, it would be better to take more account of what the public thinks, in other words people like you and me		
Strongly agree	236	21.4
Agree	482	43.7
Neutral	281	25.5
Disagree	81	7.4
Strongly disagree	22	2.0
<i>Public expectation for decision authority</i>		
Decisions about healthcare programs should be based primarily ...		
On the general public's views	289	26.2
On the advice of experts' views	813	73.8
Decisions about medical research should be based primarily ...		
On the general public's views	220	20.0
On the advice of experts' views	882	80.0
<i>Trust in healthcare systems</i>		
If the government has funded a health test or procedure, it is probably a worthwhile test to have		
Strongly agree	404	36.7
Agree	462	41.9
Neutral	186	16.9
Disagree	41	3.7
Strongly disagree	9	0.8

TABLE 1. Continued

Questionnaire items	Total (N = 1,102)	
	n	%
The government wouldn't fund a health test or procedure if they were not sure of its benefits		
Strongly agree	164	14.9
Agree	378	34.3
Neutral	343	31.1
Disagree	162	14.7
Strongly disagree	55	5.0
The government will ensure a high-quality health system		
Strongly agree	205	18.6
Agree	378	34.3
Neutral	348	31.6
Disagree	133	12.1
Strongly disagree	38	3.4
<i>Trust in medical research systems</i>		
Medical research will help to cure illnesses such as AIDS, cancer		
Strongly agree	525	47.6
Agree	431	39.1
Neutral	119	10.8
Disagree	20	1.8
Strongly disagree	7	0.6
Most medical researchers want to work on things that will make life better for the average person		
Strongly agree	423	38.4
Agree	495	44.9
Neutral	143	13.0
Disagree	29	2.6
Strongly disagree	12	1.1
The privacy and confidentiality of people who participate in medical research will be protected		
Strongly agree	429	38.9
Agree	462	41.9
Neutral	176	16.0
Disagree	24	2.2
Strongly disagree	11	1.0

Data analysis

Following survey administration, we removed respondents who sped (i.e., below minimum times per section) or “straight-lined” (i.e., providing answers to blocked items along only one column) to ensure data quality.

We dichotomized the items that assessed preferences for taking account of the public’s views into agree (strongly agree or agree) or not (neutral, disagree or strongly disagree) as a measure of public expectation for input. We used items that assessed preferences for relying on public or expert opinion in making decisions as a measure of public expectation for decision authority (more or status quo). Next, we used cross-tabs to categorize respondents with respect to their preferences for public involvement in health policy decisions across three main decision types: respondents who preferred (1) more authority (more input with decision authority); (2) more input (more input without decision authority) or (3) status quo (status quo input without decision authority; see Table 2). We recognize that a fourth category (status quo input with decision authority) might exist as a result of genuine if somewhat illogical preference, or because of respondent error or inattention, but anticipated that it would be residual in size.

TABLE 2. Preferences for type of public involvement

Questionnaire items	Total (N = 1,102)	
	n	%
<i>Preferences for public involvement: Healthcare programs</i>		
More authority: More input with decision authority	263	23.9
More input: More input without decision authority	630	57.2
Status quo: Status quo input without decision authority	183	16.6
<i>Preferences for public involvement: Medical research</i>		
More authority: More input with decision authority	202	18.3
More input: More input without decision authority	516	46.8
Status quo: Status quo input without decision authority	366	33.2

Note: Categories produced using cross-tabs of input and authority items (Table 1).

We conceived of the three main categories of preferences for public involvement as an ordered dependent variable, ranging from lowest preferred involvement (status quo) to highest preferred involvement (more authority). We ran two separate generalized ordered logistic regressions to examine factors associated with preferences for public involvement in healthcare programs and medical research, respectively. Generalized ordered logistic regressions provide a parsimonious but relatively non-restrictive approach to analyzing ordered categorical dependent variables. Using a process similar to a backward stepwise regression, the analysis identifies the most parsimonious model. Partial proportional odds ordered logit estimates identify the nature of the relationship between independent and

dependent variables, whether these are uniform (i.e., ordered) or differing across different values of the dependent variable (Williams 2006). Two-sided p-values of <0.05 indicated statistical significance. Independent variables were entered into the models at the same time. Data were managed and analyzed using Stata (version 10.1, StataCorp LP., Station College, Texas).

We generated two composite measures for (1) trust in healthcare systems (three items) and (2) trust in medical research systems (three items), using principal components factor analysis with orthogonal rotation. Two eigenvalues reached relevance with three variables loading on each. For each composite measure, we generated means and standard deviations, and used Cronbach’s alpha to assess consistency.

The composite measures were included as independent variables for both models. We also included the item set measuring beliefs about the types of knowledge that should be used in health policy decisions (healthcare or medical research) in each model, and other demographic covariates (see Table 3 for included covariates). Composite measures were analyzed as interval data; individual items were analyzed as three-part categorical variables; demographic variables were measured and analyzed as categorical variables, except for age, which was measured and analyzed as a continuous variable.

TABLE 3. Independent variables entered in regressions

Questionnaire items	Total (N = 1,102)	
	n	%
<i>Age</i>		
18–83 (entered as continuous variable)	1,102	100
Mean age		45.9
<i>Gender</i>		
Male	516	46.8
Female	586	53.2
<i>Region</i>		
East	84	7.6
Quebec	256	23.2
Ontario	420	38.1
West	342	31.0
<i>Income</i>		
Less than \$40,000	358	32.5
\$40,000–79,000	375	34.0
\$80,000+	287	26.0
Prefer not to say*	82	7.4

What's Involved with Wanting to Be Involved? Comparing Expectations for Public Engagement

Questionnaire items	Total (N = 1,102)	
	n	%
<i>Education</i>		
High school or less	347	31.5
College/CEGEP	400	36.3
University+	343	31.1
Other*	12	1.1
<i>Trust in healthcare systems</i>		
Trust in government stewardship of health care (0–12 scale) Alpha: 0.63; standard deviation: 2.2	1,102	8.0 (mean)
<i>Trust in medical research systems</i>		
Belief that medical research will bring benefit and can be trusted (0–12 scale) Alpha: 0.70; standard deviation: 1.9	1,102	9.6 (mean)
<i>Information relevant to decision-making</i>		
Healthcare programs	0	0
Decisions ... should be based primarily on the moral and ethical issues involved	198	18.0
Decisions ... should be based primarily on scientific evidence about the risks and benefits involved	904	82.0
<i>Medical research</i>		
Decisions ... should be based primarily on the moral and ethical issues involved	213	19.3
Decisions ... should be based primarily on scientific evidence about the risks and benefits involved	889	80.7

*Omitted from regression.

Results

Survey respondents

The survey participation rate was 94% (2,345/2,499; ratio of unique visitors who agreed to participate/unique first survey page visitors); of these, 1,102 completed responses met quality criteria for a 47% completion rate (ratio finished relevant sections – those excluded for quality reasons [speeding, straight-lining]/agreed to participate). This is typical of Internet surveys that target samples representing the population on key demographic criteria (Johri et al. 2009; Miller et al. 2013; Schlesinger et al. 2012). By design, our sample was representative of the Canadian population by age, gender and region. However, our sample was better educated and had a more narrowly distributed income than Canadian averages ($p < 0.001$; Statistics Canada 2011a, 2011b).

Preferences for public involvement in health policy

On the issue of preferences for public input, a majority of respondents agreed (or strongly agreed) that “it would be better to take more account of what the public thinks” in directing

healthcare programs (81.0%); a significantly smaller majority agreed to the need to take more account of public views for medical research (65.1%; $p < 0.01$). On the issue of decision authority, a majority of respondents preferred to base decisions primarily on the views of experts for healthcare programs (73.8%), while a significantly larger majority preferred to rely on experts for medical research (80.0%; $p < 0.01$; Table 1).

Preferences for type of public involvement

When categorized with respect to preferences for type of involvement in healthcare programs, the majority of respondents preferred the intermediate degree of involvement (i.e., more input, 57.2%); the next most preferred was the highest degree of involvement (i.e., more authority, 23.9%), while the lowest level of involvement was least preferred (i.e., status quo, 16.6%; Table 2).

A slightly different pattern of preferences for involvement emerged for health research. The intermediate degree of involvement was still most preferred, but with fewer respondents (i.e., more input, 46.8%). The next most favoured was the least involvement (status quo, 33.2%), while the highest degree of involvement was least preferred (i.e., more authority, 18.3%; Table 2).

As expected, a fourth residual category of responses was present in both healthcare and medical research contexts. In the former, 2.4% of respondents preferred status quo input with decision authority, and in the latter, this residual category was smaller still at 1.6%. This category was not included in either regression model.

Trust in healthcare and medical research systems

The composite measure of trust in healthcare systems had a mean of 8.0 (out of 12) and standard deviation of 2.2. The composite measure of trust in medical research systems was higher with a mean of 9.6 (out of 12) and standard deviation of 1.9.

Factors associated with preferences for more public involvement

HEALTHCARE PROGRAMS

We explored factors associated with a preference for more public involvement in decision-making regarding healthcare programs (Table 4). Several of the independent variables included in the model were associated with preferences for more public involvement in an ordered fashion, from lowest preferred involvement (status quo) to highest preferred involvement (more authority). Specifically, women were significantly more likely than men to want more public involvement ($p < 0.01$), as were those with less formal education compared to those completing university degrees (high school $p < 0.001$; college/CEGEP $p < 0.05$). As well, those with higher levels of trust in healthcare systems were more likely to want *less* public involvement than those with less trust ($p < 0.05$). However, we also identified several non-ordered relationships (see Table 4).

What's Involved with Wanting to Be Involved? Comparing Expectations for Public Engagement

TABLE 4. Factors associated with preferences for more public involvement in health policy (generalized ordered logistic regressions)

Variables	Healthcare programs		Medical research	
	Status quo versus (more input OR more authority)	(Status quo OR more input) versus more authority	Status quo versus (more input OR more authority)	(Status quo OR more input) versus more authority
<i>Demographics</i>				
Age	-0.00 (0.00)	-0.00 (0.00)	-0.01 (0.00)	-0.01 (0.00)
Female	0.42 (0.14)**	0.42 (0.14)**	0.03 (0.13)	0.03 (0.13)
<i>Region (reference: Quebec)</i>				
East	-0.03 (0.28)	-0.03 (0.28)	0.44 (0.26)	0.44 (0.26)
Ontario	0.01 (0.18)	0.01 (0.18)	0.38 (0.16)*	0.38 (0.16)*
West	-0.52 (0.21)^	-0.08 (0.21)	0.02 (0.17)	0.02 (0.17)
<i>Income (reference: \$80,000+)</i>				
\$40,000–79,000	0.07 (0.18)	0.07 (0.18)	-0.00 (0.17)	-0.00 (0.17)
Less than \$40,000	0.09 (0.17)	0.09 (0.17)	-0.13 (0.15)	-0.13 (0.15)
<i>Education (reference: University+)</i>				
College/CEGEP	0.39 (0.17)*	0.39 (0.17)*	0.46 (0.15)**	0.46 (0.15)**
High school or less	0.82 (0.18)***	0.82 (0.18)***	0.61 (0.16)***	0.61 (0.16)***
<i>Trust in healthcare systems</i>				
Trust in government stewardship of healthcare	-0.07 (0.03)*	-0.07 (0.03)*	0.02 (0.03)	-0.09 (0.04)^
<i>Trust in medical research systems</i>				
Belief that medical research will bring benefit and can be trusted	0.19 (0.05)^	-0.18 (0.04)^	0.04 (0.04)	-0.12 (0.05)^
<i>Information relevant to decision-making</i>				
Moral versus scientific: healthcare	-0.44 (0.26)	-1.02 (0.19)^		
Moral versus scientific: medical research			-1.24 (0.17)***	-1.24 (0.17)***
Peudo-R ²	0.08	0.08	0.06	0.06
N	988	988	997	997

Coefficients are partial proportional odds ordered logit estimates. * $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$. ^ non-ordered relationship, $p < 0.05$.

MEDICAL RESEARCH

We ran a comparable model exploring factors associated with a preference for more public involvement in decision-making regarding medical research, which showed a broadly similar pattern of relationships. As was seen in the healthcare programs model, several independent variables were associated with preferences for more public involvement in an ordered fashion.

One of these relationships parallels that seen in our healthcare programs model. Specifically, those with less formal education were significantly more likely than those with a university degree to want more public involvement (high school $p < 0.001$; college/CEGEP $p < 0.01$). We also found that those who preferred that decisions about medical research be based primarily on scientific evidence preferred less public involvement than those who preferred that decisions be based primarily on the moral and ethical issues involved ($p < 0.001$). In addition, we identified a positive association between Ontario residence relative to Quebec residence in preferences for more public involvement ($p < 0.05$). As above, we also identified several non-ordered relationships (see Table 4).

Discussion

We explored public expectations for public involvement in health policy decisions, comparing preferences across contexts (research, healthcare). Our findings indicated a strong belief in the need to take more account of what the public thinks, but less commitment to the belief that decisions should be based primarily on these views. This is in line with previous findings that identify a preference for having input into decisions rather than control over decision-making (Castle and Culver 2006; Litva et al. 2002, 2009; Shrimpton et al. 2008). However, there were notable differences in public preferences for engagement in medical research as compared to healthcare, with reduced expectations for public involvement in the context of medical research and greater reliance on expert advice for decision-making in this context.

These differences in public preferences between medical research and healthcare may reflect a reduced sense of ownership of the research enterprise relative to healthcare. Healthcare in Canada is a highly visible public activity, and consistently a top policy priority for members of the public (Canadian Opinion Research Archive n.d.). It may also be that there is a lack of awareness in Canada of the central role of public funding in research and of the possibility for, or value of, public engagement in this context. While there has been much attempt in Canada and elsewhere to engage the public in healthcare policy decisions, significantly less attention has been given to the role of the public in health research policy in Canada. Recently, the Strategy for Patient Oriented Research of Canada's national health research agency has brought attention to the potential for public engagement in health research, though the strategy focuses principally on patient engagement in the research process, rather than public engagement in research priority setting or policy more broadly (CIHR 2011b).

Our study also corroborates a limited literature on factors associated with preferences for public involvement with findings that suggest that the less empowered seek greater access to engagement activities. Knight and Barnett (2010) have argued that higher political efficacy, that is, the confidence that one's demands of governing systems will be adequately addressed, is associated with preferences that experts make decisions about science governance. Our models suggest some similar relationships, with preferences for expert judgment associated with reduced expectations of public involvement in medical research, and trust in health systems associated with reduced expectations of public involvement in healthcare. In a parallel vein, our results suggest that those with less education are more likely to want more

public involvement in both medical research and healthcare, and that women are more likely to want more public involvement in healthcare. These findings align with those of a 2014 Public Attitudes to Science Survey, which has shown that women and the less affluent are more likely to think that scientists should listen more to the public (Castell et al. 2014).

Several limitations must be acknowledged. First, the items examined in this paper were embedded within a survey on newborn population screening and research, and while we aimed to obtain views that were not specific to newborn screening, it is impossible to know how the context may have impacted responses. However, we believe that embedding reflection on the public role in decision-making into the context of a survey that asks challenging questions and discusses explicitly the need for trade-offs in these types of decisions also provided added value to our data. These are exactly the types of difficult decisions that necessitate public input and therefore having primed respondents to think about some of the challenges involved in a specific health policy context does not seem inappropriate.

Additional limitations include that key terms used to describe our policy contexts, “healthcare programs” and “medical research,” were not defined. Thus, while the survey as a whole did provide illustrative insight, it is possible that respondents interpreted these terms differently than we intended. Similarly, we did not elaborate the mechanism by which the public would be involved in health policy decisions; thus, interpretations here could have varied as well. Further, survey participants differed slightly from the general population on some demographic characteristics, and as members of a standing panel of individuals willing to voice their opinions on various issues, may not reflect the general population. And while panel surveys provide an opportunity to engage with a large number of individuals, Internet panelists may not have been fully engaged with our online questionnaire. Finally, the several non-ordered relationships in our models limit our ability to draw inferences from these data.

Despite these limitations, this study offers insight into public expectations of public involvement across two health policy domains: healthcare and medical research. In showing that the public expects health policy to take account of public views, but not base decisions primarily on these views, this study corroborates other work. In showing that more involvement was expected in healthcare than research policy, we offer important comparative insight. It may be that the identified difference is due to greater faith in scientific or professional expertise in the medical research context than the healthcare context. Or it may be that the limited public engagement that has occurred within medical research in Canada has fostered inattention and public disinterest. If opportunities for public involvement in medical research grow, expectations for public involvement may increase proportionally. Given the potential value of increased engagement with the general or lay public – prospective service and knowledge users and arbiters of public investments and social commitments – such an outcome is greatly desired.

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What's Involved with Wanting to Be Involved? Comparing Expectations for Public Engagement

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