Older adults' and carers' engagement in democratic governance in the context of system and government transition

Laura Funk[1], University of Manitoba, Canada
Andrea Rounce, University of Manitoba, Canada
Danielle Cherpako, University of Manitoba, Canada

Abstract: Advisory committees are some of the most prominent ways older adults and carers are represented in democratic governance in contemporary North America. Yet little is known about how older adults and unpaid carers interpret the meaning of their engagement within governmental advisory committees. A thematic, interpretive analysis of qualitative interview data from 24 current and former members of advisory committees in Manitoba, Canada, was conducted. Although all participants were motivated to serve by personal experience and/or the common good, interpretive tensions arose at times between their desire for systemic change or advocacy and the mandate and/or function of their committee. Tensions between advocacy and advising appear to be especially pronounced in the context of changes perceived by members as threatening both the quality of public supports and services, and chances for meaningfully engaging older adults and carers in governance. Perhaps in part to reconcile this tension (and in some cases their own ongoing involvement) participants often characterized these committees as at least partially valuable and effective ways to engage older adults/carers, primarily through talking about personal benefits, the quality and efficiency of meetings, and feeling valued. The subsequent emergence of COVID-19 after these data were collected will likely only intensify social changes affecting older adults and carers, highlighting an even more pressing need for their engagement in policy co-design in and beyond continuing care sectors.

Keywords: Advisory Committees; Citizen Engagement; Democratic Governance; Public Participation

Introduction

---

[1] Corresponding Author: Laura Funk, 307-183 Dafoe Road, Department of Sociology and Criminology, Isbister Building, University of Manitoba, Winnipeg, Manitoba, R3T 2N2, Canada. email: laura.funk@umanitoba.ca

Pronounced population aging in industrialized nations has prompted an emphasis on the need for older adults to be civically active; normally this is framed in terms of fairly limited forms of participation, as opposed to involvement in political, transformative or social justice processes (Martinson and Minkler 2006). Likewise, as more older adults are living at home to advanced ages and with more complex needs, there has been growing attention to the need to support family carers' participation in community life, and ideally their participation in society writ large. In Canada, three provinces have legislated Caregiver Recognition Acts that incorporate this principle (echoing similar Acts in the UK and Australia). Again however, prevailing views of the meaning of carer participation rarely extend to involvement in advocacy or system change on behalf of either carers or older adults.

The expansion of economic and cultural forms of neoliberalism throughout global, national and regional policy-making has, over decades, shaped changes to policies in sectors such as long-term care, health services, pensions, and transportation. These changes have particular implications for – even a disproportionate impact on – older adults and carers (Chappell and Penning 2005; Estes and Phillipson 2002). There is thus (even prior to Covid-19) a particular need to involve older adults and carers in democratic governance. Yet many current carers lack the time or energy for civic participation. Additionally, both older adults and carers may not conceptualize either aging or care as public issues (Funk and Hounslow 2019; Levitsky 2014). For these and other reasons (including ageism), both older adults and family carers, among other groups, are at risk of socio-political exclusion and marginalization from meaningful participation in democratic governance (Grenier and Guberman 2009; Martinson and Minkler 2006).

A general lack of effective mechanisms for such involvement at various levels of government, and in both health and non-health sectors of government, arguably compounds this problem. There has, however, been a promising movement in some Canadian health care sectors to consult with and/or engage patients (including older adults, and persons living with dementia) and families in health care system redesign. Along with Age-Friendly and carers movements, this has appeared to prompt the establishment of advisory councils or committees designed to engage (or include representation from) older adults and family carers in democratic governance. These groups are perhaps the most prominent ways that older adults and carers have been engaged, and seem popular among health authorities and governments. Generally speaking, an advisory council or committee is a group of people selected for particular reasons (such as how they reflect a particular population or subpopulation) to provide advice, input and/or feedback to policy decision-makers.

The present research is informed by concepts of democratic participation and open government, which direct attention to how advisory committees can promote open, interactive, and more democratic public policy making (Government of Canada n.d.; Fung 2006; VanDamme and Brans 2012). Some have claimed that rather than representing and legitimizing citizenship and service user experiences, public involvement initiatives have been "aimed at securing consumer feedback and advice" (Callaghan and Wistow 2006, 2292). More optimistically, councils, committees and other forms of involvement can recognize and value experiential knowledge; at least symbolically, and at best, integrating this knowledge to make services and policies more effective, responsive and accessible (Attree et al. 2011).

This latter assumption has been challenged by scholars who conclude that service users' roles in governance tend to be symbolic or tokenistic, with little effect on outcomes for the broader population or prompting structural or policy change (Abelson and Eyles 2002; Horrocks et al. 2010). In part this is because advisory committees can privilege dominant professional, management and expert perspectives rather than lay or experiential knowledge (Barnes 1999; Martin 2008). The marginalization of lay experience and its uncertain legitimacy as a form of knowledge may be exacerbated within health care systems that tend to rely on narrowly-defined expert sources of knowledge (Callaghan and Wistow 2006).

There is little known about older adults' and carers' involvement within a wide range of advisory groups in Canada. Research pertinent to public engagement tends to focus on the health care sector, and covers a broad swath of forms of involvement by a range of service users (e.g., Bee et al. 2015; Gallivan et al. 2012; Li et al. 2015; McKevitt et al. 2018). For instance, research by Abelson and colleagues in Canada is notable (e.g., Abelson and Eyles 2002; Abelson et al. 2012) yet focuses only on the health care sector, and is not specific to the older adults or family carers. Moreover, existing scholarship lacks in-depth exploration of the complex ways that older adults and family carers might understand the meaning of their involvement in democratic governance. As such, this is one of the first studies to explore this issue in-depth, using an interpretive methodological tradition (Gubrium and Holstein 2000), which regards research interviews as encounters in which meaning is created and considers how this meaning connects to individual identities (e.g., Doucet and Mauthner 2008) and to broader contexts. The questions guiding this inquiry are: a) how do older adults and carers' make sense of the meaning of their involvement in advisory councils or committees? and, b) How do they understand the meaning of the effectiveness of these groups? In line with interpretive inquiry, meaning-making

is understood as connected to context – in particular, the socio-political climate of the province during data collection.

Design and Methodology

Using the province of Manitoba, Canada, as a case study, and drawing on the perspectives of current and former advisory committee members as well as public materials, research questions for the primary study (Rounce, Funk and Cherpako in progress) which generated the data for the present analysis were: how have public advisory councils and committees that involve older adults and carers been designed and constituted; how have they operated in practice; and what explains their span of influence and effectiveness at advocating for older adults and carers? The focus was on advisory committees at multiple levels - city/municipality, regional health authority, and provincial government. The study received approval from the university's Research Ethics Board and local health authority research access committee.

These data were used to investigate the meaning-focused questions posed in the present analysis; this inquiry emerged in an inductive, more secondary way, from the original research study (Heaton 2004). There is a good fit between the primary data and the current questions, and the same research team and interviewers were involved throughout; as such, secondary analysis is appropriate (Heaton 2004; Hinds, Vogel, and Clarke-Steffen 1997; Thorne 1994).

In Manitoba, several advisory committees have operated over the last few decades at various levels of government. Some are specifically targeted to gain input from older adults (Manitoba Council on Aging, Mayor's Age-Friendly and Seniors Advisory Committee), or carers (Caregiver Advisory Committee). In addition, the regional health authority[2] has a long history of public engagement and advisory councils in various departments, including some committees that primarily target older adults and carers (and/or to serve the interests of these groups), such as the Long-Term Care Advisory Council and Home Care Advisory Council.

To recruit current and former members from these councils and committees, study information/invitations were sent through social networks, a Centre on Aging Listserve, and the Manitoba Association of Seniors Centres. Eligible participants were an older person and/or previous or former family/friend carer who had ever served on these councils or committees, and could reflect on the mandate and influence of the group. We also located publicly available lists of advisory group members and contacted some through publicly accessible social media. Lastly, after receiving institutional approval

---

[2] Winnipeg Regional Health Authority. The study did not include other regional health authorities or municipalities.

from the health authority, advisory council facilitators sent study information to current members.

In total, 24 consenting participants were interviewed either face-to-face or by telephone by the 1st or 3rd authors using a semi-structured qualitative interview guide. Participants were asked about their perceptions of the role and influence of the council/committee in which they were involved, as well as processes and factors shaping this role or influence.

Using these data, a thematic analysis was conducted for the present inquiry that foregrounded participants' interpretations of meaning, informed by social phenomenological and narrative understandings of the function of talk in interview interaction. In line with an interpretive approach, these data were also analyzed with reference to the localized (provincial) context at the time of data collection (described further below), within which these meanings need to be understood. Data were organized, coded, and analysed with a focus on the individual as the level of analysis, to trace between-person interpretive variation and within-person interpretive complexity. The analytic goal was not to measure levels of satisfaction or dissatisfaction or comment on the objective effectiveness of particular groups. Rather, the interpretive drive to this analysis placed relatively less emphasis on the objective form and structure of the councils/committees, and more emphasis on subjective participant constructions of meaning across types of committees and in relation to the broader context.

Findings

Description of Participants, Committees and Setting

The 24 participants, 6 of whom were male and 18 of whom were female, ranged in age from 59-86 years. Four had been members of the Mayor's Age Friendly Council, five had been involved in advisory committees at the provincial level, and seven had been members of the Long Term Care Advisory Council. Nine participants were, or had previously been, members of more than one advisory group, with many serving extended or renewed terms. For more detailed information about the advisory groups themselves, see (Rounce, Funk and Cherpako in progress). In general, however, three groups (one municipal and two provincial-level) can be described as direct communication advisory groups that provide 'advice to cabinet' either directly or indirectly to government officials or policy-makers (most often through government staff). There was an emphasis on providing well-informed advice, and members were appointed. In contrast, health authority advisory committees tended to operate more as user-input forums, being more 'top-down' in focus; members could only discuss

topics and ideas indicated by the health authority. Members applied to serve on these committees, sometimes having been encouraged to do so.

Data were collected between October 2018 and October 2019. Understanding the political context at this point is important for understanding the findings presented below. Two years prior to data collection, in 2016, the provincial government changed to a Progressive Conservative (PC) majority after a 17-year period of New Democratic Party dominance. Soon after this shift in power, the new government embarked on a health system transformation process that was ongoing at the time of data collection. The transformation had been described in the media and by government officials as a significant streamlining and overhaul of a 'bloated' health care system. Although the previous government had legislated a Caregiver Recognition Act in 2011, and had developed a Seniors and Healthy Aging Secretariat to engage with issues related to seniors and carers (including the province's Age-Friendly Manitoba Initiative), in 2017, the Manitoba Council on Aging and Caregiver Advisory Council were formally cut through a legislative act. Less formally, the Seniors and Healthy Aging Secretariat no longer operated as a distinct body within the Ministry of Health. The Premier called an early election for September 2019, and health issues were at the top of mind for most in the province.

These various provincial changes drove much of the public discussion about health system change, overshadowing municipal elections throughout Manitoba in October 2018. Moreoever, an unusual amount of system change has arguably affected all levels of government in the province, and led to mixed opportunities for citizens to participate in democratic governance outside of elections.

Findings

Interpretations of Personal Involvement: Experience and Commitment to Advocacy

Most but not all members of the advisory committees appeared to have, over time and prior to their involvement in the committee, developed self-identities as advocates working within the system (i.e., through official channels) for the 'cause' of older adults/carers, which could have motivated their participation. For example, one participant spoke of being motivated to participate because she wanted to increase accessibility and mobility for older adults in the local community. Previous effective efforts at advocacy were also cited by members of municipal and provincial committees, as part of the reason they were appointed.

Members of health authority committees also seemed to align themselves with advocacy-related concerns, even if they did not explicitly identify

themselves as advocates. The following participant from one committee described a time she had been caring for both her mother and her husband who were both in long-term residential care. She explicitly identifies herself as a carer, and articulates a strong advocacy orientation:

So I was taking care of both of them, while also working a full- time job, and I could see that there were issues with long-term care. And I asked to speak to some of the higher-ups, and that's how I ended up making a difference with that. I was basically an advocate for my husband. Then I was just approached by one of the facilitators, and she asked me to join this advisory council. Obviously, I already had enough reasons, and so I said yes. There were just a lot of issues which were small, and could maybe easily be addressed, but other things were more systemic. I think through just seeing how others were dealing with the same things I was, and my husband couldn't speak, and I was polite, but really stood up to some of his doctors - I saw that other people didn't have advocates. I was researching things, learning and figuring out my rights as a caregiver, but not everyone can do that or does do that. I wanted to maybe make some changes that could improve quality of life for people in long- term care.

This participant believes many members were similarly selected for their strong advocacy: "They couldn't really ignore us."

Concerns of other health authority committee members tended to focus on the quality of formal services, with only more implicit emphasis on older adults' or carers' rights. These participants likewise wanted to draw on their often extensive, challenging former experiences - as either patients or as paid and/or unpaid carers - to create positive health care system change. For at least one participant, this involved channeling their anger into trying to make a difference – they had been bothered by their family's negative experience with eldercare: "so when this (advisory committee opportunity) came along, I was like, 'okay, maybe I can make a difference." Several other participants mentioned being motivated by concern or pity for older adults within formal systems who do not have family members available as advocates.

Members of the municipal and provincial level committees cited previous work and/or volunteer experience relevant to their committee role which may have motivated them to become involved, though this was always not explicitly stated. For instance, one participant had extensive experience with and knowledge about programming for older men; being on the committee, for him, was in part about using this knowledge to advocate for older adults' rights.

Certainly at the beginning I had a story to tell and by the end, I think the story was about older men, their needs… And I think the people there, and there were sometimes people from the senior's secretariat who sat in on our meetings as well, by the time, they had heard much of the good story about [specific program].

In part, participants may place emphasis on their previous relevant work or volunteer experience in their interviews as a way to legitimate their expertise (to both themselves, the interviewer, and others) especially since participation on advisory committees might expose a sense of vulnerability given the general tendency for 'lay' knowledge to be marginalized within governance structures. Some health authority committee members also often expressed that their previous relevant work affiliations and experience made them well suited to provide important insights, though generally there was not as much emphasis on this in their interviews. These health authority groups did not generally expect or require preparatory or background research of participants (although some participants expressed an interest in this).

Just a few members, all from health authority committees, spoke of being motivated by positive health care experiences (e.g., with a particular health care facility), or a more general, vaguer desire to volunteer or to help others. The latter, more passive motivations seemed to indicate a continuation of a volunteer identity, a need for a sense of purpose during retirement, and a sense that based on their previous life experiences and connections, they might have something of worth (even just a 'perspective') to contribute. Most often, these participants did not have specific hopes or expectations about their involvement; rather, they were just interested in being involved in their communities. Two other participants who had personal health concerns hoped their committee role could lead to positive personal benefits; one wanted to create a support group that they could join, and another mentioned that being a part of the committee rather than staying at home might improve their own health.

In sum, most (though by no means all) of the committee members positioned themselves as clearly motivated to contribute to meaningful system change in some way. Members of municipal and provincial-level committees appeared to have developed stronger self-identities as advocates for older adults/carers within systems, and emphasized their extensive past experience and expertise. Health authority committee members tended to be motivated by previous negative experiences within health systems, and as such, their involvement focused on wanting to improve the quality of care for others.

Interpretations of Committee Value and Effectiveness

When participants were asked about the potential value of advisory committees, responses such as the following highlighted concerns that governments be responsive to the public: "we need to keep putting the people who are affected at the forefront of recommendations. They need to be the ones who are heard and who are talking about their experiences and what needs to change" ; and "unless you have feedback from your end users, how do you know if these policies are good? They might be working for you as government, or regional health authority, or choosing wisely, but is it actually working for people? You won't know that."

Perceptions of committee effectiveness vary depending on expectations, ranging between participants who were disappointed because they desired swifter, more significant change, to comments such as "I thought [the group] was quite effective, actually, more than I had expected it to be." Several participants spoke of witnessing the former kinds of responses among other group members; generally these participants characterized this as a problem of unrealistic expectations, rather than committee function.

In general, and acknowledging individual variation in the meaning of effectiveness, participants connected their interpretations of committee effectiveness to features such as: organization and preparedness (including research), focusing on specific tasks or topics, the role of the facilitator or chair, having suitable discussion time, clear closure to discussions and a feedback loop, formalization (e.g., official status within legislation; formalized reporting processes), and clear lines of communication, such as reporting directly to government and having a developed community network for sharing and circulating information. As examples:

It was task-focused…It really created a network, allowed for further partnerships, and it benefited both older adults and [government]... The reason it was so effective was because the chair did such a good job, and we created networks so that we could share information very fluidly, very easily.
We learned to be good at steering our conversation so that the person from the [official's] office knew what we wanted.

We have Minutes, that are shared with the upper echelons, so it's pretty transparent.

Having very capable staff providing policy analysis and research support to the committee is very important.

Committees that tended to be constituted by members with previous experience working in government, or other work experiences which helped them to understand and perhaps better navigate governance processes, tended to be perceived by their members as quite effective. Yet these committees also tended to be less diverse in their representation. Though several participants noted a lack of diversity, only two participants explicitly tied diversity to their interpretations of effectiveness: one participant, for instance, spoke of the need to reduce barriers to participation, adding, "representation and diversity is important to making the group effective, across income, age, cultural groups." Another participant noted "if it isn't accessible or equitable it isn't going to be effective."

Overall then, the meaning of effectiveness appeared to center around group structure and process; what was seen as an 'effective' structure and process made participants interpret the group as more effective in creating change. Participants may have been 'skirting around' a hard truth here – that their committees were only advisory in nature. Although an effective structure and process might increase the likelihood that a committee is successful at achieving some form of systemic change, it does not guarantee it. A similar emphasis on 'operational' or 'process-centred' definitions of effectiveness was likewise present in participant talk about what makes some committees ineffective: infrequent meetings, members that 'railroad' or commandeer discussions, informal structures, lack of group capacity, top-down approaches, a lack of a clear communication or reporting process, a lack of feedback, and not being able to prepare in advance for meetings.

Perceptions of group control over topics (i.e., a bottom-up versus a top-down approach) appeared to be related by participants in particular to perceived effectiveness. Participants in 'top-down' committees expressed some frustration or dissapointment that the topics they were asked to discuss would not produce systemic change. Such interpretations might have been exacerbated by the lack of communication about whether or not advice was taken into consideration by decision-makers. Two excerpts are illustrative of concerns with top-down approaches:

Initially we may all have thought that we would be going to a place where you openly discuss issues in the health world that are of concern to you, but that's not open for discussion. It is very, very definitely corrected.

Sometimes, I have felt that because we are not directors as to what is going to be discussed, then we're not discussing some of the topics that would be more important and pertinent to the public.

Late-stage attempts at seeking input were also interpreted by one participant as insulting:

The [health authority] used to send out pamphlets saying 'What do you think about this?' and ask for our feedback, but (the pamphlet) has already been published. And you say, do you really want to know what we think? Talk about adding insult to injury…I don't mind sharing my opinion…but don't insult my intelligence, you know?

The slow pace of change within bureaucracies, the numerous factors influencing policy-making, a lack of system resources, and the seemingly intractable complexity of some issues (especially health care) were also cited by participants as barriers to effectiveness. As such, at least some assessment of effectiveness was connected to the degree to which the groups achieved concrete change, even as identified barriers were beyond the group's ability to control. With just a few exceptions, participants accepted these barriers to implementing change as unavoidable; this was reflected in participants' expressions of either a resigned acceptance (and an emphasis on needing to lower expectations for the scale or pace of change that can be accomplished) or a dogged determination in the face of these barriers (e.g., "I'm determined. I also know bureaucracy makes it hard to make changes"). One participant positioned his own response as more reasonable or measured, in contrast to more reactive group members:

I noticed that there were a lot of people on this group who were tense when something they talked about in a prior meeting hadn't already been put in place. Now, I'm not stupid. I do realize that when you have a group like this, you're going through a number of topics that obviously are put together by someone higher up and you discuss and talk them through and you make some suggestions. It doesn't mean anything is going to be taken. It's just to see if there's somebody who's got another idea. And some people were really pissed off that it didn't happen. 'Why didn't you put that in? Why don't they listen?' And I'm thinking... whoa... it's not like they just rush out and make changes to everything just because you said it.

In this excerpt, group members who complain about this are implicitly positioned as both naive and potentially selfish, even narcissistic.

In contrast, participants openly frustrated with the ineffectiveness of committees in achieving change tended to conclude that the problem was internal to systems and processes. For instance:

I think probably the [health authority] is interested in optics. And having all of these advisory councils is good optics. It just is really frustrating for the people who participate on them and don't feel like they've done anything.

So the topics [in the annual reports based on our input], now I have seen one summary of what was discussed at that level, and I'm thinking once again, they're not really addressing what needs to be addressed. Too surface level. So I don't really think there is effectiveness. In fact, to be truly cynical, which is not hard to do, it's like, ok do you just have this council there to say that you are listening to the public? Is it just sort of something that doesn't really amount to anything?

In sum, although participants viewed advisory committees as valuable for helping governments be responsive to the public, members who were disappointed in the responsiveness of these groups tended to be portrayed as having unrealistic expectations. Moreover, only two participants connected group diversity (i.e., in sociodemographic backgrounds) to perceived group effectiveness. Overall, talk about group effectiveness tended to center around how the group operated. When change could not be achieved, participants typically understood this problem as resulting from unavoidable factors external to the group and governance system. Exceptions in this regard are elaborated in the next section, which also illuminates a contextual understanding of participant interpretations of committee effectiveness during a time of government and health system transition.

Connections to System Transformation and Government Change

Advisory committees may be viewed as particularly important in the context of health care system transformation that has been occurring since the 2016 change in provincial government. One participant described how system transformation provided an opportunity for public engagement that was missed:

…but then as chaos ensued, which was the [healthcare] reorganization, everything sort of fell apart, because it was obvious to me we were sort of reacting to whatever was sort of coming up, and we had very little part in what direction things were going to go in. So although a lot of us voiced our concerns about many of these things, closures of emergency departments, really our input had little or no say in the final decisions, and in all fairness, I think the regional

people probably also had no say in the direction things went in either, it was mostly the province taking over those changes. But I feel it was a missed opportunity, I mean we were the people that all these changes were going to affect, if they were weren't going to listen to us, who were they going to listen to?

This participant had learned that the minutes and input from their committee were not being sent to senior managers (as stated in the terms of reference).

As such, perceptions of the effectiveness of advisory committees can be understood as intertwined with the broader political context. Another participant's perceptions of committee ineffectiveness appeared to have been exacerbated by anger about health system changes (e.g., closure of Emergency Rooms). This participant concluded that their committee functioned only to provide retrospective justification for decisions already made by the health authority, rather than proactively listening to the people most affected by health system changes:

Like them closing all these emergency rooms. I think it could've been done a lot better, but they don't want to listen. Like let's get this right, because the last time it was done, it took this province 10+ years to get out of it. And it's happening again.

This same participant added:

…they would say 'well what do you want to discuss?' and they would give us 3 topics to choose from. One was health care experience, and after the meeting I said '[facilitator name], you really want to go there?' And she said 'come on, it's not that bad. You've got those 3 or 4 choices.' The choices were kind of gaseous, out there, there's no meat to it…there's no, 'we're going to take this information together to change the system.'

Notably, this participant joined their committee hoping to address some of these issues. Another participant believed their committee became less effective after the change in government: "the current government won't make decisions that cost a lot of money obviously... I mean it's possible, there is money, but the government doesn't see it as fiscally responsible or a priority." The orientation of the previous government towards advisory groups was flagged by another participant in justifying their (now-defunct) group's effectiveness:

"we were dealing with a minister and a government that was very proactive in terms of getting information from seniors and they wanted this structure." This same participant believed the previous government was more committed, in some form, to democratic governance: "if you create these structures that give advice, then you have to listen to that advice. Then if you get rid of it, you can just do what you want to do. So it really depends on the government at the time."

The two provincial advisory committees were dissolved in 2017, and the municipal committee 'rolled into' a broader committee; participants of the latter group interpreted it as having essentially ended around the time they were interviewed (2019). Some participants expressed distress about such changes, for instance:

What frustrates me is that I believed in the council, whether or not it was totally effective, I believed this was one way in which some interested people could have their input in Manitoba's public policy. Now there's nothing, and where do you go from there?

Despite apparent clarity about the advisory mandates and purpose of their committees, for several participants a sense of tension nonetheless emerged around challenges to effectively advocating for older adults, carers, and/or other service users while serving on these committees. Our analysis suggests that this tension is particularly salient or pronounced in the context of the 2016 change in provincial government and ongoing processes of health care system transformation. Only one participant joined a committee specifically to address these changes, yet concerns about the impacts of health system transformation threaded throughout several other interviews and appears to have led to frustrations, for some participants, with aspects of their group operation and structure, such as the 'top-down' approach. One participant noted how hospital closures came up in discussion at one committee:

Some people were very furious that we couldn't [make recommendations directly to the premier]. And I said, folks, when you signed onto this, you knew this was just an organization to share [best practices] … The political part of it though… we didn't meet as a network last year at all. We have a meeting scheduled, but very few people wanted to go, people were hurting too much. And I really had to clamp down and say, this isn't the forum for making recommendations directly to the premier, nor should it be.

Another participant explained their own (contrasting) perspective:

That was probably my only disappointment, we were going through some really critical times in health care, and we really weren't allowed to talk about anything other than the topics that were presented, and a couple of times people brought up other things, even some people brought in clippings from the newspaper, and we were squelched. You could not talk about that, you had to stick to this. That upset me a bit. I found what we were talking about was not really relevant.

Frustration when members were not allowed to choose topics of discussion was exacerbated for participants who believed that important topics were being purposely avoided for political reasons. In particular, many members of health authority groups referred to recent provincial budget cuts; they believed these cuts were negatively affecting health care, and that top-down advisory committee approaches reflected the interest of government and health authorities in avoiding criticism. One participant believed that issues related to the budget cuts, such as overworked nurses, were in fact a patient safety concern. After bringing this topic to the table during a meeting, her committee was told they could not discuss it. Concern about the potential for negative impacts of system transformation appeared particularly pronounced among committee members who had elsewhere in their interviews emphasized their extensive personal/family experiences within the health care system.

Moreover, felt tensions between the designated advisory role and a desire to advocate were connected by one participant to the fact that there was a lack of a strong seniors advocacy organization in the province at the time:

One of the dilemmas we dealt with was, we were there to advise government, we had to deal with the issue of advocacy, we were not there to advocate, we were there to advise, and I always felt like, not only me but others, unfortunately in Manitoba there is no official advocacy group for seniors, we thought, like there's a lot of groups, but no group that stands up and advocates for something…In the absence of this, in a way, we felt that was maybe our role, but we knew we couldn't really do that, we were there to advise the government, not be a thorn in their side. If you're doing advocacy, you sometimes need to really push, and that was not what we were there for.

In sum, disappointment and frustration with top-down committee approaches and/or the closing of particular committees was exacerbated for participants particularly concerned about the impacts of health system transformation on older adults, carers or the general public. These groups may be perceived as

ineffective in this context, best encapsulated in the sentiment that these groups were a 'missed opportunity' to get feedback and advice from the public.

Interpretive Consolation and Symbolic Effects of Involvement

The limited ability of advisory committees to achieve substantial changes coupled with many participants' desire for such change may in part be why some participants invoked definitions of effectiveness focused on immediate structure and process issues, and acknowledged mitigating circumstances beyond committees' control. In addition, it was common for participants to emphasize alternative benefits – including feeling valued (which was specifically asked about in the interviews), personal learning, and developing networks and friendships (themes which arose in response to questions about group effectiveness). Talk about these personal and symbolic benefits might represent a form of interpretive consolation.

One participant describes themselves as an outlier and contrasts their own desire to feel 'heard' against satisfaction with social prestige of being asked to sit on a governmental committee (i.e., the symbolic importance of being 'appointed'):

(Advisory committees) are currently useful in a certain way, I think the people around the table felt very honoured for being part of the group, privileged, and maybe that's good enough. But for me, kind of being an outlier, I would say that's not really enough. I would want my voice heard…

Likewise, another participant contrasted themselves from the rest of the group:

The rest of the committee members I think sort of enjoyed it, because they were on the 'inside' of things… they felt they were getting information first, and they were somehow privy to this information, and I don't think they felt, I think I was the only one who felt like we didn't really get anything done.

Both of the abovementioned participants clearly positioned their self-identities as less self-interested and more altruistic, in their talk about their approaches to advocacy.

The exact meaning of feeling one's 'voice is heard' was not always clear, and may vary between individuals. Members might feel heard if there is sufficient time built into committee meetings (noted above), to allow for people to tell their stories without feeling rushed. This might convey that the government is willing to listen, and that one's experiential knowledge, as well as worth as a person, is valued. Yet there is another component that seems to be

implied – that ideas are not only solicited but seriously considered or acted on in some way (e.g., "brought up to whatever the next level is").

Yet even participants who would not have described their group as very effective still expressed (and seemed to appreciate) that their ideas were valued by other members and facilitators, as in: "overall I felt like my ideas were really valued…everyone listened to everyone else and respected them. There was nothing really specific, just kind of overall making it about a collective effort." One participant acknowledged that although 'big picture' transformational system change cannot happen quickly, their committee was still 'somewhat' effective because they were listened to (by facilitators): "because they did listen to us when we said it [the committee's top- down structure] wasn't working how we wanted it to, and that we would need more change". Others in the group, however, disagreed with this interpretation.

An excerpt from another participant highlights potential parallels between wanting to feel heard in advisory committees and patients' and families' desires to feel heard in their interactions with health care providers:

I think that the people [health care decision makers] are hearing what [the committee is] saying. It's a huge bureaucracy so it won't change overnight but humanizing the process, that's what people [on the committee] are talking about. People want to feel that they're heard when they go to the health care system, they don't want to feel that they're being dismissed.

Participants spoke with apparent pride about feeling valued, primarily through having a voice, access to 'insider' or 'secret' information (some committees required non-disclosure agreements), and the 'ear' and attention of key decision-makers. They appreciated expressions of interest and appreciation by facilitators and group members during meetings, which signified caring, respect and acknowledgement of experiential expertise gained over time. The following examples are illustrative:

I've been in the system for a while and have found through trial and error what works. They liked the information that I gave them. It was proven over time. Experience is the word. I have lots of experiences.

Absolutely my knowledge was valued...everybody really, really contributed with what they thought, and when there was a differing of opinions, everyone respected that. It was a really good group from that perspective.

We have a really respectful group and everyone was heard and given a chance to be heard….so it's not like anyone says 'no, we don't have time, shut up,' you know? Myself, I like to put things in a story because people retain that longer, but if people don't have time, that's ok. I always feel heard, and I feel people are listened to and respected.

The use of bottom-up approaches in advisory committees may have been influential in helping group members feel heard (and thereby feel satisfied), as in: "[the facilitator] is just an exemplary individual, as a person and as a group we're not shut down, not told not to speak of certain things, it's an open, collaborative format." Another participant found it difficult to recall many examples of concrete changes made because of the group input, but believed the group was effective because: "they're willing to listen and actually looking for ideas and they seem to be quite well organized and bringing it up to whatever the next level is." Emotive and identity-related aspects of involvement were reinforced when key government contacts for the committees also listened and responded, even in small ways:

It was great because one time we were telling the mayor's office about June 15th being elder abuse awareness day, and we said 'hey, purple is the colour of elder abuse awareness.' And so the mayor ended up wearing purple in City Hall, and that speaks volumes. It shows solidarity and support and understanding.

One participant expressed that although their committee had not produced any particular changes, they learned new information about challenges in health care, from invited presenters. This appeared to shape their perceptions of group effectiveness: "I learned from the presenter within the context of the group, and the fact that we were able to have those individuals attend the meetings and have them be so open and responsive, despite… I'm sure their jobs are extremely difficult."

When participants believed that government was unwilling to hear or at least reasonably consider suggestions arising in the committee, this tended to erode their sense of feeling personally valued (as well as contributing to frustration and perceptions of other committee work as trivial). This too might be exacerbated in the context of health system transformation:

…because we didn't get to express much about what we thought, it quickly devolved into 'you people running it don't get where 99% of us are coming from, we want to change the system but you don't want to hear from us.' The frustration level was just rising…

So, in print it indicates that we want to hear what you think, what the issues are and how we can address them. But that opportunity in reality doesn't happen. So I would say even though they try to make changes, they still are not a council that is ready to truly listen.

Feeling that advisory committee service makes a meaningful impact can enhance personal self-worth. One participant, for instance, appreciated working on a subcommittee alongside government employees on specific recommendations. They felt valued because the government asked them to provide input which was used to develop the government's stance on a particular issue.

Members of groups that had ended or appeared to be coming to an end believed this meant their voices were no longer going to be heard in the same way, or even symbolically conveyed that no one wanted to hear them. One participant described their reaction:

Now, they solved the problem by eliminating the group, so they don't have to listen to us. I'm not saying they don't have any consciousness around aging, but…

In sum, the limited ability of advisory councils to achieve meaningful change may in part explain why some participants invoked alternative definitions of effectiveness and/or benefits that were more personal in nature. Although 'being heard' might have somewhat variable meanings, its ties to feeling valued signal the importance of emotive and identity-related aspects of involvement in advisory committees.

Discussion and Conclusion

This analysis of 24 interviews with current and former members of advisory committees at multiple levels of government in Manitoba, Canada during a time of government change and health care system transformation illuminates the complexity of how these members (representing groups particularly affected by the nature of such changes) interpret the meaning of their involvement. Although structured measures are available to evaluate member-perceived outcomes of public and patient engagement (e.g., Abelson et al. 2018, Abelson et al. 2019), our qualitative inquiry enriches scholarship around participation in democratic governance by highlighting the complexity of experiences and meanings of engagement.

A key finding is that we need to understand advisory committee members' subjective experiences as connected to broader contexts. Although change itself might contribute to insecurities, the nature or direction of the proposed changes appear to have been perceived as threatening by some older adults and carers in this study. Despite the potential of advisory groups, in this context some members of health authority committees believed there were missed opportunities for public engagement, and became particularly frustrated by their inability to effect change or advocate within the advisory group. In one group, such tension was overlaid by the absence of a strong seniors advocacy organization in the province. Rather than dismissing this as a problem of unrealistic expectations, it is important for advisory council facilitators to engage in ongoing discussion with members about their broader visions and concerns. Where committee mandate and structure is inflexible to members' desired nature of participation, members could be referred to other advocacy organizations and given information on how they can engage in forms of civic and collective action designed to inform policy-making.

Other contexts also shape advisory group members' interpretations, such as the broader tendency for older adults and carers to feel unheard and respected in interactions with health professionals (indeed, in society more broadly, due to widespread ageism and a devaluation of care work). This may be compounded by the tendency, in public engagement mechanisms, for lay experiential expertise to be marginalized in comparison with scientific research or system-oriented goals and interests. Emerging studies of policy co-design and other efforts to include typically-marginalized individuals (such as older adults) in advisory committees highlight the importance of identifying and combatting power inequalities between members, such as those connected to expertise, experience, and socio-economic status (Holroyd-Leduc et al. 2016; Mulvale et al. 2019). Though most participants in the present study believed their contributions were acknowledged and appreciated by their peers and facilitators, some did express concerns about others (with more professional expertise), 'commandeering' discussions, and about being unable to prepare for or research unfamiliar topics of discussion. Advisory council facilitators could benefit from training in equity, diversity and inclusion. Participants' concerns, along with the need to construct valued identities within the aforementioned contexts might explain the particular ways in which some participants emphasized their own expertise, their reasonable-ness and selflessness, and so on. Future research should continue to explore how narratives of 'good citizenship' and 'expertise' manifest in particular ways among advisory group participants.

The symbolic, subtle benefits of feeling heard or not heard, feeling valued (Attree et al. 2011) as well as the complexity of interpretations of being

heard, may be underestimated by governments. Meaningful involvement is not only important for effective democratic governance, but for the self-identities of the older adults and carers on these committees. This may be especially so in a broader context in which these groups may feel marginalized or otherwise disadvantaged, or where people have had negative previous experiences within the systems they are now trying to change. Further research into the emotive and identity-related aspects of involvement in advisory councils could inform the training of advisory committee facilitators, advice given to political figures who engage (directly or indirectly) with these groups, and governments' evaluations of the mandates and function of advisory groups.

   Although we interpret tensions between advocacy and advisory/feedback roles as particularly salient in the context of the government and health system change, more confident conclusions could be drawn only with future research that might include comparison to other provinces or historical points in time where these kinds of social changes were less prominent. Since the present data were collected, we have seen monumental social changes related to COVID-19 in Canada; now, more than ever, the input of both older adults and carers, who are fundamentally affected by these changes, is crucial. There may be an even more pressing need now, in all countries, to assess the issue of meaningful advocacy and representation of these groups in deliberative public participation (Ableson et al. 2007) and participatory policy co-design (Blomkamp 2018; Donetto et al. 2015) both within and beyond the continuing care sector. Processes for engaging these groups in democratic governance, however, not only need to attend to how best to respond to and utilize the advise they provide, but also to acknowledge the tension between advocacy and advisory. The development and expansion of advisory committees may need to be accompanied by public supports for independent advocacy organizations, for these tensions to be more effectively reconciled.

References

Abelson, Julia, Anya Humphrey, Ania Syrowatka, Julia Bidonde, and Maria Judd. 2018. "Evaluating Patient, Family and Public Engagement in Health Services Improvement and System Redesign." Healthcare Quarterly 21 (SP): 31–37.https://pdfs.semanticscholar.org/ee92/0eea8dc3fbbd303f69b5b9d6980ee98485b3.pdf

Abelson, Julia, and John Eyles. 2002. "Public Participation and Citizen Governance in the Canadian Health System." Changing Health Care in Canada,

(Commission on the Future of Health Care in Canada, Discussion Paper No.7). Ottawa, ON. Accessed online at: http://publications.gc.ca/site/eng/235919/publication.html

Abelson, Julia, Laura Tripp, Sujane Kandasamy, and Kristen Burrows. 2019. "Supporting the Evaluation of Public and Patient Engagement in Health System Organizations: Results from an Implementation Research Study." Health Expectations 22 (5): 1132–43. https://doi.org/10.1111/hex.12949

Abelson, Julia, Mark E. Warren, and Pierre- Gerlier Forest. 2012. "The Future of Public Deliberation on Health Issues." Hastings Center Report 42 (2): 27–29. https://search.proquest.com/openview/fe4a3a9d344bf6e643820888f90be304/1?pq-origsite=gscholar&cbl=49217

Abelson, Julia, Pierre-Gerlier Forest, John Eyles, Ann Casebeer, Elisabeth Martin, and Gail Mackean. 2007. "Examining the Role of Context in the Implementation of a Deliberative Public Participation Experiment: Results from a Canadian Comparative Study." Social Science & Medicine 64 (10): 2115–28. https://doi.org/10.1016/j.socscimed.2007.01.013

Attree, Pamela, Sara Morris, Sheila Payne, Suzanne Vaughan, and Susan Hinder. 2010. "Exploring the Influence of Service User Involvement on Health and Social Care Services for Cancer." Health Expectations 14 (1): 48–58. https://doi.org/10.1111/j.1369-7625.2010.00620.x

Barnes, Marian. 1999. "Users as Citizens: Collective Action and the Local Governance of Welfare." Social Policy and Administration 33 (1): 73–90. https://doi.org/10.1111/1467-9515.00132

Bee, Penny, Helen Brooks, Claire Fraser, and Karina Lovell. 2015. "Professional Perspectives on Service User and Carer Involvement in Mental Health Care Planning: A Qualitative Study." International Journal of Nursing Studies 52 (12): 1834–45. https://doi.org/10.1016/j.ijnurstu.2015.07.008

Blomkamp, Emma. 2018. "The Promise of Co-Design for Public Policy." Australian Journal of Public Administration 77 (4): 729–43. https://doi.org/10.1111/1467-8500.12310

Callaghan, Gillian, and Gerald Wistow. 2006. "Governance and Public Involvement in the British National Health Service: Understanding Difficulties

and Developments." Social Science & Medicine 63 (9): 2289–300. https://doi.org/10.1016/j.socscimed.2006.05.023

Chappell, Neena L., and Margaret J. Penning. 2005. "Family Caregivers: Increasing Demands in the Context of 21st-Century Globalization?" The Cambridge Handbook of Age and Ageing, 455–62. Cambridge, UK: Cambridge Univesrity Press.

Donetto, Sara., Pierri, Paola, Tsianakas, Vicki and Glenn Robert. 2015. "Experience-based Co-design and Healthcare Improvement: Realizing participatory design in the public sector." The Design Journal 18 (2): 227–48. https://doi.org/10.2752/175630615X14212498964312

Doucet, Andrea, and Nancy Mauthner. 2008. "What can be Known and How? Narrated Subjects and the Listening Guide." Qualitative Research 8 (3): 399–409. https://doi.org/10.1177/1468794106093636

Estes, Carroll L., and Chris Phillipson. 2002. "The Globalization of Capital, the Welfare State, and Old Age Policy." International Journal of Health Services 32 (2): 279–97. https://doi.org/10.2190/5TY7-PD68-QLD1-V4TY

Fung, Archon. 2006. "Varieties of Participation in Complex Governance." Public Administration Review 66 (s1): 66–75. https://doi.org/10.1111/j.1540-6210.2006.00667.x

Funk, Laura, and Wanda June Hounslow. 2019. "How do daughters interpret care as a public issue? Exploring identity, emotion and discourse in the narratives of activist-inclined carers of older parents." Community, Work and Family, published online first at:https://doi.org/10.1080/13668803.2019.1681939

Gallivan, Jennifer, Katharina Kovacs Burns, Mandy Bellows, and Carol Eigenseher. 2012. "The Many Faces of Patient Engagement." Journal of Participatory Medicine 4. Accessed online March 21, 2018 at: https://participatorymedicine.org/journal/evidence/research/2012/12/26/the-many-faces-of-patient-engagement/

Government of Canada. Principles and Guidelines: Public engagement. Open Government, Government of Canada. Accessed online March 21, 2018 at: https://open.canada.ca/en/content/principles-and-guidelines

Grenier, Amanda, and Nancy Guberman. 2009. "Creating and Sustaining Disadvantage: the Relevance of a Social Exclusion Framework." Health & Social Care in the Community 17 (2): 116–24. https://doi.org/10.1111/j.1365-2524.2007.00804.x

Gubrium, Jaber and James Holstein. 2000. "Analyzing Interpretive Practice. In Norman Denzin and Yvonna S. Lincoln (Eds.), Sage Handbook of Qualitative Research. Thousand Oaks, CA: Sage, 487–508.

Heaton, Janet. Reworking Qualitative Data. 2004. London, UK.

Hinds, Pamela, Vogel, Ralph, and Laura Clarke-Steffen. 1997. "The Possibilities and Pitfalls of Doing a Secondary Data Analysis of a Qualitative Dataset." Qualitative Health Research 7: 408–424. https://doi.org/10.1177/104973239700700306

Holroyd-Leduc, Jayna, Joyce Resin, Lisa Ashley, Doris Barwich, Jacobi Elliott, Paul Huras, France Légaré, et al. 2016. "Giving Voice to Older Adults Living with Frailty and Their Family Caregivers: Engagement of Older Adults Living with Frailty in Research, Health Care Decision Making, and in Health Policy." Research Involvement and Engagement 2 (1): 23–41. https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-016-0038-7

Holstein, James, and Jaber Gubrium. ''Active Interviewing.'' in Qualitative Research:Theory, Method and Practice, edited by D. Silverman. London, UK. 1997: 113–29.

Horrocks, Janice, Christina Lyons, and Paul Hopley. 2010. "Does Strategic Involvement of Mental Health Service Users and Carers in the Planning, Design and Commissioning of Mental Health Services Lead to Better Outcomes?" International Journal of Consumer Studies 34 (5): 562–69. https://doi.org/10.1111/j.1470-6431.2010.00912.x

Levitsky, Sandra R. 2014. Caring for our Own: Why there is no new political demand for new American social welfare rights. New York, NY.

Li, Kathy K., Julia Abelson, Mita Giacomini, and Damien Contandriopoulos. 2015. "Conceptualizing the Use of Public Involvement in Health Policy Decision-Making." Social Science & Medicine 138: 14–21. https://doi.org/10.1016/j.socscimed.2015.05.023

Martin, Graham P. 2008. "Representativeness, Legitimacy and Power in Public Involvement in Health-Service Management." Social Science & Medicine 67 (11): 1757–65. https://doi.org/10.1016/j.socscimed.2008.09.024

Martinson, Marty, and Meredith Minkler. 2006. "Civic Engagement and Older Adults: A critical perspective." The Gerontologist 46 (3): 318- 24. https://doi.org/10.1093/geront/46.3.318

McKevitt, Christopher, Angus I.g. Ramsay, Catherine Perry, Simon J. Turner, Ruth Boaden, Charles D.A. Wolfe, and Naomi J. Fulop. 2018. "Patient, Carer and Public Involvement in Major System Change in Acute Stroke Services: The Construction of Value." Health Expectations 21 (3): 685–92. doi: 10.1111/hex.12668.

Mulvale, Gillian, Sandra Moll, Ashleigh Miatello, Glenn Robert, Michael Larkin, Victoria J. Palmer, Alicia Powell, Chelsea Gable, and Melissa Girling. 2019. "Codesigning Health and Other Public Services with Vulnerable and Disadvantaged Populations: Insights from an International Collaboration." Health Expectations 22 (3): 284–97. doi: 10.1111/hex.12864

Thorne, Sally. 1994. "Secondary Analysis in Qualitative Research: Issues and Implications." In Critical Research Methods, edited by Jan Morse. London, UK. 263–79.

Rounce, Andrea, Laura Funk and Danielle Cherpako. In Progress. "Older Adults' Engagement in Advisory Councils and Committees : A case study of Manitoba, Canada."

VanDamme, Jan, and Marleen Brans. 2012. "Managing Public Consultation: A Conceptual Framework And Empirical Findings From Belgian Case Studies." Public Administration 90 (4): 1047–66. https://doi.org/10.1111/j.1467-9299.2011.02014.x

Acknowledgements