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**On Being Heckled at a National Health Technology Conference**

Patient Participation and Democratic Discourse

about Prescription Drugsand Commerce

by Sharon Batt

**Abstract**

*This article uses my experience of being heckled by patient advocates at a health technology conference in Canada as a springboard for discussing the politics of health technology assessment (HTA). While HTA is widely understood and practiced as a scientific endeavour grounded in rigorous quantitative research methods, numerous analysts have argued that the sociopolitical aspects of HTA cannot be separated from the scientific. Integrating the social, political and ethical dimensions of HTA into the practice of assessment means understanding the variety of actors involved, how the technology affects flows of resources, how knowledge about the technology is produced and circulated, and the power relationships involved. I examine how these factors may have contributed to the hostile reception I received when I attempted to present a paper about the biased selection of patient advocates involved in Canada’s main HTA agency. As India embarks on the challenge of establishing its own agency to support healthcare decision-making, and as patient advocacy groups rise in India with the support of the pharmaceutical Iindustry, I offer this account as a cautionary tale to those shaping the new agency.*

**An Unexpected Attack**

“You are a disgrace,” “you lied,” “you have set patient engagement back at CADTH thirty years.” These insults were among those hurled at me as I approached the doorway to a meeting room at a conference centre in April 2018, where I was about to give a paper about patient engagement in drug policy. The setting was a national meeting of the health technology assessment agency, the Canadian Agency for Drug Technology in Health (CADTH), in Halifax, Canada. The hecklers were three very angry women, two of whom I recognized as prominent patient activists. Taken aback, I said, “I’m sorry you feel that way,” which did nothing to soften their hostile looks. They seemed to be on their way to another part of the conference, however, and I needed a few minutes to orient myself to the session where I was about to speak, so I turned to make my way to the speakers’ table at the front of the room. As I did so, a woman seated in the audience gently touched my arm. “Are you ok?” she asked. I wasn’t sure that I was.

Things soon got worse. At the speakers’ table I looked up to see that the three women had taken seats immediately in front of me. They continued to openly make abusive remarks: “You should be ashamed,” “You shouldn’t be allowed to speak,” “You're just here to promote your book,” and “Oh, look at her, she’s laughing at us!” I was far from laughing, but I must have smiled nervously in my exchange with the moderator, who seemed at a loss at what to do.

“I think we need a code of conduct,” said the moderator, addressing the hostile trio.

“We need a code of conduct for *speakers*,” one shot back.

In the confusion and with the session about to begin, the moderator suggested that I might prefer not to give my paper. I weighed the situation: I had worked for many hours to prepare the talk and I believed what I planned to say was important. I had sent an abstract to the program committee outlining my intended topic, which had been reviewed and accepted, and now the room was filling up with people, some of whom presumably wanted to hear what I had to say. On the other hand, the hecklers obviously intended to disrupt my presentation and apparently felt entitled do so. Reluctantly, I agreed not to present but to take any questions members of the audience might put to me and to have my slides posted on the conference website.

My aborted talk was titled, “Patient Voices: Whose Stories are Missing, Why and So What?” (1) My failure to present illustrated the point I wanted to make, though not in the way I intended. I was not entirely comfortable with my decision; as a colleague later chided me, by not speaking I had “let them win.” Nonetheless, I soon realized that, at the conference and beyond, the “heckling activists” story set shock waves through Canada’s drug policy community and caused no small embarrassment within CADTH itself. Our session ended at the lunch break and as people milled about in the hallway a CADTH staff member, Sarah Berglas, the organization’s Manager for Patient Engagement, sought me out to apologize. She wanted me to know that CADTH was a safe place and that its conferences were venues for the discussion of diverse points of view. For support, and to assure my safety, she insisted on accompanying me to sessions for the rest of the conference. The next day I received two e-mails from CADTH, one from Sarah and one from the conference organizer, apologising again for the way I had been treated.

**Patient Engagement and HTA**

I was not so disingenuous as to think my paper would be enthusiastically received. As my abstract made clear, I proposed to call out the agency for what I saw as a systemic failure to incorporate a necessary diversity of patient perspectives. I *was* surprised to see such behaviour at a professional conference and to have it tolerated. How was it that conference participants felt entitled to overtly heckle a speaker? Why were the hecklers not told to act with civility or leave the meeting room? I return to these questions below, but first I look at the rationale for including patients in health technology assessment (HTA) agencies like CADTH in the first place.

Established in 1989, CADTH bills itself as an independent, not-for-profit, non-governmental agency. Like the National Institute for Health and Care Excellence (NICE) in the UK, and some 50 other agencies globally, the agency took its inspiration from the U.S. Office of Technology Assessment, which was founded in 1972 and disbanded in 1995 (2). The dismantling of the OTA, at a time when the Republicans were in ascendant in the U.S. Congress, underscores the fact that technology assessments, although they rely on scientific methodologies, can threaten vested interests and thus have a political dimension which is not always acknowledged. HTA agencies critically analyse the evidence from scientific research on the risks and benefits of drugs and medical devices and assess whether they are cost-effective. Based on this evaluation, CADTH’s mandate includes advising Canada’s provincial and territorial governments[[1]](#footnote-1) on whether to include a new drug or device on their public insurance formularies, or whether to remove an old one. Although regional governments are not obliged to follow CADTH’s recommendations, the agency plays a key role in determining which drugs will be available under publicly funded plans. These decisions can directly affect patients’ lives. They also affect drug companies’ bottom lines.

The drive to involve patients in HTA is widespread and based on considerations of both knowledge and ethics. As end-users of a technology, patients have experiential knowledge that complements research-based understanding of a technology’s “relevance to healthcare goals and needs” (3: 7). The patient’s status as the end-user provides an ethical basis for inclusion, based on “fairness and legitimacy through democratic participation” (3: 17).While the justification for including patients in HTA is strong, the means of achieving inclusion is not straightforward, since: “the rationales for inclusion raise issues of representation, i.e., which patient group should be represented” (3:17). My paper argued that CADTH had fallen short on the critical question of representation, which in turn distorts the issues of knowledge and healthcare relevance.

CADTH has made efforts to include patients in many aspects of its work since 2010. Initiatives include hiring a Manager for Patient Engagement (Sarah Berglas’s position), inviting patient organizations to send online comments on drugs and devices under review, and including patients on its review committees. Another facet of patient involvement is to include patients at its annual Symposium. The year I was to present, the agency’s website proudly displayed that it met the criteria set out by the international organization Patients Included, which rates medical meetings on whether they have sufficient involvement from the patient community.[[2]](#footnote-2) CADTH’s plenary session panels typically feature a high-profile member of the patient/caregiver community, and patients are encouraged to submit abstracts for posters and presentations at smaller breakout sessions -- the process I followed. In addition, patients who have endorsement from a patient organization can apply for funds to cover their travel, accommodation costs and conference fees. For the third consecutive year, CADTH awarded me travel support to attend as the representative of Breast Cancer Action Quebec, a group I co-founded 25 years earlier, following a diagnosis of breast cancer.

**Patient Engagement and Pharma’s Shadow Presence**

The talk I intended to give arose from my observation that the patients who dominate at CADTH meetings and committees seemed to represent one subgroup within Canada’s patient advocacy community, while another, equally vital, patient perspective was missing in action. Represented in abundance were patients who wanted to see new drugs placed quickly on provincial formularies, who framed concerns about cost as a disregard for their wellbeing and even survival, and who seemed willing to accept modest or preliminary evidence of effectiveness and safety because they saw access to new medicines as giving patients treatment choice and hope. Most of these patient representatives came from organizations that received some funding from the pharmaceutical industry.

Two recent analyses confirm my impression of extensive pharmaceutical industry funding among the patient organizations engaged with CADTH. The agency has two drug evaluation arms, one for medicines in general (the Common Drug Review or CDR), and one for cancer drug submissions (the panCanadian Oncology Drug Review or pCODR). Health journalist Kelly Grant found that, of more than 400 written patient organization submissions to CADTH, in 78 per cent of comments on drugs in general, and 86 per cent of comments on cancer drugs, the organization had a financial conflict of interest with the manufacturer of the drug under review (4). Physician and drug policy analyst Joel Lexchin examined all 372 patient group submissions by 93 different patient groups over a six year period up to July 2018 and found that 87.1% declared a conflict, with a median of seven conflicts per submission (5).

Findings from studies in the U.K. and Australia are strikingly similar. Among patient organizations participating in assessments at NICE, 72 per cent had accepted funds from the manufacturers of a technology or a competitor product in the same or previous year that they contributed to the appraisal of that technology (6). Furthermore, the terms of the disclosure policy for corporate funding were so inadequate that decision-makers at NICE were aware of only 21 per cent of the conflicts. In Australia, a study of pharmaceutical funding of patient groups participating on that country’s Pharmaceutical Benefits Advisory Committee found that 34 pharmaceutical companies spent a total of AU $34,507,810.00 to provide 230 organizations with 1,482 sponsorships. Among the most heavily funded organizations were those representing conditions for which companies had treatments under review for public reimbursement (7)

By contrast, BCAQ, my sponsoring organization, has a written policy on corporate donations that explicitly precludes accepting funds from the pharmaceutical industry (8). BCAQ is among a small but increasingly vocal group of patients’ organizations in Canada that openly challenge exorbitant drug prices and questionable claims of the pharmaceutical industry. When a Parliamentary health committee held hearings on issues related to a national pharmacare plan, I joined with six other health policy activists who have patient or caregiver experience to to submit a brief to the committee (9). To highlight our priorities and our lack of industry funding, we called our coalition Independent Voices for Safe and Effective Drugs (IVSED). Likeminded organizations include Faces of Pharmacare, the CML Society of Canada (representing Chronic Myelogenous Leukemia patients) and the Liv-A-Little Foundation (representing patients with Cystinosis).

The “overwhelming majority” of the patient group leaders that Kelly Grant interviewed for her newspaper investigation said that drug makers that fund their groups “have no say whatsoever in their policy positions” (4). Nonetheless, the groups articulate a perspective about new drugs and devices that aligns closely with that of the pharmaceutical industry. Joel Lexchin found that the submissions of groups that participated in CADTH’s drug assessment process were overwhelmingly positive (90.2 per cent). Nine per cent were neutral and only 0.7 per cent were negative. When pCODR recommended against funding a new cancer drug, the patient groups usually disagreed (17 of 19 cases), but when pCODR recommended *in favour* of a drug’s approval, the patient groups almost always agreed (48 of 51 cases).

**Pharma’s Web of Influence in HTA**

Given that HTA is meant to reduce the use of unproven clinical procedures on patients, which can be both useless and harmful, one might expect the HTA culture to be wary of industry influence. And yet, internationaly, HTA agencies embrace a model of partnership with industry that is endemic in medicine, and not only with respect to funding patient organizations. David Banta, a physician and international HTA pioneer, wrote a personal reflection on his 40-plus years in the field, in 2018, in which he said: “my greatest concern today is the role of industry in HTA. … how can we refer to industry as partners when our first concern is the public health? The commercial health care industry is mostly concerned with creating returns for their shareholders” (10:133).

CADTH is largely government-funded but receives some funding from industry. In 2018, Canada’s federal Minister of Health commissioned two external evaluators to assess pan-Canadian health organizations and their report questioned the degree and type of involvement CADTH should have with the private sector. Based on stakeholder interviews, the evaluators flagged CADTH’s engagement with industry in three contexts: industry’s role in the agency’s funding model, CADTH’s engagement with patient representatives whose work is funded by industry, and its work with private insurers (11: 85). Like Banta, the report’s authors stressed the need “to ensure that the organization continues to be seen as acting squarely in pursuit of the public interest” (11: 85).

In my own research, I looked at the origin and effects over time of industry funding of patient groups (12). In the 1990s, governments responded to large deficits by cutting government services and loosening regulations so that industries could flourish. In many democracies, including Canada, health advocacy groups had received public support in the prosperous post-war years as voices of civil society. They suddenly found themselves scrambling to survive. Following the rise of the HIV/AIDS movement in the 1980s, patients breast cancer and many other health conditions began to organize at the same time that new treatments were in development. The pharmaceutical industry soon recognized the potential advantages of forming partnerships with groups whose members were desperate to try the very treatments they were bringing to market. These “public-private partnerships” between patient organizations and Big Pharma were analagous to those that the industry formed in the medical research community, in medical education, and in regulatory and quasi-regulatory agencies like CADTH. Together they created a web of influence throughout the medical system that reinforced the industry’s interests. Importantly, however, within patient and health organizations, as in each of these other health sectors, a contingent of organizations resisted the privatization wave as fundamentally at odds with the public interest.

**The Roots of a Heckling Culture**

In the immediate aftermath of being heckled, and in the months since, I’ve puzzled over what happened and why. At the conference itself, a number of sympathetic people, approached me to say they thought I had “struck a nerve.” I have no doubt that is true. Prominent patient advocates who are involved with CADTH have said on the record they are “weary” of being criticized for their acceptance of pharma funding. They see such critiques as “an excuse to ignore [their] input on health policy issues” (Elias, quoted in 4) or as being “used to contain or minimize patient involvement” (12: 377). But the critique of industry funding is *not* a tactic to exclude patient input; on the contrary. Industry funding of select patient groups has marginalized and excluded those of us who see industry as a barrier to obtaining the best available evidence on health technologies. Many of us came to that understanding through our experience as patients and caregivers.

My aborted talk was a plea to bring these opposing voices into the fold and to have genuine debate. I acknowledge that patients can and do have different experiences with drugs. These, and different personal values, lead to differences of opinion – why not discuss them? Why heckle?

One answer might be that heckling, when done well, claims a proud place in political discourse as a form of intellectual engagement. Michael White, a political commentator at *The Guardian,* makes this argument, but he distinguishes “proper heckling,” characterized by wit and impeccable timing, from the blunt instrument of anger and boorish abuse (13). I put my experience in the latter camp: the attacks were pre-emptive and showed neither wit, nor true argumentation. The comments were designed to bully, humiliate and silence me. In this guise, heckling expresses an authoritarian mindset that threatens both democratic pluralism and the questioning that is essential to scientific inquiry.

In political spheres, intolerance of difference is much in evidence these days but research forums are idealized as spaces for rational discourse and we tend to overlook their political dimensions. Two scholars of HTA, Pascale Lehoux and Stuart Blume, argue that, while the approach to HTA that dominates the field tends to focus narrowly on technical and clinical evidence, HTA is political and these dimensions need to be given more attention (14). If we consider HTA as political, the bullying I experienced at the CADTH Symposium is less startling. In fact, in the literature on health technologies, egregious examples of disrespect aimed at those who contest the safety or efficacy of profitable “advances” are not uncommon.

Peter Gøtzsche’s expulsion from the Cochrane Collaboration’s governing board in September 2018 stands out as a high-profile recent case and has been discussed in many venues, including this one (e.g.,15, 16). But intolerance of critique has deep roots in HTA. In a book-length account of mammography screening debates (17), Renée Pellerin recounts the reaction surgeon Charles Wright elicited in the late 1980s when, as an invited speaker at a conference on mammography at Johns Hopkins University, he described research (18) that led him to conclude that harms of breast screening far outweighed the benefits and that only women at high risk of breast cancer should be screened. Wright was “greeted with a deathly silence and lots of people were visibly upset” (17: 71). At the subsequent coffee break, “a very angry-looking elderly radiologist came up and sort of punched me in the chest with his finger and said ‘You don’t understand boy; you’ve got your hand in our pockets.’” (17: 71). In another case, David Banta and Stephen Thacker describe the barrage of attacks on their objectivity and integrity when their research led them to question the efficacy and safety of electronic fetal monitoring (19: 764-66). In a letter to the U.S. Secretary of Health, Education and Welfare, one obstetrician wrote to say that, unless their “emotional and irresponsible outbursts” were restricted, “some babies may die” (19: 765). And when the *BMJ* published the 25-year update of the Canadian Breast Screening Study in 2014, which concluded that mammography screening does more harm than good, the study’s deputy director, Cornelia Baines, received an email from a radiologist saying he “hoped she would be haunted by the faces of all the women who would die because of her” (17: 14).

As a crude tactic to stifle debate, heckling is clearly political; but the use of such tactics in HTA venues should act as a reminder that science and politics are inseparable and sociopolitical analysis need to be part of HTA. Lehoux and Blume argue strongly for identifying the sociopolitical dimensions of health technologies and and provide a framework for systematically including a sociopolitical perspective in HTA. They identify four sets of issues for analysis: the potential actors involved, the flow of material and human resources that the technology implies, the production and circulation of knowledge, and how the technology affects the power relations (14:1092-93). They stress that actors should be seen as “reflective agents …. Organized groups may struggle to protect their assets and attempt to exercise power over the projects of others” (14:1091). With this framework in mind, we should not be surprised that obstetricians protest against evidence that undermines the use of electronic fetal monitoring, or that radiologists may attack analysts whose evidence says that mammography screening does more harm than good.

**The Politics of Patient Group Advocacy**

Nor should we be surprised that that patient advocates who work in partnership with the pharmaceutical industry show hostility to an advocate who questions their claims about the value of new drug treatments to patients. Lehoux and Blume write that controversy brings out a health technology’s social and political dimensions:

Tensions are revealed when competing definitions of a technology’s value and relevance are publicly articulated. Tensions also emerge when groups of actors feel threatened or perceive themselves at risk of losing power and authority, particularly when such groups possess the resources or “cultural capital” to express their discontent (mobilizing the media, voicing their concerns publicly). (14:1091)

The two hecklers that I recognized certainly possessed resources and cultural capital, both individually and via their leadership status in multiple organizations. One founded and is currently CEO of an organization called the GI Society, representing patients with gastro-intestinal diseases; the other is a long-time AIDS activist, who now consults for Save Your Skin Foundation, a group for patients suffering from non-melanoma skin cancers. Both organizations declare receiving pharma funds and both women’s positions are apparently paid, not volunteer. Both have served on the executive of Best Medicine’s Coalition, an organization with significant industry support, made up of patient organizations dedicated to gaining rapid access to new drug treatments. Both women had served on CADTH’s Patient Community Liaison Forum (see Postscript below). At the time they heckled me, the two women also co-led a project called Advocacy Boot Camp, described as a intensive training course in health advocacy (19). This project received funding from at least two major pharmaceutical companies (Canada does not require pharmaceutical companies to declare their funding to health advocacy organizations, despite urging from policy analysts for transparency, so public information is limited). Boot Camp participants paid Can. $5,000 each for their four-days of advocacy training. A list of past participants on the project’s (now-defunct) website indicates that many Boot Camp graduates attended the CADTH Symposium and submitted assessments for treatments for the condition their organization represents. In other words, the two hecklers would be considered “Patient Opinion Leaders”– influential patient counterparts to industry-funded physicians known as Key Opinion Leaders.

**Conclusion**

If patient involvement at CADTH and other HTA agencies is to mean anything at all, differences among patient representavives on drug policy need to be aired. The meetings of HTA organizations should be venues for informed, substantive debate of conflicting evidence claims, including evidence arising from patients’ varied lived experiences. This means discussing not just the hoped-for benefits of health technologies, but patients’ perspectives on the significant harms that drugs and devices can cause (20, 21). It means listening to patients who wonder why the drugs they take “are so ridiculously expensive, how can I possibly be using something that costs as much as my house every year?” (22).

These are precisely the discussions that the advocates who heckled me want to prevent. Their actions endanger scientific inquiry and discredit patient engagement in HTA.

**Postscript: Changes at CADTH**

In January 2019, CADTH introduced a Code of Conduct for events like the annual symposium (23). The Code states that anyone registering for a CADTH event must “agree that harassment or disrespectful conduct do not belong at any CADTH event.” The Code includes as examples, “behaviour that demeans or embarrasses a person”, “offensive or inappropriate remarks” and “sustained disruption of a speaker” and asserts that CADTH will take complaints of harassment seriously. Potential actions the organization is prepared to take range from warnings to contacting local law enforcement and excluding the offender from attending future CADTH events.

Also in the year following my aborted talk, CADTH disbanded its Patient Community Liaison Forum, an advisory group which had been active from 2013 to 2018 (24).The Forum consisted of representatives from four national patient coalitions, all of which were industry funded. In June 2019, CADTH announced the formation of of another patient consultation group, the Patient and Community Advisory Committee, in which most of the 12 members declared no industry ties (25).

These changes may have been entirely unrelated to my experience at the Symposium. Regardless of what motivated the moves, both have the potential to make CADTH a venue at which the full range of patient experiences and values can be discussed.

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1. Canada is divided into 10 provinces and three Northern territories with health care delivery designated as a provincial responsibility. Within certain parameters set by the federal government under the Canada Health Act, each province or territory makes its own decisions as to how health funds are spent, including whether or not to cover the costs of specific drugs and medical devices. Quebec has its own drug evaluation agency, INNESS, and does not look to CADTH for guidance. [↑](#footnote-ref-1)
2. See: <https://patientsincluded.org/conferences/> [↑](#footnote-ref-2)