Budget 2014: Re-balancing Innovation Support Programs
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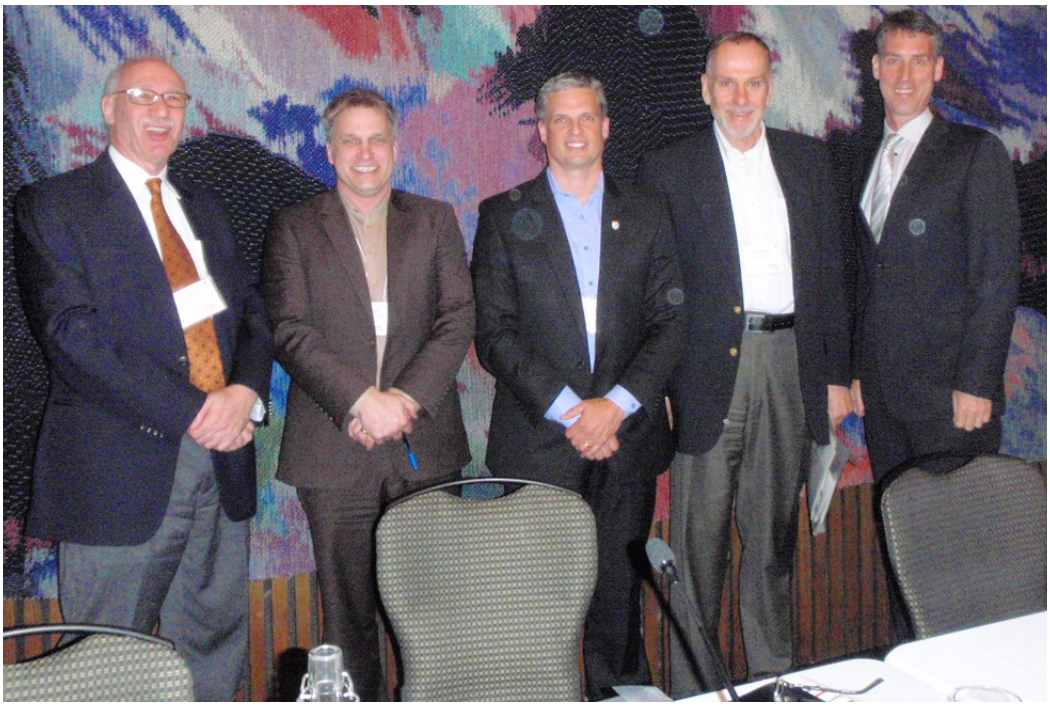
Panel Discussion

Implications of Patient-Oriented Health for Health Research & Innovation Policy



Moderator: **Jeff Latimer**, Director, Platforms and Major Initiatives, CIHR

Brian Clark, Advisor, Patients Canada
Michael Mayne, Deputy Minister of Health and Wellness, PEI
Jason Sutherland, Associate Professor, School of Population & Public Health, UBC

Latimer opened up the session by pointing out that as common sense as it may seem to put patients at the centre of health care research, it is not the norm. "Patient-oriented research in Canada is a relatively new phenomenon," he further clarified. "Patient-oriented research is somewhat different than patient-centred health care."

Clark suggested that from a market perspective, it is unusual for research not to be regarded from a patient perspective, since in any commercial context a customer's needs are paramount. "It's rather strange that we have an institution called health care that is not patient-focused," he said, noting that it is only the patient who has an overview of how the entire system operates. "It behooves health care research to look at how that can be improved, and the only way they can look at that is to ask the patient."

He described the role of Patients Canada in listening to patients and their stories about the health care system. What emerges is learning that can be translated into performance targets, with the aim of initiating cultural change.

Mayne acknowledged that it has been a major transition for him to move from industry into his current role as provincial deputy health minister, if only in terms of the requirement to spend all of one's budget money in any given year. He agreed with Clark that the health care system is highly fragmented. "Often there's pressure on patients to carry the data; we're only just getting with the program of computerized records," he said. "We're really behind the times as a nation in the basics of having solid data. That creates a lot of problems, a lot of redundancy."

He gave $225 billion as the total amount provinces will spend on health care in the coming year, an amount comparable to the federal government's entire budget. He also predicted that within the next seven years, each province will be spending at least half of its program expenditures on health care. By way of putting that in perspective, presently some 11% of provincial budgets is dedicated to social services, 15% goes to debt, while another 20% goes toward education. The remainder pays for economic development, justice and transportation, which will shrink as a result of the growth in health care costs.

Mayne further noted that R&D expenditures in health care-related fields tend to focus on "disease-busting", addressing some specific ailment and its treatment or cure. "That's not really going to generate significant cost savings over the next 15-20 years in our health care system," he said. "In fact, it has the potential to accelerate or inflate drug pressures or costs to our system. So from an innovation perspective we have a big gap between the way we operate our health care system and the way we're driving our innovation system."

He underscored Clark's point about the need for patient research. "It's important that we get more patient-driven exercises, which are still embedded in evidence." He also pointed out that

most of these research undertakings fall back on highly dated methodology, such as asking participants to sign up on a physical clipboard at their clinic. "It's the same technology that was there in 1940," he said, adding that it is usually impossible for people to enroll by telephone or on-line.

Sutherland noted that his academic interest in this field was sparked by the tremendous investment of public money in health care. For him, this also raised the question of what we are getting for this investment. "We're not able to quantify what health we're buying," he said. "This is a significant gap in our understanding of what we're paying for." This has led him to study the health care system and the institutions that populate it, including examining how they decide to allocate the money they are given.

"We're trying to design systems whereby we can collect patient experiences and patient outcomes as they journey through the system, to understand where the gaps are and the opportunities for intervening, to improve health and to maximize our investment in the health care system," he explained.

Latimer suggested that one of the harder questions surrounding this work was whether we have unrealistic expectations for positive change based on patient-oriented research, which could lead to new measures that increase costs. Clark indicated that the answer would depend on the goal of the research; if that goal is to improve the system in any way, he maintained, then it must include the patient perspective. Reiterating his previous point about commercial enterprises, he observed that they do not involve customers in the details of product or service development, but the needs of those customers come first and foremost in the development process.

"We need researchers that clearly understand the patient view, and from that patient view they can spend the research money more wisely," he said. "A cultural change needs to take place. What we have right now are researchers that are focused on disease and focused on supplies. Through that cultural change we're going to have all sorts of interventions, including patients being involved in setting priorities."

Mayne added that there is a perceptual uncoupling of the link between tax monies, about which people love to complain, and health care, which is perceived as being free though we are glad to know it works.

Diane Royce, Managing Director and COO of the AllerGen Network of Centres of Excellence, asked about how the value of specific medical interventions could be compared. Mayne responded that this is an ongoing problem that calls for a certain level of appropriateness. "Individual situations trump the epidemiology of the whole," he said. "It's about you when you're in front of your physician and about your care." Nevertheless, costing out particular procedures must be done at some point.

Sutherland responded by suggesting that improvements to health care should be regarded from a broader perspective. "It's not about redesigning the system, it's thinking about how we maximize the health of the patients in Canada and then redesign the system to support that objective." In the US, he noted, hospitals receive financial incentives to improve the quality of a patient's experience, so there are rewards or penalties associated with how that experience is provided.

"Right now we are a volume-oriented system," he said. "We talk about wait times and number of discharges, but we rarely talk about what we've achieved for this spending here." Measures other than volume can be applied to help us understand what health care is providing for patients. In addition, this opens up the larger question of how we value patient input into the system.

Ron Freedman observed that whenever he interacts with the health care system, he is regarded as a patient rather than a client. From his point of view, especially in light of the system's emphasis on volume as a key measure, he suggests that treating people as patients first actually translates into poorer care.

Clark noted that some of the most commonly treated ailments, such as heart disease, diabetes, and certain cancers, can be dealt with primarily through lifestyle changes. "And yet we persist in paying doctors fee for service when we should have an integrated system that's keeping people healthy and incorporating lifestyle changes in the mix." This kind of redefinition of health care to focus more closely on lifestyle would undoubtedly bring about a redefinition of costs, too. "If we can push back on some of those non-communicable chronic diseases, we have the potential to save billions of dollars in the health care budget."

According to Sutherland, "When you design and implement a system that pays for volume, you get a system that generates volume. That ignores effectiveness, and it also ignores the issue of access. There's a good body of literature that suggests when you design a system for volume, you will get the volume to the point where the marginal, incremental benefits to the patient are near zero." He added that there should be some sort of braking mechanism imposed on this push to improve volume measures, so that quality of care is not compromised. This is especially the case because in many smaller communities these services are essential and should not be compromised in this way.

Another question dealt with how the narrow range of information drawn from patient experiences could be applied to the vast range of activity undertaken within the health care system. Clark responded that there is nothing extraordinary involved in the use of patient stories to drive a change in how health care operates. "It's understanding a patient's perspective, and you understand that perspective through patient stories."

Mayne made the further point that patients he encounters are not asking to get involved in all the technical niceties of how health care is managed, such as complex procedures like clinical trials of new drugs. Instead, the top priority of most patients is to improve the way they are treated by

the system. "It's really a throughput issue," he said, adding that some European countries offer physicians pay for performance, i.e. more money when the health of their patients improves. "With the power of IT and health records now, you can quickly through intelligence patterns identify which group of doctors are best treating their patients for diabetes."

Latimer commented that the UK, which is far ahead of Canada in terms of engaging patients, has found it useful to engage patients in the design of clinical trials, at least to the extent of determining the desired outcome being measured by the trial. "I'm suggesting we could even go farther," he said. "Some of the research that is now coming out of the UK is saying that engaging the patient in the clinical trial — helping to design the trial, asking what are the outcomes that we should be measuring that are important to the health care system and the patient — helping the patients recruit additional patients, and then championing the results back to the health care system. A role like that could be incredibly effective."

Mayne responded to Latimer's comments by pointing out how crucial patient input has been in helping PEI and other provinces determine which are the most appropriate drugs to put on their respective formularies.

Lisa Drouillard of the Networks of Centres of Excellence, asked the panel what kind of direction they would assign to innovation in new products and process innovation. Mayne responded with an answer that he anticipated would upset many observers: we spend too much money on basic research.

"That hurts me to say that, because I was a basic researcher and it's near and dear to my heart," he admitted. "But when you look at the track record of that for the last 20 years, it's poor, very poor. We need to spend far more on process engineering. We need to spend a lot more on wellness and prevention; we need to have the patients help direct us on that."

He added that this approach would also have the unfortunate consequence of throwing many researchers out of work.

Another questioner noted that we must be careful in addressing patient perspectives, since patients cut across a wide spectrum of society and general personality. She also insisted that ethics and morality must be incorporated into this process. Latimer conceded that CIHR has also been struggling with the concept of which patients they should be surveying for information. Mayne agreed that ethics and morality are crucial, and added that major overhauls of the health care system in small, concentrated places like Denmark are difficult to emulate in Canada, which is much more decentralized.

Clark made the point that while access to care in Canada may be fairly consistent, the quality of that care can vary amongst different groups within the country's population, depending on their understanding of how the system works and whether they speak French or English. "We often

think Canada is all for one and one for all, and not stratified like the US. But we think there's stratification in the Canadian system as well."

A questioner asked how information about patient experiences are being shared. Latimer pointed to some very basic communications priorities where the health care system lags far behind the rest of Canadian society. "They're very straightforward," he said. "I'd like to be able to e-mail my doctor. I'd like to be able to book an on-line appointment. I'd like to be able to do an e-consult. I'd like to be able to have my data with me, on my iPad. We're so far away from that in Canada that it's shocking."

Mayne continued by noting that around a third of Australians can e-mail their doctors, while Canadian doctors are unlikely to provide any such access to their patients. "They typically don't give out even their phone number and you can't phone through to your doctor's clinic because typically there's no answering machine," he said, adding that cost overruns that bedevil efforts to digitize health records are being driven by a desire to see medical practitioners immediately provide the same information management services that banks currently offer. "We cannot build in 10 years what the banking system has built in 40."

Rory Francis of the PEI BioAlliance asked if we were really investing enough into the service side of the health care system, since quality of service potentially has a huge impact on how people view the system. Sutherland gave a blunt response: "We have produced two generations of health system managers whose primary function is cost minimization within their own silo. We don't have a generation of people who are thinking of either global optimization across the health care system or are trying to reduce this fragmentation." He acknowledged that revenue must be tracked by these managers, but so too should the health outcomes being provided by the system. "It is going to be an incredible amount of work over the next 10-15 years to turn the ship away from just trying to spend less to 'what are we getting for that?' and trying to recoup some revenues."

Mayne reiterated his earlier point that too much budget money was being invested in basic research, and if that did not change then demographic pressures are going lead to a crisis. He also raised the paradoxical observation that the longer someone remains outside of the health care system, the more they complain about it. "For the most part, people are 30-40% satisfied with the health care system if they haven't been in the system in the last two years," he explained. "As soon as they go into the system and you interview them the day they leave, they have 88% satisfaction."

Ron Freedman posed a final question, noting the challenge associated with the fact that the health care system is currently predicated on declining returns, the sense that it deals largely with diseases at end of life. Mayne responded that the acute care dimension of the system was originally designed for emergency treatment, but has essentially been co-opted by patients with

chronic diseases of one sort or another. "Some 30% of our medical beds across Canada right now are full of what we call bed blockers, who are awaiting long-term care and can't go home," he said. "So there needs to be some fresh thinking about how we deal with acute disease and chronic care." This trend is being exacerbated by technology that enables us to rebuild people and extend their lifespans beyond what many of us can handle, leading to further challenges on the surrounding support systems.

Latimer then asked for closing statements from each of the participants. For his part, he observed that CIHR has been tackling funding issues through its own strategy for patient-oriented research, which is this organization's single largest funding priority. These efforts include a new initiative on acute care, which addresses precisely the conflicting priorities of acute and chronic care.

Sutherland summarized his view with three questions: how do we respect the time of patients participating in research undertakings; how do we provide them with the skills necessary to contribute to these research processes; and how do we get them interested in this process in the first place.

Mayne concluded that everyone will make some use of the health care system in the future, and there is no longer any time to wait for research that addresses the specific needs of this system. He added that this is not an insignificant budget item, nor is it an insignificant priority.