Submission by Dr. D. Wayne Taylor, PhD, F.CIM (November 2017) The Review of Federally-Funded Pan-Canadian Health Organizations,

Introduction

I am almost positive that the elephant in the room will not be seen by this Review: eight federally-funded Pan-Canadian Health Organizations - to which one could add, as I will do in reference, the Patented Medicines Prices Review Board operating under the *Patent Act* and the pan-Canadian Pharmaceutical Alliance - spending over \$300 million and employing over 1300 public servants (\$230,000 per FTE) while suffering Canadians do without badly needed medicines and treatments.

For example, let's look at orphan drugs for rare diseases. In 2015 The Cameron Institute, of which I was the Executive Director then before retiring this fall, calculated that the funding required to pay for all orphan drugs for all patients for whom they were indicated would total \$625 million. The monetary value of life extensions <u>lost</u> to society for want of funding orphan drugs was \$340-560 million. And yet we spend \$300 million on PCHOs. No wonder the OECD reports that Canada has the <u>lowest</u> value-for-money of any healthcare system in the industrialized world.

We spend lavishly on PCHOs while patients do without. Patients reliant upon public drug programmes are denied access to innovative therapies. Wait times are the worst amongst comparator countries pushing our levels of care below generally accepted medical standards of care. There is scarcity of just about every kind of health professional. There is a shortage of long-term care beds which drives up the cost of hospitals running above capacity.

Is it worth it? Does the federal government believe that the outputs of these agencies are of greater value than the lives of Canadians? That is what the evidence suggests. But distraught families would disagree.

Having taught at the graduate level of university for nearly 30 years I have learned to focus my comments on the most salient points I wish to raise, within your five questions vis-a-vie each PCHO, so that my message is not lost in the chaff and so that there is no ambiguity.

One comment applying to all of the PCHOs is that none of them resonate with the Canadian public; the average Canadian knows nothing about any of them and could not care less. So who do they really serve and to what purpose?

Review of PCHOs

РСНО	Comments
CCSA	Missed the opioid crisis completely; complacent with the legalization of marijuana; no awareness that heroin is replacing fentanyl etc.
CADTH	A barrier to needed treatments using 30 year old methodologies; adds no new information to the decision-making process other than a low-ball, arbitrary cost cut-off about 20% of what the real world uses; spending money on CADTH to focus on the price of products that make up 7% of overall healthcare spending while we also have the highest healthcare labour costs in the world – the largest single healthcare cost – and the lowest productivity is ludicrous; countries that spend more on drugs have cut costs just about everywhere else
CIHI	A good repository of high-level utilization and throughput data (although never real-time) useful for comparative purposes and student research yet very little if any administrative analysis conducted as would be done in a business setting committed to quality and efficiency
CFHI	Has funded projects that have saved dollars in a micro-setting but there has been no diffusion beyond pilot projects and no return-on-investment calculation to determine whether these savings were worth the expenditure of not just the grant or programme or project but of CFHI as overhead too
СНІ	I can pay a street beggar in Beijing using my smart phone but Canada still does not have an integrated, real-time electronic medical record; the technology required is way below standards required for and used in other industries such as banking and logistics; most hospital IT is 20 years out-of-date
CPSI	Has done nothing significant to improve patient safety; healthcare remains the most dangerous of industries with the highest of system

	failure rates; adverse event reporting remains at the same level as it did when I started in this industry; remains very hospital-centric despite what its website may say
CPAC	Our international standing in cancer care and outcomes has been declining; the lack of adequate and modern palliative and supportive care remains a serious weakness just as it did when I sat on the board of Cancer Care Ontario (then OCTRF) 25 years ago; care and access to novel therapies vary greatly across Canada and even within provinces; what has CPAC done in regard to these issues?
MHCC	10 years after its founding mental health remains largely privately financed (and therefore not accessible for most) with an inadequate stock of residential capacity, hospital beds and an uneven balance of available therapies across the spectrum of mental health; substance abuse is highly correlated with mental health in many instances and we are failing there as well; number one therapy is drugs yet we have amongst the most restrictive formularies around
PMPRB	30 year old agency that has retarded Canada's level of access to novel therapies to the level of Romania and Pakistan; fixation with price rather than proper pharmaceutical utilization or socio-economic return on investment; PMPRB-set prices undermined by pCPA and/or provincial negotiations while increasingly research-based manufacturers do not even attempt to launch their products in Canada any longer thus denying Canadians cures and care, and making PMPRB redundant
рСРА	pCPA undermines/redoes the work of the PMPRB but even at a more glacial speed making patients wait while their conditions worsen

Comments on the Mandate of the Review

With respect to the Mandate of the Review allow me to say the following:

 (a) that none of the above PCHOs have "improved the affordability, accessibility and appropriate use of pharmaceuticals" except in driving down list prices in some instances which has only prevented other products from being accessible to patients in need.

- (b) To suggest that they have "optimized synergies between health data collection and IT" is absurd given the state of HIT in Canada.
- (c) "Mental health and substance abuse" remain largely police enforcement issues and not part of Canadian healthcare.
- (d) "Care at home and in the community" grows increasingly deficient in both quantity as measured by hours (minutes?) of care and complexity of care.
- (e) There is no "service delivery innovation" per se in Canadian healthcare. Innovation is the commercialization of discovery; stop using this word inappropriately; it masks the gross inefficiencies, low productivity and high error rates in our systems.
- (f) What is the goal of "pan-Canadian collaboration in priority areas"? Clearly given the lack of reportable concrete patient-based results (except for "stories") collaboration for the sake of collaboration is a waste of money. Either the provinces retain their domains over healthcare as they have accrued them over the years, and be allowed to go their own ways in the spirit of competition for improvement, or the federal government steps up and asserts it prerogative under the residual powers clause of the Constitution (which it will never have the political will to do). Having said this, PCHO collaboration really is non-existent; patients are ignored (aside from token political appointees); industry has been pushed aside; only academics from within a small, incestuous, like-minded group are engaged; opposition viewpoints ignored no matter the preponderance and strength of evidence.

As far as the value-add of PCHOs, I don't see very much. Not to say the issues are not important – they are, just as they were when each PCHO was founded 10, 20, 30 years ago; but nothing has changed, so where's the value-add? With the exception of CIHI, only because someone should collect data on a national level like every other country does, none of these PCHOs have provided any calculable value-add except jobs for 1300 public servants and monies for academics across the country – and public service jobs and academics do not create dollar value in any real economic model.

2) "Driving consistency and standardization across Canada" down to the mean is not desired and that is where we have headed. "Strengthening pan-Canadian capacity" would be great but again we have not headed in that direction. We have failed at anyone "leading innovation" as Canada is at the back of the pack. Why have a "national vision for the health system" when we do not have a national health system (unless the federal government invokes the Constitution's residual powers clause which it won't). Visions are useless – in fact, can be detrimental – if not achieved. So, why bother?

Final thoughts

All of these PCHOs should have had 5-year sunset provisions in their enabling legislation with pre-determined, quantifiable measures of success, agreed upon by all major stakeholders, built-in from the beginning and audited by a third party thus making this whole costly Review unnecessary.

Given very serious wait times, inadequate capacity, aging infrastructure, insufficient numbers of healthcare workers, denied access to novel medications and other forms of therapy, the money spent on PCHOs and a whole host of other government health system overhead drivers could be much better spent to treat patients in need of which there are many in this country overlooked by its political leaders and public servants.

To think otherwise, to think that \$300 million is just a drop in the bucket, is ignoring the elephant in the room. We study, we report, we study some more, we report some more yet we do nothing. Canadian healthcare needs to be patient-focused not public-servant or academic focused; overhead needs to be slashed everywhere so that patients CAN get access to novel drugs, CAN find a nursing home bed, CAN get needed hours of home care, CAN get their addictions and mental health issues addressed and hopefully resolved, and CAN enter a hospital knowing that they are safe and not an adverse event waiting to happen. PCHOs as we have come to know them have done – and will do – none of this.

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