

**March 3, 2014**

# **Lobbying Queen's Park: The Patient's Lobby**

**Ted Ball**

The new vested self-interest group in town is called "**Patients Canada**" -- the newly-transformed *Patients' Association of Canada*, headed by their wise and thoughtful President, **Sholom Glouberman**.

**Patients Canada** is the product of the learning done by hundreds of people engaged in generating "patient stories" and deeper insights into the patient experience over the past four years. Glouberman has attracted a clump of highly talented people skilled at developing things like *patient satisfaction/patient experience indicators*.

He also meets with governmental officials, and healthcare service providers, to explain: "what patients want".

"We know the system will be changing dramatically over the next few years. We're simply saying the patient perspective needs to be at the table as the new system is designed", says **Patients Canada's** President.

"We're interested in improving the healthcare system, and we're interested in working with providers to do that. We don't see ourselves as an isolated group arguing only for the patient perspective", says **Glouberman**. His point: when patients win, everybody wins -- healthcare professionals, administrators, boards, politicians, taxpayers.

"The most critical system change that needs to happen is the development and provision of health and social supports required by a rapidly growing population, with the various stages of chronic diseases. And the greatest savings we can make for this population is to provide support and treatment for them and their caregivers at home -- in order to avert hospitalization or institutionalization," says Glouberman.

Recent studies show that about 40 percent of people destined to go into very expensive institutions can be maintained at home -- which would of course be of greater benefit to seniors' physical and mental health.

While "aging at home" is often perceived as an option only for the wealthy, it is actually more cost-effective: the cost of homecare services for one day averages out to \$55 compared to \$1,000/day for a hospital bed, or at least \$130/day for a long term care bed.

Glouberman explains, "This means that we need more care in the community -- not only by primary care doctors, but also by nutritionists, pharmacists, physical and occupational therapists, and any other folks who can support patients and their family caregivers."

Glouberman has recruited former Deputy Minister of Health, **Michael Decter** to serve as *Patients' Canada* new Board Chair. Decter says, "My interest is to see emerging and reforming health care services informed in their design by the voices, insights and wisdom of patients. The needs and realities of the patient experience in an era of chronic disease need to come to bear more powerfully than they have historically. Now and in the future patients are far more participants than passive recipients of care. I am delighted to be part of *Patients' Canada* because of the practical and pioneering work of Sholom Glouberman and his colleagues."

Along with **Glouberman** and **Decter**, **Dr. Vaughan Glover**, the President of the **Canadian Association for People-Centred Health**, also pushes for a very different kind of healthcare delivery system. Nevertheless, despite very clear messages from Decter/Glouberman/Glover, we still seem confused about what to do in a system that is bloated with data, but starved of wisdom.

So, just where is the community health services development vision that will guide the shift from acute care to community and primary care at either the provincial or local level? There are no such comprehensive plans to my knowledge, and there does not seem to be any pragmatic focus on developing the capacity of the community sector to expand to meet the challenges of our seniors population.

As long as shifting from acute care, to primary care, as the "hub of the system" is just a talking point in the *Transformation* slide-deck, the status quo is not in danger, if they just can keep everyone talking.

That does not mean we are doing nothing. We are doing "stuff". But it is mostly unleveraged and underwhelming. The MOHLTC continues to focus their energy and attention on the "one-size-fits-all solutions", like the *Ideas From Utah Program*, and by seeking the views of the traditional vested interests power groups that I have named in my blogs on Queen's Park (i.e. the OHA, OACCAC, AOHC, RNAO, the OMA).

That's not a negative comment about the **Wynne Government**. All governments -- from all political parties -- seem to dedicate themselves to protecting the status quo. I don't know why, but they do.

People who were kinda hoping that *Health Links* might cause the unleashing of innovation at the local level, are now reporting that numerous HSP CEOs don't really seem to see this as an opportunity to "transform the delivery system". That's not an agenda that they have truly embraced at this point. They see *Health Links* as a one-off pilot project about the top 5% of users. They are not working to transform the system. They think all the hype about transformation is mostly just bunch of gobblygook from babble-speaking insiders who profit from reform rhetoric. "This too shall pass," say the long-timers who have learned how to fake compliance.

While MOHLTC officials tend to get caught in the interest group's various lobby campaigns, they ought to pay very close attention to what the Minister is saying.

The **Hon. Deb Matthews**, currently under pressure from a ground-swell of unhappy clients and staff of the CCACs, has branded herself the "*Patient-Centred/People-Centred Health Minister*". Her leadership on this strategic theme is having an impact as many health service provider organizations scramble to become more "patient, and people-centred". It's clear this is her passion. By selling the concept of "*patient empowerment*", the Minister has also paved the way for a "new voice" among the interest groups.

The Minister of Health has made a revolutionary suggestion. She suggests we **ask the patients what they think**. But this is a big complex game. No doubt there will be new jobs for *Directors of Patient Engagement* -- just like there were *Directors of TQM/CQI* in another buzz-word era. But will any of this PR rhetoric from MOHLTC result in any improvements? Is it possible that the patients could win?

**Patients Canada** and its dedicated bank of talented volunteers are stepping up to change the existing DNA of our healthcare services delivery system. They have put together a brain-thrust to develop the essential set of **patient indicators** -- which will no doubt be adopted as the *accepted standard* across the province, much like *Ottawa Ankle Rules*.

As the "*Health System Design War*" heats up, there is a new player in town with **patient indicators** saying: "***BUT THIS TIME, THE PATIENTS MUST WIN!***"

But will they win? I sure hope so, but those fires of self-interest burning all around us are now clearly out-of-control and largely ignored by a critical mass of very nice leaders who continue to hope that it will soon be their turn in the *inner-circle* and the "big bucks".

While those who have power and money can be expected to be aggressive in their efforts to maintain the status quo, it's actually too late.

The bottom-up consumer revolution has arrived on the shores of our teetering healthcare delivery system. Bye, bye status quo!

**FORWARD THIS BLOG TO PEOPLE YOU THINK WANT THE PATIENT-CENTERED REVOLUTION TO SPEED UP.**

