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Knowable Now

Knowable known unknowns of Canadian health care.

Not all that long ago, then U.S. Secretary of Defense Donald Rumsfeld attracted a fair bit of public scorn by trying to categorize the type of things which we don't know. He referred, perhaps a bit awkwardly, to known unknowns and unknown unknowns. What he meant was simply that there are some things which we know we should know, but don't, and there are other things which we don't even know are out there, waiting to bite us. This parsing didn't go down all that well, coming from a Secretary of Defense, but it would fit perfectly into the standard template of government reports on the state of the Canadian health care system.

After all, one of the running themes of reports on the state of health care in Canada from bodies like the Canadian Institute for Health Information (CIHI) is just how much we don't know about the state of our health care system.

Consider, for example, the Health Council of Canada's¹ third report, issued back in February of 2007. By way of background, The Health Council

Members of the Canadian Health Care Consensus Group (CHCCG) have come together to provide a platform for bold, reasoned and practical plans for genuine reform of the health system and to demonstrate that there is an emerging consensus among reform-minded observers about the direction that real reform must take. The CHCCG, coordinated by the Atlantic Institute for Market Studies (www.aims.ca), includes medical practitioners, former health ministers, past presidents of the Canadian Medical Association and provincial medical and hospital associations, academics, and health care policy experts, all of whom are signatories to the Statement of Principles.

This paper is one of a series of discussion papers prepared for the CHCCG, which are intended to contribute to that new debate. These papers do not represent official positions of the Consensus Group, and are not themselves consensus documents, but rather are intended to act as starting points for debate, some of which will occur on the Consensus Group's website (www.consensusgroup.ca). The first few papers will deal with aspects of the "public" versus "private" debate, while later ones will consider other issues which were raised in the Consensus Group's Statement of Principles.

was a creation of the 2003 First Ministers' Health Accord to monitor the progress which the federal and provincial governments made towards achieving the goals set out at that meeting and to, as its website puts it, foster

"accountability and transparency by assessing progress in improving the quality, effectiveness and sustainability of the health care system. Through insightful monitoring, public reporting and facilitating informed discussion, the Council shines a light on what helps or hinders health care renewal and the well-being of Canadians."

In the fiscal year ending March 2006 it spent just under five million dollars in pursuit of its mandate. To put that in what economists refer to as opportunity cost terms, a Family Practitioner in Canada bills Medicare, on average, a bit under 250 thousand dollars annually, so the opportunity cost of the Health Council is roughly twenty family practitioners, or, if you prefer, roughly twenty years worth of one Family Practitioner.

In its 2007 report, the Health Council tells us that we don't have enough information to track changes to the health care system, either in terms of specific access to care issues like waiting times, or in terms of broader issues, like whether the provinces have spent targeted federal monies on those things on which they were supposed to have been spent. As Council chair Jeanne Besner puts it, "governments simply do not collect or do not provide the data that Canadians need to properly evaluate progress. The information made available is often inconsistent, incomplete, and cannot be compared across jurisdictions."

But let's think about the wait time issue for a moment. Does it seem at all strange to say that we don't have the data necessary to evaluate what's happening to waiting times, when every single contact each of us has with a doctor or with the hospital is recorded in a Medicare data base of some sort? Every time you visit your doctor, every time a test or procedure is performed on you, a bill is submitted to Medicare giving the date of the service, the Medicare code for the services involved, and your Medicare number. And while the hospital and Medicare data bases aren't as neatly integrated as they might be, your progress through hospital treatment also can be traced, especially since the doctors you see while you're in hospital also bill Medicare directly for the treatment provided to you. That information source is probably about to be lost in Ontario if the government succeeds in moving most family physicians over to capitated Family Health Teams. Under a capitation system a doctor's income isn't tied to the specific services provided, so capitated system generally provide less information to administrative data bases than do fee for service systems, but in those provinces which resist the siren song of capitation, the problem is now, and will continue to be, not one of having too little information but one of having more information than most provinces' systems are currently equipped to process.

Consider, for example, Figure 63 of Stuart Soroka's background paper to the Health Council report, which refers to estimates of wait times for breast cancer surgery and for hip replacement surgery. For each procedure it has two estimates, but neither is drawn from Medicare and hospital records³. Rather, one comes from a survey asking the population at large how long they thought patients needing these

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procedures had to wait, and the other from a survey in which patients who had had the surgery in question were asked to estimate how long they had actually had to wait.

It's interesting to compare these two numbers, as Professor Soroka does in his discussion section, but it's more interesting to ask why we should have to rely on a survey of patient recollections for what might be regarded as the actual wait time number.

Consider an exercise along the following lines. Go into a province's Medicare data base and pull the record of every patient who had hip replacement surgery during the previous year. Then, using the patients' Medicare numbers as a link, pull from the Medicare and hospital administrative data bases every other record on those patients' interactions with the health care system over the past, say, three years. Use those data to put together a picture of the typical process leading up to hip replacement surgery in that province. You'll have every contact with physicians, every service they billed for, and a pretty good estimate of when each of those services was performed. The only thing that you'll be missing will be the time between when the patient called his GP for an appointment and the time when he actually got in to see the doctor. That's an important bit of information to be missing, to be sure, but we could still do a whole lot more with the information that's already there.

If you suggest this approach to health policy planners, you'll typically run into a number of objections. One is that this approach is backward looking, and we want to know how long patients are waiting right now. In fact, of course, all waiting time data is backward looking since you can't say how long someone wound up waiting until they've stopped waiting and have had treatment. If you mean that you want to know how long people who are currently waiting have been waiting, fair enough, but that's not going to require a massive, expensive data collection process. Just change the Medicare billing forms which physicians use to include a box the doctor can check if in their opinion, their patient needs surgery. (In fact, so long as the Medicare billing forms are filled in with sufficient detail, it wouldn't be that difficult to pull ones whose diagnoses indicate that, statistically, there's a high probability of the patient needing surgery. Administrative data bases can be wonderful things, if only they're used properly.)

A second objection you'll run into is that a patient may have several health problems, so that some of the visits that show up in the search described above will have nothing to do with the hip surgery. There are two responses to this objection. The first, and weaker one, is that the diagnostic information on the hospital discharge abstract will help filter this. The second one is that data are always noisy, and statisticians have spent the past century and more developing an armamentarium of ways to extract information from noise. To say that we shouldn't make use of the data that we have because it isn't perfect is to say that we should never do anything which requires data.

Canada's health care system, as we have already noted, produces massive quantities of administrative data, which could be exploited to help answer those questions which the Health Council is telling us we can't begin to tackle. The main reason we don't have better evidence-based health policy making in Canada is not lack of

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data, it's lack of access to data.

It shouldn't be the case. Hospital and Medicare data go from the provinces to the Canadian Institute for Health Information in Ottawa, an outfit which spent more than 67 million dollars in the fiscal year ending March 2006 and which, in the jaundiced eyes of some researchers, seems to regard its function as collecting all of the health data in Canada and burying it in the back yard where nobody can get at it. Canadian health statisticians look with envy at the amount of data that is freely available for download in the United States, and many of them either turn to using American data or move away from policy research altogether.

This is something which needs to be emphasized. We have massive amounts of data. It's not perfect, but it's there and we could make a lot more use of it for policy purposes than we do. We have researchers, health economists and statisticians in university economics and statistics departments all over the country who, while they might not actually perish if they don't publish, do need to produce good research if their careers are going to prosper. If you don't like to think in terms of overlapping self-interests here, then think in terms of synergies between those who have the data and need it analyzed, and those who would love to get their hands on data to analyze.

The provinces need to take note of something here: Ottawa is not going to be of much help in this matter. You're going to have to do it yourselves. Ottawa's data agencies seem at the moment to be reduced to near paralysis for fear that someone might possibly be able to come up with a way to use the data bases in those agencies' possession to identify specific individuals with specific diseases. Confidentially is a serious concern, of course, but confidentiality issues needn't paralyze the system - most researchers aren't interested in identifying specific individuals, and we could take a look at the work that's been going on in the United States over the recent past into ways to preserve confidentiality while still making data available.

The key point, though, is that if the provincial governments really want to know about things like waiting times for surgery in their health systems, they're going to have to find out for themselves. Some provinces have already done this, to some extent. Ontario, for example, makes its health care data available to the Institute for Clinical Evaluative Sciences (ICES) for analysis. This isn't a good model to follow for the simple reason that monopoly, in this case over data, is never a good thing.

A better model would be to let the intellectual marketplace do its thing. Smaller provinces, in particular, are well placed to do this - their health care data bases are small enough to be manageable but large enough to produce statistically meaningful results. Most of the smaller provinces have, in their departments of health, civil servants who, for purposes of policy development, want and need to have health care system data analyzed but who don't have the time or the resources to do it in-

house. Those provinces, in particular, should be looking at ways of making the data which they have readily available to the researchers who want to analyze it.

That's a process does not require massive infrastructure, a series of federal-provincial meetings, or the creation of yet another federal-provincial advisory body.

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It doesn't need to be held up while a bunch of federal-provincial advisors try and come up with a uniform method of analyzing the problem - let the market for ideas work and a whole range of approaches will be tried, all at once, until a dominant one emerges. It might be a messy process but it will produce results (because it always has) and it certainly beats spending large sums of taxpayer's money on glossy reports telling us what we don't know.

One thing that it will require governments to do is to familiarize themselves with that new-fangled world wide web thing we hear so much about these days. Ottawa in particular is stuck in a cost recovery model of data provision that was implemented just as the internet made it redundant. Ironically, back in the pre-Web days governments at both the provincial and federal level made a lot more hard data available than they do now, in the form of typed reports with pages stapled together and lacking in any glossy photos, containing instead just the graphics needed to convey the facts which the data revealed. These data used to be stored at full repository university libraries around the country, available to anyone with the patience to go in and copy the numbers down by hand. Gradually, governments came to view the making available of such data as a commercial activity, and began restricting access and charging prices which were supposed to recover the full costs of their data collection and dissemination activities.

This is a pattern which has stayed in place, even though the development of the Web has greatly reduced the costs of making detailed data available to analysts. The original collection and processing of the data still has to be done by government, but the costs of disseminating it to people who just might be able to use it to answer policy questions has tumbled. Government will still have to bear the initial costs of designing data systems which will be research-friendly, but any good SAS programmer can do that for them. Given the data system, access for policy research purposes should be made as easy as possible. Ultimately, this approach will be an awful lot cheaper than anything that comes out of one of those advisory bodies because it'll build on data that's already in the system, but which is not being exploited to anything like the extent it might.

Let's be very clear on this. The major reason we know as little as we do about things like waiting times is that, instead of looking at the messy pile of information we have and asking how we could use it to answer the questions we need answered, we've been looking for a file labelled "perfect data on waiting times" and, not seeing it, have spent our time talking about how difficult it would be to build it.

It's time we got past that. Ottawa shows no signs of being particularly helpful at this point, and meetings of provincial premiers and health ministers seem constitutionally incapable of doing anything except coming up with new complaints about Ottawa. It's time that the individual provinces, especially the smaller ones whose resources are most severely strained, started taking a serious look at what they could do with what they've got.

We have the wherewithal to convert a whole lot of the known unknowns of health care into knowns. It's well past time that we did it. Who knows, in the process we might spot a few unknown unknowns and turn them into knowns, too.

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Endnotes

For background material to some bits of the HCC the report, see <u>Canadian</u> <u>Perceptions of the Health Care System</u>, prepared by Stuart Soroka for the Health Council of Canada, February 2007, on line at

 $http://www.healthcouncilcanada.ca/docs/rpts/2007/Public\%20Perceptions\%20-\%20English\%20Final_Feb-07.pdf$

² "Data inadequate to track progress, health council says": Gloria Galloway, Globe and Mail, Toronto, Friday, 2 Feb, 2007.

http://www.theglobeandmail.com/servlet/story/LAC.20070202.HEALTH02/TPStory/

³Stuart Soroka's mandate was to collect data from a whole range of surveys of public opinion about the state of health care in Canada, so this is not a criticism of his work. Among other things, he reports that one survey asked whether people think that organizations like the Health Council will improve the quality of health care in Canada. Fortunately for the Council, 63% of respondents answered "somewhat" or "significantly" to that one. Most of the surveys reported on in his piece were apparently taken before the Canadian population decided that the environment topped health as the main challenge facing government today.

¹Health Care Renewal in Canada: Measuring Up? Health Council of Canada Annual Report to Canadians, 2006, February, 2007, on line at: http://www.healthcouncilcanada.ca/docs/rpts/2007/HCC_MeasuringUp_2007ENG .pdf