
Health Care is a Knowledge Industry, and Should Be More So

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Introduction

WHEN WE THINK OF HEALTH CARE IN CANADA, we likely think of surgery, pills, and visiting the doctor. While the pills and surgical procedures are tangible and physical, a very large portion of activity in health care involves knowledge, not primarily goods and tangible services.² The knowledge processes start with the doctor asking about a patient's health history, symptoms and problems, then offering a diagnosis and proposing a course of action to

1 I would like to acknowledge the very helpful comments of John Wright, Jennifer Zelmer and the editors. I of course remain responsible for any errors or infelicities.

2 While the hoopla seems to have died down, economists have noted the transitions underway, usually associated with the revolution in information and communications technologies, from primarily a goods and tangible services economy to a "knowledge economy." Discussion of this transition was apparently first popularized by Peter Drucker in 1959 who emphasized the distinction between manual workers and knowledge workers. Health care is quintessentially a knowledge industry in this sense.

cure, or at least ameliorate, any problems. In the direct experiences of patients, a great deal of their interactions with health care providers is knowledge flows. As a society, we train and value health care professionals at least as much for their knowledge and information processing capabilities – observing, assessing, recalling, recognizing patterns, accessing accumulated knowledge, judging, and deciding – as for their tangible skills such as operating a diagnostic imaging device, inserting a breathing tube, and performing surgery.

Similarly, at the level of health care provider organizations, a great deal of activity involves the creation, collection, and application of knowledge – though as argued below, nowhere near enough. Of course, at the organization level, there are familiar tangible activities such as hospitals providing beds and clean laundry, housing and maintaining diagnostic imaging devices, and food preparation. But we also see sequences of physicians consulting patient charts, conferring with colleagues on the most appropriate diagnosis, ordering meds, and spending hours per week keeping up to date on the latest research results published in the academic literature. Even in hospital nursing, which would appear to be an entirely physical and social interaction with patients, up to two hours in every eight hour shift may be spent in writing and consulting (still most often paper) patient charts.

Furthermore, there is growing concern, given increasing specialization and division of labour, with the “continuity of care,” as patients’ trajectories of care, especially those with complex comorbidities, involve a sequence of health care encounters often with a diversity of providers. There should be major transfers of knowledge between and among these providers and with the patient when they move from a specialist visit, to hospital, to home, with GP (general practitioner) follow-up or home care, to nursing home. As the patient is “handed off” from one provider to the next, it is fundamental that each provider should have all the necessary and cumulative knowledge about the patient’s diagnoses, treatments received, and current functional status. Patients as well need to know about what is happening and the course of care as it is planned for them – indeed they should have a real say in their treatments.

However, Canada's health system continues its failure to accord sufficient priority and systematic thinking to these knowledge aspects, not only at the individual physician level, but even more importantly at various levels of organization, from hospital to health region to province. As a result, no one really knows how effective most activity in health care is, what the many components of health care service provision actually cost, and where the system can be modified both to reduce costs, improve quality of care, and ultimately improve population health. In case this last sentence slipped by the reader too smoothly, let me repeat: no one really knows how effective most activity in health care is.

While investments in more coherent information and knowledge creation systems have recently accelerated, Canada's health care (non)system remains decades behind best practice in other sectors, like banking and airlines, and other healthcare systems, such as the Veterans Administration in the United States. Your car dealer often knows more about the repair and maintenance history of your car than your doctor does about your medical history, and certainly more than the healthcare system more generally (e.g. hospitals, specialists, ERs) knows – as evidenced by the almost continual need for an attending physician to ask about your medical history.

In this chapter, we document a number of areas where these lacunae are especially troublesome. Drawing on the limited data available we first consider the implications of “post code medicine,” where your location has a strong but seemingly random and certainly unexplained impact on your health care, and then data on what is driving health care costs. We then turn to suggestions on how best to improve this situation and close with a vision for a proper health information system – indeed one which was articulated almost a decade ago.

Consider Geographic Variations and Heart Attacks

One of the scariest events in one's own life or that of a loved one is to have a heart attack (acute myocardial infarction, or AMI). Provincial health care systems across Canada devote significant resources to the treatment of AMIs. The practice of cardiology is one of the highest profile activities in health care, and open heart surgery has, for years, been broadly considered one of the mir-

acles of modern medicine. The *Economic Burden of Disease in Canada* (PHAC, 2002) indicates that cardiovascular disease (of which AMI is a major part) had direct costs amounting to 8.1 per cent of total health care costs in Canada, and 15.1 per cent of total hospital costs in 1998.³ So an obvious question is whether Canadians are getting value for the money spent on these treatments – in other words, are the expenditures and use of highly skilled resources devoted to treating AMI patients producing improvements in their health that are at least commensurate?⁴

The short answer is that nobody knows. But there is considerable evidence, one key element of which is discussed below, that there are major inefficiencies in this area of health care. This evidence is limited precisely because the required kinds of information are not being routinely collected, nor even being collected on a sample basis, so the requisite knowledge cannot even be generated.

In the current fiscal climate, inefficiency in the provision in health care services means scarce resources are being spent on activities with at most marginal health benefits, and at worst harmful effects – in Ivan Illich’s term, iatrogenic (Illich, 1976; see also Baker *et al.*, 2004). Hence the resources could be devoted to other activities that produce higher benefits – either within health care, in which case inefficiency is equivalent to a failure to improve Canadians’ health as much as possible, or in other sectors, like education and housing, whose budgets are being squeezed by the disproportionate growth in health care spending.

The evidence we do have, and one of the most powerful indicators that something might be amiss in the way health care is managed, is variations in health care provision across small geographic areas. The main reason for the widespread attention to these kinds of indicators, which are intrinsically rather

3 The fact that, in 2011, the most recent data of this sort is for 1998 is itself an indication of the deplorable priority attached to the production of important kinds of health information.

4 There is extensive discussion in the cost-effectiveness literature of what it means for expenditure to be “commensurate” with the associated health gain. For our purposes here, “commensurate” can be taken to mean that the dollar costs per QALY (quality-adjusted life year) gained is not excessive. See Laupacis *et al.* (1992); Gold *et al.* (1996).

weak for this purpose, is that they are relatively easy to construct with routinely collected data – indeed using data that are primarily collected for other purposes (e.g. monitoring hospital budgets, paying physicians). But they have been essentially the only data available for this purpose.

It has been widely observed in many jurisdictions that the fraction of the population being treated can vary substantially from one small geographic area to another. But if the rates of illness, for example AMIs, are roughly the same across these same small regions, then “medical necessity” cannot explain wide variations in treatment rates. Some other factors, possibly ones that indicate *inappropriate* provision of health care, might be the cause. This possibility led, decades ago, to major efforts in the development of “appropriateness guidelines.” However, development of such guidelines has been slow – in part because of the difficulties in assembling the required information, and their adoption has also been slow, in part as doctors have resisted the idea of “cook-book medicine” being forced upon them.

Of course, the situation is more complex than this. In the case of AMI, it is well known that smoking, obesity, physical inactivity, hypertension, cholesterol, age, and diabetes among others are major risk factors for AMI, and the prevalence of these risk factors also varies across small geographic areas (CCORT, 2006, p.35). The CCORT (Canadian Cardiovascular Outcomes Research Team) researchers concluded:

There is a moderate to high degree of variation in hospitalization rates (for AMI) across the regions of Canada... Variations in hospitalization rates for these four cardiovascular diagnoses (AMI, CHF = congestive heart failure, angina, chest pain) could in part be a result of differences in coding practices for these conditions, although we believe that is unlikely to be the major explanation. A more plausible suggestion is that regional differences in hospitalization rates are related to factors such as physician supply and practice styles, access to ambulatory care, community and institutional resources, the prevalence of effective primary and secondary prevention programs, and the socioeconomic status of various health regions. (CCORT, 2006, p. 55)

Some of the potential explanations for these variations in hospitalization rates as just enumerated by the CCORT atlas point toward issues of primary prevention. For example, why are smoking rates higher in one region than another. But other explanations such as “physician supply and practice styles” point to questions of where doctors choose to practice, and the ways medical school enrolments and hospitals are managed. The fact that one of the best research groups in Canada, with some of the best data available, is unable to determine which of these major and very different potential explanations is dominant is troubling, especially now - after decades of evidence of such small area variations, the attendant push to develop appropriateness guidelines, and efforts to apply “evidence-based decision-making” across the spectrum of health care activities.

Unexplained small area variations in health care indicate possible inefficiencies and/or significant pockets of sub-optimal care. In a phrase, we see some smoke, but we are not sure where the fire is, nor how large it is.

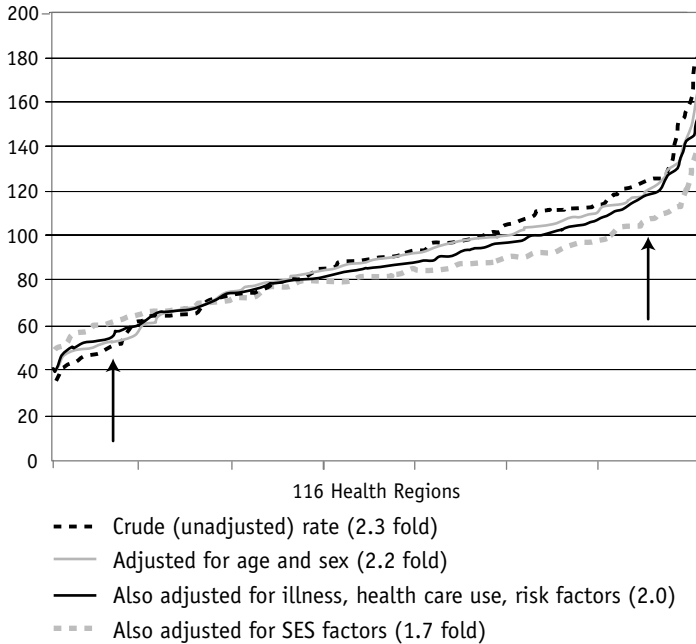
As an overall indication of the magnitude of these small area variations, Chart 1 shows the rates of hospitalization across Canada’s larger health regions.⁵ The crude hospitalization rates (the steepest line) vary dramatically from a low of less than 40 visits per thousand population to over 180 – more than a four-fold difference. With hospital costs at about 4 per cent of GDP, the resource implications of understanding these variations should be evident.

To be conservative, and to ensure the results are robust, the arrows in this chart point to the 10th and the 90th percentiles of the health regions ranked by their rates of hospitalization. The 90th percentile region had a crude rate (steepest line) of 2.3 times as many hospitalizations as the 10th percentile.

Of course, experienced health services analysts will immediately point out that some of the high rate regions likely had an older or more female population, where both of these factors could account for a higher hospitalization rate. So the results adjusted for age and sex are shown by the next steepest line. The 90 -10 ratio of these age/sex-adjusted hospitalization rates drops marginally to 2.2.

5 At the time of the analysis, there were just over 130 health regions in Canada.

Chart 1
Hospitalizations per 1,000 Population Across
116 Canadian Health Regions



Still, some of these regions might have more individuals suffering from chronic disease, or they might have more smokers and obese individuals. Indeed, one might conjecture that some of these regions have physicians who are more inclined to admit their patients to hospitals. Unfortunately, the routinely collected data have none of these obviously important covariates. The “culture” of medicine, at least as still incorporated (encrusted?) in contemporary health information systems, is dominated by a narrow bio-medical perspective, notwithstanding research and analysis going back at least to the Lalonde Report (1974) that “there is more to health than health care.”

Fortunately, Statistics Canada’s Canadian Community Health Survey (CCHS) does have these data, and the overwhelming majority of survey respondents consented to having their data linked to their health care records. This has been done in the case of hospital visits. The result of linking the CCHS data at the individual record level to the hospitalization (discharge

abstract) data described so far, and then adjusting for the mixture of factors just mentioned – including chronic disease prevalence, and risk factors including smoking and obesity, is shown by the next steepest line. These statistical adjustments reduce the 90th to 10th percentile regional hospitalization ratio a bit more, down to 2.0.

Finally, there are further, albeit more distal, socio-economic health determinants which might also account for some of these large differences in hospitalization rates across health regions in Canada. To account for this, the least steep line incorporates further statistical adjustments for these socioeconomic status (SES) factors – including income, education, race, and immigration status. The 90 – 10 hospitalization ratio now declines further from 2.0 to 1.7.

Interestingly, this last adjustment has about the same impact as the first two sets of adjustments combined – age and sex, and illness, risk factors and other health care use. Compared to the early 1990s when the idea of the social determinants of health having a major role in understanding why some people are healthy and others not⁶ was still a contested academic curiosum, it is now widely accepted. The results in this graph clearly reinforce this substantive point. But after almost two decades of discussion and effort, it still has not penetrated to the structure of Canada's health information to any substantial degree. Chart 1 required major, special efforts, and these kinds of data are not routinely produced.

Moreover, these statistical adjustments do not make the wide variations in hospitalization rates go away. Indeed, we may have over-adjusted. So there must be an important range of other factors – presently unknown – driving such large variations in utilization of one of the most expensive parts of Canada's health care sector. Similar analysis in the United States using their national Medicare data clearly indicated that the observed 3:1 small area variations indicated major inefficiencies, and these results have been central to their recent health care reforms (Fisher *et al.*, 2003; Gawande, 2009; Gawande *et al.*, 2009).

6 This is the title of the award-winning book (Evans, Barer and Marmor, 1994) which was a milestone in broadening the appreciation of the importance of social determinants of health.

A recent analysis at Statistics Canada has been able to push the CCORT (2006) and McGrail *et al.* (2011) type small area analyses considerably further, albeit with major effort, and not for all provinces (Johansen *et al.*, 2009). It is one thing, as in the CCORT atlas, to show the small area variations in risk factors on one map, the rates of AMI on another, and AMI mortality on yet another. However, there are many factors interacting in a more complicated way, so that ideally a much more sophisticated analysis is required. In particular, the analysis ideally occurs at the level of individual patients rather than small geographic areas, and the data should be longitudinal, so the patient can be tracked from risk factors to AMI to hospitalization and treatment to subsequent health status and longevity.

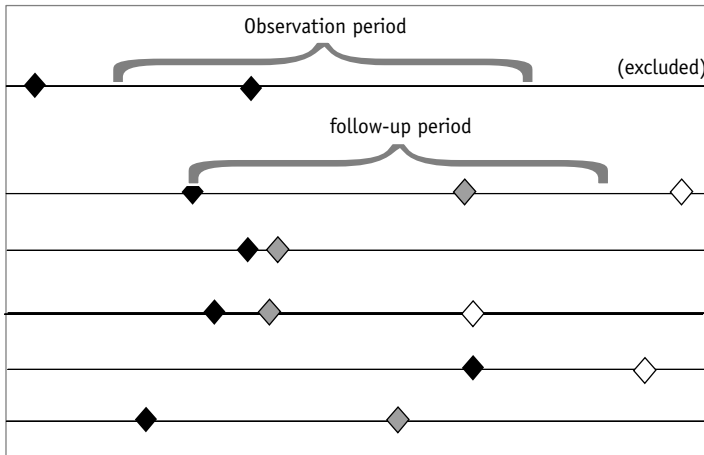
In other words, the ideal information base to disentangle the complex factors that could account for otherwise unexplained small area variations in health care would be a large set of actual patient trajectories covering not only their treatments but also their health status both before and after the treatment. Again, ideally, the health care sector should only be providing treatments where health status after the treatment is most likely to be better than before – though of course the analysis is more complex than this with chronic diseases where health care is needed over an extended period of time.

Unfortunately, the data just described do not exist. But a partial data set of this sort has been assembled (again with considerable effort) and used to examine, at the level of individual patients, the relationships among the major kind of treatment for AMIs, namely revascularization (coronary artery bypass graft (CABG) and percutaneous trans-luminal coronary angiography (PTCA)), and mortality. Specifically, only hospitalization data have been used, but for each in-patient who was diagnosed on admission with an AMI, their hospitalizations have been linked longitudinally.

Chart 2 provides a quick sketch of how the results are put together. Each horizontal line represents a highly stylized view of one patient's trajectory of hospitalizations, showing three kinds of events – black for an AMI, grey for a revascularization, and white for death.

In order to focus on the subset of individuals for whom the hospital admission was a first AMI, the linked data were examined for 12 months prior to the index AMI to see if they had been previously admitted with another earlier

Chart 2
Hypothetical Event History Data for AMI and Revascularization



- ◆ Heart attack (AMI) ◇ Death
- ◆ Treatment (revascularization = bypass or angioplasty)

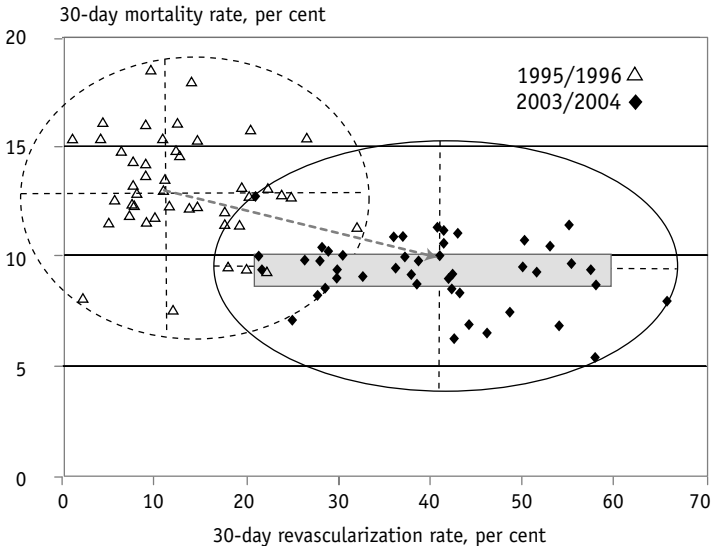
AMI. The top line in Chart 2 illustrates the trajectory of an individual who was rejected from the analysis for just this reason.⁷ The second line represents an individual who was revascularized, and survived for the length of the follow-up period, but not much longer. The other lines give examples of other patterns.

With these kinds of longitudinally-linked patient-level trajectories of hospitalizations, it is possible to begin examining small area treatment variations in Canada in a far more sophisticated manner. What the Johansen *et al.* (2009) analysis did was first assemble all of the patient trajectories into groups by sub-provincial health region, and then extract two basic statistics. The first was the proportion of all the health regions’ incoming AMI patients who were treated by revascularization. The second statistic was the proportion who died in hos-

7 Of course, one year as a “wash out” period to ensure that the index AMI was indeed a first AMI is too short in reality. But the ability to assemble linked hospitalization data in this way remains severely constrained, and this was the best that was feasible.

Chart 3

30-day revascularization and 30-day mortality rates of acute myocardial infarction patients, health regions with at least 100,000 population, seven provinces, 1995/1996 and 2003/2004



Nova Scotia, New Brunswick, Quebec, Ontario, Manitoba, Saskatchewan, Alberta.

Note: Lines cross at median values of mortality and revascularization within each year.

Source: 1995/1996 and 2003/2004 Health Person-Oriented Information Database, Statistics Canada.

pital within 30 days of the AMI, including cases who were discharged and then re-admitted.

Chart 3 “simply” shows a scatter plot of the results. Each dot in this graph represents one large health region. (Only health regions with populations over 100,000 were included to ensure sufficient numbers for statistical analysis). Each region’s revascularization rate for AMI cases is plotted along the horizontal axis, and its 30 day mortality rate along the vertical axis. (Note that the vertical axis scale is over twice as large as horizontal axis scale, to make variations in mortality rates clearer visually.) The hollow triangles show the situation in 1995/6, while the black diamonds are 8 years later.

Overall, during this eight year period, there has been a dramatic increase in treatment rates – more than a tripling from an average of 12.8 per cent in

1995/96 to 39.8 per cent in 2003/4, an increase of 27 percentage points. The reasons for this dramatic growth are not entirely clear, but are likely due in part to pressure from cardiologists who argued that increased budgets for the less invasive PTCA would substitute for open heart surgery (CABGs) and thereby reduce costs (which did not happen). There was also evidence of efficacy of PTCA from clinical trials, though ignoring powerful evidence of over-use of this procedure in the United States.⁸ And there was broad public support for increased capacity for this “miracle of modern medicine.” We might therefore expect a similarly dramatic improvement in outcomes. And we do see *some* improvement in survival. But compared to the increase in treatments, the reduction in mortality is more modest, about a 3.6 percentage point drop – from 13.2 to 9.4 per cent.

Even more importantly, the scatter of dots shows a very wide variation among health regions. In 2003/4, a number of health regions had 30 day mortality rates in the 8-10 per cent range, yet treatment rates varied about *three-fold*, from around 20 per cent to about 60 per cent (highlighted by the shaded rectangle).

If these health regions were manufacturing firms, and their input costs varied by a factor of three for what appears to be the same quality of output, almost all would be bankrupt and out of business in short order.

At least as importantly, the impression given by the scatter of points in Chart 3 is that health care practice – i.e. the treatment decisions of cardiologists, and/or the guidance offered by hospital or health region managers – is all over the place. If revascularization were really an effective treatment, as practiced across most of Canada, then within each oval, the points would cluster tightly around a line sloping down and to the right. Instead, there is no obvious trend within each oval for higher treatment rates to be associated with lower mortality rates. To put it starkly (and notwithstanding various clinical trials arguing for the efficacy of rapid revascularization for AMI cases), why should one health region do three times as many cardiac procedures than another if there is no observable difference in mortality outcomes?

8 See Boden *et al.* (2007) for evidence that the United States had been conducting 800,000 unnecessary PTCAs per year.

Of course, there are some important caveats, and herein lie many challenges. No account has been taken of other clinical factors – for example the extent and speed of thrombolysis (clot-busting drugs), or variations in the prevalence of conventional AMI risk factors like hypertension, obesity and smoking status. Nor has any account been taken of the broader determinants of health – the possibility that the higher AMI mortality rate regions are poorer, and thus subject to higher mortality rates more generally.

Also, the intended benefits of revascularization are much more than a reduction in 30 day mortality. Revascularization after AMI is intended not only to prevent immediate death, but also to improve longer term survival and quality of life, especially reduction of anginal pain. It has been possible for a smaller sub-set of provinces to link the hospitalization records to death certificates, so that for AMI cases in these provinces, a one year rather than only a 30-day mortality follow-up was also examined, as were adjustments for co-morbidity. For this smaller group of provinces, the results were essentially the same.

But the fundamental issue remains that the data are just not generally available – even something as elementary as being able to link death certificates, with cause of death information, to hospitalization records. It should be obvious that one of the most straightforward indicators of health care performance is whether or not the patient was alive 6 or 12 months after a surgical procedure. But Canadian health care is substantially driven by specialists who treat body parts rather than whole people, and by organizations which typically lose track of their clients once they go out the door (both vertical and horizontal). While there are obvious benefits from such specialization, there are also disadvantages. In particular, a “whole patient” or whole person view is lost. The health care non-system is blind to patients’ care trajectories – it pays no attention to the sequence of health care encounters, how they interact, and their cumulative impact on the health of Canadians. There is no choice: these data are not routinely available to health care providers.⁹

9 Of course, there are important exceptions. For example, some local cancer care systems do track their patients through a range of different cancer treatment and related encounters. And your personal physician has a record of his or her encounters with you. But they do not generally have records of all your hospitalizations, your visits to other doctors, nor all your prescriptions.

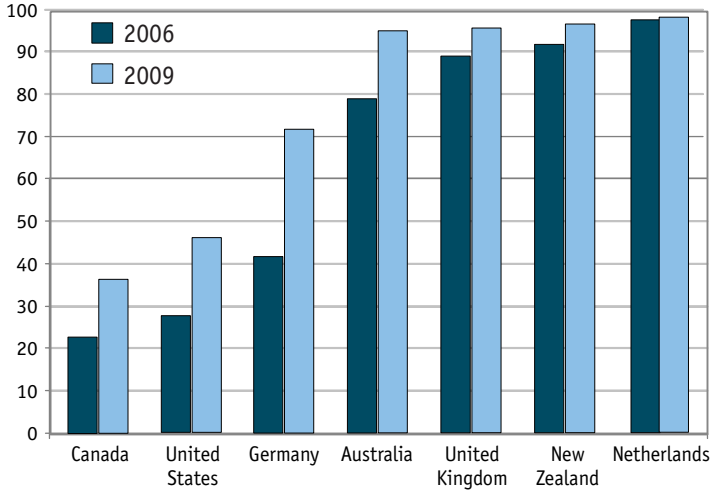
Figure 1
The “Wall of Ignorance”



Ideally, health care is managed with the basic principle of allocating resources to those activities which are most cost-effective, those which give the largest improvements in population health per dollar. Unfortunately, in this \$200 billion sector of Canada’s economy (CIHI, 2010), the information needed to tell whether or not this is happening is absent. The photo in Figure 1 was taken a few years ago in a neighbouring GP’s office. While this “paper” method of storing patient data is adequate (in some ways only barely) for one-on-one patient care, it is a “wall of ignorance”¹⁰ from the perspective of any kind of basic, let alone sophisticated, patient care (e.g. following up on screening tests, including charts from hospitalizations, complete listings of drugs especially prescriptions from other doctors) and for health system manage-

10 I am indebted to Dennis Psutka, former ADM in the Ontario Ministry of Health, for this phrase.

Chart 4
Physicians Using Electronic Medical Records
(per cent)



ment more generally. Chart 4¹¹ shows how far behind Canada is compared to other advanced economies with regard to electronic medical records (EMR).

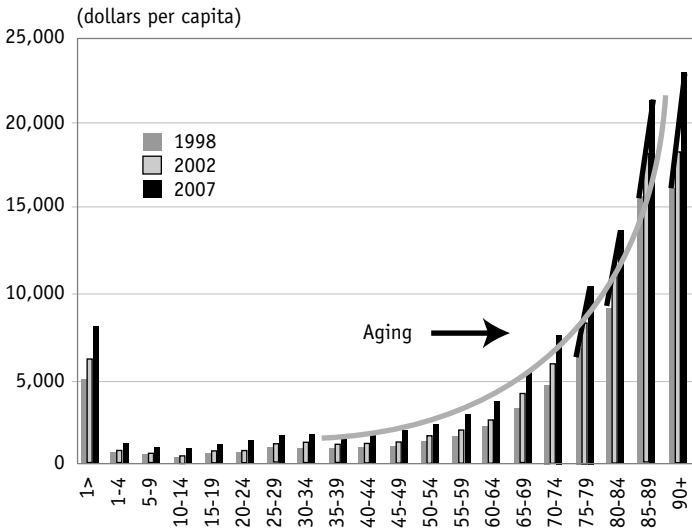
In sum, with Chart 3 we see a very large amount of noxious smoke, but we still have no idea where the fire is. And the state of Canada's health information shown in Figure 1 and Chart 4 indicates the seriousness of our lack of the information base needed to understand the location of the fire.

Why Do Health Care Costs Increase

Health care has been almost continually at or near the top of the agenda in public opinion polling for decades. This is evidenced most recently by the election platforms of all major federal political parties in the 2011 federal election, where as soon as the question was mentioned, they all almost immediately undertook to continue increasing federal fiscal transfers to the provinces at an annual rate of 6 per cent after the Canada Health Transfer expires in 2014

11 This chart was taken from Rozenblum *et al.* (2011); the original Commonwealth Fund results can be accessed at <http://www.commonwealthfund.org/Topics/International-Health-Policy.aspx>.

Chart 5
Provincial-Territorial Government Health Expenditures by Age Group



(though the duration of this commitment remains unclear). The basic reason, not unreasonably, is that Canadians treasure our universal health care system, and want strongly to protect it and free access to medically necessary care. Correspondingly, politicians of all stripes want to avoid being seen as limiting access by reigning in health care costs.

At the same time, governments are increasingly concerned about the so-called “gray tsunami” – the specter of even more rapidly rising health care costs as aging baby boomers move into the age ranges where their health care costs begin escalating dramatically. This specter was recently amply illustrated in the federal Parliamentary Budget Office’s (PBO) 2010 Fiscal Sustainability Report (Askari *et al.*, 2010). Chart 5 is taken directly from their report.

Interestingly, this graph from the PBO shows not only provincial and territorial health care expenditures by 5 year age group (produced originally by CIHI), but also changes over the period from 1998 to 2007. The public discussion, as well as the commentary in the PBO report itself, focuses on the trend highlighted by the added curved line. In the light of the aging baby boomers, this pattern of increasing health care costs with age is indeed very scary. But the PBO

report spent virtually no time discussing the much more steeply sloping added straight lines.¹² These lines show the growth in per capita health care costs *within* each of the 5 year age groups over the 1998 to 2007 period.¹³

It is important to emphasize that the increases highlighted by the short straight added lines are over only a 9 year period, not the decades involved in the very slow tsunami of population aging.¹⁴ This is about the same time interval as that covered in Chart 3 above, which showed a dramatic increase in the rate of revascularization after AMI (a tripling). But in that case, the data suggested that a high proportion of the additional expenditures devoted to treating heart attacks might not be of any value in terms of improving the population's health. Could this be a much more general phenomenon? Could it be that the broader per capita cost increases shown by the PBO/CIHI graph, while providing more revenue to hospitals and more income to doctors and nurses, may have had much more limited benefits in terms of health outcomes?¹⁵ The sad fact is that there is absolutely no way to tell whether these dramatic increases in health care spending are actually buying better health outcomes. There is no broad-based concerted effort across Canada to push the health care sector to "work smarter" rather than to "work harder."

What Should Be Done?

The results on the treatment of AMIs shown in Chart 3 are stark evidence of a health care *non*-system at work. These data were very hard to assemble in the

12 PBO in their projections referred to these age-specific expenditure trends as the "enrichment factor," and took them as given, without investing any effort to discuss or understand them.

13 In John Richards' chapter of this volume (Richards, 2011), he shows a similar graph. Unfortunately, he fails to probe the fact as just noted that most of the recent cost increases have virtually nothing to do with population aging.

14 Examination of the original CIHI data that were the source of the PBO graph indicates that the PBO failed to deflate the cost numbers. After deflation, the per capita cost increases from 1998 to 2008 (the most recent year available now) within each 5 year age group are not as large, but they are still substantial.

15 One hypothesis could be related to the fact that most health care spending occurs in the last months of life. In turn, with increasing life expectancy, more people will spend their last year of life in a higher age group. However, the rate of increase in life expectancy has been on the order of one year every five. This rate is too slow to account for the pattern shown in the chart.

first place; and they are seriously incomplete. As things stand, there is limited prospects that, in coming years, Canada's health information and knowledge generation systems will improve sufficiently so that the sources of these dramatic variations can be understood. Nor is there reason for optimism that the evidentiary base to understand the trends highlighted by the short steep lines in Chart 5 will improve significantly.

Notwithstanding the continuing escalation of health care costs, there is no concerted effort amongst the managers of health care in Canada, up to and including Ministers and Deputy Ministers of Health, or their colleagues in Ministries of Finance, to try to understand the extent to which these results indicate major system inefficiency.¹⁶ There are similar lacunae in the efforts being devoted to understanding which interventions are most likely to be cost-effective in improving the health of Canadians.¹⁷

Canada's health care industry, in this regard, stands in stark contrast to other sectors of the economy. Leading firms in forestry, mining and automobile manufacturing, for example, know their "cost functions" – they know their total spending on labour, materials, energy and other inputs. They also have an engineering level of detailed understanding of the prices and quantities required of their many inputs, and their benefits when used in various combinations – their techniques of production in economic jargon. This knowledge is, of course, not free; substantial investments are required, for example, to know the incremental costs of different kinds of mineral extraction, and further and equally importantly, their potential contributions to bottom line profitability. In many cases, this knowledge is purchased from specialized consulting engineering firms, the very existence of which emphasizes the importance of this kind of knowledge in these other sectors.

16 Of course, all senior managers of Canada's health care sector would like such information. The key point here is that efforts to do so, on the scale needed, are not apparent.

17 There are some notable exceptions, for example a number of hospitals have associated research institutes, such as the Ottawa Hospital Research Institute (OHRI), devoted both to generating new evidence and bringing existing evidence such as that assembled by the Cochrane Collaboration (<http://www.cochrane.org/>) to bear on health care practice of the Ottawa Hospital with which it is associated.

At the same time, successful firms in these other sectors devote major efforts to understanding the needs and wants of their customers, and to quality control. Of course, there are major differences between the market for cars and for health care. With regard to needs and wants, consumers generally have much better knowledge of what they are buying in the case of a car than health care. But compared to the knowledge asymmetry between car sales staff and prospective car purchasers, health care providers typically have far more knowledge – though this disparity is being reduced by the widespread availability of health information on the internet, at least for those with the propensity and ability to understand it. At the same time, though, the provider has an incentive to find more “need” for his or her services. This differential knowledge asymmetry, far larger in health care than for most other goods and services, is one of the principal arguments for publicly provided health care. But this in no way obviates the needs for governments, acting on behalf of their citizens when providing them health care services, to engage in extensive and sophisticated assessments of their needs.

There is a corresponding analogy with regard to quality control. Producers in other sectors like manufacturing have understood its importance for decades, indeed since World War II and the seminal work of Deming (1950, also Shewhart and Deming, 1939), leading to the growth of statistical process quality control methodologies. Better producers regularly sample their products, subject them to quality testing, and have clear methods for tracking which steps in the production process are the sources of any observed defects. But even though the importance of these ideas has been understood for decades, and there are well established university programs in operations research and statistics that train individuals to do these kinds of quality control, these ideas are only recently beginning to be taken up in the health care sector, for example with the creation of a number of health quality councils.¹⁸ Still, even these organizations

18 For example see the health quality councils in Saskatchewan (<http://www.hqc.sk.ca>), Ontario (http://www.ohqc.ca/en/strategic_plan.php), Alberta (<http://www.hqca.ca/>), Quebec (<http://www.csbe.gouv.qc.ca/index.php?id=63&L=2>), New Brunswick (<http://www.nbhc.ca/index.cfm>) and British Columbia (<http://www.bcpsqc.ca/>), the Canadian Patient Safety Institute (<http://www.patientsafetyinstitute.ca/English/Pages/default.aspx>) and the Health Council of Canada (<http://www.healthcouncilcanada.ca/splash.htm>).

are having difficulty due to the paucity of appropriate information, as indicated by the following statement on the Saskatchewan Health Quality Council's web site (home page):

While there are a lot of data available on discrete encounters with the health system, there is currently no way to answer the following questions: How does a person with a health problem travel through the health care system? Which services do they access and in what order? What is the relationship between patient characteristics (age, sex, etc.), the services they are using, and health outcomes? Answering these questions will allow the health system to better understand how episodes of care are related, track changes in the use health services over time, and more accurately determine the cost of treating a condition.

These comparisons between health care and leading firms in the private sector are in no way a suggestion that more aspects of health care should be privatized. There are fundamental reasons why it should remain publicly provided, including the information asymmetry problem just noted, the fundamental importance of equal access to health care services in terms of social equity, and (certainly compared to the major counter-example, the United States) the better capacity to control costs. Rather, the point of these comparisons is to emphasize that methodologies for aligning what services are produced with what is needed in the most cost effective manner, and for rigorous quality control, are well developed and widely deployed in other parts of the economy. The outstanding question is why the health care sector has been so immune to learning from these other experiences.

There are several explanations. One is like the proverbial frog in the pot of water. If the temperature is increased gradually, the animal dies before it tries to jump out of the pot. In the case of health care, costs have been increasing for decades (albeit with a significant and controversial downward movement in the mid-1990s), but only gradually. As a result, policy attention has focused more on "muddling through" than on more fundamental responses.

Another explanation is more sociological. Individuals who self-select into health care occupations tend to be preoccupied with one-on-one caring interactions, and not with broader structural issues. They also tend to be less quan-

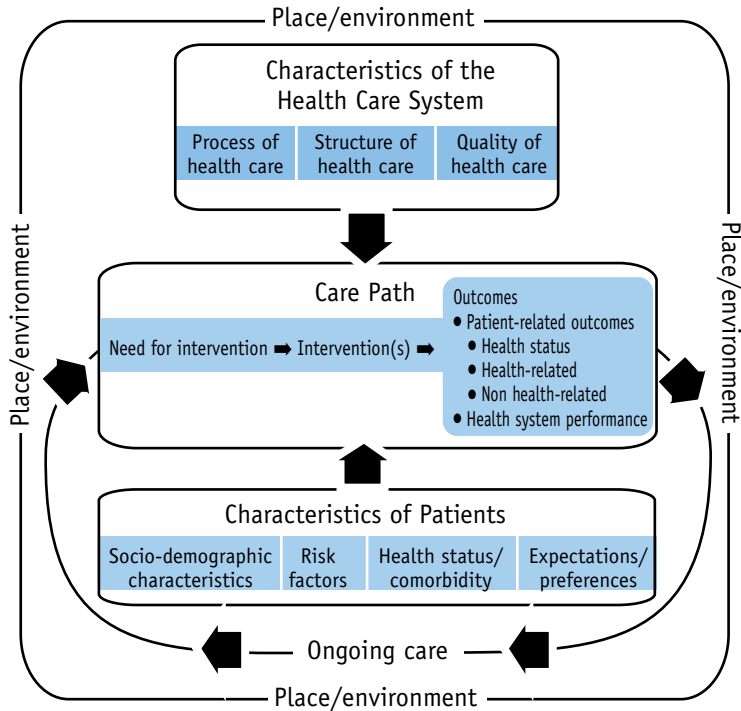
tatively inclined. Doctors, in particular, are motivated to save lives, and often with a “damn the costs” attitude. These kinds of orientations are also evident in hospitals, ministries of health, and other health care organizations which naturally recruit many of their managers from these pools.

Yet another explanation is the powerful positions held by doctors throughout the health care sector. They are used to being authority figures. They have been through a grueling training process in medical school where they have had to master huge volumes of knowledge. Practicing doctors have passed these tests, and many do not like to be told what to do. Modern health information systems, however, do have the capacity to monitor physician performance in unprecedented ways. These systems can pop up reminders or alerts that something a physician is about to do or prescribe is wrong. They can also give them statistics about their practice patterns comparing them (perhaps unfavourably) to their peers when they have little training or interest in quantitative analysis. There are, as a result, very understandable reasons why the medical profession is resistant to the kinds of “modern management” that have become standard in other sectors of the economy.¹⁹

Yet the absence of modern management of health care is the most fundamental problem. At a technical level, what needs to be done is well-known. The key ingredients in general are the collection of the right kinds of data, analysis of these data, and feedback to managers at all levels of the health care enterprise, as well as clinicians and patients. In short, not only is a major part of health care at the patient level itself a knowledge process – collecting the patient’s history, accessing prior accumulated knowledge, forming a diagnosis and deciding on a course of action – but addressing the most fundamental problems in the broader health care enterprise also requires well-designed and

19 We are tempted to use the term “scientific management” with its implications of managing with a view toward economic efficiency and the application of analysis, synthesis, logic, rationality, empiricism, efficiency and elimination of waste, standardization of best practices, disdain for tradition preserved merely for its own sake or merely to protect the social status of particular workers with particular skill sets. However, “scientific management” is also associated with Taylorism, which has unfortunate connotations of deskilling workers and dehumanising workers and the workplace. (Both preceding sentences borrow from the Wikipedia definition.) To avoid these latter connotations, we use the phrase “modern management.”

Figure 2
An Analytical Framework of the Policy and Non-policy Influences on Healthcare System Outcomes



substantial information systems and knowledge generation and diffusion processes.

The main elements of the latter kind of information framework are shown in Figure 2 (Statistics Canada and CIHI, 2008). As noted in this Statistics Canada/CIHI study on health outcomes, it builds first on Donabedian's (1966, 1988) *structure – process – outcome* framework wherein the quality of health care is assessed in terms of health improvements that can be attributed to episodes of care. It also builds on Wagner's (1998) discussion of best approaches to chronic disease management, as well as the conceptualization of population health to include a much broader range of determinants than simply the biomedical (Evans *et al.*, 1994)

The core of this diagram is the care path, the central portion where individuals have a health problem, are treated with some kind of intervention, and this intervention in turn affects their health status as well as other aspects of their lives. These include other health-related results such as biomarkers, which are not really health outcomes in any sense meaningful to patients, and non-health outcomes such as satisfaction with the way the health care was delivered, and impacts on their work lives. As well, outcomes can be assessed at an overall health system level, for example by indicators such as infant mortality rates.

In turn, the most critical requirement is routine and repeated measures of patients' health status. There is no way to tell whether or not an intervention had a beneficial impact without knowing whether the individual's health status after the intervention was better than before. This notion is so elementary that it seems trivially obvious. Indeed, it was emphasized over a century ago by A.E. Codman with his "end results" cards (Berwick, 1989). Unfortunately, however, there is no locus for developing this kind of measurement, let alone broadening consensus on its need, anywhere in Canada.

In contrast, the United Kingdom's National Institute for Health and Clinical Excellence (NICE, 2008) has mandated this approach in its guidance on technology appraisal, which is fundamental to its work. The "fundamental principles" of NICE include,

The Institute takes into account the clinical and cost effectiveness of a technology, along with other specified considerations, when issuing guidance to the NHS (National Health Service). (para 1.4.1)

In general, technologies can be considered clinically effective if, in normal clinical practice, they confer an overall health benefit, taking account of any harmful effects, when compared with relevant alternative treatments. Technologies can be considered to be cost effective if their health benefits are greater than the opportunity costs measured in terms of the health benefits associated with programmes that may be displaced to fund the new technology. In other words, the general consequences for the wider group of patients in the NHS are considered alongside the effects for those patients

who may directly benefit from the technology of interest.
(paras 1.4.2)

NICE includes in “health technologies” pharmaceuticals, medical devices, diagnostic techniques, surgical procedures, other therapeutic technologies, and health promotion activities (para 1.2.1). The appraisals undertaken by NICE are significant because “The Secretary of State for Health has directed that the NHS provides funding and resources for technologies that have been recommended through the NICE technology appraisals programme...” (para 1.5.1).

Further, in their section on “Measuring and valuing health effects,” the NICE document states, “For cost-effectiveness analysis, the value of health effects should be expressed in terms of QALYs (quality adjusted life years) for the appropriate time horizon. For the reference case, the measurement of changes in HRQL (health-related quality of life) should be reported directly from patients and the value of changes in patients’ HRQL (that is, utilities) should be based on public preferences using a choice-based method.” (para 5.4.1).

In the United States there have been important reports from the Institute of Medicine (Gold *et al.*, 1996) advocating the kind of approach adopted by NICE in the United Kingdom. The recent Obama health care reform package includes billions of dollars for health care cost-effectiveness evaluations, following in part on the kind of evidence like that in Chart 3 above produced by the Dartmouth group (Fisher *et al.* 2003; Gawande, 2009; Gawande *et al.*, 2009).

The Health Council of Canada (2009) has raised similar concerns in their report, “Value for Money: Making Canadian Health Care Stronger” where they ask:

Are we using our resources well to produce services? And more importantly, are we using services well to foster a healthy population? We need better information to answer these questions. Assessing value for money requires knowing what care is effective, for whom, and under what circumstances; and finding out whether that care actually has the desired effects. (p. 9)

Canadian researchers (e.g. Torrance, 1976; Torrance and Feeney, 1989) have been world leaders in the development of the kinds of QALY measures cited by the NICE document, and Statistics Canada has been a leader in including such measures in its health surveys. The Statistics Canada-CIHI study, from which Figure 2 has been drawn, goes on to push available data as far as possible to begin to answer these kinds of questions in the case of depression and diabetes treatments, though with limited success. But aside from these few examples, there has been little or no interest in such approaches more generally in Canada's health care sector.

Of course, adequate data on health status using some kind of QALY measure, while essential, are not the whole of the story. As indicated in Figure 2, there are many other factors affecting health status and the way it changes over time. For example, the results in Chart 3 above on AMI treatments and outcomes, at least to the very limited extent measured in terms of 30 day mortality, could be due to small area variations in smoking or obesity rates (i.e. "patient characteristics" in the bottom portion of Figure 2). If these complementary data were also available, it would be possible to adjust statistically for their contributions to observed patterns of change in health status as done in Chart 1, and thereby at least approximate the contribution that can be attributed to the health care intervention. But again, such data are not available, and the prospects for their creation remain dim.

Where is the Problem?

If important approaches to containing the growth in Canada's health care costs and improving the health of the population are so obvious, why is almost nothing being done? Or, if things are being done, why is progress so painfully slow? Some of the reasons have already been outlined – the fact that cost pressures have been growing only gradually, so it is typically easier to try to "muddle through" than take more dramatic action. There is also a bias against quantitative analysis and rigorous evaluation in many parts of the health care sector, and the self-interests (both pecuniary and in terms of autonomy) of many providers.

Another is a sort of chicken and egg question. It is very difficult to rally public opinion, and hence political will, to make difficult choices if there is no

apparent pressing issue. Canadians are generally willing to pay higher taxes in order to be assured that high quality health care will be accessible when they need it. As a result, gradual increases in health care costs will generally be accepted. The information and knowledge to show major inefficiencies in health care generally does not exist. And without the evidence of problems, the investments in improving health information and related analyses never achieve a very high priority. Hopefully, results like those in Chart 3 above will diffuse and strengthen the case that there really are potentially serious problems.

Another major factor is the concern for protecting personal privacy. There is no question that the kinds of data and data linkages needed for rigorous and systematic health outcome analysis are very sensitive. But at the same time, Canada and the provinces are suffering under a “privacy chill.” Concerns about privacy protection on the part of many data custodians are excessive. In part, this is due to a basic asymmetry. A data custodian in a provincial health ministry has far more to lose if allowing access to patient record data results in some sort of privacy breach. If, on the other hand, the data are made accessible only to *bona fide* analysts – either in a secure university setting or under the stringent auspices of some other agency like Statistics Canada or a provincial health quality council – and important benefits are then derived from analysis of those data, the data custodian receives virtually no benefit to his or her career. There is clearly a trade-off here between the competing goods of protecting privacy and advancing knowledge of “what works” in the health care sector. While there is not extensive evidence, there are indications that the general public would prefer more use of their personal data if it would improve the quality and cost-effectiveness of their health care.²⁰

Electronic health and medical records (EHRs and EMRs) are of potentially major benefit for Canada’s health information and knowledge. The federal government has provided over \$1.5 billion to Health Infoway to work with

20 As a related example, when Statistics Canada held focus groups to explore whether parents would be willing to allow the Canadian Health Measures Survey to collect bio-markers from their children, the initial reaction was quite negative. But once it was pointed out to parents that these data collections were essential to construct information like growth curves, the attitudes changed dramatically.

provincial, territorial and other partners to accelerate the deployment of such information systems. The provinces and territories are making similarly large investments.

However, until the past few years, Infoway has been reluctant to talk of EHRs in anything other than the context of direct improvements in patient care. The recent television ads, showing patients arriving in the emergency department with or without the EHR information on their allergies and prescriptions, provide a vivid example of these kinds of direct patient-specific benefits of EHRs. Yet it is likely that EHRs will provide even greater benefits in supporting health system evaluation – not least in providing the basis for appraisals of the cost-effectiveness of health interventions (or “technologies” in the terminology of NICE), and monitoring whether the interventions being provided are in fact appropriate. Unfortunately, however, these latter “health system” uses of EHRs have not been a visible priority.

Moreover, a careful analysis based on interviews with a number of stakeholders across Canada concluded that “lack of an e-health policy, inadequate involvement of clinicians, failure to establish a business case for using electronic health records, a focus on national rather than regional interoperability, and inflexibility in approach were seen as barriers to adoption of the (e-health) plan.” (Rozenblum *et al.*, 2010) Recent scandals in the procurement of EHR software have also been a major setback. And it may turn out that the EHR software being deployed has been managed with so little vision that the kinds of information needs described above will not be achievable for yet another decade.

Vision of a Coherent Health Information System

As noted at the outset, a large portion of the actual patient-level work of providing health care is intrinsically knowledge work – from gathering patient histories to prescribing courses of action. Health care is a knowledge-intensive industry. But it is nowhere near as knowledge and information-intensive as it should be. While the costs of this limitation are diffuse and difficult to identify – not least because of the catch-22 that the information needed to do so generally does not exist, they are almost certainly very substantial, both in terms of excessive expenditure on inappropriate kinds of health care, and foregone

opportunities to improve Canadians' health via more cost effective health interventions. This reality is clearly suggested by the unsettling results on the treatment of heart attacks shown in Chart 3.

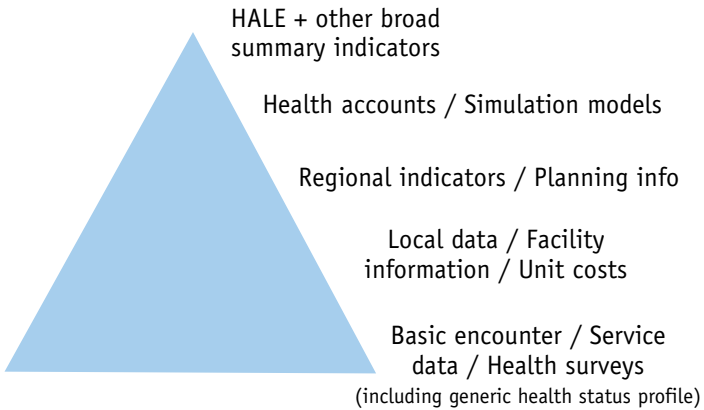
Government policy has historically been associated with the basic policy levers of raising revenues through taxation, spending money on programs and cash transfers, and promulgating regulations ranging from the criminal code to contract law. But we are now well into the "information age" and the "knowledge economy," so it is long past time for government policy to encompass more strongly and explicitly the social and economic roles of information. This is not to say that the government is not already engaged – from copyright law to regulation of internet providers to Canadian cultural content. But as in each of these areas, government policy is far behind; and it is moving far more slowly than information technology itself. The institutional structures, policy leadership, and even the basic skills in the relevant government agencies to mobilize health information via appropriate knowledge generation and diffusion are similarly weak.

What is needed, in addition to concrete policies along the lines sketched above, is an overall coherent vision for Canada's health information system. Figure 3 illustrates such a vision (Wolfson and Alvarez, 2002).

As we noted almost a decade ago, the pyramid shape is intended to convey the hierarchical character of such an information system. At the base is a combination of basic administrative and sample survey data. The administrative data should encompass the full range of individuals' health system encounters. Ideally, these data will be derived from electronic health or patient records, accessible on a need-to-know basis, not only for immediate patient care, but also (in anonymised but *not* aggregated form) for health system management and "population" or "health system" uses. The foundational administrative data should be relevant to physicians and the myriad of other health (and social) care providers at ground level (indeed to patients as well), otherwise there will be little incentive for them to generate high quality data.

The surveys should cover a broad range of items going well beyond clinical disease to gather information on health and socioeconomic status, and a range of risk factors. The surveys should include a generic measure of health status

Figure 3
A Vision for Health Information



that will support the calculation of QALYs (quality-adjusted life years) that are essential for and central to cost-effectiveness and a range of health system evaluation methods. And to meet these fundamental needs, the survey data must be linkable and linked to the individual patient care trajectories derived from the electronic health records.

The system should have a bottom up aspect – so data can be rolled up to local, regional, provincial, and then national levels. At the apex of the pyramid, the information system should offer a valid and salient but parsimonious set of top level summary indicators for the health system as a whole, particularly a basic measure of population health, and its distribution, as well as the costs and resources used in the health system. An international consensus has emerged that HALE (health-adjusted life expectancy) is the best concept, and Canada has been a leader in producing estimates.²¹ Proper estimates of HALE also require the QALY measures at the foundation.

The information system should also have a top down aspect: overall or summary indicators cannot exist in splendid isolation; they cannot risk being disconnected from practical policy choices. Given the underlying richness of

21 McIntosh *et al.* (2009); note that virtually identical concepts are sometimes called by other names, such as HLE for Healthy Life Expectancy (NCHS, 2001), HYE for Healthy Years Equivalent (Berger *et al.*, 2003; Mehrez and Gafni, 1989) and DALY for Disability-Adjusted Life Years (WHO, no date)

detail in the linked longitudinal administrative and survey data that form the foundation of the information system pyramid, the capability to allow interested parties to “drill down” to understand the “why” of various trends or patterns, is also essential. And there must be a capacity, somewhere in the middle of the pyramid, to join the resources devoted to interventions with their outcomes. The information system has to support continuous monitoring and feedback on results achieved, as well as research and analysis to determine how well various activities are “working.”

Novel for the health care sector, but standard in the economic portfolios of government, are simulation models. No federal finance minister for almost half a century has brought down a budget without staff running simulations of the impacts of proposed tax changes by family type, income and province. The information system pyramid vision in Figure 3 clearly shows not only the importance of this kind of analytical and foresight capability, but also the fact that it should be deeply integrated with the rest of the information system.

Actions

Canada has all the prerequisites to move toward one of the best health care systems in the world. These include excellence in clinical practice, world class health researchers, a strongly supportive public, and among the best statistical systems in the world. It is therefore a major puzzle why the adoption and penetration of modern management of health care in Canada remains largely a dream and not a reality. The vision shown in Figure 3 is almost a decade old, as is the founding of Health Infoway. It is truly unfortunate how little progress has actually been made.

A major opportunity was squandered with the original 2004 First Ministers’ Health Accord. While the federal government provided \$40 billion to the provinces, it received almost nothing in return. The Accord did include language on “accountability,” and there were agreed requirements for publishing a suite of health indicators to support holding the provinces accountable – though not to the federal government, but to their own citizens. Earlier drafts of the Accord included a much stronger role for the Health Council of Canada than eventually emerged. But the provinces strongly resisted the “accountability agenda,” and succeeded in severely limiting the role of the Health Council

before it was created. With weakening federal government interest in the indicator aspect of the Accord, the provinces have essentially abandoned this activity in recent years. The physician community has also failed to take on a leadership role regarding effective use of health information.

Surely, however, the lead up to a new 2014 Accord can be used as an opportunity to seek consensus on actions to move much more aggressively to improve health information, and to establish adequate knowledge generation and diffusion (obviously building on existing foundations, including Statistics Canada, CIHI and leading provincial health information nodes). The federal government carries a very big carrot in the billions of dollars to be transferred to the provinces. It is disappointing that so far, all federal parties, in the context of the recent election, have promised to keep spending money in the upcoming health Accord, at an unsustainable rate of increase, but with “no strings attached.”

Adding conditions to the next Accord need not be seen as intrusions into provincial jurisdiction. Rather, conditions with respect to information and knowledge are national mechanisms to help provinces achieve their own objectives by exploiting economies of scale associated with information standards and analysis.

Moreover, federal conditions, such as requirements for a proper health information system in a renewed Canada Health Transfer, would be beneficial for justifying these massive expenditures to federal taxpayers. Why should federal taxpayers support payments to provinces when the evidence suggests these monies are not being well spent, nor health care sensibly managed? Even to the extent that further federal conditions on managing health care costs in relation to health outcomes are seen as intrusions into provincial jurisdiction, they are also necessary to contain the long run growth in the federal portion of health care costs, which is squarely within federal jurisdiction. While some provinces may object publicly, it is certain that in private they may thank the federal government for pressuring them in directions they know full well are essential but politically painful.

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