

A Just Measure of Patience:
Managing access to cancer services after *Chaoulli*

by

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Excessive Waits with Limited Public Coverage

In this chapter we examine the issue of waiting and coverage. We consider the options to reduce wait times based on our experience with cancer services in Ontario, we comment on the promise of private provision versus private insurance in improving access, and we conclude with some of the immediate considerations for cancer services in the light of *Chaoulli v. Quebec (Attorney General)*.¹

The rationing of services is intrinsic to all health care systems. Some systems ration on the basis of ability to pay and some ration on the basis of need. How health care systems set these priorities for access is a reflection of the underlying values associated with citizenship, the social consensus on what services should be covered in a public scheme, and how health services should be paid for (tax financed, payroll financed, or privately financed). In Canada, with its history of federally mandated coverage for physician and hospitals services (and frankly little else of a national standard), we believe we ration publicly financed services on the basis of need.

Waiting lists, when appropriately managed, can be one sign of a fair and equitable system that responds on the basis of need. Appropriate management however presumes that waiting for some period does not actually cause harm to patients. The challenge comes when waiting creates risks to the patient in the form of conventional outcomes (i.e. death or progression of disease beyond a recoverable period), or quality of life outcomes (i.e. psychological distress or functional deterioration). The Supreme Court of Canada's judgment in *Chaoulli* concerned the latter; excessive waiting was deemed by the majority to be a breach of the Quebec *Charter of*

human rights and freedoms protection of the right to life, and to personal security, inviolability and freedom.² In Canada, *Chaoulli* has gripped our attention.

In our view, the practical impact of the *Chaoulli* decision in Ontario has been two-fold. First, the judgement has successfully challenged the assumption that everyone has appropriate access to necessary hospital and medical services, as they require them. This is well expressed by three of the seven judges, McLachlin C.J. and Major and Bastarache JJ. with reference to the *Canadian Charter of Rights and Freedoms*³:

However, because patients may be denied timely health care for a condition that is clinically significant to their current and future health, s. 7 protection of security of the person is engaged. *Access to a waiting list is not access to health care.* As we noted above, there is unchallenged evidence that in some serious cases, patients die as a result of waiting lists for public health care. Where lack of timely health care can result in death, s. 7 protection of life itself is engaged. The evidence here demonstrates that the prohibition on health insurance results in physical and psychological suffering that meets this threshold requirement of seriousness.⁴

The Supreme Court has suggested that the remedy for a potentially life threatening access problem is to allow the provision of private health insurance. In making this large leap of faith, an important public debate has been opened, which many of us had presumed settled, on whether private health insurance will provide a remedy to our access woes. This second consequence of opening up the question of market solutions to financing has raised the matter of what kind of social consensus we actually have in Canada regarding the provision of basic coverage for physician and hospital services. As Alan Maynard, Stefan Gress, and den Exter point out in this volume, drawing from the EU experience, established market economies finance their health sectors either through publicly financed insurance or very tightly regulated, non-commercial social insurance arrangements. The failure of commercial insurance markets to deliver comprehensive health insurance is not only a tenet of all welfare economics, but also the history

of health insurance in the civilized world⁵. As Bob Evans succinctly points out in this volume, the regularly reborn promise of “real”, comprehensive private health insurance is the marketing of powdered unicorn horn.

In Canada, as in other OECD countries with comprehensive insurance, waiting times for priority conditions have been growing over the last several years.⁶ Compared to countries such as the UK and New Zealand, where parallel private health care sectors have been encouraged, Canada’s waiting times appear to be either similar in length or shorter.⁷ The Supreme Court’s decision in *Chaoulli* underscores a growing consensus that waiting times for many health care services in Canada are becoming too long, and that the seeming inertia surrounding the improved management of waiting lists must end. Indeed it is probably an understatement to say that this message has finally been heard by Canadian governments who have collectively pledged to reduce waiting times in the most recent First Ministers agreement of September 2004.

The *Chaoulli* decision did not pronounce on what might be reasonable or appropriate waits for the condition at hand. However, an upcoming Quebec Superior Court case, *Cilinger v. Centre hospitalier de Chicoutimi*⁸ expected to be heard in 2008, will deal with these issues. The case is being brought on behalf of 10,000 Quebec breast cancer patients who were not seen for radiation treatment within eight weeks following surgery. The claim being made by the petitioner is that eight weeks is a “reasonable” amount of time, and that 12 weeks is the maximum a breast cancer patient should wait without suffering a considerable increase in the risk of adverse outcomes. The Quebec Court of Appeal recently denied leave to join the Quebec government to this class action *Cilinger c. Québec (Procureur général)*.⁹

The courts in the *Cilinger* case to date seem to be unwilling to demand that governments be held responsible to ensure the delivery of timely and effective cancer service, but the Supreme

Court appears ready to open up the delivery system to private insurance. There are several arguments as to why accountability might be demanded on the part of hospitals but not the government. Allowing judicial action to bear on the hospital sector for wait time policies directly influenced by public funding arrangements on the face of it hardly seems fair. Those of us in the cancer community will watch carefully the evolution of this case. In the case of *Cilinger*, the contentious matter of what is a 'risky' waiting period for breast cancer has developed into an important debate on the evidence of risk of recurrence for patients who wait beyond 12 weeks for radiotherapy after surgery.¹⁰

Cancer: the canary in the mine

As with all health services, the *Chaoulli* decision has the potential to affect how cancer services are organized and delivered in the future. Moreover, the upcoming *Cilinger* decision is likely to influence the cancer service providers, but possibly not the government, to an even greater extent. However, these cases are not the first wake up call for provincial cancer systems. When it comes to waiting, cancer services, particularly radiation treatment, represent the canary in the mine for Canadian health care. Although there are public and professional concerns for wait times for a number of procedures, including hip and knee replacement and cataract surgery, cancer as a life threatening illness has demonstrated for the rest of the health system what happens when waiting times for treatment reach crisis levels.

In the late 1990s, waiting times for radiation treatment in Ontario became unmanageably long and called into question the very sustainability of the provincial cancer system. The delivery system had failed to respond to a sure and steadily growing demand for treatment driven by a 3% annual rise in incidence associated with aging and population growth, as well as the intensification of services. Between 1999 and 2000, recognizing this, the Ontario Ministry of

Health and Long-term Care was compelled by clinical leaders who feared excessive waits were truly compromising survival to fund the re-referral of over 1500 breast and prostate cancer patients to the United States for radiation treatment.¹¹ As a solution, this was a costly one since the care in the US was significantly more expensive than providing the treatment in Ontario. Over and above the costs of treating these patients in Buffalo or Detroit, the government also covered their out-of-country travel and accommodation. Moreover, it almost certainly set the government back in terms of public confidence in the cancer system.

In the intervening years, a number of initiatives have been introduced in Ontario to overcome this crisis, which we discuss in detail below. Of these, a crucial one has been the improved measurement and reporting of cancer treatment waiting times. We know from this data that over the past few years, waiting times for cancer surgery have risen and more recently have been holding steady, waiting times for chemotherapy and hormone therapy are rising marginally, and waiting times for radiation treatment appear to be falling slightly.¹² On the face of it, the Ontario cancer system does not currently appear to be in crisis. However, it is important to note that what these data on waits do not show is whether or not the waits cancer patients experience are appropriate (e.g. a median wait of five weeks for both chemotherapy and radiation treatment in 2004). Moreover waiting times do not tell us much about the appropriate rates of treatment (i.e. to account for under- or over-treatment), nor the system's ability to meet the future demand for cancer treatment; it is estimated that about 25% of Ontario cancer patients who should be referred to radiation treatment are not currently receiving care for a range of reasons related to proximity to cancer services, the failure to refer, and possibly other reasons.¹³ Furthermore, over the next ten years, the number of new cancer patients is expected to grow

from approximately 55,000 per year to over 80,000 each year, almost wholly due to population growth and aging.¹⁴

It is certainly true as Charles Wright points out elsewhere in this collection, that cardiac care is one where some wait list triage is clearly required to prevent sudden death. The majority of cancers, perhaps slightly less dramatically than the minority of cardiac cases, must be treated in a timely fashion to avoid premature and in most cases certain death. This is unlike most other priority conditions for wait list reductions, such as osteoarthritis of the hip and knee and cataracts. In addition, the process of detecting and treating cancers sooner most often (but not always) confers some therapeutic and survival advantages. Indeed it is for these reasons that the majority of cancer patients now live beyond five years, and some entirely disease free beyond initial treatment.

Consider the trajectory of colorectal cancer, a largely preventable disease which is the largest killer among non-smokers in the population. This type of cancer often develops when benign polyps form on the lining of the colon. Due to genetic alterations, these polyps can grow abnormally (become adenomatous), but still be pre-cancerous. Eventually, some of these polyps will become cancerous. For average risk individuals, the pre-cancerous polyp can grow silently over 10 to 20 years. However, once malignant, the tumour must be treated to prevent proliferation through the lumen of the bowel and then metastasis (spreading to other parts of the body). Once the tumour metastasizes, it is difficult for patients to ensure full recovery even with advanced treatments currently in place. This trajectory between the onset of disease and adverse health outcomes sets cancer treatment waiting list reduction efforts apart from that for other diseases. This is in contrast to a number of fast growing tumours including those of the head and

neck. Cancer patients are likely to experience significantly greater distress from waiting than are other patients, precisely because timely treatment really is vital to prevent death in most cases.

This clinical digression is intended to illustrate three unique realities for cancer. First, cancer is not one disease but in fact represents over 100 different diseases, each with a complicated treatment pathway in which patients must see multiple specialists often in different clinic settings, and therefore often experience many sequential waits for different services. This makes determining “appropriate” waits for particular patients very difficult. Second, interventions to improve cancer service “access” exist at multiple points in the sojourn of various cancers. This means access is not just definitive final treatment, but begins with prevention and screening, potential removal of polyps with endoscopy for early diagnosis, to treatment with evidence based surgical resection to effective radiotherapy, systemic and adjuvant therapy. Third and perhaps important for the *Chaouilli* decision, for cancer patients distress is driven by the real and imminent fear of death. With few exceptions however, we do not have clear cut points for the risk of passing the point of no return, or raising the risk of early recurrence in the course of waiting for treatment following initial surgery.¹⁵ While the evidence basis is slim, consensus-based recommendations informed by current evidence and practice leaders for appropriate classification of waits for cancer patients will be forthcoming in Ontario by the end of 2005 for major cancer treatments.

While the focus may be on definitive treatments for those with advanced disease, there is no effective screening for colorectal cancer in Canada on a population basis, despite bullet proof international evidence for improved survival from screening.¹⁶

Options and Tools to Reduce Waiting Times for Cancer Service

What can be done about growing or excessive waiting times for cancer service? The *Chaoulli* decision has tended to constrain the terms of the debate to a choice between single payer versus a private insurance option. Canada has always had a multi-payer structure for services other than inpatient care and physician services. What *Chaoulli* has done is open up the debate about whether inpatient care should be open to a private insurance option, without actually suggesting how this should be done in any practical fashion. More importantly, the judgement does not even discuss a host of other options available to governments to reduce waiting times systematically and improve access to care as Colleen Flood and her colleagues note in their contribution in this volume.

Put simply, there are four principal means to reduce waiting times and improve access to cancer care. As a comprehensive proposal to reduce waiting times and increase access to care, these core strategies have been described in detail elsewhere.¹⁷ Governments, health care managers and providers can:

1. Reduce the demand for services by investing in cancer prevention and early detection,
2. Target new investments in cancer services capacity to meet the growing demand (physical plant, human resources, and new agents and technologies),
3. Better coordinate access to cancer services, and
4. Make more efficient use of existing resources.

This section reviews a series of selected and promising approaches to reduce waiting times in the context of cancer care, and describes the specific tactics that have been implemented in Ontario's cancer system.

Investing in prevention and early detection

As a solution for reducing waiting times, investing in cancer prevention and early detection is easily overlooked. The benefits, including lower rates of and less advanced disease, are well known and substantiated,¹⁸ but progress against the disease, like the incubation rate for many cancers, can take several years (and electoral cycles) to be realized.¹⁹ Still, given that at least half of all cancers are preventable,²⁰ the overall future demand for services can be significantly reduced.

Investing in tobacco control, obesity prevention, and population-based organized cancer screening have all been shown to lower the burden of disease, which directly reduces the pressures on the healthcare delivery system. It is ironic that the Supreme Court struck down laws preventing tobacco advertising in *RJR-McDonald Inc. v. Canada (Attorney General)* concluding that there was a lack of sufficient evidence of a link between advertising and consumption,²¹ as discussed by Sujit Choudhry in this volume. Long-term planning, including forecasting the coming demand for cancer services and devising ways to reduce it are more important than ever in light of the changing age structure of the population.

Public reporting

Internationally, the measurement and reporting of health performance information for quality improvement has become standard practice.²² The public reporting of cancer treatment waiting times to stimulate reductions is equally widespread.²³ As with all performance reporting, there are three key objectives in publicly reporting cancer treatment waiting times: to indicate where there are problems, to monitor progress over time, and to demonstrate system accountability to the public.

To our knowledge, no studies to date have demonstrated the specific impact of publicly reporting treatment waiting times on subsequent performance,²⁴ however, a recent controlled experiment conducted in Wisconsin sheds light on the long-term effects of performance reporting more generally. The study, which included 115 hospitals in the state, showed significantly greater quality improvements among those hospitals whose performance data was released publicly compared with hospitals receiving either private reports or no reports at all.²⁵ Furthermore, the improvements analyzed were specific to the clinical areas covered in the performance reports.

In 2003, for the first time, Cancer Care Ontario began to post radiation therapy waiting times publicly on its web site.²⁶ The information is displayed by type of cancer and by cancer centre. Making comparative and timely waiting time information transparent to the public was intended to demonstrate and strengthen the accountability of the system. The public reports result in continued media attention²⁷ and create pressure on lower performing centres to act. In addition, public reporting has the benefit of driving “purification through utilization” by creating an imperative for centres to provide the most accurate data as possible.

In 2005, public reporting of cancer performance information in Ontario was expanded in the form of the Cancer System Quality Index. The Index consists of the results of 25 quality indicators, with expanded reporting of waiting times including cancer assessment, surgery, chemotherapy and radiation treatment.²⁸ Cancer Care Ontario has mandated each of the regional cancer leaders to integrate the annual results of the Index into their planning and quality improvement cycles. The long-term impact of publicly reporting this performance information is currently being evaluated through a number of peer-reviewed grants.

Use of triage tools

To be efficient, a waiting list must reflect a prioritization of patients in the queue according to need. Patients needing a service or procedure sooner should be higher up on the list. To accurately assess the relative priority of different patients waiting for cancer services, standard and valid methods are needed to weigh symptoms, severity of disease and urgency.

The Western Canada Waiting List Project has developed waiting list management tools for five clinical areas: cataract surgery, children's mental health, general surgery, joint replacement and MRI scanning.²⁹ Although not specific to cancer, these tools have been validated and allow physicians to score different patients according to disease-specific criteria and are a useful model for managing waits for other conditions. These triage tools although viewed with growing regard by clinical leaders and managers in the health care sector nationally, were not mentioned in the *Chaoulli* decision.

Setting targets

Similar to triage tools, identifying an agreed upon "appropriate" or "reasonable" amount of time for a patient to wait for a particular treatment or service is critical for targeting reduction efforts and resources. Without the ability to run controlled experiments to determine precisely how long it is safe to wait, this is typically achieved through expert panel reviews and syntheses of the available evidence from observational studies. For example, in 2000 the UK established a two week waiting time rule for referrals to cancer specialists.³⁰ A recent systematic review in the UK was unable to determine the effectiveness of this policy on cancer patient waits³¹. A more recent discussion with the leader of the cancer program in the UK suggest progress toward the two week rule is in fact progressing well, driven in part by the huge influx of new capacity and

resources for cancer in the UK.³² In Canada, the Saskatchewan Surgical Care Network has set a waiting time target of three weeks for all cancer surgeries.³³

In Ontario, consensus-based urgency classifications and target maximum waiting times have been developed and will be forthcoming for cancer surgery by the end of the year. Currently the Canadian Association of Radiation Oncologists suggest four weeks as a maximum time from referral to treatment with a radiation oncologist. It is important to note that none of these waiting targets (for the multitude of cancer diseases) has a strong base of evidence on which to base the time frames.

Central management of waiting lists

In most jurisdictions in Canada, individual physicians maintain their own, usually paper-based, waiting lists. This makes it almost impossible to organize care so that patients waiting unreasonably long times are identified and given the opportunity to be referred to another physician.

Saskatchewan was the first province in Canada to implement a province-wide registry to manage surgical care in order to remedy this problem.³⁴ The centralized registry enables consistent measurement of waiting times, the monitoring of capacity across the province, and the use of standard tools to prioritize patients in the queue.

In Ontario, the current government has a platform to reduce waiting times for five priority procedures: cancer, cardiac, cataract, and joint replacement surgeries, and for MRI and CT scans. To achieve this goal, the government launched the Ontario Wait Times Strategy in the fall of 2004. With a deadline of December 2006, the strategy has two main components: investment in additional surgical volumes and the development of an electronic province-wide surgical registry.

Building on the Saskatchewan Surgical Care Network's surgical registry model, the Ontario Wait Time Strategy team is in the process of developing a provincial surgical registry and a provincial diagnostic imaging registry. As a result, Ontario will soon have standard metrics for measuring waiting times across the five priority procedures. Further, each registry will include information on which provider a patient is waiting for, the urgency of his or her condition, how long he or she has been in the queue, and how many patients in total are waiting. In short, the registry will provide important information for providers and hospitals to manage and report waiting times. To support waiting list management through the registry, urgency scales and benchmark waiting times have been developed by expert panels for each of the five procedures. This will be an important initiative not only for the patients who will benefit from it but also because it will stand as a tool for the effective management of waiting times, and a rebuttal to accusations of management inaction in the face of long waits in a post-*Chaoulli* Ontario.

Process innovations and system redesign

Excessive waiting times are often a symptom of bottlenecks in the care process. For example, patients waiting for cancer surgery commonly experience delays in obtaining biopsies and other diagnostic tests and pathology results.³⁵ Finding new ways of organizing care through streamlined diagnostic assessment units,³⁶ or expanding the scope of practice of nurses to bolster screening programs³⁷ are common approaches to remove these types of access bottlenecks.

System redesign initiatives, in which entire care processes within and between clinics are analysed and reconfigured, are larger scale efforts to remove a series of bottlenecks.³⁸ This strategy is particularly important in cancer in which the patient journey crosses multiple

providers, treatments and care settings and can result in multiple sequential waits. This approach has been used extensively in the UK's Cancer Services Collaborative.³⁹

In 2004, Cancer Care Ontario received provincial funds to allocate to promising innovations in cancer care designed to reduce waiting times and improve patient access. The resulting program, the Access to Cancer Services Innovation Fund, awarded money to 22 promising innovations across the province following a proposal call and review.

The projects range from streamlined breast cancer diagnostic assessment units, to expanding the scope of practice of nurses to increase cancer screening rates, to a centralized waiting list tracking system. Each project is currently evaluating its success against agreed upon measures including waiting times and utilization rates.

New funding models and metrics

To reduce waiting times, governments may need to purchase more of a particular procedure. Since funding in the context of hospital global budgets is based largely on historical spending and is not tied to patient needs, there may be little incentive for providers to increase current volumes. Funding formulas that reflect needed increases in the rates for particular treatments or procedures, and account for differences in complexity are an important mechanism for improving access and reducing waiting times.

During the *Chaoulli* decision the idea of “wait time guarantees” was advanced, originating from the Senate hearings led by Senator Kirby.⁴⁰ They have also been explored in the UK, where the guarantees have no direct patient remedy, other than reputational risk for the institution and possible employment for the chief executives. In addition, setting maximum acceptable wait times for many types of cancer and cancer treatments is a challenging task which might be better met with the classes of wait time targets used in Saskatchewan (broad windows

of time for classes of treatment). Finally, while the fiscal imperatives associated with wait time guarantees have made the concept a difficult one for provincial governments struggling to manage their health envelopes, the concept still merits exploration with the public.

Tying accountability and funding to performance: new investments

As their health performance measurement systems evolve, many jurisdictions are beginning to link financial incentives to quality improvement, often referred to as “Paying for performance”.⁴¹ This includes payments to particular physicians or to hospitals, and typically involves bonuses for high performance or improvements against a series of explicit measures.

As a core measure of quality in the Canadian context, improved waiting times are one of several indicators that can be tied to funding. However, as noted in the previous section, assessment of waiting times must be done in the context of improving access to all patients in need of a particular service.

For Ontario’s Wait Times Strategy, Cancer Care Ontario was responsible for designing the investment solution for additional cancer surgeries. The approach was explicitly intended to tie funding to performance. That is, in addition to adding almost 3000 more cancer surgeries this year than last, the 37 participating hospitals are required to have a multi-disciplinary practice setting, a commitment to developing tumour boards and surgical rounds, and a commitment to quality assurance and improvement, including a checklist approach to pathology reporting, and better capture and reporting of data on stage of cancer. Additionally, the extra funding requires participating hospitals to submit data to Cancer Care Ontario. To prepare for the downstream effects of increased access to cancer surgery, additional volumes are also being planned and purchased for chemotherapy and radiation treatment, and eight regional cancer centres are currently being expanded or newly constructed in Ontario.⁴² This will help to prevent the re-

referral of cancer patients to other parts of the province or out-of-province to receive needed treatment. Specifically, it will allow for the treatment of over 1500 new patients for chemotherapy and an equivalent number of new patients for radiation treatment by 2008.⁴³

In summary, following a crisis in the late 1990s, Ontario's cancer system has been undergoing a comprehensive campaign to reduce waiting times and improve access to cancer services. This has included greater transparency in the reporting of waiting time information, building a significant amount of new treatment capacity in the province, purchasing additional volumes of treatment tied explicitly to performance, fostering innovations in service delivery to increase both productivity and quality, and development of a provincial wait times registry with urgency ratings to adjudicate and manage lengthy waits. It will take time for the effects of some of these initiatives to be apparent, however, as the data on waiting times for major cancer treatments in the province show, waiting times for most treatment modalities have generally been holding steady in the last few years, despite significant population growth. The most recent new investments in additional surgical procedures should reduce surgical waits, but may put new pressures on systemic therapy waits, a reality that has been anticipated in the current funding model.

Increasing Private Sector Involvement: delivery vs. insurance models

The *Chaoulli* decision brings the question of the effect of a parallel private sector on waiting times in the Canadian health system to the forefront. The assumptions underlying the call for parallel private financing are that it would help to reduce pressures on the public system and reduce waiting times. However, the available evidence shows that depending on the type of private sector involvement (e.g. increasing private insurance vs. private delivery), and its relationship to the existing public system, the effects will vary.⁴⁴ In our view, given the available

evidence, the *Chaoulli* solution of increased options for private insurance would prove neither optimal nor effective, since the failure of private insurance markets are what brought about public health insurance in Canada to begin with. To borrow from Bob Evans, no powdered unicorn horn is likely to be found by sifting through the *Chaouilli* judgement.

In Australia, a 30% private health insurance rebate was introduced in 1999 to encourage the use of the private sector in order to reduce waiting pressures in the public system. A recent study, assessing the impact of the increased private activity on waiting times for elective procedures, found that the higher the proportion of public patients, the lower the public sector waiting times and vice versa.⁴⁵

In contrast, the UK introduced an approach to increased private sector supply that should theoretically prevent the negative impact on the public sector seen in Australia. To increase capacity and reduce waiting times, the National Health Service (NHS) requested bids from the “independent” sector to set up private diagnostic and treatment units. To avoid draining scarce human resources in the existing public system, the NHS set out to contract with internationally established providers who were external to the public providers in the NHS. These providers can contract with the NHS to perform an agreed upon number of procedures, based on a set price for each procedure, equal to public sector pricing.⁴⁶ Unlike in Australia, the private sector involvement being encouraged in the UK is for the *delivery* of care as opposed to its *insurance*. From the Canadian perspective, this kind of approach would allow the retention of the single payer model, including standard prices for specialized procedures would can be made more competitive with greater market segmentation. Moreover, by recruiting new professionals from outside the existing system, capacity is added while preserving the integrity of the public delivery system.

To date, there are no definitive studies on the effectiveness of the UK's private sector delivery model. However, a recent examination of the effects of private sector involvement in the health systems of five OECD countries suggested that depending on how it is structured, the expansion of private financing is more likely to weaken public coverage.⁴⁷ This is perhaps not surprising given the political consensus behind risk pooling for public coverage. As high-income contributors exit, the public commitment weakens.

Private delivery in Ontario: the CROS experiment

Seeking to increase the provincial supply of radiation treatment services during Ontario's crisis of the late 1990s, Cancer Care Ontario initiated an open bid process resulting in a contract with a private company, Canadian Radiation Oncology Service (CROS). Under the terms of the contract, CROS was required to treat 1000 patients per year without displacing staff in other clinics, in exchange for a flat fee equivalent to what the public insurance system would pay, plus a performance bonus.

The CROS approach consisted of renting existing space and using public equipment at the Toronto Sunnybrook Regional Cancer Centre during evenings and weekends – times when it would otherwise be idle.

The results of the CROS experiment included redesigning the care process, scheduling, and provided a savings over sending patients to the U.S. Essentially, however, CROS added capacity to the public delivery system, which up until recently had not been adding capacity rapidly enough to keep up with the growth of incident cancers. The CROS contract was not renewed the following year when similar incentives were provided to the public system and additional human resource capacity came on-stream. Critics of the experiment have argued that

the CROS case mix was less challenging than in other clinics, and that displacement of staff in other clinics did occur.

While the Ontario cancer system has had limited experience with parallel private sector insurance or private delivery for public services, as the next section shows the *Chaoulli* decision and the advent of a new private chemotherapy infusion clinic are obliging Ontario to consider new options for some chemotherapy patients.

Access to Cancer services post-*Chaoulli*: Wait Time Appeal and Changing IV Drug Coverage?

The Justices of the Supreme Court that formed the majority in the *Chaoulli* decision did not address the question of how long a wait is too long for medically necessary services, although we will wait for any response to this question in the *Cilinger* case. From the perspective of risk to the patient in terms of his or her prognosis, this is a difficult question to answer. In the case of cancer, an unsafe delay in treatment can depend on the type, stage, pathology or genetic expression of the patient's disease, among other factors. Should the *Chaoulli* decision result in two-tier system across Canada where patients are permitted to purchase private access (either through insurance or out of pocket) for medically beneficial services, it is possible that the evidence-based approach to treatment of patients characteristic of cancer services may no longer endure. The ability to pay for medically necessary services through private insurance could supersede rationing on the basis of need. That is, any wait at all may be too long for patients with the means to seek private care. The risk for cancer patients is that private providers may offer services, which are neither based on evidence nor cost effective. The *Chaoulli* decision has shifted the national debate away from one about unreasonably long waiting times to one about access to care as noted earlier.

Perhaps the most constructive action arising from the *Chaouilli* judgement has been a burning imperative by governments already committed to drive down wait times at least within five priority areas including cancer services. A number of important initiatives are underway in Ontario to reduce waiting times within the public system, including targeted investments in imaging, increasing the volume of surgical procedures, central electronic registration and regional management and reporting of waiting lists. In our view, these investments will have a downward effect on waiting times for cancer services. All of this adds up to the likelihood that most falling wait times are *not* likely to be appealing as a judicial target. To the extent that governments and hospitals gird themselves with systematic methods to collect comparable data and reduce waiting times, they will be less vulnerable to challenges. The recourse to private insurance, as argued elsewhere is really an empty right with little consequence for the improvement of care other than the loud message to governments to get on with reducing wait times.⁴⁸

The push for better access to care (not access to waiting) arising from the *Chaouilli* judgement in our view is and will continue to be a central public and a continued legal concern.

The emergence of the *Chaouilli* judgement alongside a national call for better and more timely provincial payment for block buster cancer drugs (like Herceptin) has the attention of cancer systems across the country. In oncology we are facing a variety of very good new cancer drugs that are both efficacious and cost effective. We also face a range of very expensive intravenous cancer drugs that have only modest medical benefits. Agents with modest survival or quality of life benefits which are not cost-effective are unlikely to make their way onto public formularies, but patients will want these agents even if the average cost of a life year gained

exceeds \$100,000. Both classes of drug are being licensed for sale in Canada and are being requested by patients and their families.

A slim majority of *oral* prescription drugs in Ontario are paid for through private insurance or out-of-pocket, however *intravenous* agents which require careful monitoring and infusion preparation have traditionally been delivered in the outpatient hospital setting and therefore within the public system, under the sweep of the *Canada Health Act*.⁴⁹ In a post-*Chaoulli* health care environment, what is the remedy for patients demanding services or drugs with modest benefits that the government does not make available in the public system? Is their recourse to cross the border for a higher priced remedy in the US, or should they have recourse to expensive life extending IV remedies at home? All formularies assess cost effectiveness and it seems a principled approach to scheduling drugs in a world of rapidly growing drugs costs. However, it probably is not a reasonable proposition to effectively prohibit access to agents which have benefit and for which oncologists will write prescriptions simply because the public payer has decided against adding these agents to a formulary.

Consider the recent opening of Provis Infusion Clinic, Inc. in Toronto. The clinic offers patients access to intravenous cancer agents that have some medical benefit, and have been approved for sale by Health Canada, but are not covered under the province's drug formulary because of either cost-effectiveness considerations or evidence considerations. Patients who have been referred to Provis by a medical oncologist and with the ability to pay, either out-of-pocket or through private insurance, can get access to infusion of drugs such as Velcade for multiple myeloma patients with advanced disease or Alimta for patients with mesothelioma. In short, the class of drugs offered to patients in this private clinic setting are those which are not paid for either because the assessment of evidence does not suggest they should or because such

agents offer modest benefits without evidence of sufficient cost-effectiveness for the province to extend payment for all affected patients. In addition, the Provis delivery model requires patients to arrive at the clinic ready to be infused, having had the preparation work of installing chemotherapy lines performed within, and paid for by, the public system.

The increasing patient demand for expensive, cost-ineffective cancer drugs and the advent of Provis to satisfy this demand could have significant impacts on the public provision of intravenous drugs. One unintended adverse consequence of an enlarged access for cost ineffective drugs may be a reduced public pressure for cost-effective drugs to be covered by the public payer on a universal basis.

Moreover there is the real possibility of further proliferation of private infusion clinics across the province. Up until now, most Ontario cancer patients travelled to Buffalo to receive these types of expensive chemotherapy agents not covered in the public system. With the advent of a local clinic, the costs to each patient have been significantly reduced. While the particular impacts of Provis Infusion Clinic, Inc. on the public system may be relatively minor, the possibility of a growing market of such clinics could create significant impacts on the existing delivery system. These include a drain on human resources from the public system and a push to relax the focus on evidence and a growing marketing pressure for ineffective or unproven remedies. With very expensive and biologically targeted agents it is very important to know which patient populations will benefit and which will not, rather than simply selling agents to everyone without regard to the evidence of benefit. It is not inconceivable that private cancer clinics could be opened, providing a range of procedures for which there is no evidence of benefit to patients, effectively holding out false hope for money.

Unlike public hospitals, private clinics – like private insurers – have the ability to “cream” cancer patients, providing services to the easiest cases and to offer care only at the final point of delivery (i.e. after chemotherapy preparation). Finally, should adverse reactions occur due to the infusion of chemotherapy agents at the private clinic, patients will need to be referred back to the public system for care.

Since only a minority of cancer patients will have the means to purchase unfunded intravenous chemotherapy agents, the advent of private infusion clinics represents an important new development in the Canadian health care system following the Supreme Court’s decision on *Chaouilli*. The national standard for all intravenous drugs was public coverage and universal accessibility guided the approach. How we handle a growing group of expensive and modestly beneficial intravenous agents may signal an important departure in Canadian intravenous drug policy. In the absence of a national standard, a patchwork of solutions is being adopted in different provinces to respond to a growing consumer demand for these intravenous agents which do not satisfy cost-effectiveness criteria. The evolution of a national catastrophic drug scheme might at least make the decision rules consistent for all Canadians as distinct to making decisions thirteen times in Canada, but such an option is not apparent on the agenda of an apparently perplexed federal government.

Unlike Ontario, the Alberta health system offers private paying patients the ability to receive intravenous cancer drugs not covered by the provincial drug benefit program within public institutions. As discussed by Tim Caulfield and Nola Reis in this volume, this is in line with a range of initiatives underway in Alberta to combine public and private health care, and to promote a two-tiered system almost without regard for cost shifting from private to public or large cross subsidies between public and private care. As another example, breast cancer

patients in Saskatchewan were able to pay for Herceptin within public hospitals prior to its being listed in the provincial drug formulary.

The range of expensive cancer agents that do not satisfy cost-effectiveness criteria is only likely to grow. The *Chaoulli* decision, the advent of the Provis clinic, and a lack of any effective national standard for prescription drugs are driving Ontario and other provinces to find a viable ongoing solution to this new access challenge for cancer services. Options range from allowing a parallel private delivery and privately financed system to grow for intravenous chemotherapy, to expanding the public system by permitting public hospitals to provide privately-financed drugs on a full cost recovery basis. Either solution will eventually require some regulatory framework to ensure quality and access within a principled framework. Finding the solution that is most likely to preserve the integrity and quality of the public system must take into account the plethora of cross-subsidy issues noted above; paying for the drugs privately covers only a portion of the cost of the service, and the remainder is picked up by the public system.

The *Chaoulli* judgement opens up a much broader set of access to care issues that have little to do with how long is too long for patients to wait for health care services. In particular, by advancing private insurance as a remedy for unreasonable waits, the decision has propelled a public debate on private financing and delivery of unfunded intravenous cancer agents for the minority of Canadian patients with the ability to pay for expensive intravenous drugs not covered by provincial formularies.

¹ 2005 SCC 35 [*Chaoulli*].

² R.S.Q. c. C-12, s. 1.

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