

## Ending waiting-list mismanagement: principles and practice

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**A**n abyss divides common understandings about waiting lists from evidence about their nature and causes and what might work to rationalize them.<sup>1</sup> In a recent comprehensive report for Health Canada<sup>2</sup> we found that the state of waiting-list information and management systems in Canada is woefully inadequate, particularly for elective procedures. Here, we identify key lessons and outline a number of initiatives that should contribute to more durable solutions both in Canada and in other countries experiencing similar problems.

### Fairness: a core public expectation

Why should we worry about how waiting lists — especially those for elective procedures — are organized and managed? The main reason is fairness or equity. A core underpinning of publicly financed health care systems is “to each according to his or her need.” Assuming that a health care intervention offers a reasonable probability of tangible benefit, those with the greatest need for the intervention should be served first, if all else is equal. The probability that tens of thousands of individual, uncoordinated decisions taken in a large, complex and diverse system will combine to yield fairness for all is vanishingly low.

Thresholds for diagnostic or therapeutic intervention in medicine are highly variable.<sup>3</sup> Practices that differ widely without justification jeopardize equity and fairness and increase the risk of adverse events or persistently unaddressed needs. If patients are to be served in order of need, clinicians need tools individually, to prioritize within their own practices, and collectively, to prioritize patients on pooled lists. Other jurisdictions<sup>4</sup> have made headway in this direction for elective procedures. Canada has selective experience with cardiac care<sup>5</sup> and hip and knee arthroplasty,<sup>6</sup> and there is some work under way in other clinical areas. But most Canadian work has, to date, been largely haphazard and opportunistic, rather than a result of any concerted, coordinated and cooperative action.

There are honest debates about whether factors such as employment status, time on a waiting list and age should influence a patient’s priority on a list. These are not questions that science will ever be able to answer, and the difficulty of sorting them out should not be taken lightly. It is

difficult to imagine public support for any system that is developed if members of the public have not had an opportunity to declare their values and preferences.

A further complicating factor will be cost. Some people will have significant needs that could be addressed by potentially effective interventions, but at huge cost. In some cases the success rate will be low, but the fortunate few will obtain greatly prolonged or improved quality of life. Others will have modest needs that can be addressed inexpensively and with near-certainty of benefit. Comparing complex and dissimilar cases requires methodologic expertise and careful attention to clinical nuance. These realities suggest that no solution is likely to apply in every conceivable case. Possibly the best system will be reasonably simple and fully transparent and will apply in 98% or 99% of cases. For the remainder (i.e., the rare high-cost, high-stakes cases mentioned above), special mechanisms — also transparent and accountable, to be sure — may be necessary.

### Information for sound, fair decision-making

There may indeed be serious waiting-list problems in Canada. The scandal is that currently available information can neither confirm whether such problems actually exist nor determine which needs should have priority. The result has been resource claims based on anecdote, interest-group pressures and political perceptions of need, more often than not unsubstantiated by clear analysis and reliable data. The discussion about waiting lists has become a duet of charge and countercharge about the sustainability of the system and the “curative” powers of money. Our survey data illustrated the clash of opinion: government respondents insisted that waiting-list problems are neither serious nor worsening, whereas all other respondents maintained the opposite.<sup>1,2</sup> And the sparse “harder” data that do exist suggest that opinion is a dangerously poor substitute for careful measurement and analysis.<sup>7</sup>

Canada is highly resistant to spending health care dollars on anything other than direct services — be it administration or information systems or analysis. Decision-makers, pressured by claims unsupported by reliable information, perceive little choice but to apply grease to the squeakiest wheels and generalize from that (often anecdotal) basis.

Thus, public policy is hostage to its own failure to invest in the fundamental infrastructure for intelligence-gathering.

## Standardizing concepts and terms

The first order of business is to create good information systems based on standardized concepts and terms. However, even the simplest notions are confounded by obtuse definitions and inconsistent application. For example, we found no consensus on when waiting actually starts.<sup>1,2</sup> We cannot know whether people are waiting too long until we know how long they have been waiting. We cannot even be sure of whether they have been waiting longer than others until we know that the clock started for all at the same point in the clinical process.

## Audit, evaluation and quality control

Clinicians' criteria for whether and when to place patients on waiting lists vary widely, as do practices for monitoring and reordering the queue in response to changing clinical circumstances.<sup>2</sup> This is problematic not only for those who manage resources, but also for patients. With few exceptions, there are no rigorous rules governing who belongs on a list and who does not. Data from the United Kingdom and New Zealand in particular reveal that failure to audit and update lists can lead to significant inflation, with overcounting of patients commonly at 30%<sup>8-10</sup> and sometimes as high as 70%.<sup>11</sup> Despite the heated rhetoric about long and growing lists, we were unable to find even one publicly available report of an independent waiting-list audit in Canada.

A good waiting-list information system must identify people at risk because of potentially excessive waits; ensure that patients are reassessed when their circumstances change; and remove those whose clinical condition improves, who have decided to forgo the procedure, who die, who move out of the jurisdiction and so on. In addition, it should track outcomes to allow for continuous refinement of the criteria and weights used to prioritize patients. And it should be accessible to the public.

## Meaning and value of waiting time

Being on a long waiting list is not necessarily a sign of trouble, although being on a list for a long time may be. Although the number of patients awaiting a procedure may influence waiting times, this number is not in itself meaningful. If 6 people are waiting 2 years for a vital procedure — say, a heart transplant — there could be a serious problem despite the low number. If 1000 people with minor visual impairment are awaiting cataract surgery and all are served within 3 months, there is no problem. Time, therefore, is the key indicator, both clinically and in terms of public perception.

Critics often define waiting lists and waiting times as lia-

bilities rather than assets. But waiting lists do more than serve bureaucratic functions. For example, many patients ultimately decide not to undergo scheduled procedures.<sup>11,12</sup> Immediate access preempts the possibility of reflective second thought or opinion, adaptation to a new condition or trial management with more conservative measures. Undergoing intensive diagnosis and surgical treatment is not a trivial decision. For some conditions, a short wait is certainly preferable, but for others, low burden associated with the condition and a period of reflection are not an unhappy combination. Canadian data have shown that for knee replacement, patients are satisfied with wait times averaging 4 weeks (but not 8 weeks) for specialist consultation and about 8 weeks (but not 32 weeks) for the surgery itself.<sup>13</sup>

## Systemic, not isolated, solutions preferred

Waiting lists and waiting times do not exist in a vacuum; they are part of the fabric of our health care system. Waiting lists addressed in isolation may entail a claim on resources (e.g., operating room time) that must come from elsewhere in the system. In a zero-sum situation — increasingly common in health care — the harm caused by a “reallocation from” may exceed the benefit resulting from a “reallocation to.”

With specific, targeted goals and vigilant management, additional resources can shorten very long waits and clear backlogs, however impermanently.<sup>14-16</sup> But providing additional funds for one procedure or another without standardizing intervention and prioritization criteria has repeatedly proven either ineffective or at best a temporary solution.<sup>1,17-21</sup> This is the public policy analogue to treating symptoms without establishing the underlying cause.

This was nowhere more vividly illustrated than in the data tracking the impact of the United Kingdom's so-called “Patient Charter,” which guaranteed that patients awaiting certain services or procedures would not have to wait longer than some given period *X*. The number of patients who waited longer than *X* plummeted. But how did this miracle occur? The evidence, such as it is, suggests that patients with more urgent needs may have ended up waiting longer.<sup>22</sup> Piecemeal “solutions” may thus compromise overall system integrity, continuity and fairness.

Prioritizing patients awaiting a particular service will almost certainly turn out to be the easy part of this task. Prioritizing patients who are awaiting different services but are competing for the same pool of resources (e.g., time in the operating room) is far more complex. And prioritizing among quite different categories of services ultimately funded from a single source will make the previous 2 tasks seem like child's play.

## Toward public ownership of lists

Recent survey data confirm that, with few exceptions, waiting lists in Canada originate with and are maintained

by individual physicians.<sup>1,2</sup> Some jurisdictions maintain central lists for certain services but have no control over whether the information they receive is standardized, accurate or even complete. Without such data, the capacity to manage and adapt is severely impaired.

Three constituencies require full knowledge of waiting lists and times: the public, physicians and managers. The public needs access to lists so that they can make more informed decisions. Referrals to specialists are often a mysterious process to patients. A patient may languish on a particular physician's waiting list for a long time without ever knowing that another physician could provide the needed service much sooner. Ontario's Cardiac Care Network has a publicly accessible Web site that reports waiting times for heart surgery by location,<sup>22</sup> as does the Montréal-Centre Régie Régional.<sup>23</sup> The trend, accelerated in the United States, is toward much more openness and transparency in the system, including public access to data such as physician-specific and hospital-specific outcomes.

Physicians and the public need to know how the system is working as a whole to meet needs fairly and with good results. Managers in hospitals, regional health authorities or provincial ministries (for some highly specialized services) are accountable for how the system performs and for balancing competing resource demands. If they do not have complete, accurate and up-to-date information about waiting lists and waiting times, they cannot make informed decisions. They will, instead, be forced to respond to criticisms and charges often based on individual physicians' privately held lists. These lists are almost certainly unstandardized and unaudited, but are no less useful to their owners in debates about system quality and making resource claims.

For most procedures, the current Canadian "nonsystem" of physician-controlled lists makes it impossible for managers to manage and actually "puts patients last."<sup>24</sup> Not only would common and transparent systems return the focus to patients' needs, they would also create an incentive to ensure that the data are accurate and that comparisons are apt.

### **Fairness among providers: a special challenge**

Providers have distributive justice entitlements and desires, as do their patients and the public. Some public preferences and goals may create conflict among providers. For example, patients may want to choose their physicians and minimize their own waiting times. Both goals may, in certain circumstances, be met by allocating more system resources to the physicians preferred by the largest numbers, which might create professional discord.

But the public also has an interest in maintaining the skill levels of both experienced and newer practitioners and in ensuring that the system is not unduly vulnerable to the departure or retirement of a few providers. To achieve these goals, all providers (including those referring pa-

tients) will need to accept the notion of integrated, audited waiting lists that allow patients to switch providers to reduce waiting times. In the current system, the allocation of operating room time also effectively allocates incomes. If long lists lever more operating room time, some practitioners will either actively build long lists or resist reallocation of their patients to those with shorter lists. For example, the mean waiting time for ophthalmological surgery (92% of which was cataract removal) in Saskatoon in late 1996 was more than 12 months for 2 high-volume surgeons and 5 months for 8 others (John Mowbray, Policy and Planning Consultant, Saskatchewan Health: personal communication, 1998). Whether there are physician-specific variations in patient outcomes in this setting is unknown, at least to the patients on the lists.

These considerations suggest a need to establish distributive justice principles for providers that are consistent with, but ultimately subordinate to, the public interest. Patients value highly the freedom to choose their doctors. But providing the public and referring general practitioners with information about the track record of all providers (procedural report cards, for example) and differences in waiting times might lead to different choices and, quite possibly, shorter waits for at least some patients.

### **Conclusion**

The waiting-list "nonsystem" in Canada is a classic case of forced decision-making in the absence of good management information. There is a surfeit of nonstandardized data and a dearth of usable, policy-oriented information about waiting lists. The most serious consequence is that information and management defects are almost always prematurely diagnosed as financial shortages.

The predictable response has been to periodically paper over the cracks with money. Inevitably the structural defects show through, and more money rides to the mirage of rescue. Without clear and consistently applied criteria, supply of service will dictate use, and more volume (and longer lists) will beget still more volume. Forceful advocates with anecdotes at the ready and access to the media will commandeer more resources at the expense of others in the system (both patients and providers). Addressing particular problems will simply rearrange the system's problems, not solve them.

It is important to emphasize that fairness and affordability are distinct concepts. An underfunded system can be fair if it does not discriminate, and an overfunded system can be extremely unfair (the United States comes immediately to mind). People will always debate whether there is enough money in health care and whether overall service availability and quality are up to par. But citizens are entitled to good, principled, transparent management of the public resources committed to health care.

Adding funds without first ensuring fairness and transparency will in the end ... add funds (and therefore increase

the costs of the system). The odds against additional funding alone improving either system quality or accountability are long. A gambler might take the bet; those interested in improving these key aspects of health care cannot.

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