



Research Spotlight

Institute of Health Services and Policy Research

Wait Times

Dr. Morris Barer

Canadians have consistently identified timely access to quality care as their foremost priority for health care system improvement. Waiting times for specialist consultations, diagnostic imaging and surgical services have become a lightning rod for public concerns about health care and the target of those arguing for the introduction of a parallel private health care system.

Addressing the wait times problem has, as a result, become a high profile political agenda. In September 2004, Canada's First Ministers agreed to build on past efforts to reduce wait times and improve access by making a series



of commitments in the Ten-Year Plan to Strengthen Health Care. The first of these was for jurisdictions to establish evidence-based benchmarks for medically acceptable wait times by the end of 2005, starting with five clinical priority areas: cancer, heart, diagnostic imaging procedures, joint replacements and sight restoration. Multi-year targets to achieve priority benchmarks are to be established by the end of 2007.

"Timely access to quality care for all" was recognized as a priority health services and policy research area in the national *Listening for Direction II* consultations that took place in 2004, the themes of which now guide IHSPR's investments and activities. In February 2005, IHSPR partnered with Canada's Provincial/Territorial Ministers of Health, as well as the CIHR Institutes of Cancer Research and Musculoskeletal Health and Arthritis, to launch a rapid-response Request

for Applications (RFA) to fund initiatives designed to inform the establishment of evidence-based benchmarks. Funded initiatives were to detail the wait time benchmarks currently in use; synthesize the evidence on the relationships between clinical condition, wait times and health outcomes or quality of life; and identify the priority areas and questions for future research, with reports timed to meet the information needs and timelines of the Federal/Provincial/Territorial Ministers of Health.

We were aware that research evidence alone would rarely be sufficient to point to an obvious benchmark. However, evidence on the relationships between waits, health and quality of life is crucial information for decision makers to take into account in setting benchmarks. It is also important, to the Federal/Provincial/Territorial Ministers of Health, and to CIHR, to understand the existing body of research, to learn from experiences in Canada and abroad, and to identify where further research is needed.

In the last few months of 2005, CIHR and IHSPR were heavily involved in knowledge translation activities surrounding the release of the second series of research reports funded under this RFA (see the *Wait Times Research Syntheses* box for links to the reports and CIHR-prepared summaries). The research supported through this RFA played an important role in the

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deliberations of our funding partners, the Provincial/Territorial Ministers of Health, as they developed their first round of benchmarks.

While this RFA represents our most targeted wait times funding initiative to date, CIHR supports an array of research projects that focus on access to care and improving wait list management, reducing wait times and improving the fairness of waits. Since 2000-01, CIHR has funded projects worth nearly \$15 million in these areas. This *Research Spotlight* highlights just a small selection of the resulting research, as well as an interview with one of Canada's best-known wait times researchers, Dr. Claudia Sanmartin, who was funded under the February wait times RFA and whose team contributed reports on two clinical priority areas. We also draw your attention to recently-funded projects (funded within the last year), which are being supported through a variety of funding initiatives, including a dedicated research synthesis program.

The announcement of the first batch of national wait time benchmarks is not likely to deflect the media spotlight far from "access to health care" issues. The benchmarks are but the first step in a process of improving access to care. Plans need to be developed by the provinces and territories to ensure that those benchmarks come to reflect actual practice; benchmarks need to be established for many other clinical conditions and types of services; the sources or determinants of waits require more detailed examination; and we need to explore the potential to reduce waits for Canadians through improved organization and management of services. There is still, alas, much work to be done.

According to the most recent Health Care in Canada survey (2005), 66 per cent of the general public believes that waiting times for elective surgery have become longer in the past two years. Fifty-eight per cent of the general public would expect to wait more than six months for a hip replacement. In addition, while less than half of Canadians state that they would be willing to pay out of pocket to purchase faster access to health services, a majority believe that allowing expanded private

insurance would result in shorter waiting times. As Claudia Sanmartin notes in the feature interview in these pages, we now need to explore the best methods for moving beyond scientific evidence and clinical opinion on wait times to reflect public expectations in established benchmarks. Research on how Canadians come to believe what they believe about access to care may provide clues as to how to better communicate about the true nature of wait lists, what causes waits and how they might be shortened.

Waiting for services can involve important opportunity costs, as the research projects focusing on early intervention services for children showcased here demonstrate. And as our article on Dr. Eduardo Franco's research on diagnostic and treatment delays in childhood cancer indicates, there are many dimensions to waiting, with a variety of aspects of importance across different conditions. Measurement alone continues to be a complex research problem.

So research opportunities and activity in this area continue. Final reports are forthcoming from the first round of teams funded under the wait times RFA in spring 2006, and a second RFA was posted in December 2005 to support initiatives in specified clinical areas not initially funded (see the *Wait Times Research Syntheses* box for more details). Research and knowledge translation activities around timely access to quality care will continue to be an important priority for IHSPR. But our ability to bring evidence into play in a timely fashion is dependent on our research capacity and the responsiveness of researchers dedicated to this critically important area. It is a pleasure to be able to feature some of their work in this *Spotlight*.



Morris Barer
Scientific Director
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Wait Times Research Syntheses

In November 2005, CIHR announced the release of eight research reports from the "Toward Canadian Benchmarks for Health Services Wait Times — Evidence, Application and Research Priorities" RFA. IHSPR launched this rapid-response RFA in February 2005, in partnership with Canada's Provincial/Territorial Ministers of Health, and the CIHR Institutes of Cancer Research, and Musculoskeletal Health and Arthritis, to fund research designed to inform the establishment of evidence-based benchmarks for medically acceptable wait times in select clinical areas.

Eight Canadian research teams were funded under this RFA to research wait times in three priority treatment areas: sight restoration, joint replacement and cancer. Each team delivered the second of three reports in October 2005 to inform the First Ministers' deliberations prior to their December 2005 milestone for establishing national benchmarks. A first set of benchmarks was announced by the Provincial/Territorial Ministers of Health on December 12, 2005. CIHR summaries of this research, and links to the full research reports are available at: <http://www.cihr-irsc.gc.ca/e/29902.html>.

A second wait times RFA was launched in December 2005 to fund initiatives in specified clinical areas not funded in the February RFA: cardiac procedures, diagnostic imaging and cancer treatments and conditions not addressed by the four cancer research teams initially funded. As with the first wait time benchmarks RFA, this RFA will be governed by an accelerated application, adjudication and funding process. The registration deadline is February 15, 2006. For more information, visit <http://www.cihr-irsc.gc.ca/e/30087.html>.

Access to rehabilitation services for physically disabled children



Principal investigator: Debbie Feldman, Université de Montréal

Co-investigators: Bonnie Swaine, Julie Gosselin, François Champagne, Raynald Pineault

Research team: Lisa Grilli, Mélanie Couture, Laurent Azoulay, Marie-Nöelle Simard

National activity around wait time benchmarks has focused on select clinical priority areas, such as joint replacement and cancer care, and the particular health or quality of life outcomes of waiting for treatment. But for many other conditions, waiting can also incur a significant opportunity cost.

For many of the 7.7 per cent of Canadian children living with a disability, rehabilitation is a mainstay of treatment. Early rehabilitation can maximize a child's function and minimize the possibility of long-term disability. Importantly, early intervention can also help families to cope with a child's disability, providing support from health professionals and ensuring access to an organized network of care.

Yet many children who need rehabilitation wait a long time for services. In a pilot study of 172 children with physical disabilities in Quebec in 1999, of the 41 per cent of children who ended up receiving therapy services within one year of follow-up, the wait was on average 119 days for physical therapy (PT) and 157 days for occupational therapy (OT).

In 2002, Dr. Debbie Feldman and colleagues at Université de Montréal were awarded an IHSPR Operating Grant to describe access to pediatric rehabilitation services for children with physical disabilities, the factors associated with delays in receiving these services and what effect delays have on children and their families.

Over the course of three years, Dr. Feldman and colleagues collected data on the waits for children referred from the outpatient departments of two Montreal pediatric

hospitals to access PT and OT services at local rehabilitation centres. Data on wait times, age, gender, diagnosis, severity of disability and family characteristics were gathered from the hospital databases and parental interviews for 224 young children with physical disabilities in Quebec.

The team found that half the children in the study waited more than 7 months for PT, and more than 13 months for OT, suggesting an increase in wait times since the first pilot study in 1999. Younger children and those with well-defined diagnoses tended to receive services sooner. Children with the more general diagnosis of global developmental delay tended to wait for a long time to receive rehabilitation.

Wait times may also be affected by the organization of service delivery within the rehabilitation centre where the child was referred. For example, the provision of services according to availability in the therapists' schedules, rather than by thematic programs, seemed to be associated with shorter waits.

The team also found that these delays can place a significant financial stress on families. Some seek private services while they are waiting. If families don't have private insurance, they may pay directly for services out of their own pockets. Additional burdens can arise for children who are referred to both PT and OT, but who cannot begin both services at the same time at the rehabilitation centre: they may be required to shuttle between interim services for one type of therapy at the hospital, and services for the other at the rehabilitation centre.

For Dr. Feldman and her team, long wait times accentuate the need to re-evaluate the current method of service delivery and to consider developing alternative models, such as more joint programs and partnerships with communities. "We believe that alternative models of service delivery need to be explored, implemented and evaluated to best meet the needs of children with disabilities and their families," says Dr. Feldman. "We need to broaden our thinking beyond the provision of traditional one-to-one treatment intervention, towards the provision of regular consultative services whereby the goal of rehabilitation is the integration of children in their communities." This would imply that therapists work in collaboration with day care educators, teachers, coaches and family members. There

may also be a need to augment PT and OT resources in rehabilitation centres to better handle the number of children who could benefit from rehabilitation services.

Dr. Feldman and her team plan to provide administrators of the rehabilitation centres with their results via personal communication and written reports. Several administrators have expressed a particular interest in the study and hope to improve service provision to children with disabilities.

Wait lists and wait times for early intervention services for preschool children in BC

Herb Chan, University of British Columbia

At the University of British Columbia, Herb Chan is also working on the issue of wait times for early intervention services, which include infant development programs, supported child development programs and therapy intervention services for preschool children. There are currently only limited data about wait lists and wait times for these services and no standardized data sources or central registries. Mr. Chan, the recipient of a CIHR/IHSPR Doctoral Research Award, is working to establish a valid measure and definition of wait list and wait time for early intervention services in British Columbia, using available administrative data from various programs, child development centres and health centres. He will also explore the current size of wait lists and the factors associated with wait times in the province. To date, about 45 agencies or programs across the province have agreed to participate in the project. Mr. Chan hopes to complete his research by September 2006 and to disseminate the results to community agencies and programs and the BC Ministry of Children and Family Development. The results of this project will help in setting benchmarks for wait times and developing tools for wait list management for preschool early intervention services.

Steven Lewis interviews Claudia Sanmartin about life as a wait times researcher



Steven Lewis is a health policy and research consultant based in Saskatoon, and Adjunct Professor of Health Policy at the University of Calgary. Prior to resuming a full-time consulting practice he headed a health research granting agency and spent seven years as CEO of the

Health Services Utilization and Research Commission in Saskatchewan. He has served on various boards and committees, including the Governing Council of CIHR, the Saskatchewan Health Quality Council, and the Health Council of Canada. He co-edited the first five annual CIHI *Health Care in Canada* reports, and has written extensively on how to strengthen medicare. He is an Associate Editor of the *Journal of Health Services Research & Policy*, and a member of the editorial board of the *Canadian Medical Association Journal*.

Dr. Claudia Sanmartin received her MSc in Health Administration from the University of Toronto and a PhD in health services research from the University of British Columbia. Claudia currently works as a senior researcher in the Health Analysis and Measurement Group at Statistics Canada. She also holds an appointment as Adjunct Research Assistant Professor in the Department of Community Health Sciences at the University of Calgary and has been a research collaborator with the Western Canada Waiting List Project since its inception.



Claudia has worked extensively in the area of access to health care services with a specific focus on waiting times, including contributions to the development of the first Statistics Canada national survey on waiting times. Claudia was a co-principal investigator, with Dr. Tom Noseworthy, on two of the eight research projects funded under CIHR's February 2005 wait time benchmarks RFA.

SL: Health care is a moving target, and waiting and wait times are “hot button” issues. There is a lot of public opinion and concern, and often very little evidence. What’s it like being a researcher on wait times in this environment?

CS: Exciting...rewarding...sometimes pressured. It is a great opportunity to work on an issue that is so timely and policy relevant, particularly when certain aspects of the research are being conducted as direct inputs to the policy making process. This means, however, that the work must be done in a timely manner under defined, and often short,

timelines. This was certainly the case with the recent CIHR RFA on wait times.

SL: Evidence-based decision-making is everyone’s goal, but it can be difficult to achieve. How important do you think recent and current Canadian research on wait times is to current policy and resource allocation discussions? Is it realistic to expect the research to influence policy-making?

CS: As a health services researcher you can only hope that the research has some impact or influence on the policy making process, acknowledging, of course, that it represents one of many inputs in the process. This is certainly the case with wait times research. There are several examples in which research in this area has been used by policy makers to effect change. The prioritization tools developed by the Western Canada Waiting List Project (WCWL), for example, have been used by a number of provincial jurisdictions to better manage patients placed on waiting lists to ensure that those who need care more urgently are at the head of the line. And both the WCWL research on maximum acceptable waiting times, and the recent work commissioned by CIHR, was considered in the formulation of benchmarks, most notably those recently announced by the Provincial/Territorial Ministers of Health.

The realistic part is recognizing that the research evidence is just one of a diverse set of inputs and sources of information being used by policy makers to deal with the issue of lengthy waits for care. The key for researchers is to ensure the evidence is timely and presented in an accessible manner. It is also important to be proactive, identifying the information gaps and anticipating the research questions before they become urgent issues for policy makers. This certainly was the case with the Health Services Access Survey developed at Statistics Canada in 2001, which currently represents the only nationally comparable information on wait times. The need for nationally comparable data on patients’ experiences in accessing care was identified and the survey was developed and designed to fill the information gap.

SL: What are some of the “eureka” results from wait times research? Do you think any of these have influenced public and political thinking about wait time issues and potential solutions?

CS: There was a key result that came out of the first national study on wait times commissioned by Health Canada in 1998 in response to growing concerns about long waits. This study highlighted the absence of valid and reliable data regarding how long patients were actually waiting for care. At the time, this was a “eureka” for the researchers involved in the work, because we had no idea at the outset that the Canadian situation was so chaotic. This result did not have an immediate impact, but as policy makers started to get serious about addressing the

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issue, the need for valid data was continually raised because they kept bumping up against the limitations in the information available to them. Developing information systems to get accurate data has been at the forefront of many of the provincial waiting time strategies since then.

Another, perhaps counter-intuitive, result from our work has been finding, consistently, that the use of targeted additional funding to increase the supply of services (such as was done in the UK and Sweden), has had only temporary effects in reducing waiting times. This type of policy, alone, does not result in sustained reductions over the long-term.

SL: What are the key questions that will have to be addressed in the next few years?

CS: There are many. We need to continue work on issues related to data definition, quality and comparability. Although not a very glamorous area of research, we need to understand what the data mean when we define wait times in different ways and how this might affect comparability across jurisdictions. There is more that can be done on the development of benchmark wait times from a methodological perspective (i.e. how best to identify/establish benchmarks?), including the development of evidence from a range of sources. To date, much of the focus has been on scientific evidence of the effects of waiting and the views and opinions of clinicians. Patients and the public also have views regarding how long individuals ought to wait for care — we need to continue to explore the best methods to gather this information and reflect it in the

established benchmarks. Given the recent establishment of wait time benchmarks in Canada, the research focus should also incorporate an evaluative component to determine how their implementation affects wait times, patient outcomes and resource requirements within the system.

We also need to take a step back and look at the broader issue of appropriateness — to ensure that individuals placed on waiting lists meet specific clinical indications for treatment at the time of placement, particularly in those cases where benchmarks have been established. International experiences with benchmarks have shown, in some cases, that they can have an effect on the thresholds and clinical indications for care. Another growing area of research interest is related to operations research and patient flow management, which promises to help us gain a better understanding of the process by which patients receive care and where changes can be made to provide care in a more efficient manner.

Finally, we have heard quite a bit lately about the virtues of establishing a private parallel system to reduce waits in the public sector, particularly since the Chaoulli Supreme Court decision. We need to look more closely at the types of private/public sector arrangements and their potential effects, not only on wait times and access to care, but also on equity. Which arrangements are likely to reduce wait times for all patients, versus only for those who can afford to pay? International experiences, such as those in the UK, may provide valuable insights on some of these issues.

Diagnostic and treatment delays in childhood cancer in Canada

*Principal investigator: Eduardo Franco, McGill University
Co-investigators: Mark Greenberg, Ronald Barr, Howard Morrison, Leslie Mery
Study coordinator: Tam Dang-Tan*

Childhood cancer continues to be the leading cause of disease-related death among Canadians under the age of 20. As with cancer in adults, delays in the diagnosis of cancer in children may worsen the stage or severity of the disease, reduce the possibility of using treatment regimens that could lead to cure, and so increase the risk of death.

But there are a number of aspects of childhood cancer that mean it should be studied separately from adult cancer. First, the



spectrum and distribution of cancers occurring in childhood is very different from those occurring in adults. Second, patient behaviour

plays a different role, because, in general, parents tend to be the first to recognize disease signs and symptoms and will bring their child to a health care provider.

However, few health studies have specifically examined the epidemiology and public health significance of diagnostic and treatment delays in childhood cancer. In 2003, Dr. Eduardo Franco and colleagues at McGill University and across Canada were awarded an Operating Grant from the Institute of Cancer Research to measure and characterize the waiting time delay of diagnosis and treatment in children between 0-19 years of age in Canada; identify the factors that influence the various delays in childhood cancer in Canada; determine whether there have been time

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trends in delays for diagnosis among children with cancer in Canada; and investigate the impact of delays in the diagnosis of childhood cancer on disease burden and survival.

Dr. Franco's team is taking advantage of a pre-existing database from the Treatments and Outcomes Surveillance component of the Canadian Childhood Cancer Surveillance and Control Program, developed and maintained by Health Canada, to conduct a retrospective cohort study. So far, approximately 6,000 Canadians under 20 years of age who were diagnosed with malignant neoplastic diseases between 1995 and 2003 are included in this study. Detailed information relating to the patients, their diagnoses and their cancer therapies have been obtained from 17 pediatric oncology centres and provincial cancer registries across Canada.

The length of delay between the onset of symptoms and a patient's first visit to health care (patient delay), and the length of delay between a health care visit and the diagnosis of cancer (diagnostic

delay) will also be ascertained from the database. Survival and disease severity will be analysed in relation to the time to diagnosis, time to treatment and other clinical parameters in the care pathway of childhood cancer patients.

This study may form the basis for new policies and programs aimed at eliminating obstacles in the diagnostic pathway for Canadian children with cancer and for improving their short- and long-term prognoses. The findings and methods from this study will also form the framework for new investigative approaches in health services research in the area of diagnostic and treatment delays for cancer patients in general. Findings from this study may help inform the development of evidence-based approaches to prioritizing suspected cancer patients waiting for diagnostic services. This, in turn, could also guide health promotion policies for primary health care providers, patients and their families to ensure more timely interventions at key steps in the care pathway of childhood cancer patients.

RECENTLY FUNDED PROJECTS

The utility of instruments for reporting waiting times for elective surgery and associated risks

Boris Sobolev, University of British Columbia

This project, funded by IHSPR under the [Research Syntheses: Priority Health Services and Systems Issues](#) program, aims to examine how useful current tools are for measuring and reporting surgical wait times. Knowledge translation is a key part of the project, with the results being communicated directly to the health system managers and policy makers responsible for developing a consistent and fair mechanism for surgical wait lists and timely health care delivery.

Patient perspectives on acceptable waiting times for hip and knee replacement surgery

Barbara Spady, University of Calgary

This project, funded by IHSPR as a [Pilot Project Grant in Strategic Health Services and Policy Research](#), will test a

method for obtaining views on how long patients think they should wait for hip or knee replacement surgery. The aim is also to understand factors that determine patients' ideas of "acceptability" around waits for care, and will be used to plan a program of research focused on the management of waiting lists for scheduled surgical services.

Organizational determinants of waiting time management for health services — A policy review and synthesis

Marie-Pascale Pomey, Université de Montréal

This project, funded by IHSPR under the [Research Syntheses: Priority Health Services and Systems Issues](#) program, examines the policy and organizational determinants associated with the management of waiting times, with a particular focus on the role of regional and local health authorities and hospitals. The resulting model will be tested through interviews with

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policy and decision makers, and will ultimately provide valuable information on the key factors associated with the successful management of waiting times.

Managing continuity of care for continuing care services in two health regions: Perspectives on wait lists

Tammy Hopper, University of Alberta and Marlene Reimer, PhD (deceased)

This project, originally funded under the Canadian Health Services Research Foundation Open Grants Competition and since transferred to CIHR, aims to better understand the nature of wait lists for publicly funded continuing care services in Alberta's two most populous health regions, and the experience of individuals as they wait for these services. The resulting data will provide managers and policy makers with systems-level and individual/client-level perspectives to aid the efficient management and allocation of resources to the rapidly growing population of older adults.

The impact of high volume service providers and short surgical waiting times on mortality and morbidity from bladder cancer

Girish S. Kulkarni, Sunnybrook and Women's College Health Sciences Centre

Girish S. Kulkarni is funded by the Institute of Cancer Research under a Clinical Research Initiative Fellowship. His research focuses on bladder cancer, a relatively rare

disease in Canada, but one often requiring complex surgery. One of his research aims is to determine whether individuals who have long waiting times for surgery are at a higher risk of bladder cancer recurrence or even death. His program of research may ultimately suggest whether care for bladder cancer should be regionalized to specialized care centres or surgeons, or whether additional funding is needed to reduce wait times for this surgery.

Strengthening the health system through improved priority setting

Andreas Laupacis, Sunnybrook and Women's College Health Sciences Centre

This team is funded by IHSPR under the [Sustainable Financing, Funding and Resource Allocation in Health Care: Options, Impacts and Public Expectations New Emerging Team \(NET\) Grants](#) program. The team's program of research will focus on public involvement in health system priority setting in two cases of high-profile resource allocation—the Common Drug Review and the Ontario Waiting List Initiative. This program of research will use a conceptual framework called “accountability for reasonableness,” which suggests that a fair priority setting process meets four conditions: relevance, publicity, revisions/appeals and enforcement. The information from the case studies, as well as other research in public involvement in resource allocation, will be shared with decision makers and the public.



IHSPR MANDATE

The CIHR Institute of Health Services and Policy Research is dedicated to supporting outstanding research, capacity-building and knowledge translation initiatives designed to improve the way health care services are organized, regulated, managed, & financed, paid for & used and delivered, in the interest of improving the health and quality of life of all Canadians.

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