

## Waiting for scheduled services in Canada: development of priority-setting scoring systems

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### Abstract

**Rationale, aims and objectives** An Achilles' heel of Canadian Medicare is long waits for elective services. The Western Canada Waiting List (WCWL) project is a collaboration of 19 partner organizations committed to addressing this issue and influencing the way waiting lists are structured and managed. The focus of the WCWL project has been to develop and refine practical tools for prioritizing patients on scheduled waiting lists. **Methods** Scoring tools for priority setting were developed through extensive clinical input and highly iterative exchange by clinical panels constituted in five clinical areas: cataract surgery; general surgery procedures; hip and knee replacement; magnetic resonance imaging (MRI) scanning, and children's mental health. Several stages of empirical work were conducted to formulate and refine criteria and to assess and improve their reliability and validity. To assess the acceptability and usability of the priority-setting tools and to identify issues pertaining to implementation, key personnel in the seven regional health authorities (RHAs) participated in structured interviews. Public opinion focus groups were conducted in the seven western cities. **Results** Point-count scoring systems were constructed in each of the clinical areas. Participating clinicians confirmed that the tools offered face validity and that the scoring systems appeared practical for implementation and use in clinical settings. Reliability was strongest for the general surgery and hip and knee criteria, and weakest for the diagnostic MRI criteria. Public opinion focus groups endorsed wholeheartedly the application of point-count priority measures. Regional health authorities were generally supportive, though cautiously optimistic towards implementation. **Conclusions** While the WCWL project has not 'solved' the problem of waiting lists and times, having a standardized, reliable means of assigning priority for services is an important step towards improved management in Canada and elsewhere.

### Introduction

It is a fact of life that publicly funded health systems have waiting lists for scheduled services. This

has become a source of unremitting management challenge in Canada. Public distress and secondary political consternation are apparent, in large part because of the uncertainty associated with waiting and concerns over the extended suffering, disability and, occasionally, death of patients on lists. The

\* See Appendix for a list of the steering committee members.

chances of a patient receiving needed services in a timely manner, based solely on clinical urgency, are uncertain. The image of Canadian Medicare as inadequate and failing to meet acceptable access provisions represents a threat to its continuing public support and sustainability.

Not surprisingly, because there is no reliable means of assessing the relative priority of patients on waiting lists, it is impossible to manage waiting lists rationally to ensure that patients with the highest urgency are served first (Hadorn & the Steering Committee of the Western Canada Waiting List Project 2000). Accordingly, the order of patients on waiting lists in most parts of Canada is based on a variety of clinical and non-clinical factors that may differ across institutions and health care providers. This situation inevitably leads to concerns regarding fairness and the risks faced by patients who may not be receiving timely and necessary care based on an assessment of relative urgency and the likelihood of benefit.

Notwithstanding the many factors underlying waiting lists and excessive waiting times, it is imperative that one of the key policy directions to address this issue should focus on the development of standardized methods that may be adopted universally for prioritizing patients for elective interventions. The mission of the Western Canada Waiting List (WCWL) project is to improve the fairness of the system, so that Canadians' access to appropriate and effective medical services is prioritized on the basis of need and potential to benefit. To this end, the overarching goal of the partnership has been the development of valid, reliable, practical and clinically transparent measures of patients' priority for wait-listed services.

We report here the work of the first phase of the WCWL project.

## Methods

The WCWL partnership of 19 organizations, with a common interest in improving waiting list management, was established in November 1998 (Table 1). It brought together researchers, regional health authorities, medical associations and provincial health departments to define the participative research agenda and to develop the steering committee, project infrastructure and work plans.

**Table 1 WCWL partnership**

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<i>Seven regional health authorities:</i>
Victoria: Capital Health Region
Vancouver: Vancouver/Richmond Health Board
Edmonton: Capital Health Authority
Calgary: Calgary Health Region
Regina: Regina Health District
Saskatoon: Saskatoon District Health
Winnipeg: Winnipeg Regional Health Authority
<i>Four provincial ministries of health:</i>
British Columbia Ministry of Health
Alberta Health and Wellness
Saskatchewan Health
Manitoba Health
<i>Four medical associations:</i>
Canadian Medical Association
Alberta Medical Association
British Columbia Medical Association
Saskatchewan Medical Association
<i>Four research organizations:</i>
Department of Community Health Sciences, University of Calgary
Centre for Health Services & Policy Research, University of British Columbia
Health Services Utilization and Research Commission, Saskatchewan
Centre for Health Policy & Evaluation, University of Manitoba

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Five regional health authorities were chosen to serve as primary host centres for panels constituted to deal with five clinical areas: Saskatoon District Health (cataract surgery); Winnipeg Regional Health Authority (general surgery procedures); Capital Health Authority (hip and knee replacement); Calgary Health Region [Magnetic Resonance Imaging (MRI)], and Vancouver Richmond Health Board (children's mental health). Cities were selected primarily on the basis of their interest and demonstrated leadership and commitment. Clinical areas were chosen as being representative of known long waiting times in Canadian centres, with an attempt to include diagnostic as well as medical and surgical interventions that had been the subject of public attention.

Each panel was co-chaired by a local, experienced and respected leader in the relevant clinical area and

the project's research director (D.C.H.). Clinical co-chairs were nominated by the host regional health authorities. Panels consisted of up to 12 members, including primarily community-based and academic specialists involved in the relevant clinical areas. Referring specialists, family physicians and health administration or research participants were also on each panel. Steering committee members attended most meetings.

To improve generalizability of tools and to promote input from the diversity of practice and practitioner models, approximately half of the panel members were drawn from nominees of the host city's regional health authority, with the remainder from the other six centres across Western Canada. Panels met on three to five occasions, with the mandate to guide the formulation, development, testing and refinement of priority-setting tools.

Development of the tools was a highly iterative and clinically oriented process, involving several stages of input and empirical assessment of reliability and validity. In essence, this formative or action research was focused on modelling clinical judgement (Stringer 1999). Panellists chose to develop point-count measures, not dissimilar to an earlier approach followed in New Zealand (Hadorn & Holmes 1997a, 1997b). Each panel identified major clinical criteria (e.g. frequency of painful episodes) currently used (if informally) to determine patients' relative urgency, as well as frequency or nature of symptoms within each criterion (e.g. none, occasional, often, constant). All panels chose to incorporate personal and social measures, such as the ability to perform roles and live independently. Sociodemographic characteristics such as age, gender and socioeconomic status, although discussed in depth, were not judged to be relevant or appropriate in the assessment of urgency for treatment. Accordingly, they were not included as criteria.

Literature reviews focusing on factors influencing urgency for and outcomes of interventions were prepared in cataract surgery and hip/knee replacement. These provided another level of input to panel deliberations, supporting individual clinical judgement, and were important for consensus building. Because the general surgical panel chose to include all the case types for which a surgeon would normally make an elective booking in an operating room, represen-

tative and selected literature reviews were conducted on laparoscopic cholecystectomy, breast cancer, colorectal cancer and inguinal hernia. The decision was made to include the entire case mix of those waiting for children's mental health and MRI services. Similar literature reviews were not carried out for these panels, since little or no information was available upon which to make determinations of urgency across such a broad case mix. Thus, while all panels approached tool development and subsequent refinement in a generally comparable fashion, case mix and interventions were more highly specific for cataract surgery and hip/knee replacement, while all diagnoses and interventions were covered in the general surgery, MRI and children's mental health panels. In these latter panels, the range of diagnostic and therapeutic options was diverse and, arguably, more comparable to the current trade-off considerations of practising clinicians. To enhance the perceived utility of the tools (at the cost of complicating tool development), the hip/knee replacement panel included both primary and revision arthroplasties, the cataract tool included both 'bad' and 'good' eyes and the general surgery criteria incorporated both cancer and non-cancer cases.

### Pilot testing

Initial priority-setting criteria were incorporated into additive scoring tools and were used by panellists and designated clinical colleagues ( $n = 146$ ) to score a series of consecutive patients in their practices. Data collection took place between November 1999 and May 2000. Participating clinicians assigned each patient an appropriateness level for each criterion (e.g. mild pain, moderate limits in role function) and also rated each patient on a 100 mm visual analogue scale, ranging from 'not at all urgent' to 'extremely urgent, just short of an emergency'. This latter rating served as the dependent variable in regression analyses, which were used to determine the initial and statistically optimal set of weights for each criterion, to best predict overall urgency ratings. Linear regression analyses were constrained by retaining all predictor variables (criteria), regardless of inter-correlations among criteria. Panellists wished to retain all criteria in order to ensure clinical sensibility and adequate face validity, even where significant

intercorrelations did exist among criteria. Thus, it would probably be unacceptable from a clinical point of view to remove from the questionnaire explicit consideration of, say, the extent of symptoms patients are experiencing, even if these tended to correlate with or were captured by scores on other items. Calculated item weights reflected the relative contribution of each criterion to the total urgency score. The criteria and weights for each case type were the focus of at least three meetings of each panel, at which there was considerable discussion and reflection on the clinical sensibility of criteria and the weights generated by regression analyses.

To evaluate the extent of inter-rater reliability associated with each tool, six standardized patient cases were developed, representing a range of urgency. Panellists and clinical colleagues ( $n = 73$ ) independently rated each scenario within their clinical area, using the tools in their then-current state of development. General surgery and cataract surgery panellists viewed videotapes of interviews and examinations of scripted patient-actors; hip and knee panellists used videotapes of actual patients' assessments, whose participation and consent process was approved by the Ethics Committee (Panel B) of the University of Alberta. MRI and children's mental health raters reviewed a series of 'paper cases'. Inter-class correlation coefficients (ICC) and Kappa statistics were used to evaluate the degree of inter-rater reliability for each criterion. Panellists discussed cases in conference, using these exchanges to improve the criteria, remove ambiguity and refine the weights.

At their final meetings, clinical panels reviewed the final results of regression analyses, the reliability testing, comments by participants in the pilot testing and reliability exercises, and experiences gained during the data-collection period. Following detailed discussion and debate, the panels made modest changes to the criteria and/or weights, based primarily on considerations of clinical face validity. Additionally, brief guides were developed for use of the tools in clinical practice.

The revised tools were then subjected to a second phase of reliability testing, where 72 clinicians participated in the inter-rater, and 54 took part in the intra-rater assessments. Clinical scenarios were the same as those used in the earlier phase, with

one exception: children's mental health cases were revised to include a broader range of urgency. The presentation sequence of cases was modified to control for order effects. Observers were asked to estimate the maximum acceptable waiting time for each case. Twenty-eight clinicians took part in small-group sessions to discuss selected cases and clarify ambiguities in the priority criteria or instructions.

### Environmental analysis

Upon completion of the tool development period (December 2000), an implementation panel of opinion leaders from regional health authorities (RHAs) was established to assess usability and potential for uptake and implementation of the WCWL priority tools in the RHAs participating in this project. This panel commissioned a survey of current waiting list management practices in each of the seven RHAs. A semistructured interview schedule was pilot tested within the partnership and completed in each city. Information was collected through individual and small-group discussions, including Chief Executive Officers (CEOs) and Chief Information Officers (CIOs) senior administrators and clinical and physician managers. This was analysed for thematic content in an attempt to define critical success factors and to develop strategies for implementation.

To assess broader perceptions of current waiting lists and perspectives on the WCWL scoring systems, public opinion focus groups were conducted in Victoria, Vancouver, Calgary, Edmonton, Regina, Saskatoon and Winnipeg. Households were contacted randomly by telephone, and individuals were selected through a screening process that ensured both a range of sociodemographic profiles and participants with direct experience of, or at least some interest in, health care waiting times. All work was reviewed, together with general discussion of waiting list issues and specific interaction regarding the criteria, implementation issues and participants' comfort with the approach and tools. This input was similarly analysed for thematic content and repetitive elements related to usability and acceptability.

During the course of the project, the 19-member WCWL partnership met three times to review work

in progress, to obtain advice from experts in the field and to provide strategic direction. This was complemented by a project steering committee, which provided overall guidance and direction to the project, by internal and external communications plans, a web site, regular news briefings in the media, presentations to professional groups and partner organizations and financial and progress reports to Health Canada. At the concluding meeting of the partnership, the final report, together with recommendations for additional work, was approved for submission to Health Canada and distributed broadly ([www.wcwl.org](http://www.wcwl.org)). Partner organizations' leadership were also requested to review and consider endorsing the work and their ongoing participation.

## Results

Perhaps of greatest practical and policy significance with regard to future work on this problem, and a direct result of the Health Transition Fund and the WCWL project, was the ability of a partnership of Canadian governments, regional health authorities, research centres and medical associations to make significant progress in developing and testing tools for use in prioritizing patients on elective waiting lists. Such broad-based action research in waiting list management is unprecedented. All partner organizations' governance or management bodies endorsed

the final reports and contents, and made a commitment to ongoing participation.

One hundred and forty-six clinical panellists and their colleagues in the four Western Provinces completed 2690 priority criteria forms during tool development, pilot testing and refinement. This ranged from 406 cases for hip and knee replacement to 766 for children's mental health (mean per panel = 538). Based on the comments made during the testing, participating clinicians felt that the criteria and weights had demonstrated good to excellent face validity and were practical and usable in clinical settings.

The five tools may be found through [www.wcwl.org](http://www.wcwl.org). Individual criteria in each tool sum to a maximum score of 100 points for the most urgent cases. Table 2 illustrates the variance in overall ratings of urgency, which can be explained by these criteria ( $R^2$ ), ranging from 0.36 (cataract surgery and MRI scanning) to 0.62 (hip/knee replacement). These results predated both the construction of an explanatory user's guide and additional efforts that were made to remove ambiguity and lack of clarity from the criteria.

Results from the first phase of inter-rater reliability testing are summarized in Table 3. Over all tools, 24% of the items resulted in an excellent reliability rating ( $ICC > 0.75$ ), 45% were fair to good ( $ICC 0.40-0.75$ ) and 31% were poor ( $ICC < 0.40$ ). Inter-rater agreement for the overall urgency scores was highest for general surgery and hip/knee

**Table 2** Historical summary of the priority tool development

Priority criteria form	First panel meeting		Pilot testing		Final panel meetings
	Original tool (October 1999)	Sample size	Clinicians (n) <sup>c</sup>	R <sup>2</sup>	Revised tools (June 2000)
Cataract surgery	9	550	9	0.356	7
General surgery	8	561	13	0.514	7
Hip and knee replacement	8 <sup>b</sup>	406	17	0.621	7
MRI	10	407	15	0.365	5
Children's mental health	21	766	92	0.417	17
Total		2690	146		

<sup>a</sup>Totals do not include the response variables used to gauge overall urgency (VAS).

<sup>b</sup>Tool revised at January meeting: two items combined into one, one item deleted or one item added.

<sup>c</sup>Number of clinicians contributing completed forms to the data collection.

**Table 3 Results of reliability testing**

Panel	Raters	Process	Distribution of items by ICC <sup>a</sup> scores <sup>b</sup>			Ranking <sup>c</sup>	VAS urgency <sup>d</sup>	Maximum waiting time <sup>e</sup>
			>0.75	0.40–0.75	<0.40	ICC	ICC	ICC
Cataract surgery	10 surgeons	Videotape	4	2	3	0.64	0.51	0.35
General surgery	9 surgeons	Videotape	4	3	1	0.85	0.76	0.58
Hip and knee replacement	14 surgeons	Videotape	1	6	0	0.77	0.85	0.41
MRI	9	Paper cases	1	4	5	0.18	0.03	0.00
Children's mental health	18	Paper cases	3	10	8	0.29	0.26	0.30
Total			13 (24%)	25 (45%)	17 (31%)			

<sup>a</sup>Interclass correlation coefficient – ranges from 0 to 1, with higher values indicating better reliability.

<sup>b</sup>Number of criteria rated: cataract surgery (9); general surgery (8); hip and knee replacement (7); MRI (10); children's mental health (21). For MRI and children's mental health, data are presented for all raters; for the surgical panels, data are reported for surgeons only.

<sup>c</sup>Relative ranking of all six cases on a visual analogue urgency scale.

<sup>d</sup>VAS is 10 cm. Visual analogue urgency scale, recorded by clinicians for each of the standardized cases.

<sup>e</sup>Raters' judgement of the maximum acceptable waiting time for each case.

replacement and lowest for the MRI and children's mental health tools.

At the final panel meetings, in addition to changes to the tools to improve understandability and usability, user-friendly explanatory users' guides were prepared to clarify criteria and definitions. Limited changes to the original tools included the combination, addition or deletion of items, resulting in a decrease in criteria for all tools (Table 2). Subsequent results of Phase II inter-rater reliability testing of the revised tools showed overall improvement, with 39% of items showing excellent reliability (ICC > 0.75), 29% fair to good (ICC 0.40–0.75), and 32% poor (ICC < 0.40). Test-retest reliability revealed 55% of items with excellent reliability.

### Environmental analysis

The survey of current waiting list management practices in regional health authorities included 39 group and solo interviews (66 respondents). Substantial differences existed in the way waiting lists were established and managed in the health authorities. Interviewees reported that the length of patient waits was not always commensurate with the urgency of conditions. Respondents were generally and consistently supportive of WCWL point-score measures

as being transparent, theoretically sound and potentially applicable. With respect to usability and acceptability, it was acknowledged that change management strategies would have to be developed and would be of critical importance to successful implementation.

The seven public focus groups (66 participants) demonstrated extremely strong support for the WCWL approach to the development of clinically relevant and transparent measures of relative urgency. In fact, many participants were surprised and disappointed to learn that no standardized method existed for priority setting for elective cases. Widespread agreement was apparent for the appropriateness of including such social and role factors as ability to work and live independently, and care of dependents. Invariably, public respondents indicated that they would be prepared to be scored this way for elective interventions, but cautioned that implementation required not only valid and reliable tools, but also clear operational policies and guidelines.

### Discussion

'The causes underlying lengthy waiting lists and times are many, varied and changeable. So too must

be the solutions' (Western Canada Waiting List Project 2001a). In 1998, a report to Health Canada stated that there is widespread interest in standardizing data and coordinating and integrating waiting lists and that significant investment is needed in waiting list infrastructure (McDonald *et al.* 1998). The WCWL project was formed to address this agenda, choosing initially to focus on five clinical areas: cataract surgery, general surgery procedures, hip and knee replacement, MRI scanning and children's mental health. These represent a range of procedural, diagnostic and consultative interventions, permitting comprehensive consideration of factors believed to be important in determining urgency and benefit to patients. Because WCWL tools cover a broad array of conditions and interventions, they provide broader insights to priority setting. Options for further development include expanding the current scoring systems: for example, from joint replacement to all elective orthopedic cases; from cataract surgery to general surgical ophthalmology, or prioritization tools for referrals or for use by primary care providers.

Of particular importance is that three of the five clinical areas spanned a comprehensive case mix for scheduled services. This understanding, together with our position paper on managing lists to achieve distributive justice (Western Canada Waiting List Project 2001b), are meant to further thinking on the themes/criteria and considerations relevant to making decisions, which cut across a broad case mix or range of interventions.

That point-count measures such as these have been developed for use in New Zealand and the United Kingdom suggests some commonality of problems with access to care (Hadorn & Holmes 1997a, 1997b; Mid-Hampshire Health Authority 1999). This should facilitate international comparisons of surgical waiting lists and collaborative approaches to developing effective and fair solutions.

Each tool has undergone clinical iteration, refinement and reliability testing. Early analysis suggests that these physician-scored tools are, to a varying extent, able to discriminate between patients of differing levels of urgency and ability to benefit. Regional health authorities and the public have been consulted on the approach, work to date and implementation.

The scoring systems developed in the WCWL project were designed to assess patients' relative clinical severity or urgency as assessed by clinicians (Hadorn & the Steering Committee of the Western Canada Waiting List Project 2000). Similar point-count measures are used throughout medicine to assess severity of conditions and risk of adverse events, including assessment of neonatal stability (Apgar Score) and categorization of the level of consciousness following closed head injury (Glasgow Coma Score). In these measures, priority criteria are additive or linear models from a statistical perspective. Such measures can be used to assess and compare waiting lists across regions and over time.

In addition to serving as indicators of clinical urgency, priority criteria should encompass psychosocial indicators, such as impact on role function, care for dependants or living independently. Such indicators were incorporated into WCWL surgical examples and, in modified form, in the children's mental health criteria. Criteria of no clinical value, such as age, gender and socioeconomic status, were not considered as relevant to inclusion by panellists or by the public. This is clearly an area of substantial importance to bioethics, and an issue with dynamic characteristics, which will be influenced as higher-quality epidemiologic data emerges from health services research and outcomes studies.

A significant question raised is whether the WCWL criteria have demonstrated sufficient validity to warrant implementation by RHAs. In this regard, it has to be appreciated that there is no accepted indicator or 'gold standard' of validity, or of urgency for that matter. The  $R^2$  values shown in Table 2 represent the extent of correspondence between the priority scores and clinicians' considered judgements of patients' overall urgency. But these latter judgements are not sufficiently objective or reliable to warrant consideration as 'gold standards' against which the criteria may be validated confidently. As such, evidence of criterion validity is lacking. However, the face or construct validity of the criteria – the extent to which the criteria reflect the bases of doctors' best judgements of urgency – is adequate for purposes of implementing the criteria in evaluative settings. Ultimately, it will become possible to assess criterion validity by reference to the 'gold standard' of patients' health outcomes. This has

not been done as yet. The MRI tool presented a particular challenge, given its reliance on probability estimates of test results and subsequent clinical outcomes from presumed interventions. The resulting poor reliability of this tool, in our assessment, was due to a variety of such factors. This tool will require further development and attention before consideration of implementation.

Measures cannot be more valid than they are reliable. It is here that WCWL offers important contributions to the international effort to develop priority criteria. Little work has been directed towards assessing intra- and inter-rater reliability. The only formal example of which we are aware is unpublished work conducted in the mid-Hampshire region of England, which found good agreement between the priority scores assigned by GPs compared with those assigned by specialists for patients with hip or knee arthritis or cataracts (Mid-Hampshire Health Authority 1999).

The inter-rater reliability test results represent a baseline, 'worst-case scenario' insofar as no special prior efforts were made to prepare participants for the process, or to develop explicit standardized meanings for the criteria (and their components). With additional experience and discussion, subsequent reliability was improved. It is likely that higher levels of reliability are achievable with further efforts directed at tool refinement and standardized usage.

Good inter-rater reliability is also important to ensure fair and uniform application of the criteria and to foster confidence in the prioritization system. In particular, demonstrating consistency in rating is essential to reducing concerns about gaming of the system. While it might be argued – and is true to some extent – that gaming cannot be prevented, having a standardized reliable scoring system will be of help to clinicians and offers opportunities for peer review and audit.

In terms of concurrent validity, further testing of WCWL tools is underway to compare the tools to known alternate measures, such as health-related quality of life, WOMAC (hip and knee) and VF14 (cataract).

As such work continues and critical next steps are being undertaken, the assumption and limitations of the WCWL project must be acknowledged. We started with the assumption that patients placed on

elective waiting lists need to be there. Not discounting its importance, we did not directly consider the issue of appropriateness for waiting lists. Panels were reluctant to accept a low cut-off score as implicitly or explicitly leading to such a definition. However, this may argue for accumulation of 'points' for the mere act of waiting, i.e. length of the waiting time. Furthermore, automatic reassessment and rescore of patients would be needed for those who fail to reach some arbitrary threshold and whose condition/scores may change. This, of course, would represent sound clinical practice, regardless of cut-off scores, for any patients at risk of deterioration on waiting lists. Neither of these issues is addressed directly by current WCWL tools, but could represent important further work.

While there is logical support for why the panels were designed almost exclusively for clinical input, the fact is that the public was not included in the panels. This means that the views of the public are not embedded explicitly in the original scoring systems. Confirmatory support later on is of importance but is not seen as a substitute. Moreover, the tools in essence model clinical judgement. While this is how medicine is practised, clinical judgement is amorphous, multidimensional and may not always reflect best practice. The limitation in content and applicability of available evidence to support such clinical judgement is, of course, an added detriment.

Ultimately, irrespective of any further tool adaptation or reliability work, validation compels investigation of patient score in relation to clinical outcome, and determination of whether the scoring systems offer advantages to the rational management of waiting lists and benefits to patients. It is anticipated that this will be a key feature of evaluation during implementation, as recommended by WCWL in respect to these first versions of the tools.

As WCWL completes this phase of its work, we acknowledge that we have not solved the problem of waiting lists and wait times, although we believe this to be an important contribution to better management in Canada and, for that matter, elsewhere.

### Acknowledgements

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## Appendix

### Members of the Steering Committee of the Western Canada Waiting List Project

Chair: Dr Tom Noseworthy, Professor, Health Policy and Management, Department of Community