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PUBLIC REACTION TO WCWL WAITING LIST TOOLS

FOCUS GROUP STUDY

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PUBLIC REACTION TO WCWL WAITING LIST TOOLS

Focus Group Study

Prepared By: Ipsos-Reid Corporation

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Western Canada Waiting List Project
13-103 Clinical Sciences Building
University of Alberta
Edmonton, Alberta
Canada T6G 2G3
(780) 492-1012
www.wcwl.org

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EXECUTIVE SUMMARY

In order to address the lack of standardized methods for prioritizing patients on waiting lists, the Western Canada Waiting List Project (WCWL) has developed tools to help manage and administer waiting lists for certain planned medical treatments and procedures. In order to gather public feedback about these tools, Ipsos-Reid conducted a series of focus groups between February 5 and 16, 2001 in seven Western Canadian urban centres. The following executive summary will outline the most salient findings from this research.

Participants hold negative perceptions of the state of current waiting times, believe that waiting lists are managed inconsistently, yet are quite unaware of how the system operates.

Strong levels of concern about the current state of waiting times for planned medical procedures or treatments are identified by individuals in all focus group sessions. Such comments are formed by personal experiences, word-of-mouth, and media coverage. With respect to the management of waiting lists, participants hold varied views about how the prioritization of wait lists is determined and by whom lists are handled. Participants acknowledge that they are, in fact, quite unaware of how the system operates and express a desire to learn more about this issue.

The criteria used in the tools to establish prioritization of waiting lists are perceived as relevant and are widely accepted.

Although individuals consulted may lack awareness about how the waiting list system works, they understand the concept of a waiting list and can appreciate the complexity with which prioritization is handled. In this light, participants believe that the most important criteria to be used in determining priority order of waiting lists involve the patient's need, urgency and severity of the case. All other factors are perceived to be secondary in nature, including the belief that social factors (e.g. independence, having dependants), or emotional impact should be included as determining criteria.

Participants recognized the criteria they believe to be important in the tools they reviewed, and with a few minor modifications, widely accept the reasonableness of the content of the forms. This is strongly reflected in almost all participants' willingness to have these tools applied to them or their loved ones to determine their priority order on waiting lists.

The concept "from chaos to order" is collectively embraced and supported.

Given that the existence of waiting times is part of a much larger issue at play in the public domain, the proposed approach to use the WCWL tools for waiting list prioritization is seen as an improvement to the overall system. This is exacerbated by the priority all Canadians, including Western Canadians, place on health care in this particular era. To this end, participants collectively support the WCWL concept and believe that the tools should be implemented upon finalization of their suggested modifications.

I do think that overall it would go towards alleviating peoples' fears, and would allow for a better understanding and acceptance that they are better being served.

The remaining issue at play is: Where do we go from here . . .

The focus group research has illustrated that the public supports the WCWL concept and accepts the criteria used in the tools – with minor suggested modifications. The remaining issue that participants leave for the WCWL's consideration as it moves forward involves the implementation of the tools. Participants would like to know that clear processes and guidelines are in place with respect to:

- Who completes the tool (they prefer the doctor to complete the tool with considerable patient input);
- The amount of patient input and the sharing of scoring results (generally, participants prefer not to know their scores, but may want to see the completed form with the scores excluded);
- The number of allowable assessments for the initial prioritization assessment (participants believe that a second opinion should be allowed, but that third opinions should be prohibited);
- The need for reassessments due to deterioration while waiting (e.g. within what timeframes can one return to have their condition and relative urgency reassessed?);
- The management of tie-breakers (all things being equal, who goes first?); and,
- The management of the lists (who is handling this data?).

Communication is the key to success.

Participants want to be involved and informed about decisions made within their treasured health care system. They express a desire to be educated about any changes that could potentially take place. This communication and messaging can indirectly and

positively impact individuals' perceptions of the state of waiting times by showing the efforts in place to address issues of fairness within the system.

Based on the comments made by participants, it is apparent that through addressing ways to standardize how waiting lists are developed and managed, this indirectly relates to a sense that efforts are being made to improve waiting times for planned or elective medical procedures.

INTRODUCTION AND BACKGROUND

Health care has remained the number one issue across Canada, predominantly focused on waiting times and quality care. In fact, the latest Angus Reid Express (Jan 2001), a national syndicated study run by Ipsos-Reid Corporation, reports that 50% of Canadians feel health care is the most important issue facing the country today. Health care is consistently the number one issue across the country, including in each of the western provinces.

Many studies have been conducted among the public and medical professionals in an attempt to address growing concerns about waiting times for elective or planned medical procedures. One such study sponsored by Health Canada, *"Waiting Lists and Waiting Times for Health Care in Canada – More Management!! More Money??"* indicated that there are no standardized sources of data for compiling information on waiting lists. Essentially this means that waiting lists for planned procedures are currently being managed on an ad-hoc basis, often varying from physician to physician.

In an effort to address this issue, a group of individuals from medical associations, regional health authorities, health research centres, and ministries of health, have formed a co-operative group entitled the Western Canada Waiting List Project (WCWL). The mission of the WCWL Project is to develop tools to help manage and administer waiting lists for certain planned treatments or procedures. In essence, the tools are meant to offer a standard method to determine who should go ahead of whom for specific medical services based on a range of criteria, such as urgency of need for care, or the ability to benefit from the care received.

To begin this task, the group has focused on developing tools or lists of criteria to prioritize patients in five specific service areas:

1. Cataract surgery;
2. Children's mental health;
3. General surgery;
4. Hip and knee replacement; and,
5. MRI scanning.

The group has developed and tested these draft tools (each consisting of a series of items which doctors have identified as important in assessing the patient's priority) among medical practitioners, and subsequently sought additional feedback from the public's perspective. To this end, WCWL commissioned Ipsos-Reid Corporation to conduct a series of focus group sessions across Western Canada to gather public reaction to the tools.

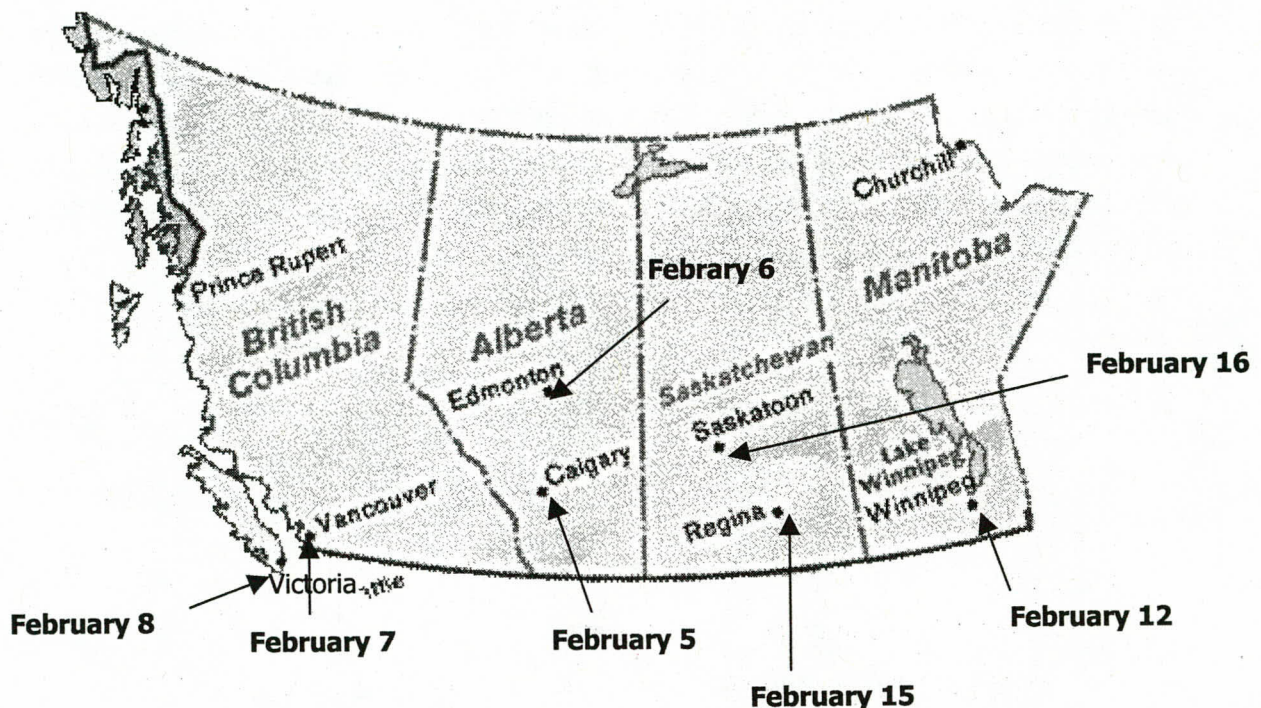
Research Objectives and Methodology

The primary objective of the focus group research was to collect feedback from the general public with respect to the five draft tools developed by the WCWL Project. More specifically, WCWL was interested in feedback regarding:

- Public perceptions and knowledge of current waiting lists for planned medical procedures;
- What criteria the public believes currently are being used and should be used to assess priority order in medical waiting lists;
- Who the public believes currently is and should be managing waiting lists for elective medical procedures;
- Non-clinical feedback with respect to the five tools developed by WCWL including:
 - initial impressions;
 - reaction to criteria used in tool;
 - suggestions on other criteria to include in the tool;
 - opinions with respect to the concept of weighting scores associated with response categories;
- Issues and "what if" scenarios related to possible implementation strategies of the tools including:
 - level of comfort with this tool being used to prioritize patients for various medical treatments/procedures;
 - who should manage the waiting lists;
 - patient involvement in completing the form;
 - if implemented, how and what to communicate to the public about the tool; and,
- Recommendations to the WCWL Project.

Due to the in-depth discussion, and the complexity of the tools being presented, a qualitative research approach was selected to collect input. In particular, a series of focus group sessions were conducted across Western Canada with members of the public. A focus group comprises of gathering a small group of people together to have an in-depth discussion about a topic of interest. A focus group enables the researcher to probe participants to collect detailed information about a specific issue or topic, and allows for group interaction – which produces a greater deal of information and ideas than if each participant was interviewed on their own.

As all individuals living in Canada are affected by the public health system, it was determined that the focus group sessions should include all individuals from the general population. The WCWL Project is considering the possible implementation of these tools across Western Canada, and, therefore, focus group sessions were conducted in major cities in Manitoba, Saskatchewan, Alberta, and British Columbia. One session was held in each of the cities listed below between February 5 and 16, 2001, including the “host” cities of each of the tools:



Screening criteria for these general public groups was necessary to ensure that a broad range of individuals participated in the study. Therefore, the following screening criteria were utilized when recruiting individuals to participate in the focus group sessions:

- Are at least somewhat concerned about health care waiting times;
- A good mix of age groups from 18 to 75;
- A good mix of socio-economic status (e.g. income and education);
- A good mix of gender representation;
- An identifier to determine if the participant or their close relatives or friends have ever been on a waiting list for any of the target areas (the majority of participants had experience in this area); and,
- Disqualification of individuals who work or have worked in the health care field (including those whose family or household members fall into this category) or for the media, market research firms, or an advertising agency.

Households were randomly contacted and the individual who answered the phone was read the screening document. If this individual met all the criteria listed above, they were invited to attend the focus group session. Ten people were recruited for each focus group session with the expectation that eight would show and participate. A total of 66 people attended the seven sessions. One moderator conducted all workshops to maintain a consistent approach in all sessions. The recruitment screening questionnaire and moderator's guide are attached in the Appendix.

The following table outlines the broad socio-demographic characteristics of the focus group participants.

Demographic Categories	Number of Participants	Percentage
Gender:		
Male	31	47%
Female	35	53%
Age:		
18-24	8	12%
25-44	20	30%
45-64	24	37%
64+	14	21%
Annual Household Income:		
Less than \$30,000	10	15%
\$30,000-\$49,999	26	40%
\$50,000-\$69,999	16	24%
\$70,000 or more	12	18%
Refused	2	3%
Highest Level of Education Partially or Fully Completed:		
High School	26	39%
Technology School	11	17%
College	12	18%
University	16	24%
Refused	1	2%

The reader should note that the results presented in this report are qualitative in nature and reflect the opinions expressed only by selected participants who attended the focus groups. Although consistencies and logic lend confidence to the analysis and interpretation, there is no way of determining the degree to which the opinions expressed are reflective of the study population at large.

A number of verbatim comments provided by participants in the sessions have been included in this report, which illustrate opinions and generally reflect a general consensus of the individuals within the focus group sessions.

PERCEPTIONS, KNOWLEDGE, AND VIEWS

To initiate the group discussion, participants were asked a series of general questions related to current waiting times. This initial discussion assisted in providing participants with a point of reference regarding the key issues related to waiting lists and waiting times for planned medical procedures.

General Perceptions of Waiting Times

When asked about their opinions on waiting lists for elective medical procedures, almost all participants commented that they are relatively unaware of how waiting lists are currently developed, managed, and maintained. Several base their opinions on what they hear in the media and/or stories recounted by friends or family members who have been placed on a waiting list. Overall, perceptions of waiting lists and times for elective medical procedures are described negatively such as: too long, inconsistent and subjective to each situation, reflected negatively by the media, or as primarily caused by a lack of resources and funding.

"They seem to be longer than what I would expect them to be."

"Seems like waiting times vary from case to case."

"Very suspicious. You never hear the full story."

"All I know is what I read in the paper."

"Anything you read in the paper you need to take with a grain of salt."

"Not enough doctors to meet the needs."

Definition of a Waiting List

Participants were also asked to describe in their own words the definition of a waiting list. Consistently, the definition involved a collection of patients needing attention placed in a priority order. More specifically, participants state that a waiting list is a wait for service based on a predetermined set of criteria such as the need for service and/or on a first-come-first-serve basis. Verbatim comments by participants defining a waiting list include:

"Booking an appointment for a procedure with a non-specific date that can be bumped based on others' needs."

"An allocation of people needing attention and put in order."

"A list of people waiting to have an operation."

"It's like lining up at the bank on payday."

"Too many people who need help and not enough helpers."

Participants were then asked *why* they believe waiting lists exist. They believe that the reason is a simple function of demand for services exceeding the supply of resources available. Several comments provided by participants illustrating this demand over supply include: shortage of funding, shortage of nurses and physicians, lack of modern equipment, and the allocation of scarce resources. Some also suggest that lists exist because people abuse the system by *"jumping the queue,"* or because doctors are restricted to perform surgery at one hospital which may be busier than other hospitals.

An overall sentiment emerged that waiting lists exist to prevent "chaos" in the system – e.g.: an effort to make the allocation of services as smooth and fair as possible. This sentiment supportively touches the heart of the WCWL Project initiative, as highlighted in the WCWL Interim Progress Report.

Participants were also asked how they felt or would feel if or when they were placed on a waiting list for a medical procedure. They described a range of emotions: stressful, excruciating, anxious, or angry. They also indicate that being on a list creates a feeling of uncertainty as urgent cases may emerge while they are waiting. One described waiting lists as a "hope line" for life, while another commented that being on a list can make life planning difficult. Overall, participants feel a level of uncertainty and confusion because they do not know the "real" status of their case.

"You can't make arrangements or plan your life."

"You've always got something hanging over your head."

Perceived Management of Waiting Lists

A key finding throughout all focus group sessions is that participants do not have a strong understanding of how lists are currently managed or of who maintains them. When asked, participants believe the following agencies and/or individuals manage waiting lists, although with some level of uncertainty:

- Hospitals;
- Registered nurses;
- Hospital clerks;
- Physicians;
- Some kind of Board;
- The health district; or,
- The provincial ministry of health.

Participants felt strongly that "someone must do it," but were not overly confident as to which agency or individual does so. It is clear that the public is relatively unaware of how the system is managed; however, they are concerned and curious about this process.

Suggested Criteria to Determine Priority on Waiting Lists

Most participants admit that they do not know what criteria are "officially" used in determining priority on medical waiting lists. However, participants speculate that priority is currently based on:

- The level of need/severity of case;
- Whether the patient is a provider of a household;
- Whether treatment is likely to increase quality of life;
- A first-come-first-serve approach;
- The doctor's connections or effort to push a case forward;
- Whether the patient will be hospitalized and for how long;
- How long the patient has been sick;
- The cost of maintaining the health of the patient while waiting;
- The age of the patient;
- The procedure that needs to be performed;
- The potential threat to a patient's life; and,
- The probability that the patient will live through the treatment/procedure.

Participants express mixed views on a number of these points. In particular, a consensus was achieved among participants that severity of the patient's case is currently being used to determine priority order of waiting lists. However, criteria that create debate include most others, such as the age of patient or whether the patient has any dependants.

When asked what criteria they think should be used to evaluate the priority order of medical waiting lists, the following items were identified:

- Severity of pain/case/condition/urgency and/or risk of death, (this criterion is noted as significantly more important than any other mentioned);
- Doctor's overall recommendation;
- First-come-first-serve;
- Quality of life prior to and after treatment;
- Potential deterioration if not treated – life threatening;
- Whether patients have dependents to care for;

- The type of procedure;
- The length of time patient has been on a waiting list;
- The effect the condition may have on patient's employment; and,
- The ability to return to work after treatment / contribution to society.

The following table summarizes the criteria participants believe are currently used and the criteria they believe should be used to determine priority on waiting lists:

Should be Used	Criteria	Believe is Currently Being Used
✓x	Severity of pain	✓
✓	Risk of dying if not treated	✓
✓	Quality of life before/after treatment	✓x
✓	Risk of loss of life	✓x
✓x	Age of patient	✓x
✓	How long patient has been sick	✓x
✓	Probability that patient will live through procedure	✓x
✓x	Doctor's recommendation	✓
✓x	First-come-first-serve	✓x
✓x	The cost to society (e.g. social services) while waiting for treatment	x
✓x	If patient works and contributes to society	x
✓x	If patient has dependants	✓x
x	Doctor's connections	✓
✓	Likelihood of deterioration of patient's health	✓x
✓x	If the patient has money to pay for the procedure	✓x

Legend:

✓ = Most Agree

✓ / x = Some Agree / Some Disagree

x = Most Disagree

As illustrated in the previous table, participants believe that many of the criteria that they think should be used to assess priority of medical treatments are currently being considered, although not in a consistent, standard manner. They feel, therefore, that the current approach may not be fair to the patient.

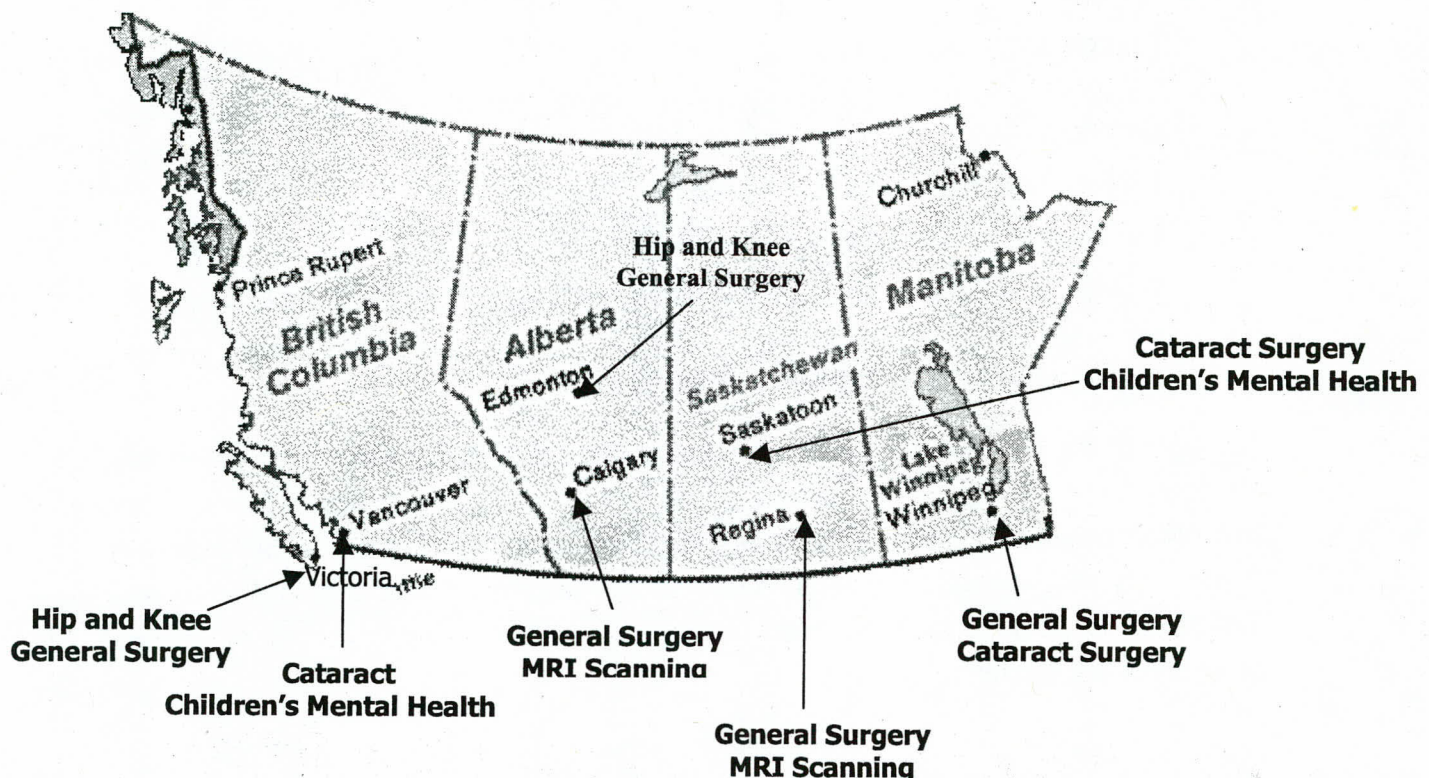
Participants also provided a range of input on how to improve current waiting lists:

- Provide more funding and/or resources (physicians, nurses, equipment, health centres);
- Charge user fees;
- Pay for patients to have operations outside of the province and/or outside Canada;
- Make the system run more efficiently;
- Reduce the number of administrative personnel;
- Provide financial incentives for medical practitioners to stay in Canada; and,
- Make the public aware of how lists are developed and maintained to create a greater understanding of why people need to wait.

Throughout the discussions participants acknowledge that they do not like waiting lists, although they have come to expect some sort of wait for service. Concern and frustration develops when the wait times become what they believe to be excessive. Participants have different opinions as to what a "reasonable" wait is according to each individual's situation; however, most believe that current waits for many medical procedures are too long.

FEEDBACK ON WCWL PROJECT TOOLS

After the initial discussion, participants were introduced to the Western Canada Waiting List Project initiative, and the tools for review (see appended moderator's guide and tools for further reference). Two tools were presented in each focus group session and were rotated between the sessions. Each tool was presented to at least two different groups, as illustrated in the following chart:



Participants were informed that the tools are in draft format and designed to be completed by the physician, usually a specialist, during or immediately following a session with a patient. They were also informed that the responses to the items will be based on the consultation between the patient and the specialist, plus the patient's history, physical exam, lab or x-ray results, or other relevant medical information. In addition to this description, participants were presented with the concept of weighting responses to various criteria questions; the more severe the case, the more points awarded to the assessment (e.g. a maximum score of 100 is possible in each tool, and quantifies the level of urgency for each patient).

After this introduction, participants were provided approximately 5-10 minutes to review the tools individually and provide written feedback. The purpose of this written exercise is to collect a top-of-mind reaction from each individual participant prior to the group discussion. The participants also rated each tool they reviewed on a scale of 1 to 10, where 1 means "completely unreasonable and unacceptable" and 10 means "completely reasonable and acceptable."

Ratings from each group are provided below; however, these numbers represent a general broad consensus among focus group participants and are not representative of the population. Caution should be exercised when referring to these averages. The numbers merely represent the general direction of whether participants find the tools acceptable and reasonable, and should be used as a guide, as the figures are not statistically significant conclusions.

Acceptability Ratings of Tools

City	General Surgery	Children's Mental Health	Hip & Knee Replacement	MRI Scanning	Cataract Surgery
Calgary	7.9	-	-	6.7	-
Edmonton	7.1	-	7.8	-	-
Vancouver	-	8.8	-	-	7.4
Victoria	7.1	-	7.3	-	-
Winnipeg	8.0	-	-	-	7.8
Regina	6.7	-	-	7.9	-
Saskatoon	-	8.8	-	-	8.8
Overall Average	7.4	8.8	7.6	7.3	8.0

As illustrated, average ratings for all the tools range from 6.7 – 8.8, suggesting in general that participants believe the tools are reasonable and acceptable. The reader should note that the participants recognize they are not clinical experts in the fields related to the tools they reviewed. Participants do; however, provide a reaction based on what they feel is common sense, reasonable from the perspective of the patient, and acceptable from a societal viewpoint. Detailed feedback on each tool is presented on the following pages.

In summary, participants are supportive of the concept of the WCWL-proposed approach to prioritization of patients on these specific waiting lists. Participants see the criteria as relevant to assessing a patient's level of urgency for planned medical procedures, and believe that all of the most important factors have been included in the tools. Certain participants have suggestions for additions or slight modifications which are outlined for each individual tool in this report.

Participants are also comfortable with the levels or ranges provided for each criteria (e.g. "none" to "severe"); however, they suggest that guidelines be developed to assist physicians in consistently evaluating the meaning of each of these categories as it pertains to the various medical situations assessed.

Overall, participants are fairly comfortable with the concept of assigning scores to the various categories to determine the degree of urgency of the patient's needs. Nevertheless, some participants believe that certain criteria are more objective (based on clinical outcomes of tests) compared to other criteria noted as more subjective (based on assessment of pain thresholds, social or emotional impact of the condition). This observed subjectivity is perceived by a few participants as potentially problematic. However, most participants indicate that they place a large amount of trust in their physician to accurately assess their condition, and in this context, would ensure that they are placed in the most appropriate priority order by using the "scoring" system as presented in these tools.

"The relative weight given to each consideration may be open to questioning, with no perfect answer."

In addition, participants spontaneously discussed issues related to the implementation of these tools when assessing the criteria and allocation of scores. The feedback provided in these areas can be found in the "Implementation Issues" section of this report. The modified tools used for the application of the focus group project are attached.

Children's Mental Health

This tool was presented in two centres: Vancouver and Saskatoon. Overall, the acceptability of this tool is strong. Participants are pleased with the criteria included in the tool, believe that it is very thorough, and would be comfortable having this tool administered to a loved one if they potentially required children's mental health services. Initial comments include:

"This criteria is right on the money."

"Seems good to me. All the important things are mentioned."

"Good that they focus on the person."

"The scoring is a little off."

The most significant issue that developed through the review of this tool was related to the scoring. A number of comments were made regarding the overall weights for various criteria, and the weights for specific responses within each criteria. Overall, most scoring suggestions emphasized using a more graduated allocation of points within specific criteria. For example: in the item "danger to self" where "none" = 0 and "severe" = 10, participants believe that points allotted for "minor" and "moderate" should be somewhat evenly positioned between 0 and 10, rather than skewed towards one end. Specific scoring suggestions are discussed further in relation to particular listed criteria items.

Another issue arising from the discussion related to the information needed to complete the assessment. That is, participants believe that input from several individuals such as a psychologist, teacher, parent, coach, etc., is required to accurately evaluate the child because *"interviewing the child may not give you the full assessment."* Overall, participants believe that only qualified individuals should complete the form, such as a psychiatrist or psychologist, but not someone such as a high school guidance counsellor, *"I believe a school counsellor might not be qualified enough to evaluate a child to this degree."*

Specific comments related to listed criteria in the children's mental health tool are as follows:

Danger to Self: Participants agree that this item should be included; however, many feel there is not enough weighting difference between "minor" and "moderate" for this question, and/or that too large of a gap exists in the scores between moderate and severe.

Danger to Others: Many participants believe greater weight should be applied to this item, *"as high as 10 points for severe,"* and do not necessarily understand the difference in point allocations between "danger to self" and "danger to others."

Children's GAF Score: A few participants believe that this is the most important criterion on the list, and should be scored accordingly (e.g. higher).

Significant biological family history of mental illness: One participant expressed concern that if this history is "unknown," the patient does not receive any points. Along with certain others in agreement, a suggestion was made to *"assume the worst and give a score."*

Family functioning or factors affecting child: One participant felt strongly that this item should receive higher weight than a maximum of one point because of the belief that severe family problems can significantly affect a child's development.

Degree of likely benefit with further intervention: Some comments focussed on the speculative nature of this question. For example, these participants believe that it could be difficult to assess a child's potential benefit of treatment as they are unsure of how a specialist may be able to accurately assess this item. As well, some believe that this assessment may be difficult because the information being considered could be reliant upon the input of others (the child's parents, school teachers, other clinical experts, etc.), and the extent of this input may not be available at the time of assessment.

Suggested Additional Criteria and/or Changes: The only criterion suggested to be added to this tool is the maturity level or age of the child, as certain individuals believe that some of the behaviours assessed in this tool can change with age.

Cataract Surgery

This tool was presented in three centres: Vancouver, Winnipeg, and Saskatoon. It is observed that because this tool is perceived as more "*cut and dry*" than other tools, the relative level of acceptability of this tool is strong. Participants believe this tool is more objective because it relies on clinical outcomes such as results from an eye test, rather than judgements such as "level of pain." Overall, most participants believe this tool is reasonable and acceptable. Additionally, most would agree to be scored on these criteria if they required cataract surgery. Some of the comments provided by participants that illustrate initial reactions include:

"It doesn't allow for as much influence of the doctor."

"Seems quite fair and non-judgemental."

"I like that the document takes into consideration the discomfort the patient would suffer, as well as the definite medical aspects."

"Everyone is treated the same."

Conversely, a small number of participants believe that this tool focuses too much on the disease and not enough on the emotional and social effects on the patient, "[*this tool is*] *treating the disability instead of the patient.*" Many believe "emotional trauma" should receive greater consideration.

Given that cataract surgery is typically performed on older individuals, age commonly emerges as an issue with this tool. In particular, participants debated whether a relatively younger person should receive the surgery over an older person. The groups are divided on this issue; however, basing priority on the pre-treatment and potential post-treatment quality of life regardless of age, "*it should be based on need not age.*"

Discussion also spontaneously and consistently centred around score weights within a number of the criteria. In particular, many individuals question the negligible difference in points provided to "mild" and "moderate."

Specific comments related to listed criteria in the cataract tool are as follows:

Visual acuity: This criterion appeals to all participants as they believe it is an objective evaluation of the patient's vision. Additionally, they see this as one of the key items in assessing priority of service.

Glare: Many participants commented that the number of points provided for "none" and "mild" should be different on this criterion. Additionally, they believe the range of points between "mild" and "moderate" is too great. Certain individuals also question whether ophthalmologists consider whether actions could be undertaken to reduce glare or pain.

Extent of impairment in visual function: Participants generally believe that this item is very important to the overall assessment tool. Certain participants believe that the response should be considered *"in relation to lifestyle and life-stage."* In other words, participants believe that individual quality of life elements need to be taken into account (e.g. reading is most important for some patients, while driving is most important for others).

Other forms of comorbidity: Certain participants mention that the point allocation for this item is low (maximum of two points) and would consider potentially eliminating this item. A few others believe that the impact of diabetes should be given specific and notable weighting scores.

Other substantive disability: A few participants questioned *"what does this have to do with cataract surgery."* They believe other disabilities such as hearing loss should not be taken into account. However, most participants identify that this item indirectly relates to quality of life, an important criterion to participants, and should be included in the tool. Certain participants also mention that the points allocated to this item should be at least equal to, if not higher than, scores for "glare."

Ability to work or live independently or care for dependants: Participants are pleased to see this item on the tool. It was mentioned by a small number of participants that this question is too general and should list specific items such as *"is the patient able to care for their dependants?"* or *"does the person have a support group?"*. However, the majority believe that this and other social or lifestyle elements would be taken into consideration when responding to this question.

Suggested Additional Criteria and/or Changes: Criteria certain participants do not currently see in the tool and suggest to also consider include:

- Rate the patient's mental condition separate from "other substantive disability" (some feel that very severe mental conditions may not require as high as priority, while others are philosophically opposed to taking this into account);
- Consider Workers' Compensation Board recommendations (as applicable);
- Emphasize the rating for the patient's quality of life; and,
- Assess the potential deterioration of the patient's condition.

Hip and Knee Replacement

The hip and knee replacement tool was tested in two centres: Edmonton and Victoria. Overall, participants react quite favourably to this tool and would feel comfortable having the tool applied to their own personal situation. Participants agree that all of the listed criteria should be used in waiting list decision-making for these procedures and provide targeted comments to improve the tool.

"It was excellent because age wasn't a factor, urgency was, and because suffering was considered."

The criteria related to pain received the greatest amount of attention from participants. Participants agree that criteria related to pain should be included in a tool determining the prioritization of patients on a waiting list for hip or knee replacements. However, many participants feel that the allocation of points for pain suffered should be higher. Others feel that it will be difficult for physicians to determine the relative category of pain the patient endures and feel that the completion of these pain-related questions could be somewhat subjective in nature according to the physician's point of view.

"I think that it's a very practical approach to determining need. I might increase the relative importance of 'pain at rest'. This could really mess you up."

"These questions can sometimes be difficult to answer due to the fact that pain is difficult to remember or scale."

"Not everyone handles pain in the same way."

Further, certain participants believe that criteria items related to the ability to walk without significant pain, and other functional limitations are better indicators of pain than the measurements of "pain on motion" or "pain at rest."

Participants agree that the potential for the progression of the disease and the threat to a patient's role and independence in society should receive a high allocation of points. Nevertheless, many participants feel that items related to pain should receive higher scores relative to these factors (independence and progression of the disease).

Additional specific comments related to each of the listed criteria in the hip and knee replacement tool are as follows:

Pain on motion: While participants believe that pain should receive a higher level of importance in terms of the allocation of points, several individuals share the feeling that *"some pain is controllable; other pain is not"* and, therefore, the categorization of *"pain on motion"* is perceived to be somewhat subjective.

Pain at rest: Participants appreciate the distinction between "pain on motion" and "pain at rest" in the tool. However, certain participants believe that "pain at rest" should receive at least as many points as "pain on motion" because they see this type of pain as *"extreme."*

Ability to walk without significant pain: Several comments arise regarding this item. First, many individuals point to the lack of any point differentiation for the ability to walk over five blocks versus the ability to walk one to five blocks, *"why have a category if you're not going to have any difference between the two?"*. To this end, participants commonly suggest that points be allocated to the category capturing the ability to walk one to five blocks. Certain participants also suggest that timeframes be included in this measurement to capture a patient's ability to walk without significant pain in relation to the number of times per day or week. Finally, other participants recommend that the ability to walk up hills or even dance without significant pain should be considered in addition to the ability to walk without pain, *"I can walk five blocks, but if I have to walk up a small hill, I have to rest two or three times on the way up due to extreme pain."*

Other functional limitations: Those participants who indicated that dancing or walking up hills should be considered did not recognize these activities as a component of the assessment of "other functional limitations" - although they could likely be taken into account with this criterion's rating. While most participants generally accept this item in its present state, certain individuals believe that the importance of this item is *"over-represented"* and that the allocation of points in this area could be decreased.

Abnormal findings on physical exam related to affected joint: As with most criteria items related to clinical or medical evidence, participants accept this item favourably and believe it to be quite objective and worthy of inclusion in the overall assessment tool. As one participant comments, *"this can lead to other severe conditions"* which most participants believe will be adequately determined by the treating doctor or specialist.

Potential for progression of the disease documented by radiographic findings:

Given that participants all share the view that waiting list urgency should be determined by the relative "life-threatening" situation facing the patient, it is not surprising that participants are in agreement that this item should play a significant role in the overall assessment. As with the previous item, participants consider this item to be more objective and less subjective in nature as it is based on medical evidence.

Threat to patient role and independence in society: This specific item carries a great deal of importance to participants in the use of the assessment tool. In fact, some participants recommend separating this item into various elements covering earning potential, family stability, or care-giving. This area is important to include according to participants because *"it affects the ability to provide for one's family"* and can also have an effect upon society as well should a patient require social services while waiting for the procedure. Very few participants believe that the point allocation should be decreased in this area; this tended to stem from a trade-off between increased points for pain and decreased points for independence.

Suggested Additional Criteria and/or Changes: Participants do not necessarily seem to understand whether other medical conditions are taken into consideration, such as whether a patient also has a heart condition. Others feel that the general health of the patient should be considered in the assessment to measure the relative quality of life the patient currently has and could hope to enjoy following the procedure. The only other comment that emerged focused on age; several participants mention that age should not be a determining factor in this assessment tool and are pleased to see that it is not presently included in the list of criteria.

MRI (Magnetic Resonance Imaging) Scanning

The MRI tool was tested in two centres: Calgary and Regina. Participants generally accept the criteria used in this tool; however, they provide certain suggestions towards modifications they feel would better represent their views on the prioritization of patients waiting for MRI scans. Comfort levels with having the tool applied on their own personal situation are fairly solid.

It seems to hit the main points of pain, seriousness of illness, deterioration, the use in diagnosis and success. It focuses on the before, during, and after which is good.

One of the more common reflections offered about this tool relates to the criteria being somewhat vague in nature. For example, many participants believe that there could be a number of reasons why a patient may need an MRI and wonder how the array of circumstances will be taken into account in this assessment tool. Another reason noted for the relative vagueness of this tool involves the lack of clinical evidence used in the evaluation form, *"the questions are not based on fact," "I would expect my doctor to be a fortune teller to use that effectively."* In addition, many participants feel that the tool offers a good emphasis on considering the doctor's input. However, they feel this medical input is somewhat blind or speculative in terms of not knowing the outcome of the MRI, *"the questions are hard to answer without the results of the MRI."*

Specific comments related to each of the listed criteria in the MRI tool are as follows:

Usual duration/frequency/intensity of pain and/or suffering: Several participants believe that this factor contains *"too many questions in one"* and feel that the questions should be separated to capture each distinct area. This is characterized by comments such as *"it may be a bit vague as it has only three choices and four questions in one,"* and, *"question one is quite difficult to specify what symptom the answer is rating."* Also, some participants comment that *"if you don't have pain, you might not get any points, but you might need it [the MRI]."* For this assessment tool, unlike the hip and knee replacement tool, participants feel pain is not as significant a factor in determining the scoring outcome.

Severity of illness/impairment: The severity of illness is perceived to be more important than the pain suffered, for certain participants who comment, *"you may have no pain associated so you get zero points but yet you could die within two months."* At the same time, pain is seen by others to be an important factor for consideration in this tool but is considered relatively less prominent than the severity of illness in the overall scoring scheme.

Probable time course of clinical deterioration: Some participants see this item as the primary factor of the MRI assessment tool and suggest raising the relative scores assigned to the response categories. In general, participants agree with this item and do not offer any suggested changes.

Probability of MRI providing clinically significant diagnostic information: This item is considered by participants to be difficult to assess in complete accuracy, *"how can you say this if you don't know what's wrong?"*. Others wonder about the relevance of this question considering that they believe the reason a patient would be waiting for an MRI is because the patient needs the diagnostic information, *"it's not a cure; it's not surgery; it's a process to diagnose patients," "surely an MRI would not be used if you know for certain what the problem was."*

Probability of successful treatment resulting from the diagnostic information: Overall, the probability of successful treatment and the probability of the MRI providing clinically significant diagnostic information are perceived by many participants to encompass the same line of thought. They, therefore, suggest combining these two elements, *"get to the heart of the matter – is this procedure going to make a difference?"*. In many cases, participants generally feel that the difference an MRI could make should be the most important element in this tool and feel the scores should reflect this. In assessing this item, certain participants also suggest that medical professionals consider the possibility of mistreatment without an MRI scan and the possible speed in treating the patient's ailment.

Suggested Additional Criteria and/or Changes

With respect to the criteria related to the probability of clinically significant diagnostic information, certain participants suggest that results of MRIs be tracked to identify how effective an MRI actually is in providing an accurate diagnosis of various diseases or conditions. These individuals feel that this information, in turn, could be used in the assessment tool to rate the appropriate category for this question item. An underlying theme surfacing during the discussion of the MRI tool involves the desired improvement felt by participants of the management of the equipment and staffing resources to operate the equipment. Participants feel this is connected to a larger issue related to waiting times pointing to insufficient resources and funding within the health care system.

General Surgery

This tool was presented in five locations: Calgary, Edmonton, Victoria, Winnipeg, and Regina, and acted somewhat as a control tool for the study. Overall, the initial reaction to this tool is positive; however, participants see this tool as a bit more broad in scope. Overall participants believe this tool is generally reasonable and acceptable.

"It's pretty good. It dealt with the patient's experience and the doctor's assessment."

"[This tool] is a good start, but needs a bit of refinement."

"I would hope there would be more questions than seven."

Participants spontaneously make the connection between the list of criteria on this tool and the criteria they personally developed earlier in the session, *"the questions seemed to cover what we as a group believed were important."* A number also remark that they believe these criteria are currently being used to assess priority for elective general surgery although perhaps not in such a formal structure, *"a mental check list is already there."*

Some participants commented that *"General surgery is too nebulous a topic for one simple form. You would need more specific tools."* As they thought about some of the different general surgery cases, many participants agree that this tool may overlook certain issues because of the lack of specifying the surgery in question and issues related to it, *"general surgery is too wide a spectrum and can't address all issues."* However, some participants comment that *"[you are] not going to get it perfect. It would need to be very long."*

The groups have mixed views on the level of importance pain should have in relation to other criteria for general surgery. Some believe *"pain should rank higher than it does,"* while others questioned: *"is pain everything?"* Unlike reactions to the hip and knee replacement tool wherein participants expected pain levels to be a significant factor, many participants acknowledge that pain may not be as involved with one's need for surgery (e.g. surgery to explore a suspicious breast lump), *"pain doesn't always indicate an illness,"* or *"sometimes you can't detect certain medical conditions without the surgery."*

Additional specific comments related to each of the listed criteria in the general surgery tool are as follows:

Usual Frequency of painful episodes/suffering: Participants are generally pleased to see this item included in the tool, and see it as an important component of the assessment; however, many would like to see clear definitions of the category choices, *"does 'Often' mean hourly or daily... -- seems blurry."* Participants believe that the development of a set of guidelines for users of tools to follow would assist with a common understanding of how to consistently rate each category.

How Intense is the pain at its worst: Participants believe this criterion could be subjectively evaluated yet feel it is important in assessing a patient's level of pain, *"some people have a higher tolerance for pain."* As with the previous criterion, participants question the meaning for various levels within this item, *"what is moderate pain to me may not be the same to another."*

Usual intensity of other forms of suffering: Certain participants wonder if various types of suffering should carry higher or lower respective weights (e.g. vomiting versus fatigue), and additionally question how the weights would be applied if multiple factors interact.

Degree of impairment in usual activities due to surgical condition: While some participants state they like the approach used in these response categories, some others recommend clarifying the responses. A few participants also suggest expanding this item to include the impact of the condition upon a patient's social life.

Recent history of major complications: Some participants question only having two response categories for this item (e.g. "No" = 0 points, and "Yes" = 8 points). It was suggested by some of the group members that a more gradual scale be employed to reflect in-between cases or the relative degree of complications, instead of the *"all or nothing"* choices.

Life-expectancy implications of condition without procedure: Participants clearly and consistently point to this item as the most important assessment criterion in the tool. Participants believe this factor addresses several issues indirectly, such as patients who do not experience pain, yet may be in high need of treatment. Some participants suggest that the score values for this life-expectancy criterion should be even higher. In addition, they believe that if a patient's condition is likely to be fatal within six months, then they should move to the top of the list or even be transferred to an "emergency waiting list," *"pain will seem quite small in the face of dying within six months."*

Expected improvement in life-expectancy with surgery: Participants believe this is another very important criterion in the tool, and that the scoring should continue to reflect this level of importance, *"the last two categories are dominant, and rightfully so."* Nevertheless, several individuals believe the rating could be subjective or speculative, *"can you estimate the risk and outcome?"*

Suggested Additional Criteria and/or Changes: A small number of participants suggest that the tool should include a rating for the lifestyle of the patient *"How does a smoker score versus a non-smoker?"*; however, the majority of participants disagree with the use of this type of criteria in assessing priority on waiting lists. Some participants believe that the social or economic situation of patients should be valued for the priority placement of surgery, (e.g.: does the patient have dependants to care for, is the patient able to afford prescriptions while waiting for surgery, etc.). Further, another suggestion was to consider how well the condition could be safely controlled prior to the surgery (e.g. use of pain medications).

IMPLEMENTATION ISSUES

After a thorough review of the tools, participants were asked a series of questions related to the possible implementation of the tools. The purpose for this line of questioning was to gain an understanding of how participants envision these tools being used in the "real world."

Who should complete the tool?

Participants expressed mixed views on who should complete the forms – a medical practitioner, the patient, or a combination of the two. Initially, a moderate number of participants expressed that they would like to complete the form themselves or together with their doctor. However, upon further discussion on this issue, some participants acknowledge potential drawbacks to this approach. For example, certain individuals believe that the patient should not complete the form because if they know how the forms work, *"patients can exaggerate how bad their case is"* to receive higher scores. In general, participants' comments indicate that patients crave active input and open communication with respect to their situation, and seem to need recognition that their input is being considered in the process.

Certain participants comment that patients have varied thresholds to pain, and they believe that it could be difficult for physicians to accurately assess a patient's intensity of pain. After further discussion, many participants believe that a physician is trained to assess patient pain levels and is more objective at quantifying pain than are patients; however, they agree this criterion would need to be carefully assessed by the physician. A few participants also expressed concern that the physician will need to know the patient quite well to be able to answer a number of the questions, *"the doctor has to know patient to separate the whiners from the stoics."*

What about the possibility of people exaggerating their condition to receive a higher score?

The "honesty" issue has been spontaneously identified in every session as a serious potential problem: *"If this is put into effect, and I find out the weights, I'm going to lie. How will the doctor tell the difference?"* and *"Human nature will compel patients to answer the questions to their benefit."* Most participants believe that by having the physician complete this tool, it will prevent over-inflated scoring as doctors can remain more objective, and have a greater understanding of the severity of one patient's case relative to that of another. Despite this common conclusion, a small number of participants are convinced that patients will lie to increase their scores. Overall, some participants believe that patients are currently abusing the system by lying and that the tools still leave room for dishonesty or *"gaming"* to occur.

Should the patient know their score?

Many participants believe they should know their score once the tool has been completed so they *"know what they are up against."* However, some of these same individuals believe that it may be better to not know their score to avoid the issue of *"gaming."* Mixed views were expressed as to whether the patient should see the completed form itself – without the scores. Most participants place trust in medical practitioners to complete the tools properly. Despite this, some participants believe that they should have the right to see the responses the physician places on the tool (excluding the associated scores) or to *"sign off"* on the physician's recommendation. Some believe this interaction will allow the patient to discuss differences of opinion on various criteria, if necessary, and would generally provide patients with a sense that they were part of the process and that their input was reflected in the assessment.

What should be done if a patient does not agree with their score?

When asked what options may be available to a patient if they do not like their score, the most common response in all groups was to *"go get a second opinion."* However, most participants were quick to put a limit on the number of "opinions" a patient could receive: *"You shouldn't be allow to get more than two."* They commonly agree that the patient should be able to have reassessments in the future to track the potential progression of case severity. Other individuals suggest that alternatives available to the patient could include *"talk to the doctor, find out why, keep questioning him"*, and even *"have an appeal process after two opinions."*

What if you get a low score and never receive service?

Participants have a variety of opinions with respect to patients receiving lower scores and potentially never receiving service. A large number of participants feel that *"if the system works properly, then in the long run you should get treated."* Further to this sentiment, many participants believe that reassessments at intervals determined by the physician will ensure that patients with low scores be evaluated to ensure their condition has not changed. In the event the patient's condition worsens, they would likely receive higher scores, and thereby receive service sooner, *"eventually your case will get worse, and you'll get higher scores."*

When thinking about patients with low scores, many participants believe that the system needs to place a *"time constraint on the wait."* However, participants feel that it is equally important to deliver on the time frame quoted to the patient. Certain participants also suggest that patients on waiting lists should only be bumped once; however, they also did acknowledge that *"if you score really low, maybe you don't need surgery."*

As well, some debate occurred with respect to the priority of someone who has been on a waiting list for a very long time versus someone who is clinically determined to be in higher need of the treatment. Overall, patient need is considered to be most important, although empathy is expressed for less urgent cases still requiring the treatment or procedure that have been waiting for lengthy periods of time. A small number of participants also remarked that private sector options could be a valid alternative for some of those who are ranked lower with respect to urgency (e.g. those who can afford this option).

How important is it to get your own choice of surgeon?

Participants were asked how important it is to them to have their choice of surgeon if it increases the wait time they may experience. A clear message from all groups is that they would like the right to choose whether to select a surgeon; however, opinions vary as to whether the participants would like to exercise this right. All groups believe that if a patient wishes to wait for service from a doctor of their choice, they should expect to wait longer.

Many indicate that the decision to select their own surgeon versus accessing another surgeon who may be available earlier, rests significantly on the person's case. For example, in a somewhat serious case, some participants would be willing to *"take whoever you can"*; however, if the case is not severely life-threatening, many would be inclined to wait for service from a surgeon of their choice.

Should there be a standard time frame associated with certain scores?

Most participants responded favourably when asked if standard time frames should be in place for patients receiving high scores. Many indicate that *"ballpark"* estimated timeframes would be very beneficial; however, they admit that providing a time frame may not be realistic due to varied demands for treatment of emerging cases of higher severity. In general, participants would like an indication of expected time frames as it *"reduces anxiety"* and is helpful to *"planning your life."*

Who do you think should be responsible for managing waiting lists?

When asked who they believe should manage waiting lists, based on the tools reviewed, participants seek an objective resource in the medical field. Suggestions provided by participants include:

- Hospitals;
- Administration;
- A humanitarian, someone who cares;
- A private enterprise;
- One central agency across the province; and,
- Mixed views emerged regarding suggestions of a health district.

Should there be a standard structure administered across a province or regional health district?

Participants in all groups feel strongly that if this type of system is implemented then consistency across a province is essential: *"it's got to be consistent within the province."* Most feel indifferent if neighbouring provinces chose either to adopt or not to implement a standard waiting list procedure. However, some participants are concerned that individuals from neighbouring provinces could potentially find this new system more attractive than what may be available in their "home" province and therefore attempt to receive services in the "host" province by being placed on this waiting list and receiving faster treatment, to the detriment of the residents of the "host" province. Generally speaking, participants believe health care should be universal in all aspects, including a preference for a national waiting list strategy, although they do not see this as a necessity.

How do you deal with tie breakers?

Many participants wondered how the management of the lists would deal with tie breakers. Overall, no suggestions were tabled, yet participants were curious to know how this would be handled.

Will the doctor have time to complete the form?

"This is theory, not practice," commented one participant. This individual and a number of others question whether physicians will be accepting of and committed to this new system, *"I just don't see my doctor wanting to fill this out."* Many comments focus on perceptions that doctors are already overloaded and that *"this is taking up the doctor's time in adding to an already busy schedule,"* or *"would busy specialists get nurses to do this?"*

COMMUNICATION

Participants were asked "What should the public know?" if the tools are implemented. Nearly all participants believe that the public should be informed to some degree. They agree that the public does not need to know the details of the system, but should be made aware of general information including:

- The current state of waiting lists;
- How the new system works; and,
- Why it will improve the current waiting list system.

Participants suggest that the communication should convey honesty in that the proposed new system *"may not be perfect, but it is the best we have,"* and that it is fair. As seen from the low levels of awareness of the existing waiting list system, participants agree effective education would greatly improve the level of understanding of how the lists are managed. In turn, they feel this communication could reduce anxiety levels and negative perceptions, and dispel the myths about the current state of the system.

One participant suggested developing a telephone "hotline" to assist with the implementation and communication of information about this project.

Based on the comments made by participants, it is apparent that addressing ways to standardize how waiting lists are developed and managed implies that efforts are being made to improve waiting times for planned or elective medical procedures. Individuals see this initiative as a positive step towards addressing wait times and improving the system, appreciate the opportunity to provide their input, and hope that the public would receive communications regarding this initiative should implementation take place.

PARTICIPANTS' CLOSING COMMENTS

Participants were provided a final opportunity to write and communicate their final thoughts about the topics discussed. The following list summarizes the themes of the participants' comments:

- Many provide words of support and encouragement for the initiative;
- A number provided their thanks for being asked to participate and be involved in the development process of the tools;
- A number stated that the public should be informed of the new system if implemented;
- Several provide comments that the larger issue of why waiting lists exist needs to be addressed;
- Some feel the implementation costs should be kept low and bureaucracy within the system to a minimum;
- Some stress that doctors should complete the forms and the public should not be privy to the scoring system;
- A few comment that some of the tools are too generic and need more detail added; and,
- A few emphasize that the suggested allocation of scores provided by participants be reviewed by the WCWL Project.

Copies of the written verbatim comments are attached on the immediately following pages for further detail.

VERBATIM FINAL WRITTEN COMMENTS

Calgary Focus Group – Final Comments

I agree that a centralized booking agency should be established to book the various procedures based on the doctors recommendation of urgency. The patient should have some say in determining how flexible they are as to location of where the procedure is done with their understanding that any restrictions they place upon their procedure could result in delays of them receiving the procedure ie. If you can go anywhere the wait is 1 month, if you want to be at XX hospital, it will be 3 months. Doctors should not recommend you to this clinic or that specialist because they have some tie to them (specialist is a friend or they will refer only between themselves) that is where the independent agency will make sure your wait is based on your condition & your restrictions.

I don't believe that the patient should be told their scores. And I don't like the scoring idea. If one area scores low and another scores high, will that determine your waiting time? I would like to think that my doctor is the best judge of how quickly I should be treated. I trust his judgement and hopefully he has my best interest at heart.

I think you should NOT make the public aware of a "scoring system". This will increase public urgency – everyone will immediately have serious criteria, and need to be dealt with first. This will "taint" the doctors' diagnosis.

I think the progress being made to improve the waiting list time is very good. Finally the government will be doing something good and important to the average citizen. You should continue the work you guys are doing to make things better - especially the state of health care easier for everyone.

I feel that we do need more facilities and qualified staff. Now matter how good the system of determining the waiting list priority, you still have to have somewhere to send them. Use operating rooms on a round the clock basis (which of course means more nurses, etc.) These facilities cost money so lets make the best use of the existing ones and then look at how many more are required.

Fill in all cancellation times either for M.R.I. or operating rooms.

Good idea.

People come first.

Is compassion overlooked on a waiting list – being a number or a score.

Making lists from scores and pre diagnosis not always the score determines the placement of on the list (e.g.) painful hip – versus – failing heart over time.

That the people not be told about numbers in system you are putting together, for list's of time ETE! Hospital, x-ray, UIR

I think that patients should be evaluated on a scoring system. The patient should not be informed of this scoring system. The scoring system should have more to do with medical information than "how do you feel?" A Central Agency should be set up within each area of specialty (of medicine). That specialty of medicine should place you on the waiting list according to your score. You should only get bumped from the list once. If you have your choice of doctors your place on the list will probably go down. Re-evaluation of patient's who are on the list for a long time.

There is a need to determine how important a medical procedure or surgery is to a person. This also needs to be determined by medical reasons not money.

A centralized agency to book appointments according to regions sounds like a good idea. Patients could go to a hospital or clinic that becomes available next. Private facilities could also be included but at reasonable rates.

I agree that formalizing a number of criteria in order to rank a patient is good, but I would worry that the questionnaires we saw would be too generic to be effective if used on their own. I don't think patients should be aware of scores or the specific criteria in the questionnaires, because of the abuse that may arise from patients (e.g. Doctor shopping, exaggeration).

Central agencies would be good for diagnostic tests like an MRI when there is little contact (like we do for x-rays), but in situations that you would see a specialist a number of times & develop a relationship, it may not be effective to book a surgery without that doctor.

I feel line-ups are TOO LONG but it is good what you are proposing. Hopefully though they will be made ever better as we have such varied things for surgery and MRI's that things cannot wait forever – We need more hospital beds, more doctors, more MRI machines – then we can figure out the way we categorized for the lists...hopefully people will not have to wait years for something that maybe scored

not as important as something else. Doctors wouldn't recommend using these things if they don't think they were important.

Good Luck!!!

Edmonton Focus Group – Final Comments

Get going on it, don't get caught up in discussing it forever.

6 months or 1 year evaluations of tools and system with ongoing evaluations.

Children should be treated separately. I think they should be given higher priority.

I don't think it should be a public notice (might become corrupt).

Might need different forms for different illnesses.

If made public, people are going to want to know what this questionnaire will do for waiting lists.

Make sure that this system can not be manipulated to suit the person's whims.

The doctors are the ones who should fill out the forms.

Recommendations to Team

Keep money costs low.

Public release on new program.

Stress importance of accuracy with the doctors.

Use existing staff to operate program.

Don't hire more staff.

GO FOR IT.

It is about time we were made aware of how waiting lists are made.

Public awareness-GREAT.

Educating the sick people as to what lies ahead for them re-surgery-time.

Forms are a great way to prioritize who goes ahead of who.

I hope these forms are implemented in the near future.

TOOLS GREAT.

GOOD LUCK!

Prefer Tools to first come first served.

It should be made "Public".

Only the doctors fill out the ratings.

If implemented it should be a provincial objective. Not to be installed on a regional basis.

Implement the system as soon as possible.

Inform the public re progress on this plan.

Have patient access to second opinion.

Finally if needed, have independent body to review case .

Listen to what I put on my two top 1 things regarding the marks.

Listen to what was said and try to pick up on what was not said, and it would have been nice if I could have said two things earlier while I remembered them.

Vancouver Focus Group – Final Comments

The tools are good, and thorough but implementation and delivery are also important to the success or value of the tool.

Except for some scaling adjustment on the Children's Mental Health "form", I approve of the system.

As an added thought, (ideally) I'd like to suggest that to reduce waiting lists, in the long term, is to control population growth.

Time frame should be implemented.

Concept is excellent, go forward with it.

Ensure that only qualified persons complete the forms.

Should be made Canada wide.

There should be room for a second test, if client does not agree with scoring.

To please consider and think in a realistic way: as a Humanitarian a persons of Honor, and reverence for life and Humanity!! To Spiritually and moralistically to do the right thing in all these very great life force issues!!! Which comes from a persons of professional integrity!!!

Strive to improve the system-Constantly.

Use urgency as a criteria.

Allocate as much funding as possible.

Aim to reduce waiting time all the time.

Like idea but don't want a huge bureaucracy built up to handle this, where the money allocated to surgeries goes to pay a lot of high priced help.

In one way, it's kind of a "Big Brother" knows best concept, but in these times maybe we have to go this route.

I suggest this be explained in clear terms to the public though media, meetings, open forums, group discussions etc., in open and honest terms, with good and bad and no hyperbole.

I would like to be able to have my choice of surgeon for any and all procedures and

what would be the ramification of not accepting the surgeon when my scheduled time arrived.

Tools are good for the problem and explain very detailing to the public. It should be really work.

Ensure that the format for the forms are standardize.

Ensure that all forms for all waiting list are prepared by multi disciplinary teams.

Ensure that the process will guarantee that all patients are taken care of within a reasonable time frame and that no one would be passed over more than a specific period of time (ie 6 months or 1 year)

It would be preferable if the system was implemented in all provinces simultaneously.

Beta test

Victoria Focus Group – Final Comments

Primary Advice:

Put this type of system in place as quickly as possible.

Get doctors and staff on-side through effective communication.

Tell the people what you're doing and why.

Proceed with project – the idea is sound.

Inform the public when project is in place.

We still need more money for people and equipment to shorten waiting lists.

Also the public needs to be educated with regard to the over-use & abuse at all levels.

Do not advertise or reveal results – just do it!!

My advice is that doctors & patients should work more closely together.

I think the whole thing is a really great idea but one thing I feel strongly about is if this goes ahead the public should be informed about it. All of us here tonight have agreed that we don't really know what presently goes on in the hierarchy of our medical system and if something like this is to work we should be informed and take a more proactive approach.

My advice, is this, with what I was approached with.

I find this fairly reasonable. However re-allocate the point system (general surgery #6 should be more points.

Get the patients more involved, ex. Have the patient complete their own form and then compare it with the doctor's (there's no one else who knows my body best).

If this ever does become in use, communicate it with the public. We're too much in the dark already!

Take action. Don't get slowed up on details. A lot of new ideas never get implemented simply because by the time the research is done, the interest in the idea has faded.

Continue to get feedback from the public.

I think that what you're doing is great. Good luck and thank you for letting me express my views.

The standardized assessments need more detailed information to avoid large score numbers from tilting the result.

The sooner this happens (the tools) the better.

My personal comments on how this should happen is as follows:

Come up with 3 sets of plans.

Issue them out to each & every person in the province so they may vote on which one is their preference.

Once all of these ballots or surveys are received. Then and only then the decision should be made.

If & ever this should happen, I think these orders should be publish in all hospitals & clinic so they can be perused.

Institute the tools, once fine tuned to be effective, as inexpensively as possible. Ie: don't over manage the system publications: public opinions and pills are fine if used sparingly & effectively; look at the little costs that are adding up. Don't print a million + flyers in colour and distribute... don't do it so flagrantly. Cut costs, be thrifty in the administration of this project and save money for what matters.

Winnipeg Focus Groups – Final Comments

The tools are a good start (a step in the right direction).

Try to consider the tools as just that – tools, your “points” should not be written in stone, because there is a lot more to consider in the long.

Just because you score low, you should not be denied treatment until you are extremely sick.

Perhaps there should be one form for doctor, one for a patient to fill out. Both should be seen by a committee.

To deal with “too long” waiting list for these non-threatening maladies, your proposal is a good first step, provided you make very clear that the prioritizing will not solve any real shortage of staff and facilities, if that is the situation in fact for too many waiting too long.

Try the list process out on a group of patients (a trial).

To evaluate acceptance from all concerned.

To flush out required changes.

To see how it stands up to existing processes.

Reasonable waiting period???

Why are we short of Doctors?

Keep more doctors here that graduate here, instead of moving to USA or Alberta.

Explain publicly the score system and let the patient know where they stand on the list.

In order for the doctor to fill out the document comprehensively, they must discuss the issues with the patient so that they can have the patients input. In this way, all factors can be taken into consideration.

I hope you have listened carefully to what was said and revise, if necessary, these forms. E.G. weighing, additions, deletions.

When giving information make sure it is understandable and to the point. Not too many details that tend to confuse rather than clear up.

Will we be informed as to what is the outcome of this?

The forms are important to the public and leveling the playing field gives us a say in our health care.

What has happened in the past?

Move forward.

The issue is facilities and professionals. When we expect to have 'comfortable' access to . The reality is that there is more demand than accessibility. It is prudent to serve those who need surgery more critically before those that can 'comfortably' wait.

The filling out of the form should be cooperatively with the physician and the patient together.

There may be extraordinary situations that should be considered e.g. (extreme dementia or contribution to society, dependants etc.).

Regina Focus Group – Final Comments

Not enough doctors/beds/time/nurses.

Don't think it works that well : "some of these things, by the time you get them, it's too late". People will die.

We're dealing with the symptoms of the problem.

Just knowing how the waiting lists work is a comfort to people.

It's really complicated – but I think it should be so simple.

Support the efforts being made to try to improve health care and waiting times.

Believe we need better and more efficient management of facilities and equipment - better use of space and time.

Believe schedules and many other hospital administrative functions could be better managed by people with proven management skills versus a 'head nurse' or some other such person with medical experience only.

Perhaps we need to put more money into our facilities and medical services, even if it means paying for hospitalizations, realizing that money alone is not the answer E.g. When nurses numbers were being depleted a few years ago, administrative positions did not seem to be reduced.

It is great to have a say, to have my voice heard about issues that concern many people, and to hear views from people like myself on the wait list topic.

I feel physicians need a control criteria to verify waiting list conditions.

I feel these project teams are doing something wonderful to improve the long waiting lists for surgeries and MRI's.

This gives the patient a better understanding of how lists are analyzed.

I feel that physician's offices should communicate with hospital administrative staff with surgeries, Whether it be immediate urgencies or cancellations.

Prioritizing is a necessity – discuss with a group of surgeons, doctors, nurses, and public how to prioritize. Pain and suffering is probably the number 1, life expectancy and quality of life is important.

We also need to come up with ideas for money. What would be wrong with in this province paying 1-2 dollars every doctor visit. Think of how much that could generate for opening beds and hiring nurses and surgeons.

I think waiting list should be no longer than 3 months.

Points are a good idea – do not let patient see and do not waste paper informing public until they get to a point when necessary.

I feel that certain areas of these pilot tools will in fact aid in the waiting time. But I also feel that in other areas it will, and can, create more havoc than there already is. In particular the MRI tool is great!! The general surgery tool will create problems if people find out the scoring system, as people will tend to stretch the truth to speed up the process.

The project could prove very effective – providing the results of your meetings (e.g. opinions expressed) could be boiled down to a good presentation It then should go to the medical associations and the government for action.

We need a logical system for surgical waiting lists that are appropriate and considerate to patient needs. The tools suggested are a good start and I hope you can at least give them a trial run in Saskatchewan. Then improve and have them implemented permanently. Good luck!!

I think this evening was very informative. I believe if it was implemented it would help people to understand the problems of priority on waiting lists. Erin was a great moderator and our group was great to speak out. Very good!!

I think that the new tools are a very good idea to determine on how and when a patient is in need of surgery and how they are rated. I think we all need to do something new and this is a very good start.

Saskatoon Focus Group – Final Comments

Adopt a consistent approach throughout all provinces.

Have a waiting list consistent throughout.

Administered through Health Care – Board and professionals.

Advise the public and media , do a survey to get public opinion.

The criteria needs to be implemented.

People are getting frustrated with systems used now.

Waiting lists need to be minimized because if I need surgery immediately - it is very scary as to how long I would have to wait to have it done.

I am fearful of getting sick or need surgery done in Saskatchewan.

Age should not be a factor to be on a waiting list.

I would hope that you are assessing each case fairly and that **every** person that is in need of treatment is getting as soon as possible. In order to shorten waiting lists you must increase many areas. E.G. more doctors, more money, more tools, more time.

Hopefully one day there will be no waiting lists.

Patients should be asked according to their needs there in most need to come first.

More open talk with doctors, 24 surgery in hospital, more money for health care, more with the people.

Severity, progression, age, life threatening

Based on our discussions re: prioritizing waiting lists. I feel it is a very sensible approach; one we should welcome.

Review weights of scoring, makes them all consistent e.g.: Moderate = 2, Severe = 6, instead of Moderate = 2, Severe = 2.

I feel this could be improved upon and would provide for a feeling of everyone being assessed from the same level playing field.

Funds have to be available to allow hospital boards to administer, collate and collect information into a database.

Communicate this process to all – minister in the department of health so that it is consistent across provinces and fair to all clients.

The people in charge of these decisions (e.g. doctors) need to be consistent and fair. Doctor to doctor with in the city.

Specialists need to be on the board.

Keep the tools simple.

Inform the public in a positive way.

Consultation of patient/specialist is very important.

Could "wellness" approach be associated with a waiting list? This could give patients something to do to maintain their health or improve health while they are waiting.

APPENDIX

Circle One

Calgary	Edmonton
Vancouver	Victoria
Winnipeg	Regina
Saskatoon	

WCWL Project
Recruitment Screening Questionnaire
General Population
Project # 06-3248-01 (#8659)

Hello, my name is (Interviewer's name) and I'm calling from Ipsos-Reid, formerly the Angus Reid Group, a national public opinion research company. From time to time, we gather opinions by sitting down and talking with a group of people aged 18 years or older. We are having one of these discussion sessions about waiting lists and waiting time for certain elective medical procedures. I am calling to see if you are interested in participating in a discussion on these issues. The session will involve about 8 to 10 people, and will only take about 2 hours. Refreshments will be served and those who qualify and attend will receive \$50 as a token of our appreciation. Participation is completely voluntary and we want to assure you that the sessions will be strictly confidential.

Would you be interested in providing your opinions by attending a focus group?

- ☐ Yes → **CONTINUE**
- ☐ No → Thank you for your consideration.

Great. I'd just like to ask you a few questions to collect more information about yourself.

1. Do you or does anyone in your household work or volunteer in any of the following areas? **[READ LIST]**

The medical or health care field or research

[This would include the following types of positions: physicians, specialists, service providers such as nurses or chiropractors, employees of provincial or federal departments of Health, or any other employment or volunteer role that primarily deals in the health sector]

An advertising agency

A market research company

The media, that is for TV, radio or a newspaper

IF "YES" TO ANY - THANK AND COMPLETE CALL

2. NOTE GENDER.

Male

Female

WATCH QUOTAS – RECRUIT EQUAL NUMBER

3. How concerned are you about the state of waiting lists or waiting times for elective medical procedures such as: cataract surgery, children's mental health, general surgery, hip and knee replacements, and MRI scanning? Please rate your concern on a scale from 1 to 5 where 1 is not concerned at all, and 5 is very concerned. **[CIRCLE NUMBER]**

Not concerned 1 2 3 4 5 Very concerned

OBTAIN A GOOD MIX OF 3-5
THANK AND DISCONTINUE FOR 1-2

4. Have you or has anyone in your immediate family ever been on a waiting list to receive medical treatment for the following services in Canada: **[CHECK ALL THAT APPLY]**

- ☐ cataract surgery
- ☐ children's mental health
- ☐ general surgery
- ☐ hip and knee replacement
- ☐ MRI scanning
- ☐ No, never

5. What is the highest level of schooling that you have had the opportunity to obtain?

- ☐ Completed High School or some high school
- ☐ Technical school or college
- ☐ Completed University or Post-graduate degree

6. Which one of the following categories best describes your age? **[READ LIST]**

- ☐ Under 18 years
- ☐ 18 to 24 years
- ☐ 25 to 44 years
- ☐ 45 to 64 years
- ☐ 65 years or older

THANK AND COMPLETE CALL [DQ]

OBTAIN A GOOD MIX

7. Which one of the following categories best describes the total annual income, before taxes, earned by all members of your household? **[READ LIST]**

- ☐ Less than \$30,000
- ☐ \$30,000 to \$49,999
- ☐ \$50,000 to \$69,999
- ☐ \$70,000 or more

Thank you. The focus group will be held on the evening of _____ February _____ at 5:30 p.m. and will be 2 hours in duration. Please arrive 10 to 15 minutes early to make sure we are able to start on time.

The session will be held at:

Location	Date	Phone #	Address
Calgary	February 5 th	(403) 294-5167	Ipsos-Reid 600-635 8 th Ave. SW
Edmonton	February 6 th	(780) 423-0708	Criterion Research 10155 114 Street
Vancouver	February 7 th	(604) 257-3248	Ipsos-Reid 1100 – 1199 West Hastings St.
Victoria	February 8 th	(250) 381-4494	Copelan 536 Broughton St, 3 rd Floor
Winnipeg	February 12 th	(204) 989-8999	Western Opinion Research 213 Notre Dame Ave. Suite 804 Portage Ave. and Main St.
Regina	February 15 th	(306) 359-337	The COR Group 1840 McIntyre St Albert St. and Victoria Ave.
Saskatoon	February 16 th	(306) 652-5160	Norsask 220 3 rd Ave South, Suite 401 21 st Street East & 3 rd Ave.

I will call you a couple of days prior to the session to confirm your appointment. We are reserving a place for you so if for some reason you are unable to attend the focus group, please call us at [INSERT NUMBER]

Name: _____

Daytime Phone: _____

Evening Phone: _____

Recruited By: _____

WCWL**Moderator's Guide**

06-3248-01

1. INTRODUCTION: (10 minutes)

- Welcome, thanks for coming
- Ipsos-Reid - who we are, what we do
- Focus Groups - what they are, why we use them
- Interested in honest opinions, feelings, positive and negative comments, no right or wrong answers.
- Microphones, audio-taping for reporting purposes only, one-way mirror, colleagues in back room
- "Rules": talk one at a time, hear from everyone, respond to others' comments, informal discussion
- Overview: Tonight we are here to discuss a new approach designed to improve access to elective health care. We have a number of questions and exercises for you to participate in this evening. You may have many personal experiences with medical waiting times, but we would like to focus the discussion on just a few key areas for the purpose of our session tonight, particularly elective medical procedures. Planned care or treatment is medically necessary but not urgent and a waiting period is typically common.
- Respondent introductions: First names only, family, length lived in this city, experience with medical waiting lists, and contact with health sector

2. WARM-UP: BASIC WAITING TIME INFORMATION (5 minutes)

- ^{1a} What are your perceptions of the current wait times for elective medical services or treatments in [city/province]? General impressions, both positive and negative. ^{1b}
- ^{1c} Probe to cover the 5 key areas: general surgery, cataract surgery, MRI scanning, children's mental health, hip and knee replacement.
- ^{2a} And what do you base your comment on – your own personal experience? Media reports? ^{2b} Experiences of family members or friends? [Probe differences between media coverage and personal experience] ^{2c} ^{2d}

3. KNOWLEDGE AND VIEWS (20 MINUTES)

[WRITE DOWN IDEAS ON FLIP CHART AS APPROPRIATE]

Some people feel that waiting lists and times are concepts that are not well understood. That's why I'd like to get your feedback tonight. The key issue for discussion is waiting lists and times for planned care and your feedback will greatly assist in helping to understand how the public sees them.

- 3 ➤ How would you define or explain what a waiting list is?
- 4 ➤ Why do you think waiting lists exist in [CITY/PROVINCE]?
- 5 ➤ What does it mean to you personally if you are placed on a waiting list for an elective medical procedure?
- 6 ➤ How do you think waiting lists for elective procedures are currently managed and maintained in [CITY/PROVINCE]?
- 7 ➤ Generally what criteria do you believe are currently used to determine the priority order of waiting lists?
- 8 ➤ What criteria do you think SHOULD be used to determine priority order of waiting lists?
- 9 ➤ What do you believe can be done to IMPROVE waiting lists?

4. PRESENTATION OF WCWL PROJECT TOOLS (50 MINUTES)

Thank you for your input. Now that you've given me your feedback about what is and should be included in waiting lists for medical procedures, I'd like to discuss a related topic.

Introduce the Western Canadian Waiting List Project:

Many studies have been conducted among the public and medical profession regarding waiting lists in an attempt to address growing concerns about waiting times. One such study sponsored by Health Canada indicated that there was no standardized sources of data for compiling information on waiting lists. The Western Canada Waiting List (WCWL) Project was formed to address this issue.

The WCWL Project is a partnership of medical associations, regional health authorities, health research centres, and ministries of health. The mission of the WCWL Project is to develop tools to help manage and administer waiting lists for certain planned treatments or procedures. Basically it is intended to be a standard way to determine who should go ahead of whom for specific medical services based on the urgency of the need for care and the ability to benefit from the care.

This group is currently focusing on planned treatments or procedures which will benefit patients, however, is not a life or death situation and for which a reasonable wait will not have serious negative consequences for the patient.

To begin this major task, the group has focused on developing tools or lists of criteria to prioritize patients in 5 specific service areas: cataract surgery, children's mental health, general surgery, hip and knee replacement, and MRI scanning.

The group has developed AND tested draft tools and is now looking for feedback from the public. Each tool consists of a series of items which doctors have identified as important in assessing the patient's priority. The components of these draft tools are included in handouts that I will share with you.

This tool is designed to be completed by the physician, usually a specialist, during or immediately following a session with a patient. The responses to the items will be based on the consultation plus the patient's history, physical exam, lab or x-ray results, or other relevant medical information. There would also be information coming from the doctor who referred the patient – usually in the form a letter of referral.

In each tool, scores are allotted to the response categories for each item listed as criteria. The maximum score is 100. The more urgent the patient, the higher the score, the shorter the wait. Urgent cases or emergencies would not be scored, but would go directly to the service needed.

I'd like to review the criteria for [TOOLS ARE TO BE ROTATED THROUGHOUT THE SESSIONS. PARTICIPANTS WILL REVIEW 2 TOOLS PER SESSION]. [MODERATOR HANDS OUT ONE TOOL AT A TIME. FOR EACH TOOL, PARTICIPANTS ARE ASKED THE FOLLOWING QUESTIONS]

11-Tool 1
11-Tool 2
What is your initial impression of this tool?

12a b
#2
Do you believe that this tool covers the important elements of a waiting list as you mentioned earlier? [MODERATOR TO REFERENCE COMMENTS GIVEN ABOUT WHAT CRITERIA SHOULD BE USED TO DETERMINE THE PRIORITY OF PATIENTS ON WAITING LISTS]

13x2
What are your general feelings with respect to the criteria suggested for this tool?

14abx2
What do you agree with? Disagree with?

15x2
Is there anything missing?

16x2
What are your feelings about the weighting scores?

17abx2
Do you believe there should be any changes made to this tool? Explain.

18x2
Should the patient complete parts of the form with the physician or should the physicians complete it on their own?

- Should the patient see what score the physician is giving them as the form is being completed? What about after it has been completed? *19ab, 20x2, 19a, 19b*
- Should patients know their score and where they stand on the waiting list? *20a*
- Overall, do you believe this tool is reasonable and acceptable? If you or your loved ones were in need of [REFER TO TOOL], would you agree to be scored on these criteria? Why/why not? *21ab, 22, 20b, 24c*

5. IMPLEMENTATION (30 MINUTES)

Now that you have seen the tools this committee has developed, I would like to ask you a series of questions related to the possible implementation of the tools.

Acceptance of Tools

- What should be done if a patient does not agree with the score they have received? Should they be able to go to another physician to get a higher score? What alternatives might they have? *22ab, a, b*
- What about the possibility of people exaggerating their condition to obtain a higher score? Does this concern you? How do you think this could be addressed? *23abc, 23a, b, c*
- What if you get a low score? You could potentially never receive the elective surgery you want, as others keep bumping ahead of you. How should this be addressed? *24abc, a, b, c*
- What if you get your score, but cannot get your choice of surgeon? How important is that to you? Why? *25abc, 25a, b, c*
- Should there be a standard time frame associated with certain scores (ex: 85-90 points out of 100 needs to be addressed in 48 hours)? *26*

Standard Structure

- Who do you think is currently responsible for managing waiting lists? *27*
- Who do you believe SHOULD be responsible for managing waiting lists? Who chooses who goes first? Who is accountable to you as the patient? *28a-7c, 28a, 28b, 28c*
- Should there be a standard structure to this program administered across a province or across a regional health district? *29*
- What if one province or health district decides not to participate? *30*

Communication

- 31a → c
- Let's say the concept moves ahead - how should this approach be communicated to you and the public? What would people want to know? How much communication do you think would be required? 31b

Closing Remarks

- 32a → c
- Should this be implemented? Why/why not? [PROBE: usefulness and fairness]
- 33
- If you could provide recommendations to the WCWL project team, what key things would you suggest? [PARTICIPANTS TO WRITE OUT THOUGHTS INDIVIDUALLY – 5 MINUTES]

CLOSING (5 minutes)

- 3A
- Do you have any final comments about what we have talked about tonight?

CATARACT SURGERY PRIORITY CRITERIA

PLEASE REVIEW THIS DOCUMENT IN ITS ENTIRETY AND THEN COMPLETE THE QUESTIONS AT THE END OF THE DOCUMENT.

PLEASE CHECK THE BOX THAT MOST ACCURATELY DESCRIBES THE PATIENT'S CURRENT SITUATION.

This form will be completed with the patient's history in mind. This means, additional information will be taken into account when answering these questions.

- 1. Best corrected visual acuity: (this is the result of the basic eye test. 20/20 would be good vision and is not on this sheet – it starts with 20/30 which is just one step worse than good vision and progresses worse and worse down the scale)**

Points will be allocated according to the severity of visual impairment (e.g. ranging from 0 to 17 points).

Right Eye:

- ☐ 6/9 or better (20/30)
☐ 6/12 (20/40)
☐ 6/18 (20/60)
☐ 6/24 (20/80)
☐ 6/36 (20/120)
☐ 6/60 (20/200)
☐ Count fingers/hand movements or worse

Left Eye:

- ☐ 6/9 or better (20/30)
☐ 6/12 (20/40)
☐ 6/18 (20/60)
☐ 6/24 (20/80)
☐ 6/36 (20/120)
☐ 6/60 (20/200)
☐ Count fingers/hand movements or worse

- 2. Glare: (this refers to discomfort or pain in the eye caused by a bright light entering the person's field of vision)**

- ☐ None
☐ Mild

- ☐ Moderate
☐ Severe

- 3. Ocular comorbidity (e.g. age-related macular degeneration, chronic simple glaucoma): (these are some conditions that will have an impact on urgency and are identified by the ophthalmologist)**

	None	Mild	Moderate	Severe
Age-related macular degeneration.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	0	2	6	15
Other forms of comorbidity.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	0	0	1	2

If other form of comorbidity, what?

- ☐ Diabetic retinopathy
☐ other retinal disease
☐ chronic simple glaucoma
☐ hypertensive retinopathy
☐ other: _____

4. Extent of impairment in visual function (e.g. reading, recognizing faces, seeing steps or curbs, watching TV, driving, and reading traffic signs):

- ☐ No impairment
- ☐ Mild impairment
- ☐ Moderate impairment
- ☐ Severe impairment

5. Other substantial disability (e.g. hearing loss, uses wheelchair, partially reversible dementia): *(this assesses the impact of other conditions upon the urgency for cataract surgery)*

- ☐ None/mild
- ☐ Moderate
- ☐ Severe

Please specify disability: _____

6. Ability to work or live independently or care for dependants:

- ☐ Not applicable
- ☐ Not threatened or no difficulties
- ☐ Not threatened but more difficult
- ☐ Threatened but not immediately
- ☐ Immediately threatened or unable

A) Please rate this tool on a scale of 1 to 10 where "1" means "completely unreasonable and unacceptable" and "10" means "completely reasonable and acceptable". Simply circle the number that best describes your point of view.

1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	----

B) Please explain why you gave this tool the rating you circled above. Include your thought on what you agree or disagree with and any general comments you may have.

[illegible]



Western Canada Waiting List Project

CHILDREN'S MENTAL HEALTH PRIORITY CRITERIA

PLEASE REVIEW THIS DOCUMENT IN ITS ENTIRETY AND THEN COMPLETE THE QUESTIONS AT THE END OF THE DOCUMENT.

PLEASE CHECK THE BOX THAT MOST ACCURATELY DESCRIBES THE PATIENT'S CURRENT SITUATION

This form will be completed with the patient's history in mind. This means, additional information will be taken into account when answering these questions.

1. Danger to self

☐ None

☐ Minor

☐ Moderate

☐ Severe

2. Danger to others

☐ None

☐ Minor

☐ Moderate

☐ Severe

3. Psychotic symptoms (*a serious mental disorder characterized by derangement of the personality and loss of contact with reality, such as delusion or hallucination*)

☐ None

☐ Mild

☐ Moderate

☐ Severe

4. Global age-appropriate developmental progress (*this refers to a child's physical growth*)

☐ No delay and/or no risk of delay

☐ Minor delay and/or minor risk of delay

☐ Moderate delay and/or moderate risk of delay

☐ Severe delay and/or high risk of delay

5. Children's GAF score (see Attachment, Children's Global Assessment of Functioning—higher is healthier)

☐ 40 or less

☐ 41 to 50

☐ 51 to 60

☐ More than 60

6. Internalized symptoms (*such as depression and worry – they are within the child and not behaviours*)

☐ None

☐ Minor

☐ Moderate

☐ Severe

7. Externalized/disruptive behaviour (such as disruptive behaviour or behaviours that are acted out)

- | | |
|---|--|
| <input type="checkbox"/> No problems | <input type="checkbox"/> Moderate problems |
| <input type="checkbox"/> Minor problems | <input type="checkbox"/> Severe problems |

8. Comorbid medical conditions (this refers to other diseases or physical conditions the child may have which may influence urgency for mental health intervention, such as asthma)

- | | |
|--------------------------------|-----------------------------------|
| <input type="checkbox"/> None | <input type="checkbox"/> Moderate |
| <input type="checkbox"/> Minor | <input type="checkbox"/> Severe |

9. Comorbid psychiatric conditions (this refers to other mental disorders which may influence urgency such as Attention Deficit Hyperactivity Disorder – ADHD)

- | | |
|--------------------------------|-----------------------------------|
| <input type="checkbox"/> None | <input type="checkbox"/> Moderate |
| <input type="checkbox"/> Minor | <input type="checkbox"/> Severe |

Please specify: _____

10. Harmful substance use/misuse

- | | |
|---|--|
| <input type="checkbox"/> No problems | <input type="checkbox"/> Moderate problems |
| <input type="checkbox"/> Minor problems | <input type="checkbox"/> Severe problems |

11. Significant biological family history of mental illness

- | | | |
|------------------------------|-----------------------------|----------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No | <input type="checkbox"/> Unknown |
|------------------------------|-----------------------------|----------------------------------|

12. School and/or work (this refers to whether the child is functioning well or experiencing any problems at school and/or work)

- | | |
|---|--|
| <input type="checkbox"/> No problems | <input type="checkbox"/> Moderate problems |
| <input type="checkbox"/> Minor problems | <input type="checkbox"/> Severe problems |

13. Social/friendships/community functioning (this refers to whether the child is functioning well or experiencing any problems with friends or in social settings)

- | | |
|---|--|
| <input type="checkbox"/> No problems | <input type="checkbox"/> Moderate problems |
| <input type="checkbox"/> Minor problems | <input type="checkbox"/> Severe problems |

14. Does the patient have problems in the context of the home? (this refers to the child's behaviour in the home such as disobedience, or abusive behaviour towards siblings or parents)

- | | |
|---|--|
| <input type="checkbox"/> No problems | <input type="checkbox"/> Moderate problems |
| <input type="checkbox"/> Minor problems | <input type="checkbox"/> Severe problems |

15. Family functioning or factors affecting child *(this looks at whether the family situation contributes to the urgency for treatment)*

- ☐ No problems
☐ Minor problems

- ☐ Moderate problems
☐ Severe problems

16. Prognosis without further intervention *(this assesses what the outlook for the child is if further treatment is not available)*

- ☐ Good
☐ Moderate

- ☐ Guarded
☐ Poor

17. Degree of likely benefit with further intervention *(in other words, how likely is it that the child will benefit from the treatment for which the assessment is being done)*

- ☐ Very High
☐ High

- ☐ Moderate
☐ Low

Children's Global Assessment of Functioning (GAF) Scale (revised)

Rate the subject's most impaired level of general functioning for the specified time period by selecting the lowest level which describes his/her functioning on a hypothetical Continuum of health-illness. Use intermediary levels (e.g. 35, 58, 62). Rate actual functioning regardless of treatment or prognosis. The examples of behaviour provided are only illustrative and are not required for a particular rating.

Specified Time Period: 1 month

- 91-100** Superior functioning in all areas (at home, at school, and with peers); involved in a wide range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organized group such as Scouts, etc): likeable, confident; "everyday" worries never get out of hand; doing well in school; no symptoms
- 81-90** Good functioning in all areas; secure in family, school, and with peers; there may be transient difficulties and "everyday" worries that occasionally get out of hand (e.g. mild anxiety associated with an important exam. occasionally 'blowups' with siblings parents, or peers)
- 71-80** No more than slight impairment in functioning at home, at school; or with peers; some disturbance of behaviour or emotional distress may be present in response to life stresses (e.g. parental separations, deaths, birth of a sib), but these are brief and interference with functioning is transient; such children are only minimally disturbing to others and are not considered deviant by those who know them
- 61-70** Some difficulty in a single area, but generally functioning pretty well (e.g. sporadic or isolated antisocial acts, such as occasionally playing hooky or petty theft; consistent minor difficulties with school work; mood changes of brief duration; fears and anxieties which do not lead to gross avoidance behaviour; self-doubts); has some meaningful interpersonal relationships; most people who do not know the child well would not consider him/her deviant but those who do know him/her well might express concern
- 51-60** Variable functioning with sporadic difficulties or symptoms in several but not all social areas; disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings
- 41-50** Moderate degree of interference in functioning in most social areas or severe impairment of functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, poor or inappropriate social skills, frequent episodes of aggressive or other antisocial behaviour with some preservation of meaningful social relationships
- 31-40** Major impairment in functioning in several areas and unable to function in one of these areas, e.g. disturbed at home, at school, with peers or in society at large, e.g., persistent aggression without clear instigation; markedly withdrawn and isolated behaviour due to either mood or thought disturbance, suicidal attempts with clear lethal intent: such children are likely to require special schooling and/or hospitalization or withdrawal from school (but this is not a sufficient criterion for inclusion in this category)

- 21-30** Unable to function in almost all areas, e.g., stays at home, in ward, or in bed all day without taking part in social activities or severe impairment in reality testing or serious impairment in communication (e.g., sometimes incoherent or inappropriate)
- 11-20** Needs considerable supervision to prevent hurting others or self (e.g. frequently violent, repeated suicide attempts) or to maintain personal hygiene or gross impairment in all forms of communication, e.g. severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.
- 0-10** Needs Constant supervision (24-hr care) due to severely aggressive or destructive behavior or gross impairment in reality testing, communication, cognition, affect, or personal hygiene

Children's Global Assessment Scale was adapted from the Global Assessment Scale for Adults
Children's Global Assessment Scale- Shaffer et al 1229

PLEASE ANSWER THE FOLLOWING QUESTIONS

- A) Please rate this tool on a scale of 1 to 10 where "1" means "completely unreasonable and unacceptable" and "10" means "completely reasonable and acceptable". Simply circle the number that best describes your point of view.

1	2	3	4	5	6	7	8	9	10
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- B) Please explain why you gave this tool the rating you circled above. Include your thought on what you agree or disagree with and any general comments you may have.

GENERAL SURGERY PRIORITY CRITERIA

PLEASE REVIEW THIS DOCUMENT IN ITS ENTIRETY AND THEN COMPLETE THE QUESTIONS AT THE END OF THE DOCUMENT.

PLEASE CHECK THE BOX THAT MOST ACCURATELY DESCRIBES THE PATIENT'S CURRENT SITUATION.

This form will be completed with the patient's history in mind. This means, additional information will be taken into account when answering these questions.

1. Usual FREQUENCY of painful episodes/suffering:

- ☐ None
- ☐ Occasional
- ☐ Often
- ☐ Constant

2. How INTENSE is the pain at its worst?

- ☐ No pain
- ☐ Mild
- ☐ Moderate
- ☐ Severe

3. Usual INTENSITY of other forms of suffering. Please specify form of suffering – CIRCLE all that apply: Nausea or vomiting... Fatigue.... Itching.....Psychological stress such as anxiety or depression. List others: _____

- ☐ None
- ☐ Mild
- ☐ Moderate
- ☐ Severe

4. Degree of impairment in usual activities due to surgical condition:

- ☐ Not impaired at all/mildly impaired
- ☐ Able but difficult and/or somewhat impaired
- ☐ Able but very difficult and at much reduced level
- ☐ Totally dependent (Unable to perform any usual activities)

5. Recent history of: Major complications of condition OR significant physical exam results OR significant test results.

- ☐ No
- ☐ Yes

6. Life-expectancy implications of condition without procedure:

- ☐ 0 Minimal threat to life
☐ 10 Patient faces somewhat reduced life expectancy
☐ 15 Patient faces substantially reduced life expectancy
☐ 20 Patient has condition that is likely to be fatal between six months and two years
☐ 25 Patient has condition that is likely to be fatal within six months

7. Expected improvement in life-expectancy with surgery:

- ☐ 0 None
☐ 5 Minimal
☐ 10 Moderate
☐ 20 Major

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HIP AND KNEE REPLACEMENT PRIORITY CRITERIA

PLEASE REVIEW THIS DOCUMENT IN ITS ENTIRETY AND THEN COMPLETE THE QUESTIONS AT THE END OF THE DOCUMENT.

Patients must be on appropriate non-surgical treatment prior to evaluation (e.g. medications, walking aids, shoe inserts)

PLEASE CHECK THE BOX THAT MOST ACCURATELY DESCRIBES THE PATIENT'S CURRENT SITUATION

This form will be completed with the patient's history in mind. This means, additional information will be taken into account when answering these questions.

1. Pain on motion (e.g. walking, bending): *

- ☐ 0 None/mild
- ☐ 6 Moderate
- ☐ 13 Severe

* Take into account usual duration, intensity, and frequency of pain, including need for narcotic vs. non-narcotic medication.

2. Pain at rest (e.g. while sitting, lying down, or causing sleep disturbance): *

- ☐ 0 None
- ☐ 3 Mild
- ☐ 8 Moderate
- ☐ 11 Severe

* Take into account usual duration, intensity, and frequency of pain, including need for narcotic vs. non-narcotic medication.

3. Ability to walk without significant pain :

- ☐ 0 Over 5 blocks
- ☐ 0 1-5 blocks
- ☐ 4 Less than 1 block
- ☐ 7 Household ambulator (*this means the patient can only walk within his or her home*)

4. Other functional limitations (e.g. putting on shoes, managing stairs, sitting to standing, sexual activity, bathing, cooking, recreation or hobbies):

- ☐ 0 No limitations
- ☐ 4 Mild limitations (able to do most activities with minor modifications or difficulty)
- ☐ 11 Moderate limitations (able to do most activities but with modification or assistance)
- ☐ 19 Severe limitations (unable to perform most activities)

5. Abnormal findings on physical exam related to affected joint (e.g. deformity, instability, leg length difference, restriction of range of motion on examination):

0 ☐ None/mild

5 ☐ Moderate

10 ☐ Severe

6. Potential for progression of disease documented by radiographic findings (e.g. recurrent dislocation, x-ray evidence of protrusion, significant bone loss, component wear, impending fracture): *(this question refers to the evidence from x-rays that shows the disease has a potential to get worse)***

0 ☐ None

4 ☐ Mild

11 ☐ Moderate

20 ☐ Severe

**** Predominantly applies to revisions, use in primary cases only in special circumstances (e.g. ligament instability, bone loss)**

7. Threat to patient role and independence in society (i.e. ability to work, give care to dependants, live independently (difficulty must be related to affected joint):

0 ☐ Not threatened but more difficult

10 ☐ Threatened but not immediately

20 ☐ Immediately threatened or unable

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MRI PRIORITY CRITERIA

PLEASE REVIEW THIS DOCUMENT IN ITS ENTIRETY AND THEN COMPLETE THE QUESTIONS AT THE END OF THE DOCUMENT.

PLEASE CHECK THE BOX THAT MOST ACCURATELY DESCRIBES THE PATIENT'S CURRENT SITUATION.

This form will be completed with the patient's history in mind. This means, additional information will be taken into account when answering these questions.

1. Usual duration/frequency/intensity of pain &/or suffering:
☐ 0 None/mild
☐ 10 Moderate
☐ 20 Severe
2. Severity of illness/impairment:
☐ 5 Low
☐ 10 Medium
☐ 20 High
3. Probable time course of clinical deterioration: *(the physician is asked to estimate the time frame within which the patient's current condition will deteriorate)*
☐ 5 Long-term (> 6 months)
☐ 10 Mid-term (1 – 6 months)
☐ 20 Short-term (< 1 month)
4. Probability of MRI providing clinically significant diagnostic information: *(this assesses how likely it is that the MRI test results will provide information that will help the doctor complete the patient's diagnosis)*
☐ 5 Low
☐ 10 Medium
☐ 20 High
5. Probability of successful treatment resulting from the diagnostic information: *(this assesses how likely it is that the information from the MRI scan will lead to successful treatment of the patient's condition)*
☐ 5 Low
☐ 10 Medium
☐ 20 High

PLEASE ANSWER THE FOLLOWING QUESTIONS

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