

horizons

2015

ENHANCING EXCELLENCE
AND CAPACITY
IN KIDNEY RESEARCH

Consultation Report

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Message from the Conference Chairman

Horizons 2015 was a joint initiative of The Kidney Foundation of Canada (KFOC), the Canadian Society of Nephrology (CSN), The Canadian Society of Transplantation (CST) and the Canadian Institutes for Health Research (CIHR) Institute of Nutrition Metabolism and Diabetes (INMD). It assembled a cross-section of individuals who brought a broad range of perspectives about the many dimensions of kidney research.

The Consultation involved nine months of extensive planning by the *Horizons 2015* Steering Team. In addition, a special Kidney Research Recommendations Group (KRG) worked throughout the meeting and afterwards to identify, refine and summarize the results of the Consultation.

Six recommended strategic kidney research directions were identified during the Consultation:

- Mechanisms, prevention and progression of chronic kidney disease
- Innovative models to enhance kidney health care and quality of life
- Preventing renal allograft loss
- Chronic kidney disease as a risk factor for cardiovascular disease
- Novel strategies to maximize cell, tissue and organ donation and allocation
- Acute kidney injury

This Consultation Report provides a summary of the keynote presentations and detailed information about the six strategic research directions identified by the participants. I encourage everyone to read this carefully as it provides a meaningful summary of the entire process.

In February 2008, a Steering Team comprised of members of the kidney research community including key kidney research funding agencies will meet to continue the process of implementing the recommendations of *Horizons 2015*. This process will undoubtedly involve further consultation within the broad kidney research community. The commitment and engagement of this community will be critical to advancing the key strategic directions identified at *Horizons 2015*.

I would like to close by thanking the members of the Steering Team and the Kidney Research Recommendations Group for their extraordinary commitment to this endeavour, which will ultimately result in improved health for those who suffer from kidney disease.

Dr. John Harnett
Memorial University of Newfoundland



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I. Introduction

Horizons 2015 was a joint initiative of The Kidney Foundation of Canada (KFOC), the Canadian Society of Nephrology (CSN), the Canadian Society of Transplantation (CST) and the CIHR Institute of Nutrition, Metabolism and Diabetes (INMD). Its purpose was to consult with key stakeholders in the kidney research community on the development of a national, strategic research agenda for kidney disease in Canada. The objectives for this consultation were:

- To describe the current range and state of kidney disease research in Canada,
- To identify and describe key strategic directions to guide kidney research from 2008 – 2015 with a longer term outlook to 2020,
- To name and describe areas where capacity building is required to support the identified strategic directions in a national kidney research agenda (i.e. funding, developing collaborative approaches, knowledge translation, training programs, technology, platform development, networks), and
- To continue building a strong, well-informed and supportive kidney research community in Canada.

For the purposes of this consultation, kidney research was defined as research related to the kidney and organ donation, as well as the prevention and treatment of kidney diseases. Kidney research encompasses biomedical, clinical, health systems and population health research pertaining to the kidney.

In Canada, most kidney research is currently funded by the Canadian Institutes of Health Research, The Kidney Foundation of Canada and the pharmaceutical industry.



II. Advancing Kidney Research: Yesterday and Today

In November 1999, The Kidney Foundation of Canada hosted the Horizons 2000+ National Consensus Conference which assembled, for the first time, all the stakeholders in kidney (K), genitourinary (GU) and kidney transplantation (KT) research in Canada. The 1999 conference was organized in response to the emergence of the Canadian Institutes of Health Research (CIHR) and the potential opportunity to engage in research priority planning.

The primary recommendation of the 2000+ Consensus Conference was that transformative research in K/GU/KT be promoted by the formation of a research alliance that would include public, investigator, professional, academic, governmental and industry representation. This alliance would advocate for enhanced research capacity through a significant increase in the number of investigators, the amount of funding and a supportive infrastructure; the development of a national kidney research strategy and strong K/GU/KT representation at the CIHR.

Subsequent to the 2000+ Conference, there have been significant advancements in kidney research. For example, the Kidney Research Scientist Core Education and National Training (KRESCENT) program has been heralded as one of the most innovative opportunities available to scientists about to embark on a career in kidney research in Canada. This landmark initiative represents a major investment in the future of renal research and related fields of study. The Canadian Institutes of Health Research Institute of Nutrition, Metabolism and Diabetes (INMD) and the Institute of Circulatory and Respiratory Health (ICRH) also provide significant support to this initiative and participate with The Kidney Foundation of Canada (KFOC) and the Canadian Society of Nephrology (CSN) on the KRESCENT Governance committee.

In addition, over the past eight years, the kidney research community has provided considerable input into the work of the CIHR. Kidney related research is represented in a variety of CIHR institutes, especially the CIHR-INMD. Much work has also been done to advance the formulation of a national research strategy for kidney research and *Horizons 2015* was organized in order to further this process.

Kidney Research Today: The *Horizons 2015* Consultation

At the *Horizons 2015* Consultation, Dr. Brendan Barrett of Memorial University in Newfoundland provided an overview of the current state of kidney research in Canada. His presentation was based on information obtained primarily from The Kidney Foundation, CIHR and a search of the Medline database.

Between 2000 and 2006, CIHR funded kidney research grew from just over \$7 million to almost \$16 million annually. During this same time period, The Kidney Foundation funded research remained relatively stable at just below \$4 million annually. The KFOC and CIHR funds contribute to KRESCENT salary awards which have also grown substantially. By far, the majority of kidney research expenditure is focused in the biomedical area, followed by clinical research and research that falls into the categories of health services and population health.

Of the approximately 50 peer review committees at CIHR, over half have received applications related to kidney research. The annual growth rate of kidney research in Canada is 5.37% which is slightly higher than the annual growth rate of the country's total health research output (5.05%). Kidney related clinical trials are increasing at a faster rate (13%) than the overall Canadian growth in clinical trials (4.7%).

Note: Dr. Barrett's slide presentation is provided in Appendix 1.

Pre-consultation Survey Report

A Pre-conference Survey Report was prepared by Strachan-Tomlinson and Associates based on participants' responses to a web survey. The purpose of this report was to summarize participants' perspectives on the current situation in kidney research and served as a starting point for discussions at the consultation. This report also provided a basis for the meeting agenda.

The report synthesized 55 questionnaire responses out of a possible 75 which were received by the cut off date (73% return rate). Respondents indicated that the major accomplishments in kidney research in Canada over the past ten years have focused on capacity building, funding, and knowledge translation. Respondents also reported on significant accomplishments in the biomedical and clinical realms. Capacity building gaps were identified in the areas of funding, research personnel/infrastructure and knowledge translation, as well as in the clinical, biomedical, health system/services and research funding agencies. Key strategic research directions and research funding challenges were also identified.

Participants

The participants in *Horizons 2015* included an extraordinary cross-section of individuals who represented a broad range of perspectives on the many dimensions of kidney research. They included representatives from the Canadian Society of Nephrology (CSN), the Canadian Society of Transplantation (CST), The Kidney Foundation of Canada (KFC), The Canadian Institutes of Health Research (CIHR), the Canadian Association of Nephrology Social Workers (CANSW), the Canadian Association of Nephrology Dietitians (CAND), the Canadian Council for Donation and Transplantation (CCDT), provincial health research foundations, universities, hospitals and health centres and the pharmaceutical industry. A complete list of participants is included in Appendix 2.

III: Recommended Strategic Kidney Research Directions

The six strategic kidney research directions that were identified at the *Horizons 2015* Conference were (not in priority order):

1. Mechanisms, prevention and progression of chronic kidney disease
2. Innovative models to enhance kidney health care and quality of life
3. Preventing renal allograft loss
4. Chronic kidney disease as a risk factor for cardiovascular disease
5. Novel strategies to maximize cell, tissue and organ donation and allocation
6. Acute kidney injury

1. Mechanisms, prevention and progression of chronic kidney disease

The following alphabetical list of key words and phrases describe aspects of this strategic direction:

- Aging
- Better measurements (markers)
- Biomarkers
- Breakthroughs in other disciplines, i.e. Diabetes
- Clinical depository – information/database
- Early detection
- Environment
- Fetal programming
- Fibrosis
- Genetics/Genotyping – micro-array
- Hyperfiltration
- Hypertension
- Injury/Renal death
- Lifestyle / Environment / Lifecycle
- Obesity
- Prevention within vulnerable, at risk populations
- Progression
- Public awareness
- Reactivity
- Replacement therapy
- Risk Stratification
- Screening
- Surveillance
- Testing
- Tissue depository
- Tubular atrophy
- Vascular

Mechanisms, prevention and progression of chronic kidney disease (cont'd)

Relevant CIHR research themes - prioritized

Basic biomedical, e.g., genetic, molecular, cellular, tissue physiology	Applied clinical, e.g., drugs, devices, social intervention	Health systems, health services, e.g., epidemiology, health care quality, cost-effectiveness	Societal, cultural and environmental influences on health and the health of populations
1	2	4	3

Determinants of health* (prioritized)

Income and Social Status	5	Personal Health Practices and Coping Skills	3
Social Support Networks	4	Healthy Child Development	2
Education		Biology and Genetic Endowment	1
Employment/ Working Conditions		Health Services	
Social Environments	4	Gender	4
Physical Environments		Culture	

* See Appendix 4 for a complete description of each determinant.

Comments:

All vital inter-related determinants apply; however, specific focal points are often driven by research granting agencies.

Examples of Current Research

- **Biomedical:** Vascular injury (impaired protective mechanism), genetics, fetal endowment, kidney cell injury, stem cells.
- **Clinical:** Risk reduction and stratification, better markers, diabetic complications, hypertension and albuminuria. Clinical studies showing that 33% of patients with type II diabetes are being screened for kidney disease, while 66% are not (and are supposed to be).
- **Health Systems:** Health economics, multidisciplinary approaches to management and risk factor reduction.

Population Health: not enough knowledge of field.

Mechanisms, prevention and progression of chronic kidney disease (cont'd)

Possible research partnerships to support this research direction:

- Chronic renal failure – AB
- CKD – Memorial University
- CRISP (US) Diabetic nephropathy
- Genetic development (multiple)
- HALT PKD – ACE/ARBs (US)
- Health Services (cancer focus) ON
- Kidney – natural progression of PKD
- TEMPO 3/4 - International includes two sites in Canada

Recommendations for new research priorities

Priority	Potential Benefits
Define mechanisms related to kidney disease and develop integrated solutions with biomedical/clinical/prevention/intervention.	<ul style="list-style-type: none"> • Reduction of the burden of disease • Multidisciplinary approach • Large population affected • Improved health economies
Define the environmental determinants of kidney disease.	<ul style="list-style-type: none"> • Identification of risk factors
Develop best modalities for renal replacement therapy.	<ul style="list-style-type: none"> • Quality of life • Survival • Fewer complications • Lower morbidity • Economic impact
Examine the genetic determinants of kidney disease, e.g. genomics, surveillance and susceptibility.	<ul style="list-style-type: none"> • Targeted diagnostic and treatment strategies • Early detection and prevention • Individualized treatment • Health economics
Consider fetal programming and its impact on later development of CKD.	<ul style="list-style-type: none"> • Prevention and early intervention • Identification of risk
Generate new knowledge to improve screening and understanding of kidney disease.	<ul style="list-style-type: none"> • Improved ability to target those who would best respond to therapy
Optimize screening for early detection of kidney disease.	<ul style="list-style-type: none"> • Early detection for those who will/or will not go on and progress to CKD • Screening for those who are known to be at risk and identifying those who may be at risk • Screening for who will respond to therapies <p>Note: This priority can achieve a large benefit in a relatively short time frame.</p>
Optimize the management of kidney disease within a risk population.	<ul style="list-style-type: none"> • Populations/therapies

Current capacities

There is limited collaboration among specific interests related to the mechanisms, prevention and progression of chronic kidney disease. There are changes in approach that are beginning to take place, especially in larger scale type research and common themes of research do exist. It is clear that the environment needs to be more supportive of research in this area.

- **Capacity to use research:** Individual investigators have stored bio-samples and clinical data and there are good participation rates for trials.
- **Environmental capacity:** Socialized medicine provides a greater capacity for database development and long-term cohort follow-up of CKD patients.
- **Human resource capacity:** Although excellent kidney researchers exist in many Canadian institutions, we need more experts in specific research areas.
- **Specific resources:** CRI/CKD clinics, the REB environment, NGOs/Health Charities (KFOC/CDA, etc), provincial agencies, technology platforms, CFI infrastructure, genome project, increased team grants, increased success in CIHR funding, external funding opportunities.

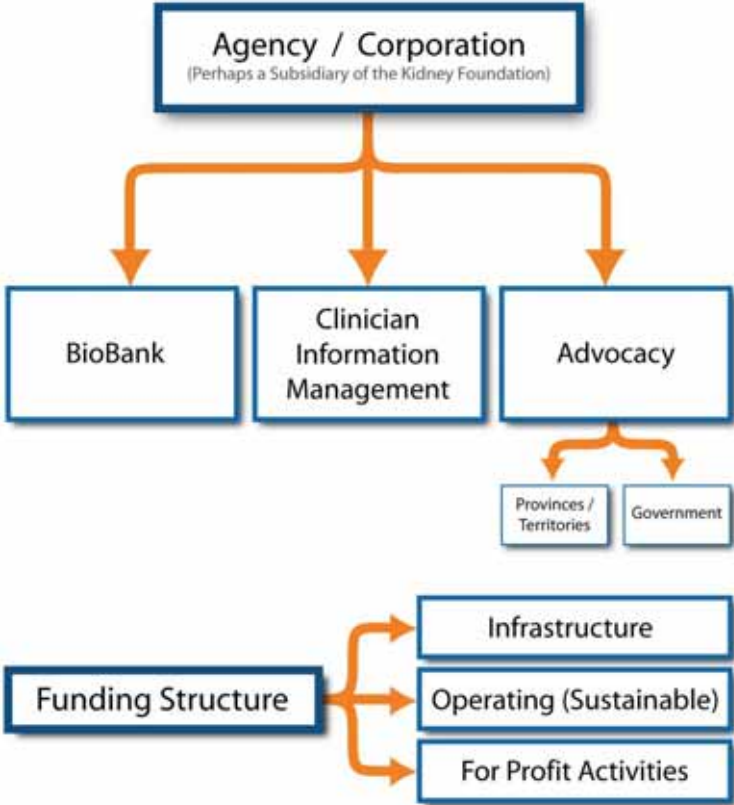
Factors for success

- Central registry or biobank (human DNA, human tissues, patient data)
 - Application for and feedback on use of biobanks
- Enhanced network collaboration
 - Mechanisms that bring investigators together (meetings)
 - Group of investigators
 - Collaboration with the pharmaceutical industry
 - Government partnerships, strategic alliances
 - Use of new technologies for more efficient collaboration
 - Corporate alliances
 - Advocates
- Establishment of Clinical Research Platforms
- Identity within CIHR (renal disease branding)
- Increase in investigators – attracting trainees
- Knowledge translation and development
 - New metrics to evaluate science and promotion
 - Cataloguing of gene polymorphisms
 - Ownership, management, access to information/samples, interoperability

Mechanisms, prevention and progression of chronic kidney disease (cont'd)

- Link to platforms – experimental medicine, proteomics
- Strategies and approaches for increasing funding:
 - Branding for CKD and a possible new agency
 - Private donations from grass roots sites and nationally
 - Specific causes
 - Involvement of researchers
 - Infrastructure
 - Accessing provincial funding
 - Opportunities for site specific funding as part of larger structure
 - Strategies or approaches to increase funding
- Sustainable structure for managing database and tissue
- Targeted institute/centers
- Technology

Recommended actions and broad timelines

Action	Broad timeline	Who to be engaged and how
Establish a national agency to support the systematic study of genetic/environmental determinants of the prevention and progression of kidney disease.		

Mechanisms, prevention and progression of chronic kidney disease (cont'd)

Action	Broad timeline	Who to be engaged and how
Form a biobank working group (stakeholder meeting to develop approach, linked to clinical database).	<ul style="list-style-type: none"> 6 – 12 months 	<ul style="list-style-type: none"> Establish KFOC working group. Engage researchers and institutions. Obtain large-scale funding.
Hold an annual conference on CKD.	<ul style="list-style-type: none"> 6 – 12 months 	<ul style="list-style-type: none"> KFOC/CSN/CIHR (model: FASEB/Gordon Conferences). Develop research themes; call for applications; competition; → funding (CIHR already has funding program).
Improve collaboration and buy in for kidney research.	<ul style="list-style-type: none"> Not specified 	<ul style="list-style-type: none"> Chair Awards, mentoring, salary awards, KRESCENT, protected time. Engage the National Alliance of Provincial Health Research Organizations.
Lobby CIHR to increase funding based on demonstrated success rate.	<ul style="list-style-type: none"> ongoing 	<ul style="list-style-type: none"> KFOC has infrastructure and can engage patients and families. Involve the research community.
Support clinical research platforms.	<ul style="list-style-type: none"> Not specified 	<ul style="list-style-type: none"> Centers of excellence.

Top priorities for change

- Engage provincial funding agencies to increase capacity for funding.
- Establish a political lobby that includes patient advocacy (CSN).
- Expand new KRESCENT investigators to 5 years (3 years plus 2 years - competition between) to maintain capacity.
- Extend Kidney Foundation of Canada operating grants from 2 years to 3 years; increase \$75,000/year.
- New funding for meetings (from multiple sources) to establish research themes resulting in network.

2. Innovative models to enhance kidney health care and quality of life

The following alphabetical list of key words and phrases describes aspects of this strategic direction:

- Access to care to prevent kidney disease/maintain health
- Culturally relevant
- Decision-making along the continuum
- Different approach
- Family centered
- Health service and social support networks
- Humane
- Holistic (values, beliefs)
- Improve kidney health
- Interdisciplinary approach
- Multidimensional determinants of quality of life
- Non-device/non-drug
- Optimize quality of life
- Patient and family expertise and recognition
- Patient education, needs, experience, supports
- Patient focused (not disease)
- Primary prevention
- Shift emphasis in point of care
- Survival
- Technology
- Translational aspects

Relevant CIHR research themes - prioritized

Basic biomedical, e.g., genetic, molecular, cellular, tissue physiology	Applied clinical, e.g., drugs, devices, social intervention	Health systems, health services, e.g., epidemiology, health care quality, cost-effectiveness	Societal, cultural and environmental influences on health and the health of populations
	2 Interventions resulting in improved quality of life	1 Direct impact on Quality of life	✓ Causes before interventions

Innovative models to enhance kidney health care and quality of life (cont'd)

Determinants of health* (prioritized)

Income and Social Status	✓	Personal Health Practices and Coping Skills	3
Social Support Networks	4	Healthy Child Development	✓
Education	5	Biology and Genetic Endowment	
Employment/ Working Conditions	✓	Health Services	1
Social Environments	✓	Gender	✓
Physical Environments	✓	Culture	2

* See Appendix 4 for a complete description of each determinant.

Quality of Life is included in some RCT trials of dialysis and Treatment/outcomes.

- CAN PREVENT
- Cardiac determinants of renal disease
- Caregiver issues
- CKD and co-morbidities – patient experience
- Collaborative CKD and DM and CVD
- Decision-making
- Exercise in CKD
- Expanding home dialysis
- First Nation’s needs
- Modality-decision-making
- Nocturnal dialysis
- Quality of life
- Remote care (tele-health)
- Wearable kidneys

Recommendations for new research priorities

Overarching theme:

Make quality of life research a strategic priority in kidney disease research.

Potential Benefit: Improved quality of life among patients at risk or with CKD.

Priority	Potential Benefits
Develop methods and tools to measure quality of life across diverse populations at risk of or with kidney disease across the lifespan.	<ul style="list-style-type: none"> • A better understanding of the meaning of quality of life in the context of CKD.

Innovative models to enhance kidney health care and quality of life (cont'd)

Priority	Potential Benefits
Develop models of care that include communication and relationships, collaborative models including patient, and family and transitions/continuum trajectory.	<ul style="list-style-type: none"> • Maximize efficiency and effectiveness of current resources. • Improve outcomes and quality of life. • Lends itself to RCTs.
Use new methods and tools to understand the effect of health care systems on quality of life and to develop new health care system interventions to improve quality of life.	<ul style="list-style-type: none"> • A more effective health care system for patients with CKD.
Use new methods and tools to determine the impact of social and cultural environments on outcomes, including quality of life, in patients with CKD.	<ul style="list-style-type: none"> • An improved continuum of care for people with CKD.
Identify determinants of quality of life including cultural relevance.	<ul style="list-style-type: none"> • Evidence on which to base interventions – e.g. for different population groups.
Identify the most effective methods to translate knowledge of best practices to enhance quality of life into effective care across the continuum.	<ul style="list-style-type: none"> • Effective practice and care with a focus on quality of life for patients with or at risk of CKD.
Improve evaluation and knowledge translation, including the education of the entire health care team (patient, family, professionals).	<ul style="list-style-type: none"> • Maximizes research investment. • Evaluates “real world” impact of previous interventions. • Raises the bar through translation of findings through education.
Improve symptom management.	<ul style="list-style-type: none"> • Improved quality of life and improved survival.

Current capacities

- Other disciplines (e.g. cancer) have more developed quality of life methods and research.
- Some researchers are already doing quality of life research. i.e. CANPREVENT.

Innovative models to enhance kidney health care and quality of life (cont'd)

- There are existing quality of life tools for kidney disease population.
- There are some examples of regional cooperation for ethics reviews (BC, Toronto).
- There is a federal body working on electronic records.
- There is a good body of qualitative research about the life experience of patients with kidney disease.
- The determinants of quality of life are highly relevant to the kidney disease population.
- There are a large number of health care professionals involved.
- There is an inter-professional health education initiative.
- We have good access to the kidney disease population.

Factors for success

- Centralized ethics review (federal and provincial)
 - Strategies to better manage ethics reviews
- Electronic health record
- National centers of excellence
- National database on kidney symptoms/standard recording and reporting
- National monitoring centers of research support for kidney research
- Need to know more about capacity in all disciplines (i.e. - who is doing what research where it is being done and what expertise is out there)
- Participatory/collaborative approach to quality of life research questions/design/priorities
- Formal linkage across disciplines in all categories
- More collaboration among national organizations
- Quality of life tools that are appropriate for vulnerable population
- Recognition of quality of life issues as priority for KFOC
- Researcher support staff infrastructure required
- Training opportunities for quality of life researchers. (fellowship, mentorship)

Innovative models to enhance kidney health care and quality of life (cont'd)

Recommended actions and broad timelines

Action	Broad timeline	Key Players
Create a focus for quality of life research in kidney disease: <ul style="list-style-type: none"> • Conduct an environmental scan of quality of life research in Canada across a range of chronic diseases. • Hold a conference involving a broad range of quality of life researchers to engage them in developing methods and collaborations related to CKD. • Issue an RFA for teams investigating quality of life issues for patients with or at risk of CKD. 	<ul style="list-style-type: none"> • 2 – 3 years 	<ul style="list-style-type: none"> • Researchers (across multiple disciplines and diseases) • Patients • Families • Funders
Create specific “quality of life” positions in KRESCENT which are open to participants from any training background (e.g. medicine, allied health professionals). Enhance the curriculum on quality of life in the KRESCENT program.	<ul style="list-style-type: none"> • 1 – 2 years 	<ul style="list-style-type: none"> • KFOC • Researchers • Trainees
Create an RFA for Team Grants in partnership with KFOC and CIHR for quality of life research.	<ul style="list-style-type: none"> • 3 – 5 years 	<ul style="list-style-type: none"> • KFOC • CIHR • Researchers with expertise on quality of life.
Develop a collaborative network of (kidney and non-kidney) quality of life researchers.	<ul style="list-style-type: none"> • 2 – 7 years 	<ul style="list-style-type: none"> • KFOC • Researchers (kidney and non-kidney)
Influence Accreditation Council to include standards and criteria that best practice guidelines are being implemented and evaluated in nephrology.	<ul style="list-style-type: none"> • 5 years (1 review cycle) 	<ul style="list-style-type: none"> • CSN - Guidelines and KFOC advocate working with the CSN on implementation

Innovative models to enhance kidney health care and quality of life (cont'd)

Action	Broad timeline	Key Players
Create database of researchers and research infrastructure for kidney disease, nationally.	<ul style="list-style-type: none"> • 1 – 2 years 	<ul style="list-style-type: none"> • CIHI • Renal program managers • CSN • KFOC • CASN • RPN • CANSW • CANNT • CAND • CST
Develop centres of excellence to support, link, and coordinate clinical research.	<ul style="list-style-type: none"> • 1 – 2 years 	<ul style="list-style-type: none"> • KFOC – strategic call for four centers of excellence
Develop national database from electronic clinical record.	<ul style="list-style-type: none"> • 3 – 10 years 	<ul style="list-style-type: none"> • CORR • CIHI • Government

Top priorities for change

- Create stronger kidney disease and research marketing initiatives for lobbying, profile, and thus funding. Market success stories.
- Develop partnerships with (across) other disease groups and research funding agencies that have a broad interest in quality of life research. (e.g. develop team grants for quality of life research).
- Engage professional organizations and industry to support quality of life research.
- Enhance capacity of allied health professionals in research arena such as supporting the development of clinician/scientist positions, opening up clinician/scientist competitions, proactive mentorship.
- Explore linkage with CDA and Heart and Stroke and other charities around specific research initiatives such as centers of excellence.
- Increase opportunities for knowledge exchange between researchers and volunteers who do fund-raising.
- Provide specific funding for quality of life research (KRESCENT, operating grants).
- Solicit funds from other health charities to develop research and training in quality of life issues.

3. Preventing renal allograft loss

The following alphabetical list of key words and phrases describe aspects of this strategic direction:

- Drug toxicity
- Immunological injury includes compliance issues)
- Inflammation (in particular viral)
- Ischemia and reperfusion
- Mechanisms and treatments
- Progressive vascular disease

Relevant CIHR research themes - prioritized

Basic biomedical, e.g., genetic, molecular, cellular, tissue physiology	Applied clinical, e.g., drugs, devices, social intervention	Health systems, health services, e.g., epidemiology, health care quality, cost-effectiveness	Societal, cultural and environmental influences on health and the health of populations
1	2	3	4

Comments:

- There is a lack of information particularly in social causes, and in the translation between the biological and the clinical.
- There is a lack of conformity and agreement in approach to post transplant care.
- CCDT noted we need to maximize organ donation.

Determinants of health* (prioritized)

Income and Social Status	4	Personal Health Practices and Coping Skills	2
Social Support Networks	4	Healthy Child Development	
Education		Biology and Genetic Endowment	1
Employment/ Working Conditions		Health Services	3
Social Environments	4	Gender	
Physical Environments		Culture	

* See Appendix 4 for a complete description of each determinant.

Preventing renal allograft loss (cont'd)

Current research

There is a lot of focus on basic mechanisms of injury but no uniform clinical application.

Recommendations for new research priorities

Priority	Potential Benefits
Optimization of the use of immunosuppression (investigation and evaluation).	<ul style="list-style-type: none"> • Optimize graft survival • Lower toxicity • Higher adherence • Better health and rehabilitation • More cost effectiveness
Diagnosis and treatment of transplant injury, (vascular injury, ischemic reperfusion and inflammation).	<ul style="list-style-type: none"> • Longer survival • Slower progression back to CKD • Marries well with CKD strategies
Management and identification of viral infection (CMV, POLYOMA, Epstein Barr in children).	<ul style="list-style-type: none"> • Less morbidity and mortality • Save up to 5% of grafts • Lessen lymphoma risks in children

Current capacities

- Various groups are addressing biomedical mechanisms
- Various groups are addressing bio markers (BC, AB, MB)
 - (above two are fragmented with no coordination)
- CST Group (Canadian Renal Transplant Study Group, CRTSG)
- Alberta Kidney Disease Network
- CIHR/CST/KFOC Training Program
- Drug Industry Trials

Preventing renal allograft loss (cont'd)

Factors for success

- Coordination of diagnostics
- Coordination of mechanisms (molecular sciences)
- Coordination of medical : Allied Health Clinical Sciences
- Framework for infrastructure
- National Data Base with biobank
- Strengthening of training programs.

Note: we need the thread to tie the patchwork together

Recommended actions and broad timelines

Action	Broad timeline	Key Players
<p>Develop an integrated framework around a national team which would link to major priorities.</p> <p>Hold theme based meetings to link existing research teams with an interim report after 2 years to be presented in 2010 to International Congress of Transplantation Society.</p>	<ul style="list-style-type: none"> • 2008 CST Meeting reporting to 2010 congress (ICTS) 	<ul style="list-style-type: none"> • CST • CIHR • KFOC • AST
<p>Create a national renal transplant database to capture real time data.</p>	<ul style="list-style-type: none"> • 1 – 5 years 	<ul style="list-style-type: none"> • CORR • CIHI • CST • Institutions • Transplant teams

Preventing renal allograft loss (cont'd)

Action	Broad timeline	Key Players
Create a biobank with integrated policies protocols strategies, technologies.	<ul style="list-style-type: none"> 5 – 10 years 	<ul style="list-style-type: none"> CST CSN CIHR Transplant teams, Labs KFOC Biobank specialists (existing functioning biobanks in cancer, etc)
<p>Formally connect research trainees to clinical teams.</p> <p>Enhance training component of CST/KFOC/CIHR fellowship by formally linking it to the CST meeting.</p> <p>Provide new opportunity for CIHR training program for near future.</p>	<ul style="list-style-type: none"> 1 – 2 years 	<ul style="list-style-type: none"> CIHR CST KFOC

Top priorities for change

- Develop CIHR/KFOC/Industry partnership to fund research.
- Investigate strategies to advocate for funding of a national transplant research infrastructure. E.g. support/advocate for an operational mandate for CCDT (building on consensus building through to implementation).
- Strengthen relationship between KFOC, Heart and Stroke, CDA and others to leverage funding.

Issue: Uncoordinated information systems exist both inter and intra provincially.

4. Chronic kidney disease as a risk factor for cardiovascular disease

The following alphabetical list of key words and phrases describe aspects of this strategic direction:

- 1.9-2.1 million people are at risk
- Acute outcomes in CVD improving chronic outcomes in CVD is a new key issue and the kidney is a major player (marker and modifier)
- CKD involves all stages, including ESRD (dialysis, transplant)
- CVD Risk reduction in CKD
- Early identification
- Kidney vascular disease concept
- Patients are dying before they get to ESRD. Patients with CKD are not recognized; their burden of CVD is high and it too is not recognized
- Predictors outcome: death vs. progression
- Re-label CKD as a vascular disease
- Sub-optimal treatment
- Traditional vs. novel markers of CVD
- The bidirectional interaction “heart-kidney talk”
- Understanding fundamental mechanisms

Relevant CIHR research themes - prioritized

Basic biomedical, e.g., genetic, molecular, cellular, tissue physiology	Applied clinical, e.g., drugs, devices, social intervention	Health systems, health services, e.g., epidemiology, health care quality, cost-effectiveness	Societal, cultural and environmental influences on health and the health of populations
✓	✓	1	2

Note: One group commented that they rejected the model that any two CIHR research themes were more relevant than others. They stated that all themes are integral to the (pursuit of the) “research direction”.

Chronic kidney disease as a risk factor for cardiovascular disease (cont'd)

Determinants of health* (prioritized)

Income and Social Status	5	Personal Health Practices and Coping Skills	4
Social Support Networks	✓	Healthy Child Development	4
Education	5	Biology and Genetic Endowment	5
Employment/ Working Conditions	✓	Health Services	2
Social Environments	4	Gender	2
Physical Environments	1	Culture	3

* See Appendix 4 for a complete description of each determinant.

Examples of current research

Note: There is a paucity of nephrology-led clinical trials in this area. Examples of trials led by nephrology include:

- CANPREDICT Biomarkers and Risk prediction
- CANPREVENT Health Services in CKD and CVD
- EVOLVE Parathyroid therapy
- FHN: Frequent Hemodialysis Network
- SHARP (Lipid therapy)
- TREAT (Anemia therapy in diabetic CKD)

Recommendations for new research priorities

Priority	Potential Benefits
Advocate for the inclusion of kidney patients in the large CVD trials (default historically has been exclusion of CKD).	<ul style="list-style-type: none"> • Relevant to the health of all Canadians because it acknowledges the cultural breadth of Canadians with CKD.
Begin the first (simple/effective trial) led by Canada in the area CKD and CVD.	<ul style="list-style-type: none"> • Opens the door on the process. • Patient outcomes are the priority. • Stresses the fundamental importance of both treatment and prevention.

Chronic kidney disease as a risk factor for cardiovascular disease (cont'd)

Priority	Potential Benefits
Create a clinical trials network in Canada that embraces kidney – CVD trials.	<ul style="list-style-type: none"> Avoids recreating the same infrastructure each time and in each site.
Develop Determinants of sub optimal care.	<ul style="list-style-type: none"> Leads to a better understanding of how to deliver care and would inform trials to overcome barriers.
Identify CKD and CVD refinement tests and implementation risk stratification.	<ul style="list-style-type: none"> Better targeting of health care.
Study mechanism-based questions pertaining to the CKD/CVD link (i.e. defining the risk factors).	<ul style="list-style-type: none"> Provides translational research targeting identified risk factors.
Test chronic care models for CKD and CVD.	<ul style="list-style-type: none"> Lower CV morbidity/mortality in dialysis.
Maintain salt and water control in CKD and dialysis patients.	<ul style="list-style-type: none"> Better health outcomes. Lower costs.

Current capacities

- Automated reporting of eGFR
- Cardiac (APPROACH) – cath-lab registry
- CIHR funding of kidney research; diverse nature of kidney and Institutes
- CFI – (Ottawa KRC)
- DREAM (provincial database)
- Government
- Horizons (II) as a voice/forum to enhance and discuss research issues
- Heart and Stroke Foundation (open competitions)
- Industry support
- Kidney Foundation
- KRESCENT
- Linking drug use to diagnoses
- National Diabetes Strategy
- Other collaborative networks exist in which we could embed
- Provincial Funding Agencies
- STATS CAN – Canadian Health Measures Survey

Chronic kidney disease as a risk factor for cardiovascular disease (cont'd)

Factors for success

- Advocacy and education
- Clear research questions, direction and overt structure to include junior and senior investigators
- Dedicated research infrastructure to ensure effective implementation of multi-centre trials
- Electronic health records. Increase in patient awareness of the link between CVD and CKD
- Integration and coordination
- Infrastructure and administrative network
- Increase in public awareness of CVD/CKD and research
- Institutional support for themes
- Inter-professional research teams
- Linkages with existing Heart Health and other groups
- National database: patient material (clinical and lab/medical), research activity
- Network investigators of kidney disease training and recruitment of combined CKD/CVD specialists

Recommended actions and broad timelines

Action	Broad timeline	Key Players
Advocate provinces to establish an electronic health records database which is researchable.	• 1 – 3 years	• Piggy-back on Diabetes Surveillance System
Enhance and sustain KRESCENT capacity (sustainability) – develop the combined CVD/CKD specialist position.		• KRESCENT Steering Committee • Graduates • Participants
Establish Canadian Trials Network.	• 6 – 18 months	• Leaders in clinical research • Geographically broad • Administrative support

Chronic kidney disease as a risk factor for cardiovascular disease (cont'd)

Action	Broad timeline	Key Players
Establish National Network Nephrology Clinical Investigators.	<ul style="list-style-type: none"> 1 – 3 years 	<ul style="list-style-type: none"> Kidney Foundation CSN CIHR Health Canada PHAC
Link with Heart Health/ Strokes/Diabetes Strategies.	<ul style="list-style-type: none"> 1 – 3 years 	<ul style="list-style-type: none"> Investigators KFOC Others
Partner (content) with HSFC for personnel support and training awards for CKD/CVD (interdisciplinary/cross-specialty). <ul style="list-style-type: none"> Lobby banks and insurance companies. 	<ul style="list-style-type: none"> 12 – 24 months 	<ul style="list-style-type: none"> HSF KFOC KRESCENT Public Policy

Top priorities for change

- Determine a strategic priority and mechanism for funding large dollar projects, apart from usual operating grants.
- Develop a national strategy to fund the research agenda.
 - Leveraging existing infrastructure, CSN, industry, banks, insurance and others.
- Encourage CIHR Institutes to offer specific funding opportunities that would be open to projects with a kidney focus. Extend time or dollar amounts for KFOC grants, e.g., currently \$50,000 x 2 years; increase this dollar amount or extend the timeframe to three years.
- Segregate review of KFOC and other grants submitted to KFOC into clinical and basic scientist. (Review both on excellence, allow flexibility in how grant ceilings are decided and separately decide on funding thresholds.
- Target donors for specific research projects.

5. Novel strategies to maximize cell, tissue and organ donation and allocation

The following alphabetical list of key words and phrases describe aspects of this strategic direction:

- Access and optimal use of organs
- Balancing equity with allocation
- Basic research policy/ethics
- Behavioral
- Bio – kidney
- Cell – therapy
- Consent
- Donor/recipient
- Improving rigor of investigation – importing organs
- Living/deceased (medical/psychosocial and financial outcomes)
- Maximizing incentives
- Minimizing disincentives
- National/ international
- Optimization of health care delivery
- Protection from AKI/DGF – pre-conditioning
- Public awareness/social marketing Stem cells
- Understanding culture of individual critical care units
- Xenotransplant living donation and - DCD – most impact in terms of volume

Relevant CIHR research themes

Basic biomedical, e.g., genetic, molecular, cellular, tissue physiology	Applied clinical, e.g., drugs, devices, social intervention	Health systems, health services, e.g., epidemiology, health care quality, cost-effectiveness	Societal, cultural and environmental influences on health and the health of populations
		✓	✓

Determinants of health*

Income and Social Status	✓	Personal Health Practices and Coping Skills	
Social Support Networks	✓	Healthy Child Development	
Education	✓	Biology and Genetic Endowment	
Employment/ Working Conditions		Health Services	
Social Environments	✓	Gender	✓
Physical Environments	✓	Culture	✓

* See Appendix 4 for a complete description of each determinant.



Novel strategies to maximize cell, tissue and organ donation and allocation (cont'd)

Examples of Current Research

- Access to transplant – optimization
- Bioengineering (matrix)
- Biokidney development
- CCDT and others – exchange of organs
- Cell therapy
- Ethnic cultural diversity in organ donation
- Kidney progenitor cells
- Living donor outcomes
- Loeb research consortium

Recommendations for new research priorities

Priority	Potential Benefit
Improve Donor Performance: <ul style="list-style-type: none"> • Establish methods and measures of organ donation performance on a national and/or international basis in deceased and living donors. • Include donor rates, conversion rates organ utilization, etc. 	<ul style="list-style-type: none"> • Note: To gauge the impact of any public health/clinical practice with societal interventions requires a metric of donor performance.
Assess factors that impact donor performance and interventions (LRD, cadaveric, DCD).	<ul style="list-style-type: none"> • Determinants of donor conversion and novel interventions to improve it. • This includes assessment of non-altruistic factors– social marketing registration and financial incentives.
Assess the impact of different organ allocation strategies on outcome and access.	<ul style="list-style-type: none"> • Inform decision making to maintain or change current organ allocation strategies.
Identify/characterize/isolate progenitor cells for cell-based therapies to treat patients with kidney disease, improve status of “donor kidneys”, and ultimately to “grow” kidneys ex vivo.	<ul style="list-style-type: none"> • Decrease # of patients requiring kidney treatment, increase # of viable donor kidneys.

Novel strategies to maximize cell, tissue and organ donation and allocation (cont'd)

Current capacities

- Existing provincial/national data in Canada which could be used/leveraged (CORR, CIHI, provincial health administrative data)
- Funding opportunities: NET grant opportunity
 - KRESCENT
 - private industry
 - CIHR funding/salary award CIHR/CST partnership
 - KFOC
 - private foundations (McConnell, Gates)
- Human resource capacity
 - Interest
 - Expertise
 - Enthusiasm/cooperation
 - Clinical researchers
 - Stem cell NET
 - Loeb Foundation
 - Clinical trials capacity
 - PALLIUM, CCTG, CRTS, DONOR network
- National forum for discussion: CCDT and knowledge translation

Factors for success

- Development of Academic Surgical Transplant Group.
- Development of multidisciplinary investigators who identify organ donation as a primary research focus and have the time to commit to it and to integrate with transplant professionals.
- Development of standardized mechanisms for translation of results to policy makers.
- Engagement of familiarized donor families in the mechanism to inform research.
- Mechanisms to implement national cohesive management.
- Resolution of jurisdictional barriers which impede research.

Recommended actions and broad timelines

Action	Key Players
<p>Establish Organ Donation Research Network;</p> <ul style="list-style-type: none"> • Hold a think tank (planning meeting) with multidisciplinary representation and clear outcomes/deliverables focused on organ donation research. • Discuss current funding opportunities and the ability to acquire resources for the network. 	<ul style="list-style-type: none"> • Multidisciplinary representation
<ul style="list-style-type: none"> • Issue a call for research proposals in a two-phased approach similar to NIH format. • Hold a Pilot phase with clear objectives and deliverables. • Large scale effort if deliverables met. 	<ul style="list-style-type: none"> • CIHR/KFOC and other organ societies/Industry/private foundation; CHSRF
<p>Leverage existing expertise in stem-cell network, cell related research, to deal with problems in organ donation and kidney disease format.</p>	<ul style="list-style-type: none"> • Existing researchers in these fields, have a planning meeting

Top priorities for change

- Develop mechanisms for partnership/consolidated funding from all sources; specifically consolidation of corporate funding.
- Exploit existing and untapped funding sources, private foundations, corporate, etc.
- Illustrate cost/benefits to government.
- Include multi-disciplinary research (not exclusively a transplant health professional field).
- Partner with current/new initiatives in health outcome /health care delivery.

6. Acute kidney injury

The following alphabetical list of key words and phrases describe aspects of this strategic direction:

- Basic mechanistic studies
- Clinical and biological data collection
- Clinical questions regarding acute dialysis – when to start/modality/dose
- Epidemiology
- Existing human AKI models
- Network/database
- New AKI animal models
- Prognostic implications
- Translational research (link basic science to clinical research)
- Validating/studying definitions

Relevant CIHR research themes

Basic biomedical, e.g., genetic, molecular, cellular, tissue physiology	Applied clinical, e.g., drugs, devices, social intervention	Health systems, health services, e.g., epidemiology, health care quality, cost-effectiveness	Societal, cultural and environmental influences on health and the health of populations
2	3	1	

Determinants of health* (Prioritized)

Income and Social Status	✓	Personal Health Practices and Coping Skills	
Social Support Networks		Healthy Child Development	✓
Education		Biology and Genetic Endowment	2
Employment/ Working Conditions		Health Services	1
Social Environments		Gender	✓
Physical Environments		Culture	

* See Appendix 4 for a complete description of each determinant.

Note: These do not apply well to this research topic.

Examples of current research

- Basic – development of animal models
- Biomarkers – animals – human (translational research)
- Epidemiology – defining extent of problem – formation/evaluation of definitions

Acute kidney injury (cont'd)

Recommendations for new research priorities

Priority	Potential Benefits
Improve understanding of human AKI <ul style="list-style-type: none"> epidemiology both hospital and community, and burden of illness, natural history. 	<ul style="list-style-type: none"> Definition of the scope of the health problem.
Improve early diagnosis and characterization of human AKI with emphasis on translational research in pathophysiology.	<ul style="list-style-type: none"> Greater understanding of disease; design specific interventions; timing of treatments.
Develop and validate of animal models with direct relevance to human AKI.	<ul style="list-style-type: none"> Greater understanding of the pathophysiology of human AKI Development of diagnostic and intervention strategies that may actually apply to humans.
Study/test/develop management and disease-specific treatments of AKI.	<ul style="list-style-type: none"> Improved health outcomes.

Current capacities

- Animal data (models of AKI).
- AKI Definition.
- Early biomarker studies and labs which measure these.
- Early efforts to establish an AKI network.
- Existing databases including serum creatinine data.
- NIH AKI initiatives.

Factors for success

- Collaborative effort to support RCTs.
- Consider industry collaboration for RCTs.
- Design AKI – specific database (including clinical and biological specimens).
- Identify and utilize existing databases (e.g. ICU and administrative datasets).
- Include other disciplines (e.g. cardiology, critical care) in AKI-related research and database formation.
- Increase dialogue/interaction between basic and clinical researchers..

Acute kidney injury (cont'd)

Recommended actions and broad timelines

Action	Broad timeline	Key Players
Identify and recruit key players (clinical, basic) who have goal of making an AKI network. (I.e. generate a symposium or committee stemming from existing Canadian AKI groups.)	<ul style="list-style-type: none"> 1 year 	<ul style="list-style-type: none"> Clinicians Basic scientists in nephrology and other disciplines with interest in AKI.
Design multi-centre clinical and biological specimen collection database, of hospital – acquired AKI. Build upon existing outpatient databases to begin hypothesis generating of long term outcomes.	<ul style="list-style-type: none"> 3 years 	<ul style="list-style-type: none"> The proposed Canadian AKI consortium (from Action A) individual hospitals custodians of data provincial health bodies, ethics committees, etc.
Develop a platform for standardizing experimental protocols (e.g. Development and validation of specific animal models, reagents, clinical protocols).	<ul style="list-style-type: none"> 5 – 7 years 	<ul style="list-style-type: none"> The proposed Canadian AKI consortium (from Action A) with all partners, including basic scientists.

Top priorities for change

- Develop a Canadian AKI consortium and fund this as a strategic priority.
- Add on to existing studies/initiatives (eg. Building AKI into an existing CKD cohort study).
- Fund large clinical trials (including consolidation of small “funded” trials, or industry generated funding). i.e. money for multi-center trials.



IV. Kidney Research Recommendations Group Conclusions

Throughout the Consultation, members of the Kidney Research Recommendations Group (KRG) met to discuss the input from the participants at large. On the final day the KRG presented their conclusions and recommendations for future directions.

Dr. Brendan Barrett reminded participants of the advancements that had been made since the original Horizons 2000+ Consensus Conference in 1999. Since that time, national kidney research had been strengthened through developments such as the KRESCENT Programme and through increased capacity for CIHR funded kidney research.

Dr. Lee Anne Tibbles summarized the recommendations about capacity building. She acknowledged that there had been a strong need expressed to increase capacity by strengthening links between existing databases (such as CORR) and by developing new databases and biobanks. She also observed that there had been numerous calls for an improved clinical trials platform and a network for kidney research. It is clear that kidney research could benefit from stronger partnerships with the federal and provincial governments as well as organizations such as the CIHR and CHSRF. Dr. Tibbles also acknowledged the need for increased funding for kidney research.

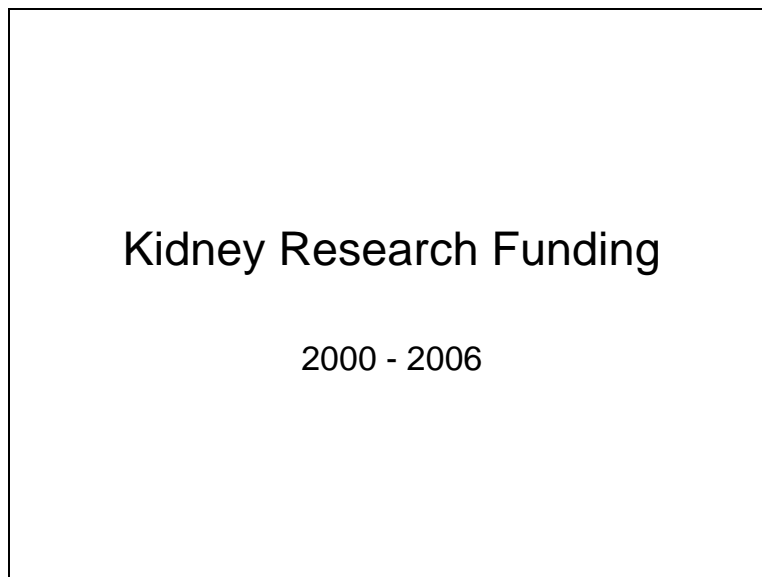
Dr. Kevin Burns laid out several important actions that must be carried out in order to accomplish the priorities and strategic directions that had been identified at the Conference. These actions will include:

- Building on the momentum created at the Consultation Conference by establishing an ongoing process for kidney research planning. This process should be led by The Kidney Foundation and other stakeholders.
- Examining the resource requirements for the implementation of each of the six identified research priorities. This may be carried out at a workshop which should take place before the end of 2008.
- Developing a funding framework that would ensure that the priorities can actually be achieved. The framework should focus on both infrastructure and capacity and include innovative approaches such as partnerships with the for-profit sector and other charities and stakeholders.

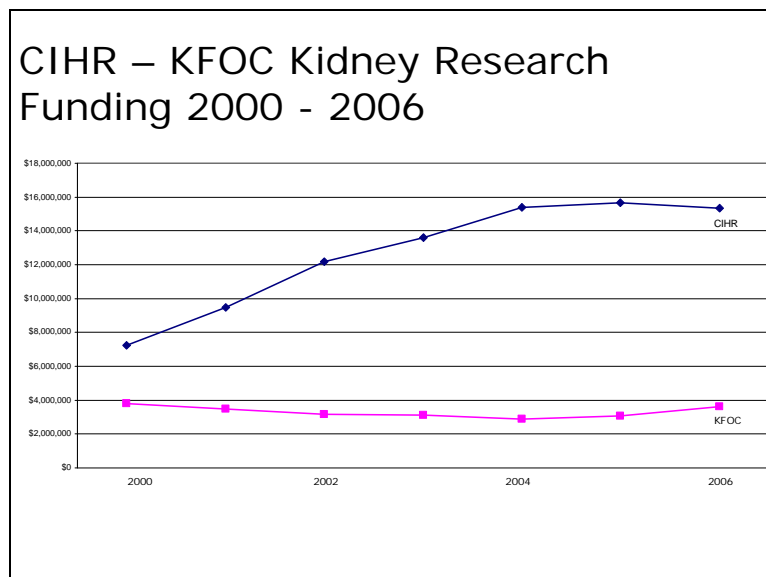
Mr. Gavin Turley, National Executive Director of The Kidney Foundation of Canada and Dr. John Harnett, Conference Chairman, thanked the participants and assured them of their ongoing commitment to continue building a strong, well-informed and supportive kidney research community in Canada.

Appendix 1: Presentation Slides: Kidney Research Funding by Brendan Barrett

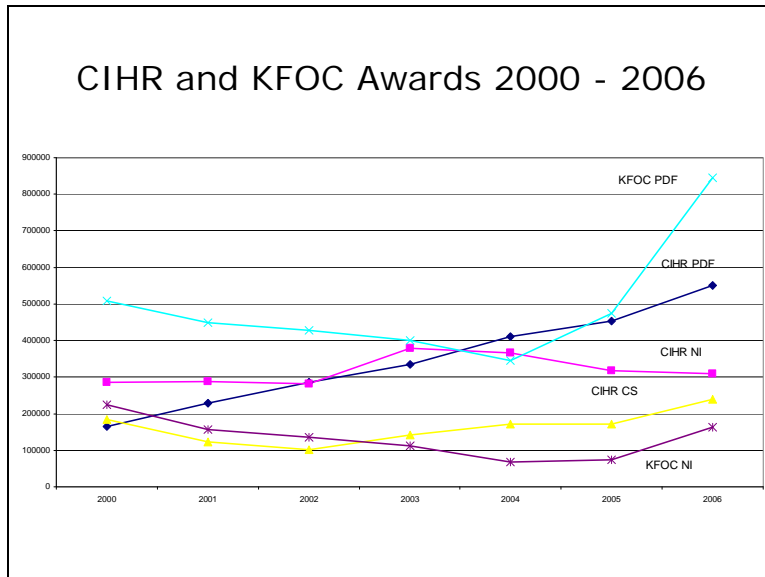
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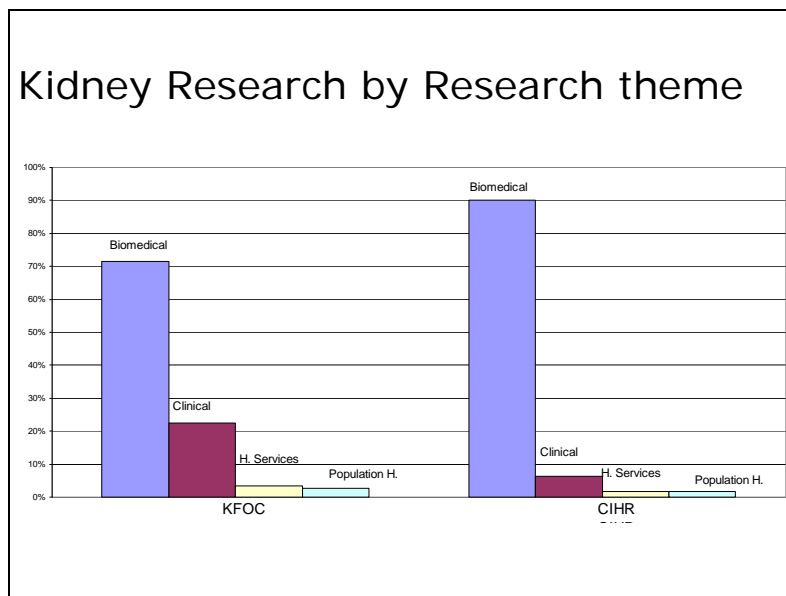
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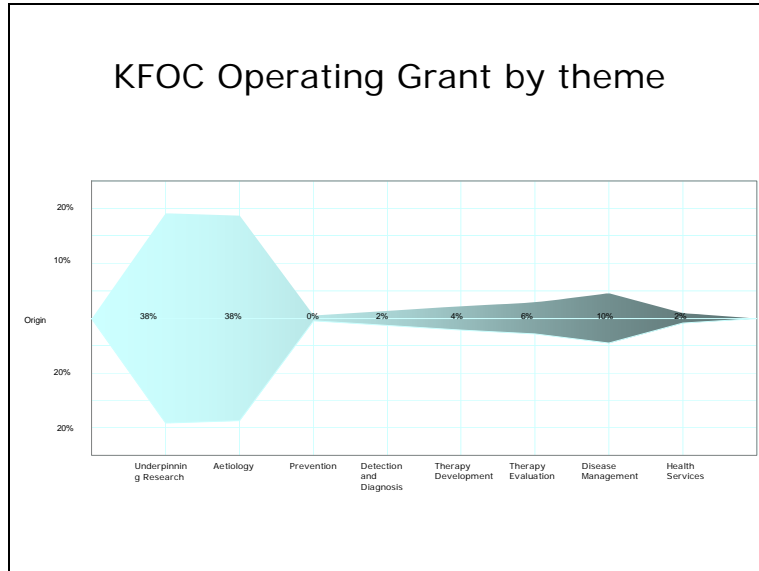
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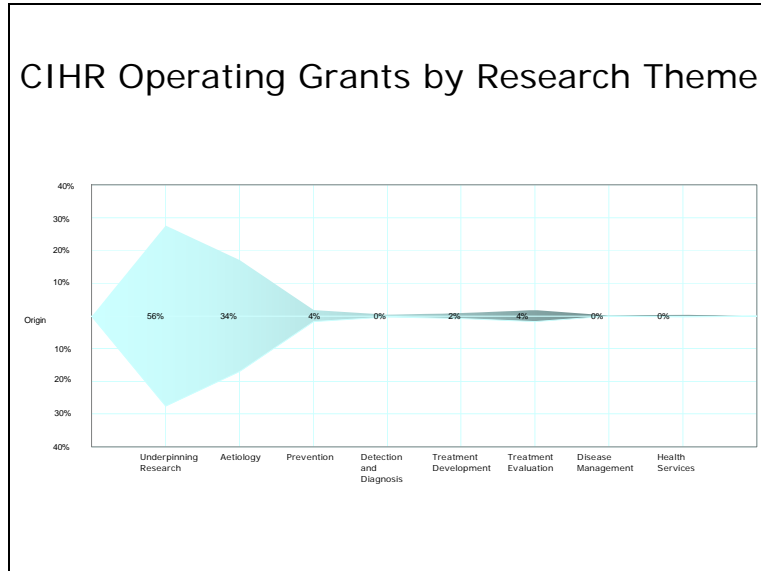
Slide 5



Slide 6

- ### CIHR Peer Review Committees
- CIHR has approx. 50 Peer Review Committees
 - Kidney Researchers have applied to over 50% of the Committees in 2006
 - 2000 19 Committees
 - 2006 26 Committees

Slide 7



Slide 8

Total Health Research Output : 1997-2006
 (ranked by number of articles per 1,000,000 inhabitants)

Rank	Country	Articles per 1,000,000 inhabitants	Articles per 10,000 physicians	Original studies: annual output	Annual growth rate, %
1	Sweden	656	2057	5859	1.89%
2	Netherlands	423	1285	6790	4.67%
3	USA	362	1542	103398	3.31%
4	Australia	333	1316	6535	6.68%
5	Canada	330	1564	10338	5.05%
6	UK	325	1539	19259	5.63%
7	Belgium	270	691	2791	4.27%
8	Germany	204	615	16760	4.92%
9	Japan	198	1012	25132	2.19%
10	France	191	573	11373	2.40%
11	Italy	189	460	10848	4.76%
12	Spain	147	459	6110	8.02%

Slide 9

Kidney Research Output in Different Countries 1997-2006
(ranked by number of articles per 1,000,000 inhabitants)

Rank	Country	Articles per 1,000,000 inhabitants	Articles per 10,000 physicians	Original studies: annual output	Annual growth rate, %
1	Sweden	15.0	47.4	134	-1.20%
2	Netherlands	13.5	40.7	217	3.39%
3	Australia	7.9	31.3	155	1.90%
4	Belgium	7.8	20.0	80	2.60%
5	USA	7.6	32.5	2175	1.96%
6	Canada	7.3	34.4	227	5.37%
7	Japan	6.5	33.0	818	0.81%
8	UK	6.4	30.6	379	1.30%
9	Italy	6.3	15.3	362	4.40%
10	Germany	6.3	19.1	519	0.50%
11	France	5.0	15.1	298	2.40%
12	Spain	4.8	15.1	199	6.40%

Slide 10

Total Number of Clinical Trials in Different Countries: 1997-2006
(ranked by number of trials per 1,000,000 inhabitants)

Rank	Country	Trials per 1,000,000 inhabitants	Trials per 10,000 physicians	Clinical trials: annual output	Annual growth rate, %
1	Sweden	68.2	214	609	1.22%
2	Netherlands	58.3	174	936	6.46%
3	UK	31.1	147	1845	6.56%
4	Australia	30.6	121	603	9.96%
5	Belgium	27.9	71	289	5.95%
6	Canada	27.5	131	864	4.70%
7	USA	26.5	113	7560	3.87%
8	Italy	24.5	60	1411	4.33%
9	Germany	19.5	59	1609	6.33%
10	France	16.0	48	957	3.93%
11	Spain	11.8	37	491	9.28%
12	Japan	9.7	50	1235	4.53%

Slide 11

Kidney Research Clinical Trials : 1997-2006
(ranked by number of trials per 1,000,000 inhabitants)

Rank	Country	Trials per 1,000,000 inhabitants	Trials per 10,000 physicians	Clinical trials: annual output	Annual growth rate, %
1	Netherlands	2.37	7.13	38.0	6.50%
2	Sweden	1.81	5.72	16.2	12.36%
3	Belgium	1.43	3.65	14.8	15.0%
4	Italy	1.15	2.81	66.2	5.30%
5	Germany	0.91	2.76	74.9	5.50%
6	Canada	0.88	4.16	27.5	13.0%
7	USA	0.79	3.38	226	3.88%
8	UK	0.78	3.73	45.9	0.13%
9	Australia	0.78	3.03	15.4	32.0%
10	France	0.75	2.26	44.8	8.40%
11	Spain	0.71	2.23	29.4	14.0%
12	Japan	0.53	2.68	66.7	2.90%

Appendix 2: Participants

	Name	Organization	Region
Dr.	Philip Acott	IWK Health Centre	NS
Dr.	Mohsen Agharazii	Hôtel-Dieu de Québec	QC
Ms.	Irene Aguzzi	The Kidney Foundation of Canada	QC
Ms.	Silvana Anania	The Kidney Foundation of Canada	QC
Ms.	Kathryn Andrews-Clay	Canadian Institutes of Health Research	ON
Dr.	Barbara Ballermann	University of Alberta	AB
Dr.	Brendan Barrett	Memorial University of Newfoundland	NF
Dr.	Heather Beanlands	Ryerson University	ON
Mr.	Paul Bélanger	Canadian Institutes of Health Research	ON
Dr.	Alan Bernstein	Canadian Institutes of Health Research	ON
Ms.	Niloufer Bhesania	The Kidney Foundation of Canada	ON
Dr.	Daniel Bichet	Hôpital du Sacré-Coeur de Montréal	QC
Ms.	Diane Boisjoli	Canadian Association of Nephrology Social Workers	ON
Dr.	Maxime Bouchard	McGill Cancer Centre	QC
Ms.	Tina Britt	The Kidney Foundation of Canada New Brunswick Branch	NB
Ms.	Karen Buchanan	The Kidney Foundation of Canada New Brunswick Branch	NB
Dr.	Kevin Burns	The Ottawa Hospital	ON
Dr.	Teodor Burtea	sanofi-aventis Canada	QC
Dr.	Christopher Chan	Toronto General Hospital	ON
Dr.	John Chan	Université de Montréal	QC
Dr.	Xing-Zhen Chen	University of Alberta	AB
Dr.	David Churchill	Amgen Canada Inc.	ON
Ms.	Krista Connell	Nova Scotia Health Research Foundation	NS
Dr.	Bruce Culleton	Baxter Corporation	ON
Dr.	Andrey Cybulsky	McGill University Health Centre	QC
Dr.	Pauline Darling	St. Michael's Hospital	ON
Ms.	Pamela Dill	The Kidney Foundation of Canada Nova Scotia Branch	NS
Dr.	Roland Dyck	University of Saskatchewan	SK
Dr.	Carmen Enciu	Novartis Pharmaceuticals Canada Inc.	ON
Dr.	Adrian Fine	The Kidney Foundation of Canada Manitoba Branch	MB
Dr.	Diane Finegood	CIHR, Institute of Nutrition, Metabolism and Diabetes	BC
Dr.	Bethany Foster	Montreal Children's Hospital	QC
Ms.	Deirdre Freiheit	Health Charities Coalition of Canada	ON
Dr.	Amit Garg	London Health Sciences Centre	ON
Mme	Marielle Gascon-Barré	Fonds de la recherche en santé du Québec	QC
Dr.	Nathalie Gendron	Canadian Institutes of Health Research	ON
Ms.	Lorraine Gerard	The Kidney Foundation of Canada British Columbia Branch	BC
Dr.	John Gill	University of British Columbia	BC
Ms.	Cathy Gillis	Queen Elizabeth II Health Services Centre	NS
Dr.	Paul Goodyer	The Montreal Children's Hospital	QC
Dr.	Josée Guimond	Canadian Diabetes Association	ON
Dr.	John Harnett	Memorial University of Newfoundland	NF



Mr.	Elmer	Harris	The Kidney Foundation of Canada Newfoundland Branch	NL
Dr.	Brenda	Hemmelgarn	Foothills Medical Center	AB
Dr.	Jacqueline	Ho	Children's Hospital Boston	MA
Dr.	Martha	Horsburgh	University of Saskatchewan	SK
Mr.	Doug	Hubatsch	Hoffmann-La Roche Limited	ON
Dr.	Nina	Jones	University of Guelph	ON
Ms.	Mary Lou	Karley	School of Social Work	ON
Dr.	Christopher	Kennedy	University of Ottawa	ON
Dr.	Paul	Keown	Vancouver General Hospital	BC
Dr.	S. Joseph	Kim	Toronto General Hospital/University Health Network	ON
Dr.	Scott	Klarenbach	The Kidney Foundation, Northern Alberta and Territories Br.	AB
Dr.	Gregory	Knoll	The Ottawa Hospital	ON
Dr.	Joan	Krepinsky	St. Joseph's Hospital	ON
Ms.	Dianne	Kurina	Canadian Association of Nephrology Social Workers	AB
M.	Guy	Langlois	La Fondation Canadienne du Rein	QC
Mr.	Dan	Larson	PKD Foundation	MO
Dr.	Adeera	Levin	St. Paul's Hospital	BC
Dr.	Peter	Liu	Canadian Institutes of Health Research	ON
Dr.	Rodger	Loutzenhiser	University of Calgary	AB
Dr.	Mark	Lundie	Pfizer Canada Inc.	QC
Mr.	Matt	MacFarlane	The Kidney Foundation of Canada P.E.I. Branch	PEI
Ms.	Jana	Machan	Baxter Corporation	ON
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Appendix 3: Acronyms

ACE / ARB	Angiotensin-Converting Enzyme Inhibitors/ Angiotensin Receptor Blocker
AKI	Acute kidney injury
APPROACH	Alberta Provincial Project for Outcome Assessment in Coronary Heart Disease
AST	American Society of Transplantation
CAND	Canadian Association of Nephrology Dietitians
CANNT	Canadian Association of Nephrology Nurses and Technicians
CAN PREVENT	The Canadian Prevention of Renal and Vascular Events Trial in Chronic Renal Disease
CANSW	Canadian Association of Nephrology Social Workers
CASN	Canadian Association of Schools of Nursing
CIHR	Canadian Institutes of Health Research
CIHR-INMD	Canadian Institutes of Health Research-Institute of Nutrition, Metabolism and Diabetes
CKD	Chronic Kidney disease
CKD CRISP (US)	Consortium for Radiologic Imaging Studies in Polycystic Kidney Disease
CORR	Canadian Organ Replacement Registry
CRI	Chronic Renal Insufficiency
CSN	Canadian Society of Nephrology
CST	Canadian Society of Transplantation
CVD	Cardiovascular disease
DCD	Donation after cardiac death
DGF	Delayed graft function
DREAM	Diabetes Reduction Assessment with Ramipril and Rosiglitazone Medication
eGFR	Estimated glomerular filtration rate
ESRD patients	End-Stage Renal Disease patients
EVOLVE	Evaluation of Cinacalcet Therapy to Lower Cardiovascular Events
FASEB	Federation of American Societies for Experimental Biology
FHN	Frequent Hemodialysis Network
KFOC	The Kidney Foundation of Canada
LRD	Living related donor
NGO	Non-governmental organization
PHAC	Public Health Agency of Canada

PKD	Polycystic Kidney Disease
REB	Regional Ethics Board
RPN	Renal Pharmacists Network
SHARP (Lipid therapy	Study of Heart and Renal Protection (a clinical trial of lipid lowering therapy)
STATS CAN	Statistics Canada
TREAT (Anaemia therapy in diabetic CKD)	Trial to Reduce Cardiovascular Events with Aranesp Therapy

Appendix 4: Key Terms

Collaboration: is a process through which parties who see different aspects of a problem can constructively explore their differences and search for solutions that go beyond their own visions of what is possible. Collaboration involves joint problem solving and decision making among key stakeholders in a problem or issue.

Four features are critical to collaboration:

1. the stakeholders are interdependent
2. solutions emerge by dealing constructively with differences
3. decisions are jointly owned
4. stakeholders assume collective responsibility for the future direction of the domain.

In collaboration it is common to have:

- lack of clarity about who is a stakeholder
- disparity of power and/or resources among stakeholders
- complex problems that are not well defined
- scientific uncertainty
- differing perspectives that lead to adversarial relationships
- dissatisfaction with previous and existing approaches and processes.

Community

A community is a specific group of people who:

- share a common culture, beliefs, values and norms
- exhibit some awareness of their identity (personal/social/professional) as a group
- may live in a defined geographical area
- share common needs and a commitment to meeting them
- are arranged in a social or professional structure according to relationships which the community has developed over a period of time.

(Adapted from the WHO definition)

Consensus

Substantial agreement. The degree of consensus that has been achieved is measured by asking participants to express one of the following positions:

- **I agree** with the proposal
- **I can live with** the proposal
- **I disagree**, or **remain undecided**.

Silence is not interpreted as consent.

Key questions to determine consensus are:

- Can you live with this?
- Will you support this decision or action within this group?
- Will you support this decision or action outside of this group?

If unable to answer “yes” to these questions, a participant is asked, “What has to change in order for you to support this decision or action?”

Innovation

The degree to which new approaches are used for solving problems and exploiting opportunities in research, and/or the degree to which the research will focus on new types of important or potentially important issues. (See also the Industry Canada Paper “Achieving Excellence” at www.innovationstrategy.gc.ca)

Innovative Research

Research initiatives that produce something new that will have a significant impact in an area.

Integrated Approach

An inclusive, holistic approach to research, e.g., across CIHR research themes, health disciplines, determinants of health.



Kidney Research

Kidney research is research related to the kidney, organ donation, as well as prevention and treatment of kidney diseases. Kidney research encompasses biomedical, clinical, health systems and population health research pertaining to the kidney.

Knowledge Translation (KT)

Within a complex system of interactions, knowledge translation (KT) is the process that transfers research results from knowledge producers to knowledge users for the benefit of Canadians. Moving beyond the traditional domain of academic publication, it comprises three interlinked components: knowledge exchange, synthesis, and ethically sound application. The goal of KT is to improve health processes, services, and products as well as the health-care system itself. It employs broad-based and often interactive mechanisms of uptake, dissemination, and debate and entails a complex set of interactions among producers, users and contexts. (CIHR)

Network

Individuals, groups and organizations working collaboratively in support of mutually agreed-upon goals, principles and benefits.

Partnership

For the purpose of this workshop, a partnership is a relationship involving two or more parties who have agreed to work collaboratively toward the goal of addressing an issue or a set of issues. A partnership requires the sharing of power, work, support, resources and information with others. A partnership accrues benefits to each partner while fostering an achievement of ends which are mutually acceptable. Three common types/levels of partnership are: principal, collaborating and consulting.

Stakeholders

Stakeholders are organizations or individuals who have a strong interest or stake in the success of the strategic research agenda.

Strategic Research Directions

For the purposes of this consultation, strategic research directions are research areas or applications that are central to collaborative, cross-disciplinary kidney disease research. These directions tend to cross disciplines, determinants of health and CIHR research themes. They may vary in scope but should be focused enough to enable the identification of appropriate approaches or methodologies.

Criteria for determining strategic research directions:

- High degree of need (urgency)
- High potential for impact
- Addresses high risk or vulnerable populations
- As appropriate, integrates Biomedical, Clinical, Health Systems and/ or Population Health approaches to research
- Facilitates links and connections amongst research partners
- Contributes to building the Canadian Kidney Research community
- Facilitates opportunities for innovation
- Likelihood of successful outcomes, given Canadian resources to implement

These are examples of research questions that could fit into a strategic research direction. They give an indication of the scope of the research direction and help define how the research direction could contribute to the overall research agenda.

Appendix 5: The Determinants of Health

DETERMINANTS	UNDERLYING PREMISES
Income and Social Status	<p>Health status improves at each step up the income and social hierarchy. High income determines living conditions such as safe housing and ability to buy sufficient good food. The healthiest populations are those in societies which are prosperous and have an equitable distribution of wealth.</p>
Social Support Networks	<p>Support from families, friends and communities is associated with better health.</p> <p>The importance of effective responses to stress and having the support of family and friends provides a caring and supportive relationship that seems to act as a buffer against health problems.</p>
Education	<p>Health status improves with level of education.</p> <p>Education increases opportunities for income and job security, and equips people with a sense of control over life circumstances - key factors that influence health.</p>
Employment/Working Conditions	<p>Unemployment, underemployment and stressful work are associated with poorer health.</p> <p>People who have more control over their work circumstances and fewer stress related demands of the job are healthier and often live longer than those in more stressful or riskier work and activities.</p>

KEY DETERMINANTS	UNDERLYING PREMISES
Social Environments	<p>The array of values and norms of a society influence in varying ways the health and well-being of individuals and populations.</p> <p>In addition, social stability, recognition of diversity, safety, good working relationships, and cohesive communities provide a supportive society that reduces or avoids many potential risks to good health. Studies have shown that low availability of emotional support and low social participation have a negative impact on health and well-being.</p>
Physical Environments	<p>Physical factors in the natural environment (e.g., air, water quality) are key influences on health. Factors in the human-built environment such as housing, workplace safety, community and road design are also important influences.</p>
Personal Health Practices and Coping Skills	<p>Social environments that enable and support healthy choices and lifestyles, as well as people's knowledge, intentions, behaviours and coping skills for dealing with life in healthy ways, are key influences on health.</p> <p>Through research in areas such as heart disease and disadvantaged childhood, there is more evidence that powerful biochemical and physiological pathways link the individual socio-economic experience to vascular conditions and other adverse health events.</p>
Healthy Child Development	<p>The effect of prenatal and early childhood experiences on subsequent health, well-being, coping skills and competence is very powerful. Children born in low-income families are more likely than those born to high-income families to have low birth weights, to eat less nutritious food and to have more difficulty in school.</p>