CIHR IRSC

2011

INTERNATIONAL REVIEW

OF THE

CANADIAN INSTITUTES OF HEALTH RESEARCH

Expert Review Team Report
for
Institute of Circulatory and Respiratory Health

Submitted by: Professor Stephen Holgate
Chair, Expert Review Team
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Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

Canada

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Summary

In both the written documentation and in the discussions that took place at the ERT event in Ottawa, we were favorably impressed by the influence that the Institute of Circulatory and Respiratory Health (ICRH) has had on both the quantity and quality of health related research. Since its inception 10 year ago, and especially over the last 5 years, research activity has adopted a greater translational direction towards public and patient benefit. This has been achieved by the catalytic influence of the Institute in encouraging multidisciplinary, multi-institutional and multi-funded research that has been especially effective in circulatory diseases, but less so in lung diseases, blood disorders and sleep. However, in each of these latter fields we perceived new activity in the right direction. It is our view that establishing a firm productive translational agenda with support for clinical and health scientists has provided the substrate for increasing Canada's international competitiveness in health research and its beneficial impact on patients. We commend the outgoing Scientific Director Dr. Peter Liu for these achievements in fulfilling the Institute's mandate.

Going forward into the next quinquennium, we would encourage the Institute to further its efforts in this general direction. During our evaluation of the future we have identified nine areas where we believe attention might be directed for additional gains: networks, capacity-building, metrics, translation, balance of funding, public engagement, clinical trials, ethics and governance and data access. For each of these we have made recommendations that are we consider should further improve the scope, relevance and competitiveness of research in those diseases that fall under the remit of the ICRH. We recognize that some of our recommendations are disease-specific while others have a broader coverage, but in all cases hope that the suggestions made are helpful to the ICRH and CIHR more generally.

The Expert Review Team (ERT) was privileged to have been given this opportunity to input into CIHR's review and forward planning process. We would like to offer our sincere thanks to all those at CIHR who prepared the documentation made available prior to our visit, to those staff who greatly facilitated the period spent in the review process and to those individuals who took valuable time to give us evidence we received on the day.

Section 1 – Institute mandate

Our mission is to support research into the causes, mechanisms, prevention, screening, diagnosis, treatment, support systems and palliation for a wide range of conditions associated with the heart, lung, brain (stroke), blood vessels, blood, critical and intensive care and sleep. Our mandate, which is equally broad, is to engage the research community and encourage interdisciplinary, integrative health research that reflects Canada's emerging health needs. Our mandate further encourages facilitating partnerships and accelerating the transfer of new knowledge into benefits for Canadians.

CIHR Institute of Circulatory and Respiratory Health – Internal Assessment for 2011 International Review, pg 1

There is agreement among the researchers interviewed that the mandate of ICRH is very broad that needs to engage multiple stakeholders and covers a wide range of diseases (whose connectivity is not always natural). Hence it is difficult for the Institute to develop the proper programmatic balance and satisfy all the constituents. Certainly, some scientific areas feel that they are somewhat under-represented and under-developed.

Section 2 - Status of this area of research in Canada

The ICRH covers a very broad field of health that includes cardiovascular, blood, respiratory and sleep-related disorders. The shear breadth of its scope creates the possibility for considerable inequity in the funding opportunities for each of the fields and the potential for inequalities in the way projects/programmes are prioritised for support. Overall, however, we are of the view that circulatory health is generally strong in Canada both from a national and international standpoint. This is especially true for clinical trial activity and the establishment of strong collaborative and multidisciplinary networks such as the Canadian Atherosclerosis Imaging Network (CAIN), the National Sodium Working Group and the CVD-Diabetes network.

The situation in lung disease is rather different. We received evidence that the lung research community has found it difficult to transition from the strong position that Canada held in the field of respiratory physiology in the 1950s-90s, to embrace modern cell and molecular technological advances, and that any transition that did occur was too heavily dependant on industrial sources of funding rather than competing in open competition for CIHR resources. We learnt that, for the open competition, there exist 4 cardiovascular versus 1 respiratory grant assessment panel. We recognize that this mainly reflects a lower number of applications received relevant to respiratory; however, this still may represent a meaningful indicator of the overall research activity in the field. From an international perspective, this has influenced Canada's competitiveness in lung-related research which, although relatively strong with respect to clinical trials, is not as strong in discovery science. Although, over the last 5 years we noted a progressive increase in total grant support going to lung disease, it seems that this was still below what is needed to match the perceived disease burden. This is especially the case for chronic diseases such as chronic obstructive pulmonary disease (COPD), idiopathic

pulmonary fibrosis (IPF) and asthma where the international competitiveness of Canadian researchers may be further reduced by supporting smaller individual projects rather than integrated programmes. The documentation of the ICRH also reflected relatively little strategic activity in lung research although the formation of the National Lung Health Framework to improve lung health in Canada was a new opportunity. How much of a research focus this embraced was unclear to us.

We also heard that 4 Centres had been identified in taking forward national research in sleep disorders, but as currently configured, we understand these are undertaking separate activities, and not working as an integrated whole. International sleep research in Canada is considered competitive and certainly, if individual centres in this area came together effectively then this could be a substantial success story for the Institute.

Little information was presented to us on research into blood disorders, though we are aware of Canadian competitive groups in clotting disorders, considerable activity in stroke prevention and treatment and an emerging activity in transplantation.

Since 2006, knowledge translation has been a major focus of the CIHR and we saw some good illustrations of this in relation to policy development and health service development. It is clear that this activity is fundamental to the ICRH mandate and we make specific recommendations below as to how this can be expanded.

Overall impression of the Canadian research landscape in this area

It is our view that circulatory research is doing well, and is likely to be further strengthened from a range of new initiatives that are beginning to deliver on their promise. Most of these relate to the formation of highly active collaborative networks that have embraced the challenges of inter-institutional and multidisciplinary working. What was also clear was the great success the ICRH has had in driving forward strong networks in imaging, a model that could now be extended to other disease areas such as lung disease.

Translation of research outcomes in cardiovascular diseases into clinical practice is another example of effective activity that has been facilitated by the Institute's considerable input into the Canadian Heart Health Strategy and its implementation of a 6-point prevention plan and also the Canadian Cardiovascular Harmonized National Guideline Endeavour (C-CHANGE). The ERT was impressed with the effectiveness of such implementation programmes that illustrated the large change that had occurred since forming the Institute in engaging with downstream application of research. Over the next 5 years, we would strongly encourage similar development in the other disease areas within ICRH's mandate.

The network and partnership approach to research and knowledge transfer also seems to be a very positive development in a country so large in size and where the research is necessarily spread out over vast geographic distances. We heard some concerns that the ICRH might be trying to please too many people and in doing so spreading its limited resources too thinly. Identifying priorities to guide direct funding where it can be most

effective is a challenge for CIHR generally, a point we will return to later. While it was felt that clinical research in the form of trials and diagnostic science was strong, we were less sure about the strength of the underlying fundamental basic science base. While we welcome the progressive increase in both CIHR's central and ICRH's strategic budgets over the last 5 years, we are concerned about the flat baseline funding line that we assume provides support for basic fundamental science. A mechanism needs to be considered on how to link more closely together the strategic budgets and open grant funding mechanisms as part of the "seamless" translational agenda. Maybe the ICRH could play an important role in this more coordinated approach to grant funding as well as developing mechanisms to facilitate basic discoveries to human application and commercialisation.

While certain aspects of clinical science were seen as strong, we were concerned about the state of population health sciences, e-science and point-of-care research. Canada has some excellent, large and well phenotyped adult and child cohorts that deserve greater attention, not only in providing effective observational science and epidemiology, but also facilitating experimental medicine and related activities in nested samples so that the results can be extrapolated to a broad population.

Section 3 - Transformative Impacts of the Institute

It should be recognized that the above successes reside primarily in the cardiovascular area. For lung, sleep and blood areas, more work is needed. One approach is to develop interconnected, interactive consortia of funded investigative hubs in these areas (e.g. connecting the 4 centres of sleep) that exchange data and develop collaborations thereby achieving more critical masses and synergies.

The last 5 years of investment by the ICRH in a wider level of activities has been rewarding. The ERT would like to acknowledge the considerable efforts in time and energy that Dr. Peter Liu has made over this period to deliver on the ICRH mandate. We heard how strongly the research community and stakeholders valued his contributions, which are already delivering transformative impacts in the following areas:

1) The establishment of highly effective partnerships with relevant stakeholders especially the government departments, hospitals, universities and patient charities to funding research and transferring knowledge (e.g. joint workshops and consensus conferences). This was especially apparent in the cardiovascular field, but some signs that success was also being seen in the other disease areas. Essential to the success of these joint endeavours has been the recognition of the importance of mutual trust, fairness and transparency of operation.

2) The ICRH has been a catalyst for a major increase in the overall investment in strategic priorities. A good example is the Salt Reduction Strategy. However, researchers and stakeholders alike were not clear about the process through which such priorities were selected and both requested more transparency and greater participation in this process. Some also questioned about the composition of the Institute Advisory Board (IAB). The ERT is also cognisant of the importance of

the basic science that underpins truly innovative projects and enables these strategic programmes to succeed. The ERT would recommend that the ICRH formulate a short-, medium- and long-term strategy for the research within its mandate and in so doing engage with a wide spectrum of researchers, stakeholders and the public in order to arrive at priorities that all can buy in to. While recognising the need for focus, we heard requests for openness and transparency of process.

3) The bringing together of the diverse research communities, with each other and with their stakeholders including international researchers to collaborate on many initiatives, has been another transformative process. This new model of conducting research has allowed large projects to be effectively taken on, while recognizing the valuable contribution of individuals and groups to the outcomes. Having now established this for cardiovascular research, greater advantage needs to be taken by moving this joint effort into other disease fields. Although in many respects this is a "hearts and minds" exercise, bringing the communities together in workshops and related joint working is generating considerable added value for the Canadian research dollar.

4) Because of the change in emphasis of ICRH towards delivering public benefit, we were made strongly aware that outcomes research was now a major activity and heard some good examples of such networks (the Clinical Imaging Initiative, the Resuscitation Outcomes Consortium, the IMPACT stroke network, the new Heart Failure Network and various Global Trials). We were also impressed by the ability of the ICRH to respond rapidly to evidence and research demands as exemplified by the H1N1 pandemic in 2009 by establishing the InFACT Network.

5) The ability of the ICRH to leverage funding from other organisations is impressive and is clearly a model that works for Canada. We heard evidence that this successful model will form the basis of new work by the Institute that brings in a wider range of stakeholders such as the Provincial Governments, and international funding sources (beyond the US). This was considered an excellent way of continuing the journey of supporting bigger science and large expensive clinical trials.

Section 4 – Outcomes

The ICRH set itself a number of challenges to deliver on its mandate over the last 5 years. The ERT has assessed these using the headings provided in the Internal Assessment Report:

1) Advancing knowledge

As a feature of its strategic directions, the ICRH has focused on increasing the number and size of clinical trials, especially in circulatory disorders. This increase in activity has been especially apparent over the last quinquennium as reflected in both the total number and quality of trial work published in high impact journals. While, there has been some growth in the other research areas, as noted earlier, this is still pretty limited. Moreover, it was not clear to the ERT that investment in research necessarily reflected burden of disease and we were concerned that an attempt to capture such information effectively and to link it to health economics was lacking. We are of the view that in the upcoming period this needs addressing.

We acknowledge the considerable strides taken in building an impressive clinical imaging research activity in cardiovascular disorders across Canada, from what was previously a patch work of isolated and individual efforts. The success of this should encourage extension into other disease fields under the ICRH, especially lung disease where there is a great need for improved non-invasive imaging. We recognise the success of the initiative is an excellent example of the multidisciplinary model in action.

While publication output is one measure of success, we consider that more effort needs to be spent on capturing the breadth and significance of impact on health, wellbeing and policy benefits. The UK Medical Research Council (MRC) eVal system might be one model to explore since this undoubtedly strengthened the case for maintaining the MRC's budget in the 2010 Comprehensive Spending Review (CSR). Being able to quantify impact based on research 10-15 years earlier and putting in place a system to do this on an ongoing basis will strengthen CIHR's case for science funding in the future.

2) Capacity building

We acknowledge the success of the Strategic Training Initiative in Health Research (STIHR). However, we are concerned that the level of support for mid-career scientists (whether clinical or non-clinical) is heterogeneous across Canada and that it is largely left to the universities and/or hospitals to provide. The availability of funding for this critical dimension is very different across the various Provinces. This is not entirely satisfactory when Canada is attempting to roll out an integrated national research programme supported by CIHR. We heard that Dr. Rouleau, the new Scientific Director of ICRH, intends to meet with the universities, hospital management and provinces research/health organisations to engage them in working more closely together. We consider ensuring support for young talented scientists progressing through their careers essential for sustaining the research effort in these key fields.

We are also concerned that the emphasis on large team based clinical trials without a clear strategy of developing fundamental science researchers, mid-career researchers and health economics investigators may result in a pipeline problem in the long-run.

We believe it is a responsibility of the ICRH, and CIHR more generally, to encourage the development of a coordinated and comprehensive framework for support spanning the career path of its clinical and basic researchers. Capacity building also extends to the non-biological sciences recognising the importance of the physical sciences, social sciences and economics in the modern research paradigm and, as such, we believe plans need to be in place to stimulate this activity.

The CVD-Diabetes initiative is a good example of how larger teams can create a strong focus for training and career development in various scientific fields and we wish to encourage the Institute to use the model in other consortia and networks as an integral part of its capacity-building activity.

3) Informing decision making

The ERT was impressed by the success that the cardiovascular community has had in influencing policy in some areas, but we were made aware of a less than ideal impact on public health in cardiovascular, blood and lung diseases; in particular, the role of the ICRH in defining preventative and public health priorities in its disease remit and how community (population)-based science translates into policy. One area that was brought to our attention is a lack of effective primary care research and how this interfaces with secondary care research and care pathways.

We were somewhat disappointed by the limited involvement of industry in the entire Institute portfolio although we recognize there have been some successes in the Networks of Centres of Excellence. The demise of the large pharmaceutical sector, the emergence of stratified (personalized) medicine and the development of high quality discovery science with its associated well-funded technology platforms provide a unique space for researchers in Canada to build and capitalize on intellectual property (IP). From what we were shown, IP activity seems to be decreasing and little attempt appears to be made in moving basic discoveries forward into first in human interventions. We suggest that the CIHR explores possible new funding partnerships with industry that might include the creation of “Development Gap” support that enables critical work to be completed on a project to move it to a stage of commercial interest.

Equally, new CIHR grant schemes that encourage this aspect of translational research should be considered as integral to the overall funding envelope such as developmental clinical studies (first into man), efficacy and mechanism evaluation (grafting on experiments onto ongoing clinical trials to give insight into disease mechanisms) and developmental pathway funding (does not fund discoveries of new disease causes or risk but takes these as starting points and supports their application to improve healthcare and benefits for patients).

4) Health and health system/care impacts

We had the opportunity of hearing some great success stories in this domain especially in improving survival of myocardial infarction, strokes and hypertension. However, in terms of delivering health technology assessment (HTA), it seems that this activity fell within the remit of the health departments of provinces, was happening piecemeal and was not well coordinated. We consider HTA to be central to an effective translation of research towards patient benefit and we see real value in ICRH and CIHR playing a role in

coordinating this activity and connecting it with the upstream science-driven program and downstream national health implementation plans such as the Salt initiative and C-CHANGE.

Section 5 - Achieving the Institute mandate

Much of this has been covered in the sections above. However to crystallise the ERT's view on the success of this:

1) Support research into the causes, mechanisms, prevention, screening, diagnosis, treatment, support systems and palliation for a wide range of conditions associated with the heart, lung, brain (stroke), blood vessels, blood, critical and intensive care and sleep.

Yes, in part. Strong in most of the circulatory-related activities with good outreach and impact, quite a bit less so in respiratory research that comes over as much more fragmented. New initiatives in sleep disorders look promising but have yet to deliver. For blood-related research, we were not sufficiently informed.

2) Our mandate, which is equally broad, is to engage the research community and encourage interdisciplinary, integrative health research that reflects Canada's emerging health needs.

Good evidence of considerable success in this domain with ample evidence given on leverage of funding and added value. This new model of supporting collaborative research in Canada offers great promise at a time when research is becoming ever more costly and requires many different skills and disciplines.

3) Our mandate further encourages facilitating partnerships and accelerating the transfer of new knowledge into benefits for Canadians.

Excellent delivery of this domain but with greater benefit if wider partnerships and greater stakeholder input were obtained in determining priorities and translating research into patient and public benefit.

Section 6 - ERT Observations & Recommendations

The text in sections 2-5 above introduces some of our observations and recommendations in context. Below these are listed individually:

1) Networks

The ERT recognises the considerable value in establishing collaborative multidisciplinary networks in key areas across Canadian academic and clinical institutions. Most of this success has been achieved in the cardiovascular field including imaging and we note that 50% of the Heart and Stroke Foundation of Canada's (HSFC) funding has been with the CIHR and its institutes. However, given the limited resources of the Lung Association, this is not the case for respiratory or blood research. We wish to strongly encourage further activities of this type not only in cardiovascular disease but in lung, blood and sleep. We note in all of these fields such networks are either being proposed or have just started. Some observations we have made in relation to these are:

- The need for early stakeholder engagement in the prioritisation and implementation of a network or consortium (e.g. charities, industry, health departments in the Provinces etc).
- A clear sustainability plan needs to be presented at the start of the process of developing a new network and the investigators informed as to whether or not such networks are time-limited in their funding from the Institute or CIHR strategic budgets.
- If a network is established, plans should be put in place for capacity building and training both of clinical and non-clinical students and staff with sufficient flexibility to take account of gender and other equality issues. We believe such multidisciplinary networks are a model training ground for health-related scientist of the future.

Some effort needs to be expended to ensure that some large and important initiatives instigated by one ICRH Scientific Director can be sustained over the transition to a new Scientific Director, while at the same time ensuring that there is sufficient flexibility in the strategic CIHR and ICRH funds to allow new activities to start up. In some ways this mandates the need for a clear strategic plan for the Institute to be put into place that adequately reflects the current and forward activities. This is not dissimilar to the CIHR Roadmap, but reflecting the needs of disease specific activity and interactions with other institutes and partners. A delivery plan should follow with benchmarking to assess success or not of achieving targets that the strategic plan has set for itself.

Behavioural change was one field that was identified as a major focus in preventing and treating chronic circulatory and lung diseases in the context of a healthy environment. There has been quite a bit achieved in this important public health space over the last 5 years, but this appears to have dropped off the strategic priority list. The ERT would urge the ICRH to reconsider this key field of translational research inn collaboration with other CIHR institutes.

2) Capacity Building

This is the area of most concern to the ERT. We were made aware of concerns over capacity-building in the health sciences. Specifically, issues were raised about bringing in clinician scientists since many of them are supported by clinical dollars and have no university salaries. We are concerned over the pipeline of fundamental scientists. Also capacity building in the related health sciences needs to be considered. New scientific expertise is required to incorporate into the new networks such as health economists, social scientists and informaticians. Mechanisms might be considered to explore ways of enriching programmes by involvement of these specialities. From the experience gained in establishing the imaging initiative, we learnt that there are few difficulties in drawing in the physical sciences into the teams, indeed this success might be a model for other networks. The right balance of research expertise to populate and drive forward these large initiatives is essential as is ensuring a strong pipeline of young, diverse and skilled researchers. We were especially impressed by the STIHR programme and encourage greater use of this type of award in those fields where new capacity is required (e.g. health economics). However, STIHR supports only postdoctoral and graduate students.

3) Research and Development Metrics

There is a need for the Institute leadership to develop clear strategic and operational goals with specific metrics (key performance indices) that are transparent and accountable. Also, there is a need for adequate metrics for measuring success (or not) of these large initiatives. This is essential if the case is to be made for sustainable funding. We heard several examples of programmes being abruptly stopped with little in the way of information being available to back a case for sustainability. While end of grant reports are of some help, their evaluation needs to be connected to more robust metrics and evaluation and future translation planning. Without such metrics this task becomes all the more difficult.

The ERT placed considerable emphasis on a need for measures of impact (significance and reach) and the need for new forms of evidence such as case studies and data on the impact "environment" in a network/institution.
The UK MRC eVal (http://www.mrc.ac.uk/Newspublications/Publications/EvaluationReports/index.htm , http://www.admin.cam.ac.uk/offices/research/documents/local/presentations/2011_01_26_MRC.pdf) and the UK Research Excellence Framework's document on Impact Pilot assessment might be of value (http://www.hefce.ac.uk/research/ref/pubs/other/re01_10/). Such impact data should be based on underpinning research which may date back 5-20 years, nevertheless collecting such examples does make a good case both to government and the public of a need for research funding. More traditional metrics such as research outputs, bibliometrics, funding, PhD studentship numbers and clinical scientists and KT would also be of considerable value in making the case for productivity of an activity and a need for sustainability.

4) Research Translation

At a number of levels we received encouraging evidence for greater translation of ICRH activity into patient benefit. But we also heard that there has been a decline in new patents registered over the last 5 years and relatively weak engagement with the

pharmaceutical, biotechnology and device industries with the notable exception of Networks of Centres of Excellence which are a great success (http://www.nce-rce.gc.ca/Index_eng.asp). The ERT considers more activity needs to be focused on the developmental pathway from new discoveries and IP possibly by establishing new grant schemes for developmental clinical studies, partnership grants and training programmes with industry where their needs are very much at the heart of the project The recognition that the precompetitive space is much larger than previously envisaged also creates the opportunity of joint industry initiatives in target discovery and early clinical studies (e.g. experimental medicine, stratified medicine and biomarker identification and validation).

We also heard that the more basic biomolecular sciences maybe under threat as the push for greater translational activity increases. We wish to emphasise the importance of this sector as the "engine" that drives Canada's health research competitiveness and that along with maintaining facilities funding and technology platforms, scientists in this sector are protected.

5) Balance of Research Funding

The dominance of circulatory research funding was apparent and expected. However, despite some increase in funding of lung and blood research over the last 5 years, it was not clear how decisions about funding priorities are made by the Institute and on what basis. We heard that the Research Funders Forum was not adequate for this purpose. We received a plea from both stakeholders and researchers for a more open and inclusive process and to have greater presence in the crucial decision-making bodies at CIHR such as the IAB. In order to be able to make a stronger case for research and development funding, Canada needs to have available robust data on disease burden and its economic impact as has been conducted in other countries (http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085151; http://www.chronicdiseaseimpact.com/). Such data enable both the public and parliament to understand why research dollars are being spent in specific areas. Lung disease is a particular example where there are pockets of good centres in Canada but not an overall strategic sense of direction (according to the World Health Organization, lung disease is now the 4th greatest cause of mortality worldwide). Different from cardiovascular research, the CIHR is almost the only source of research funding for lung-related research.

A strong competitive advantage that Canada has is its adult and child cohorts. We recommend that an inventory is constructed that catalogues and describes these and that attempts be made to merge data sets around well-defined phenotypes for further in-depth analyses. Such cohorts are also of great value for clinical trials, experimental medicine and biomarker studies as exemplified by the Canadian Healthy Infant Longitudinal Development and Ontario Health Studies. Linking exposures to phenotype over the life course involving epigenetics would seem an especially advantaged area for the Institute to invest in.

6) Public Engagement

While we were informed that the level of public awareness of scientific and medical issues transmitted through the media was high in Canada, we learnt that there is a low public awareness of the ICRH and its activities and a poor perception of its value. Some effort might be spent in working to improve this possibly by helping create a recognisable Institute "branding". The message the Institute can convey of big science, collaboration and working in common disease areas is strong. Such visibility can only be enhanced if the strong links to the patient-based charities can be included. Indeed, the charities can serve as one useful mechanism for connecting the work of the ICRH to the broad community and to patient groups. We commend the Institute for its participation in Café Scientifiques and YI Forums. We also heard of the impact that lay individuals are having in helping research funders such as the NIH (e.g. The Council of Citizens, the UK James Lind Alliance (http://www.lindalliance.org/)) and suggest that the ICRH and CIHR explore greater public and stakeholder input into its activities.

7) Clinical Trials

This has been a great success story for the ICRH over the period since its inception, but especially in the last 5 years under Dr. Peter Liu's leadership. However, the larger impacting trials on health tend to be in the cardiovascular fields. We would encourage a wider spread of trials across the Institute's disease areas and greater international engagement with countries beyond the US. Thus, we welcome the recent initiatives in China and Finland and, as the EU's Framework Programme 8 is being designed, we encourage the Institute's involvement as well as looking for further opportunities with the National Heart, Lung and Blood Institute. Efforts to galvanise the lung community towards greater multicentre clinical trial activity should also be encouraged.

8) Ethics and Governance

As might be expected, we heard some concern over the time and effort it takes to pass multicentre grant proposals through many different internal review boards at different centres and research delivery units and hospitals. This was considered a major factor in delaying the start up of new research. This has been compounded by the ethics committees being answerable to individual provinces. It was suggested that some central ethics committee for multicentre studies needs to be put in place in Canada. This is especially important for large clinical trials where timeliness of delivery is a key factor in success. The Institute maybe interested in the recent UK Academy of Medical Sciences Report on the subject with suggestions about ways to resolve the problems (http://www.acmedsci.ac.uk/p118.html).

9) Wider Access to Data

Increasingly, the accumulation of large datasets lend themselves to data mining and novel analytical approaches especially in the field of e-science and connecting phenotype measures to environmental exposures and lifestyle activities. However, a restriction over wider access by researchers outside those who initiated and conducted the study is causing difficulties.

With public funding, a clear access policy for opportunities for wider use of data should be considered as part of the grant submission and assessment process. We were also aware that the federal department responsible for delivering the public heath agenda was

not always sufficiently consulted as a study was being designed and implanted and, more importantly, not made sufficiently aware of the outcomes so that working them into policy is delayed or does not occur at all. This is a lost opportunity for important translation for public gain.

Overall impression of the performance of this Institute

There is little doubt that the last 5 years of activity of the ICRH has been productive in building quality research in cardiovascular and to a lesser degree the other disease areas under its remit. This is in large part due to the catalytic activity of the Scientific Director in encouraging and facilitating multidisciplinary, multi-institutional and multi-stakeholder partnerships in the form of networks and consortia in key areas of health need. Having demonstrated the added value and productivity of this model, we encourage that such activity forms the central plank of the new quinquenium for this Institute with due regard given to goals, metrics, focus, capacity building, sustainability, translation into public benefit, engagement of industry and international interactions. Greater consideration of the impact of disease burden and their economic impacts and greater openness and inclusivity in research priority setting should also help deliver high quality outcomes in these disease areas where there remains considerable unmet clinical needs set against an aging population, changing lifestyles and living with environmental change.

Appendix 1 - Expert Review Team

Chair - Professor Stephen Holgate
MRC Clinical Professor of Immunopharmacology
School of Medicine, University of Southampton, UK

Expert Reviewer – Dr. Duncan Stewart
CEO and Scientific Director and VP of Research
The Ottawa Hospital,
The Evelyn and Rowell Laishley Chair,
Professor, Dept of Medicine, University of Ottawa, Canada

International Review Panel – Professor Victor Dzau
Chancellor for Health Affairs, Duke University
President and CEO, Duke University Health System
James B. Duke Professor of Medicine
Durham, NC USA

Appendix 2 - Key Informants

Session 1 – Review of Institute

1. **Dr. Jean Rouleau, ICRH Scientific Director**

2. **Dr. Yves Berthiaume, Chair – Institute Advisory Board**
   Professor, Faculty of Medicine
   Université de Montréal

3. **Dr. Pavel Hamet**
   Director of Research, Centre Hospitalier Université de Montréal
   Professor, Department of Medicine, Division of Experimental Medicine
   Université de Montréal

4. **Dr. Rob Beanlands**
   Director, National Cardiac Positron Emission Tomography Centre
   Chief, Cardiac Imaging and Director of the Molecular Function and Imaging Program, University of Ottawa Heart Institute
   Professor, Divisions of Cardiology and Radiology, Department of Medicine
   University of Ottawa

Session 2 – Consultation with researchers

1. **Dr. Art Slutsky**
   Vice President of Research, St. Michael's Hospital
   Professor, Departments of Medicine, Biomedical Engineering and Surgery
   University of Toronto

2. **Dr. Jean-Claude Tardif**
   Director, Montreal Heart Institute Research Centre
   Professor, Faculty of Medicine
   Université de Montréal

3. **Dr. Jack Tu**
   Head, Cardiovascular and Diagnostic Imaging Research Program, Institute for Clinical Evaluative Sciences, Toronto
   Professor, Faculty of Medicine, Department of Health Policy, Management & Evaluation
   University of Toronto

Session 3 – Roundtable with stakeholders

1. **Ms. Linda Piazza**
   Director of Research
   Heart and Stroke Foundation, Ottawa

2. **Ms. Marla Israel**
   Director, Chronic Disease Management Division
   Public Health Agency of Canada

3. **Ms. Michelle McEvoy**
   Manager, National Research Programs
   The Lung Association, Ottawa

4. **Dr. Norman Campbell**
   President of Blood Pressure Canada
   Professor, Faculty of Medicine, Departments of Medicine, Pharmacology and Therapeutics, and Community Health Sciences
   University of Calgary