Evaluation of the Canadian SARS Research Consortium (CSRC)

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Cat. No.: MR21-62/2005E-PDF
ISBN 0-662-40402-5

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EXECUTIVE SUMMARY

CONTEXT

The Canadian SARS Research Consortium (CSRC) was created in June 2003 to ensure that Canada's health research community, funding agencies and industry were able to mount a rapid and effective research effort in response to SARS. The aims of the evaluation of the CSRC were to determine its overall effectiveness, efficiency and relevance and to provide the Consortium with recommendations on how the performance of this model could be improved.

METHODS

The main source of evaluation information was 25 key-informant interviews with 27 participants and stakeholders in the CSRC initiative and a review of key documents. Interviewees included representatives of the CSRC Management Group, CSRC Scientific Advisory Committee, successful and unsuccessful researchers in the SARS I and SARS II research competitions and other stakeholders, including Canadian and international researchers involved in relevant areas, SARS I and SARS II peer review committee members and CIHR institute and corporate senior managers.

MAIN FINDINGS AND LESSONS LEARNED

Views of the stakeholder community on the effectiveness of the CSRC were varied, with most seeing it as a qualified success. There was wide agreement that many valuable lessons had been learned through the SARS experience and the CSRC experiment and that these should be applied in building an ongoing research response capacity for future emerging health threats.

Lessons learned

1. **The Canadian research community is willing and able to mobilize**, to work in partnership and collaboration across sectors and institutions, putting personal and organizational interests aside in the interest of responding to a health crisis, and to innovate in finding new ways of working together so as to respond more quickly and effectively.

2. **There is a need to create a permanent national coordination entity to coordinate a rapid research response** to emerging infectious diseases. This entity should proactively develop structural and research facilitation mechanisms, including:

Structural issues

- **Flexible and contingency funding,** so that adequate funds can be immediately accessible. This will ensure that the research community's attention is entirely focused on the research issues, rather than on where the money will come from, and that hard choices about siphoning resources from other existing priorities do not have to be made in the context of a crisis.

- **Overcoming organizational barriers to formal partnerships.** The legal and liability issues involved in the CSRC partnership model should be examined and resolved, resulting in generic templates that can be adapted expeditiously when needed.

- **Creating mechanisms of effective international collaboration.** The relationships and processes required to ensure effective information sharing and facilitation of collaborative international research efforts (for example, through exchange of patient materials, epidemiological data, etc.) should be put in place prior to a new emerging crisis.

- **Creating an inventory of expertise.** Creating and maintaining a national inventory of relevant research expertise in areas of likely future health threats could expedite the mobilization of the research community and the mounting of coordinated research efforts in the face of an emerging threat. Effective collaboration among researchers in different parts of the country could be enhanced if members of the inventory also had opportunities to interact and build trust and goodwill prior to a crisis situation.

- **Considering alternatives to the standard open competitive funding model,** for example, by targeting funds more directly to teams with known capacity and expertise. The advantages and risks of alternative models should be considered and debated outside the crisis situation.

Research facilitation issues

- **Rapid and appropriate peer review.** Concerns raised about the appropriate composition of peer review committees should be addressed, perhaps through the creation of a roster of potential peer reviewers with a wide range of expertise who are willing to be part of an emergency peer review process if needed.

- **Expedited and effective ethics review for research conducted in the path of an ongoing outbreak.** Proactive, anticipatory attention to ethical issues and their review is required to ensure that patient safety remains paramount, that standards are consistent and that procedures do not cause loss of precious time.

- **Coordination of access to patient specimens.** The importance and complexity of this issue became apparent during the SARS outbreak, as the lack of coordination probably contributed to some inefficiencies in the research effort. Establishment of mechanisms and protocols for sample coordination prior to outbreaks would prevent this and the tensions that result.

- **Protocols for the conduct of clinical trials in an ongoing outbreak or epidemic.** Having protocols in place and ensuring adequate communication among sites involved in clinical trials would address the difficulties encountered in the SARS outbreak. Mechanisms could also be developed for facilitating the participation of researcher/clinicians most directly involved in managing the outbreak, in research during the outbreak itself.

1. CONTEXT AND BACKGROUND

1.1 The CSRC and its mandate

The Canadian SARS Research Consortium (CSRC) was created in June 2003 to ensure that Canada's health research community, funding agencies and industry were able to mount a rapid and effective research effort in response to SARS. Its mandate was to coordinate, promote and support SARS research in Canada and to develop international linkages and partnerships to control and eradicate SARS. The CSRC was to establish research priorities, coordinate funding and facilitate integration of the funded research projects. It aimed to develop and coordinate the implementation of a national research agenda on SARS in five broad research areas: diagnostics, vaccine development, therapeutics, epidemiology and databases, public health and community impact.[1]

1.2 Evaluation of the CSRC

This document presents an evaluation of the CSRC. The aims of the evaluation were to determine its overall effectiveness, efficiency and relevance, and to provide the Consortium with recommendations on how the performance of this model could be improved. In addition, the evaluation aimed to contribute to development of a generalized model for evaluation of research responses that could be built on in subsequent evaluations of the Canadian research community's actions in response to emerging health threats.

The evaluation report is presented in four sections. Following this introduction, the data collection methodology is summarized. In the third section, an analysis of the results relating to the key issues areas is presented. The last section provides an overall conclusion and a set of recommendations on suggestions for improvements for future situations.

2. APPROACH AND METHODS

2.1 Evaluation questions

The overall proposed approach to this evaluation was driven by the need to provide, in a timely fashion, high-level strategic information. Taking into account that most of the research supported through CSRC-related activities is still ongoing or just beginning, the evaluation questions addressed were:

- **Relevance/rationale:** To what extent was the CSRC model relevant to and adequate for addressing the overall mandate of coordinating, promoting and supporting SARS research in Canada and developing international linkages and partnerships to control and eradicate SARS?

- **Organization design/delivery:** To what extent was the initial vision of the CSRC appropriately and effectively designed and delivered?

[1] http://www.cihr-irsc.gc.ca/e/16003.html

- **Effectiveness/success/impact:** To what extent was the CSRC successful in realizing its expected outcomes in its three main functions: establishment of research priorities for SARS, coordination of research funding among funding partners and in line with international activity and facilitation of integration of research findings? To what extent can observed responses to SARS in the research community be attributed to the contributions made by CSRC's actions?

- **Efficiency cost-effectiveness/alternatives:** Do more efficient and effective approaches exist for addressing the mandate of the CSRC?

2.2 Evaluation Committee

An Evaluation Committee was created to provide advice and guidance on the evaluation strategies and processes as well as to facilitate contacts with the stakeholder community. It consisted of: the Manager, Programs and Evaluation, of the CIHR Institute of Infection and Immunity (CIHR-III), a representative of the Evaluation and Performance Management group within CIHR and one member of the CSRC Management Group.

2.3 Logic model for the CSRC

The first step in the evaluation, based on review of available documentation and initial discussions with the CSRC secretariat, was the development of a program logic model for the CSRC (Figure 1). The documents reviewed included background material provided by the Consortium and review of minutes and decision records of meetings of the Management Group and the Scientific Advisory Committee. The logic model outlined the inputs, activities, outputs and expected short-, medium- and long-term outcomes of the CSRC and the logical linkages among them.

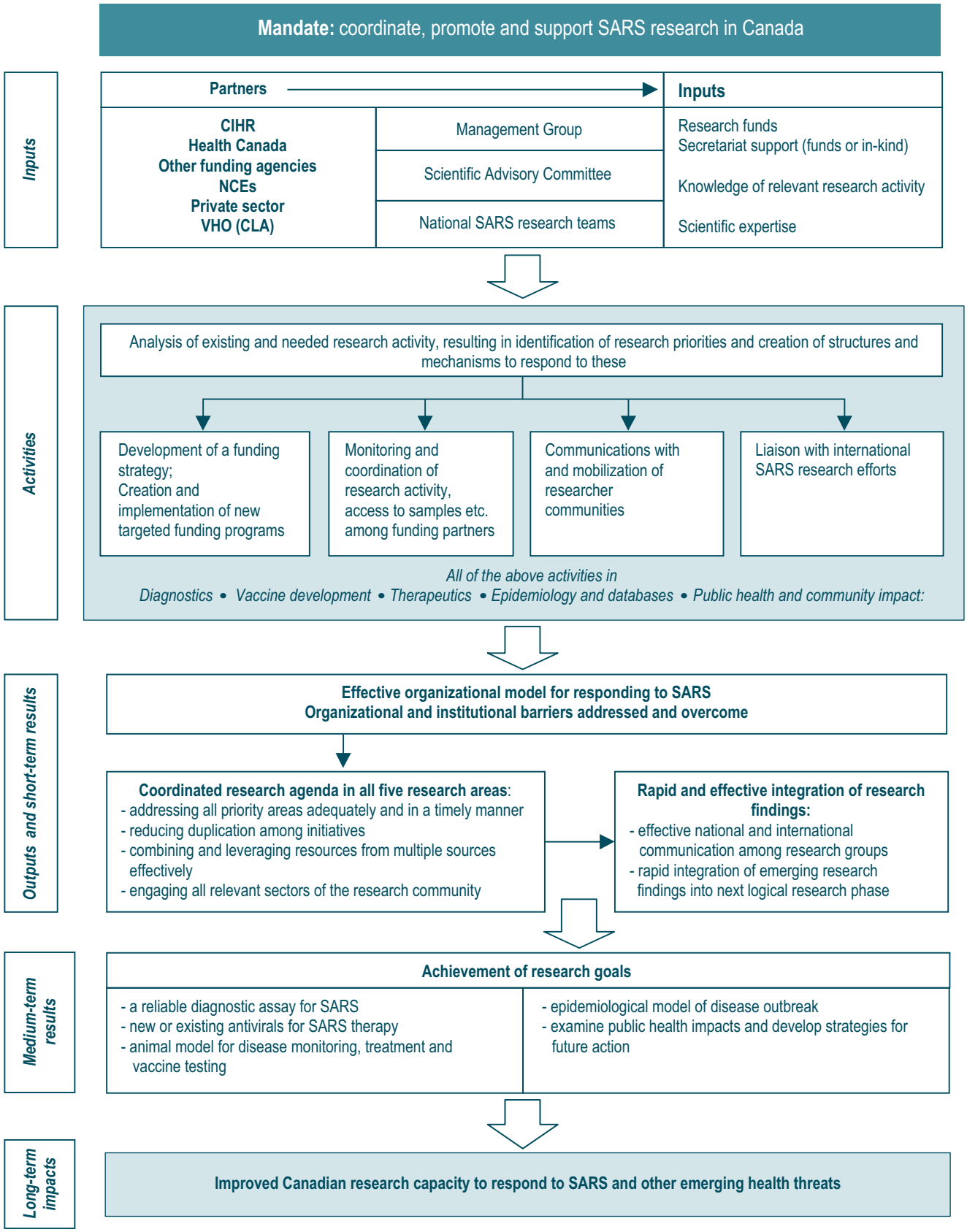
The logic model was validated by the Evaluation Committee and then used as the basis for developing the evaluation tools.

2.4 Data collection and analysis

The main source of evaluation information was 25 key informant interviews with 27 participants and stakeholders in the CSRC initiative. Potential interviewees were identified from four categories: CSRC Management Group, CSRC Scientific Advisory Committee, successful and unsuccessful researchers in the SARS I and SARS II research competitions and other stakeholders, including Canadian and international researchers involved in relevant areas and SARS I and SARS II peer review committee members. This latter group included four CIHR Institute and corporate senior managers. The sample was identified in consultation with the Evaluation Committee and the Management Group chair so as to maximize the diversity of perspectives on the CSRC, in terms of both sector and role.

All interviews but one were conducted individually by telephone. One interview was conducted in person, with three individuals. All interviews used a semi-structured interview guide (found in Appendix 1), based on the evaluation questions and program logic model. The guide was reviewed by the Evaluation Committee. The table below shows the number and type of interviewees. (The total adds to more than 25 because several interviewees had dual roles.)

Figure 1: CANADIAN SARS RESEARCH CONSORTIUM Logic Model



Respondent Type	Number of interviews
Members of Management Group	6
Members of the Scientific Advisory Committee	8
SARS researchers: national and international, funded through SARS I, SARS II, or other funds, including one unsuccessful applicant	9
SARS I and SARS II review committee members, including 4 CIHR senior managers	5

3. FINDINGS

3.1 Relevance/rationale

Need for a coordinated research response to SARS. There was complete consensus among those interviewed, regardless of their role or relationship to the Consortium, that there was indeed a need for a coordinated research response to SARS in Canada. Respondents maintained that there was a need to rapidly mobilize research resources while ensuring that there would be no unnecessary duplication of effort, in order to drive the research effort forward as effectively and efficiently as possible. Even with the hindsight afforded by the quickly diminished health threat, interviewees agreed that a quick, incisive response had been absolutely necessary. The Canadian response was compared favorably to that in some parts of the world (notably the European Commission, which took much longer to organize) and less favorably to others (as in Hong Kong, where much research was conducted during the course of the outbreak).

Appropriateness of the CSRC model. Views on whether the CSRC was the most appropriate model for a coordinated research response were consistently positive. However, several of those interviewed – including most of the researchers and members of the review committees – were not fully aware of the CSRC's structure and mandate, and so were not able to comment in depth. Some of the interviewees most knowledgeable about the CSRC stated that the partnership model involving stakeholders from multiple sectors and across the country was essentially the best that could have been constructed at the time but that, with the benefit of hindsight, some aspects could probably have been improved. These are addressed in section 3.2

Adequacy of the CSRC mandate. Most views were that, in retrospect, the mandate of the CSRC had been adequately broad, and no respondent stated that it should have been narrowed. Some respondents argued that the mandate was to have served as a tool for enabling effective use of resources, but other factors, including resource limitations, hampered the CSRC's effectiveness more than the mandate (see section 3.2).

Continued need for the CSRC or a similar organization. Responses to this question varied according to interviewees' perspectives. Researchers still involved in SARS, particularly those concerned with its re-emergence internationally, felt that there is still a need for a national, SARS-specific coordinating body.

All other respondents, however, including some of the researchers, believed that there is an ongoing need for a national coordinating body charged with preparing for emerging viral health threats but that it need not, and should not, be confined to SARS. In fact, for many respondents, the need for this national coordination function was the most critical lesson learned from the SARS outbreak.

The vision of the continued coordination role among these stakeholders was quite consistent, with the main feature being the capacity to put mechanisms, structures and resources in place that will make a response to the next health threat even more effective. Many of those interviewed referred to an expected influenza pandemic as the next situation where this organization will be needed. The specific areas of action for this organization are indicated in Section 4, under lessons learned.

3.2 Organization design/delivery

Partnership structure and partners' roles. The partnership structure of the CSRC was generally regarded as appropriate and effective, with one main exception. Several respondents felt strongly that the health system (public health and health services infrastructure) should have been represented through the Management Group, as theirs was a key role in managing the outbreak. There was agreement that the inclusion of private and public partners was appropriate and effective, and that no key partners had been excluded. Respondents noted that there had been some discussion about the membership and avoiding conflict of interest – especially as some members of the committees became directly involved in the research activities. It was suggested that some non-Canadian participation might have been helpful. Some interviewees questioned the size of the Management Group and the Scientific Advisory Committee, noting that too large a group – as can result from a process that values inclusiveness most highly, leading to too many interests at the table – can paralyse functioning. Some interviewees felt that a smaller group might have been just as effective.

There was some disagreement among interviewees about the equity of the partnership structure. While there was support for a partnership model with equal financial contributions from all partners, some non-federal partners felt that the federal commitment (through CIHR) should have been greater.

Effectiveness of Management Group and Scientific Advisory Committee's respective roles. The dual structure of the Management Group and Scientific Advisory Committee, while not rejected by any respondent, was seen as a good idea in principle, notwithstanding that, in practice, their interaction was not optimal. Many of those involved in the Scientific Advisory Committee did not feel fully engaged in an ongoing effort, having participated in only one or two meetings early in the process. They were not aware of how the Management Group had used the results of their discussions and had little contact with the CSRC after the initial activities. The Management Group members, on the other hand, felt that their group had been quite successful in accomplishing most aspects of its coordination mandate.

The main advantage of the dual structure was that it separated the scientific function from the core management function, the latter requiring familiarity with the agendas and operations of the various stakeholders.

CIHR-III Leadership. The stakeholders interviewed from all sectors were very satisfied with the leadership provided by the CIHR Institute of Infection and Immunity. It provided coherent coordination and leadership and was able to rally the partnership group in an inclusive process with a minimum of bureaucratic complications.

Overcoming organizational and institutional barriers. Interviewees recognized that there were significant organizational and institutional barriers in the partnership model and that the CSRC had been unable to completely resolve them. Many factors contributed to the complexity of these barriers, including those related to ownership and intellectual property, information systems management and privacy concerns. One of the key barriers that hampered some aspects of the CSRC's functioning was the inability to obtain agreement on memoranda of understanding for the partnership. Because these involved the Government of Canada and private sector partners, complex legal and liability issues arose that were not resolved during the active life of the CSRC. Many respondents insisted that these issues should be addressed in an interim period between crises, so that generic templates can be created and adapted expeditiously when needed.

The private sector partners noted that they had relinquished intellectual property rights for the purpose of expediting the processes, but also noted that the economic potential for SARS-related research results was largely unknown.

Resource adequacy. One of the most serious problems encountered by the CSRC, according to several informants, was that, despite the willingness of partners to mobilize and contribute resources, there were no contingency funds available at CIHR and little capacity for flexibility in the existing funding structure. Those partners with greater flexibility and with deliberate or serendipitous contingency funds were able to contribute to the research effort, but the overall assessment among many of those interviewed was that it was a patchwork effort. In the event of future outbreaks of SARS or other infections, these interviewees argued that CIHR should maintain an adequate and accessible contingency fund, possibly at the level of the President. This lack was a particular concern among provincial partners.

Overall, most respondents agreed that the resources available, especially through the research programs, were not adequate to address the SARS health threat. Several respondents made comparisons to international efforts, compared to which Canada's was relatively small, particularly given the impact of SARS in Canada.

3.3 Effectiveness/success/impact

3.3.1 Effectiveness of research coordination

Establishment of research priorities for SARS. From their members' perspective, as well as that of respondents in other roles, the Scientific Advisory Committee accomplished its main task of identifying research priorities quite effectively — although it was pointed out several times that the priority areas were fairly obvious from the outset and that it would have been hard to imagine a different set.

Liaison with and mobilization of Canadian research activity. The key informants knowledgeable about the relevant Canadian research communities agreed that those communities, in both the academic and public sectors, had been effectively mobilized: the most qualified teams became engaged in the competitions and no significant pockets of expertise were unengaged. An exception, and one that many felt deserves attention for future situations, was the difficulty of involving the researcher/clinicians who were most directly involved in managing the outbreak, in research during the outbreak itself. Although these individuals obviously would have had much to contribute in ongoing development of research programs, their capacity to participate at that time, in particular to write grant proposals, was limited.

The capacity to create and maintain a national inventory of relevant research expertise in areas of likely future health threats was suggested by some respondents as a means to expedite the mounting of coordinated research efforts. This would have been an essential precondition for the more-directed alternative research strategy proposed by some interviewees (see below). It would also possibly guard against the perceptions that existed among some of the researchers associated with the SARS effort of funds being allocated among an "old boy's system." Effective collaboration among researchers in

different parts of the country could be enhanced if members of the inventory also had opportunities to interact and build trust and goodwill prior to a crisis situation.

Deployment and coordination of research funding streams. According to key informants, there was mixed success in the implementation of the new funding streams as part of the overall SARS research funding strategy.

Many respondents felt that the rapid deployment of the SARS I competition was a key success of the coordinated initiative, demonstrating a heretofore-unsuspected capacity for the CSRC partners and the research community to quickly find funds, put together an RFA, run a competition and get research started. Part of this success was due to the agile and rigorous peer review process for this competition. The partnership funding structure was seen to have been quite helpful in bringing resources to the table, although some partners, especially non-federal partners, pointed out that they had carried a larger share of this charge.

The deployment of SARS II was not seen as positively as SARS I. Respondents involved in this initiative were dissatisfied with the extremely long delay within CIHR to conduct the peer review, pointing out that this time lapse was so long that some SARS research was funded in the 2003 Open Competition before the SARS II grants were awarded. This was seen by some participants as undermining the credibility of the CSRC and the sponsoring CIHR Institutes. However, others felt that the pace was commensurate with the reduced level of emergency by the time this competition was in place.

As noted above, the accelerated peer review process was seen as an important contributor to the effective deployment of the research programs. However, there was some feeling that it was not appropriate for senior CIHR scientific staff (Institute Scientific Directors and senior management) to have been part of the peer review committee, as this might have been perceived as compromising CIHR's arm's length stance.

The issue was raised in some interviews about the effectiveness of the standard competitive model in a crisis situation, with some respondents arguing that a more-directed funding process would have resulted in research that was better targeted and with less potential for duplication. It was noted that while the competitive process looked good as a paper-based ideal, in practice it resulted in some serious limitations. An example was given where a research group awarded funds had no direct access to clinical materials, while groups working directly with SARS patients had no access to research funds. Had a positive history of collaboration existed between these groups prior to the competition, more effective coordination might have been achieved, but, particularly in the absence of such a history, it was argued that directed research funding might have been effective. However, support for this approach would be far from unanimous if proposed more widely: Respondents both within and outside of CIHR, as well as researchers involved in these situations, were strong defenders of the need to guarantee excellence through tested peer review processes.

In terms of coordination of existing research funding streams among partners and in line with international research activity, the CSRC had less reach and less success. One large research group had an ongoing research program within which they were able to redirect funds into SARS research, carrying this out relatively independently of the CSRC. While there was some communication and coordination among the researchers involved, it was mainly through contacts made by individual

researchers. However, in one case, a research group reported that contacts with a team in another part of the country that they had known of, but never communicated with before, were facilitated through the coordinated SARS research effort.

Effective accomplishment of the research coordination mandate. Overall, key informants felt that, within its mandate, the CSRC was able to effectively implement procedures and tools for supporting research coordination. However, the particular issue of coordinating access to patient samples was a major problem in the SARS outbreak, and many respondents felt that it had not been effectively resolved. There were several factors involved. First, once the outbreak subsided, the potential pool of Canadian patient samples was drastically reduced; at the same time, there was no mechanism for Canadian researchers to obtain international samples (although researchers from other countries such as Germany and England were able, for example, to gain access to Chinese samples). Second, there was no coordinated bank, registry or protocol for managing the distribution of samples, with each hospital handling SARS patients proceeding according to its own decision-making processes. Some researchers were dissatisfied with their access to samples and some experiments were unnecessarily duplicated because of the lack of coordination. Some interviewees also expressed concern about the absence of protocols because, over and above their value to the research programs, the patient samples clearly posed a health threat and there was a need (as demonstrated later in China) to protect workers handling the samples. This issue is now being addressed through the creation of a national specimen bank with established protocols for access by Canadian and international researchers.

According to some respondents, an area where more facilitation would have been helpful was ethics review for SARS research involving humans. The ethics review processes were seen as problematic because each hospital with SARS cases – some of which had less highly developed research capacities than others – had to conduct its own ethics review of each protocol. It was suggested that proactive, anticipatory attention to ethical review is required so that the procedures do not cause loss of precious time, while ensuring that patient safety remains paramount and that standards are consistent.

In addition, a need was seen for protocols for the conduct of clinical trials in an ongoing outbreak or epidemic. Concern was raised by some interviewees about the lack of coordination among various clinical research efforts in SARS, due to lack of communication and mechanisms for sharing and collaboration. For some interviewees, the concern was due, in part, to some of the research activities in SARS therapeutics (antivirals with known toxicities) that may have put patients at unnecessary risk, which could have been avoided if more adequate clinical research mechanisms had been in place.

Coordination with international research activity. There was fairly strong consensus that the CSRC had not been successful in coordinating Canadian research efforts with the international community. Although there was a good deal of collaboration and information sharing that served to advance the Canadian and international research agendas, this was driven through the networks that already existed among individual researchers. As noted above, one area where more effective coordination could have facilitated Canadian researchers' work was in access to patient samples. Happily, in the eyes of some of the researchers involved, international research groups such as the International Consortium on Anti-Virals (ICAV) have continued to develop, with Canadian research occupying an appropriate place in them, albeit through individual rather than CSRC initiatives.

Communication with the general public about SARS research. According to most respondents, this aspect of the CSRC's responsibilities was not necessarily executed the most effectively, but for reasons that were somewhat external to the Consortium. First, the media were seen as having been overzealous in fanning public reaction to SARS, making measured and thoughtful public communication difficult to manage. Second, by the time that there was news about research results, public interest had waned as the perceived crisis had already passed. However, it was noted that the sequencing of the genome was widely reported and recognized in many public arenas as having been a significant Canadian contribution to the advancement of knowledge about SARS. Several respondents also noted that lessons had been learned about media behavior in public health emergencies (e.g., the tendency for the press to fixate on a credible spokesperson), and that this could be used in future situations.

Overall satisfaction of the research communities. Overall, most interviewees felt that research communities were quite satisfied with the SARS research coordination efforts or that, at least, there had been less dissatisfaction than is usually seen in targeted research processes. The researcher interviewed who had been unsuccessful in the competition was also satisfied with the process and had, in fact, gone on to submit related proposals to two subsequent competitions with other agencies.

3.3.2 Success of the research agenda

Success in each of the prioritized research domains. Respondents were asked to identify, from their perspective and based on their current knowledge, the most important research successes in the five research domains prioritized by the CSRC. They were also asked to assess the extent to which those successes are attributable to the CSRC's actions.

Diagnostics. For most respondents, the identification of the virus and the sequencing of the genome by the team led by researchers in British Columbia was the single greatest Canadian SARS research achievement, as the team achieved this before teams from other, better-resourced, countries. According to key informants, this success was facilitated by the existing platform technology and relationships among researchers at different institutions. Advances in the area of diagnostics immediately followed the genome sequencing and the recognition of the commonalities between SARS and known viruses. However, many respondents pointed out that this success was not attributable to the CSRC, as it happened just as or immediately before the CSRC was formed.

Vaccine development. Some progress was seen as having been made in vaccine development, although views differed on how much and the amount of progress attributable to the CSRC in these developments. While some advances were cited – for example a major contribution in terms of identifying liver toxicities associated with a candidate vaccine – other respondents felt that some research had gone off on unproductive tangents and that there was insufficient coordination of efforts. It was, however, noted that public-sector support was a necessity, as there would have been little incentive for private investment in SARS vaccines at that point. A need for more high-containment animal testing capacity in Canada was noted, as some work had to be done in the US.

Therapeutics. Some promising results in therapeutics are likely forthcoming, as clinical and experimental trials underway are expected to lead to new therapies, to which the CSRC will have contributed.

Epidemiology and databases. Many respondents felt that considerable progress had been made in terms of understanding the epidemiology of SARS through the development of models. Others, however, felt that Canadian contribution to the clinical epidemiology aspects of SARS has been quite weak, in part because of the lack of a coordinated information management systems for clinical and epidemiological information.

Public health and community impact. The SARS II research program addressing public health and community impact began only recently and most respondents were not able to comment on the findings to date. A few researchers mentioned the gains that had been made in recognizing the ineffectiveness of quarantine as a control measure, a contribution that clearly had been enabled by the CSRC's activities. Other results were noted on the issue of communication around the coordination of care for affected patients and their families. Respondents pointed out that because SARS was so localized, its health system impacts would not have been of much interest to other funders, and there would have been few other opportunities to obtain funds for this type of research.

Overall contribution of the CSRC to progress toward the research goals. According to key informants, the CSRC support provided necessary funding and the formal processes required to produce many of existing and expected research results. While respondents did not exclude the possibility that the same results would have eventually been obtained in the absence of the CSRC, its overall contribution was to have made the research easier to conduct, more rapidly.

Facilitation of integration of research findings. Integration of research findings is partly an unfinished story, as much of the funded research is still ongoing. In some ways, integration was built into the research process, as the proposals were to involve combining expertise from multiple research groups. Nonetheless, some stakeholders commented that there is an important need to ensure that integration is facilitated, and that mechanisms to link research across the five subgroups are particularly lacking. Several suggested that CSRC organize national conferences for the researchers funded through its activities. For some, this would reduce the relative isolation in which they felt they are working.

Peer review processes for publication were also cited as a factor limiting integration of research findings, as they slow the dissemination of results. An example was given of a result that was found in three weeks, but then took four more weeks to get published. It was suggested that emergency or expedited peer review processes could help ensure that research results are rapidly shared with the scientific community.

Enhancement of Canadian capacity for SARS research. There was consensus that Canadian capacity for SARS research has been enhanced through the activities of the CSRC but that, more importantly, Canadian capacity to mobilize a coherent research response to a threat such as SARS has

been enhanced. Moreover, it was noted that the overall perceived importance of both applied public health research and antiviral research has been enhanced, which will strengthen these overall domains in the future.

While the CSRC-enabled research results did not directly translate immediately into improved health for Canadians in the context of the 2003 SARS outbreak – the outbreak having been controlled before research results could be widely applied – respondents believed that it will contribute to the future health of Canadians by enabling an even more effective response if outbreaks occur of SARS or other infections.

3.4 Efficiency/Cost-Effectiveness

All respondents involved in the management of the initiative, as well as those researchers who could comment, felt that the CSRC had provided excellent value for money, in that almost all of the funds made available were dedicated to research activities. Overhead and administration costs were minimized through teleconferences rather than face-to-face meetings and there was a minimum of wasted time or inefficiency. The costs were judged to be reasonable in terms of outcomes generated. However, when asked this question, key informants were very likely to point out that the main issue in terms of cost-effectiveness was that the initiative had been under-resourced and that more resources would have generated even more important outcomes.

One important contributor to cost-effectiveness from the private sector partners' point of view was their insistence that the funds they contributed be used as grants and not industrial collaboration funds, which mean that they were not subject to the 40% to 50% overhead charged by universities for the latter.

4. CONCLUSIONS AND LESSONS LEARNED

In summary, the views of the stakeholder community on the effectiveness of the CSRC were varied, with most seeing it as a qualified success. There was wide agreement that many valuable lessons had been learned through the SARS experience and the CSRC experiment, and that these should be applied in building an ongoing response capacity for future emerging health threats. From respondents' various perspectives, the main lessons learned through the CSRC that they would want to see applied in future situations calling for a concerted national research response to a disease outbreak are:

1. **There is capacity and willingness to mobilize and respond effectively** to emerging health threats. Over and above all the areas of the Canadian research response to SARS that could have been improved, there is wide acknowledgement that the most important lesson learned was that the Canadian research community is willing and able to mobilize, to work in partnership and collaboration across sectors and institutions, putting personal and organizational interests aside in the interest of responding to a health crisis, and to innovate in finding new ways of working together so as to respond more quickly and effectively.

2. **Before the next serious threat emerges and as an ongoing process, there is a need to create a permanent national coordination entity to coordinate a rapid research response** to emerging infectious diseases. This entity (network or organization) should develop mechanisms to address the difficult issues that arose with the SARS outbreak, including:

Structural issues

- **Flexible and contingency funding,** so that adequate funds can be immediately accessible. This will ensure that the research community's attention is entirely focused on the research issues, rather than on where the money will come from, and that hard choices about siphoning resources from other existing priorities do not have to be made in the context of a crisis.

- **Overcoming organizational barriers to formal partnerships.** The legal and liability issues involved in the CSRC partnership model should be examined and resolved, resulting in generic templates that can be adapted expeditiously when needed.

- **Creating mechanisms of effective international collaboration.** The relationships and processes required to ensure effective information sharing and facilitation of collaborative international research efforts (for example, through exchange of patient materials, epidemiological data, etc.) should be put in place prior to a new emerging crisis.

- **Creating an inventory of expertise.** Creating and maintaining a national inventory of relevant research expertise in areas of likely future health threats could expedite the mobilization of the research community and the mounting of coordinated research efforts in the face of an emerging threat. Effective collaboration among researchers in different parts of the country could be enhanced if members of the inventory also had opportunities to interact and build trust and goodwill prior to a crisis situation.

- **Considering alternatives to the standard open competitive funding model,** for example by targeting funds more directly to teams with known capacity and expertise. The advantages and risks of alternative models should be considered and debated outside the crisis situation.

Research facilitation issues

- **Rapid and appropriate peer review.** This is recognized as essential to a successful research response and, while the CSRC processes were generally seen as effective, the concerns raised about the appropriate composition of peer review committees should be addressed, perhaps through the creation of a roster of potential peer reviewers with a wide range of expertise who are willing to be part of an emergency peer review process if needed.

- **Expedited and effective ethics review for research conducted in the path of an ongoing outbreak.** Proactive, anticipatory attention to ethical issues and their review is required to ensure that patient safety remains paramount, that standards are consistent and that procedures do not cause loss of precious time.

- **Coordination of access to patient specimens.** The importance and complexity of this issue became apparent during the SARS outbreak, as the lack of coordination probably contributed to some inefficiencies in the research effort. Establishment of mechanisms and protocols for sample coordination prior to outbreaks would prevent this and the tensions that result.

- **Protocols for the conduct of clinical trials in an ongoing outbreak or epidemic.** Having protocols in place and ensuring adequate communication among sites involved in clinical trials would address the difficulties encountered in the SARS outbreak. Mechanisms could also be developed for facilitating the participation of researchers/clinicians most directly involved in managing the outbreak, in research during the outbreak itself.

In sum, while not all aspects of the CSRC were judged to have been entirely successful, the lessons learned will be invaluable in many future outbreak situations, for SARS or other infections.

Appendix 1: Interview Guide

Evaluation of the Canadian SARS Research Consortium (CSRC)
Key Informant Interview Guide

Thank you for agreeing to participate in this evaluation. Its objectives are: to determine the overall effectiveness, efficiency and relevance of the CSRC and to provide recommendations about how the performance of this model might be improved in future situations calling for a concerted national research response to a disease outbreak. ***Note that interviewees will be asked to respond to only those questions for which they judge they can contribute an informed opinion.***

1. Relevance and rationale

1.1 In your view, was there a need for a coordinated research response to SARS in Canada?

1.2 Was the CSRC the most appropriate model for coordinating and responding to SARS research needs in Canada? Was it the model most likely to facilitate the development of new knowledge and its translation into improved health for Canadians?

1.3 Was the CSRC's mandate adequate for addressing the need for research coordination in SARS-related research? Should the mandate have been expanded or restricted?

1.4 In your view, is there a continued need for the CSRC, or a similar organization?

2. Organization design

2.1 How appropriate and effective were each of the following aspects of the design of the CSRC?

- the partners that were involved (and not involved) in the CSRC?
- the partnership structure, with equal inputs from all partners?
- CIHR-III's leadership?
- The Management Group and Scientific Advisory Committee and the links between them?
- The links between the CSRC and the researchers involved in SARS research?

What alternatives would you propose as potentially more effective?

2.2 Did the CSRC have all the resources necessary to accomplish its mandate? What resources, if any, were lacking or ineffective?

2.3 How effectively did the Management Group and the Scientific Advisory Committee play their respective roles?

3. Activities

For these questions, where appropriate please indicate any differences according to the five research domains addressed by the CSRC: diagnostics, vaccine development, therapeutics, epidemiology and databases, public health and community impact.

3.1 How effective was the CSRC's analysis of existing and needed research activity in SARS? How successfully did this analysis lead to the identification of research priorities?

3.2 How successful was the development and implementation of the new funding streams as part of the overall SARS research funding strategy?

3.3 How successful was the CSRC's coordination of existing research funding streams among partners and in line with international research activity?

3.4 How successfully did the CSRC monitor and liaise with Canadian research activity? In what ways?

3.5 How effectively did the CSRC carry out its research coordination mandate? In particular:

- How effectively did the CSRC facilitate coordinated access to resources such as patient samples?
- Did CSRC have effective and clear procedures and criteria to support its decisions?
- Did the CSRC have the tools and procedures to ensure proper accountability and performance measurement?

3.6 How successfully did the CSRC inform, communicate with and mobilize the Canadian research communities (academic and private sector/industry) involved in SARS-relevant research?

3.7 From your knowledge, how satisfied are the research communities with the service and support offered by the CSRC? What aspects do you see as most and least satisfactory?

3.8 How effectively did the CSRC monitor and liaise with international SARS research efforts?

3.9 How successfully did the CSRC inform and communicate with the general public about SARS research?

4. Outputs, short-term results and achievement of research goals

4.1 In your view, what were the CSRC's most important results? Most important shortfalls?

4.2 How successfully did the CSRC identify, address and overcome organizational and institutional barriers in carrying out its mandate?

4.3 How successful was the CSRC in producing a coordinated research agenda, resulting in progress toward research goals, in each of: ***(comment in any or all of those research domains you are knowledgeable about)***

Research domain	Success of the research agenda	Attribuable to CSRC
4.3.1 Diagnostics, toward the goal of a reliable diagnostic assay for SARS	• How successfully were the research priorities in this domain identified? • Did the research agenda address all priority areas adequately and in a timely manner? • Was duplication among initiatives reduced? • Were resources from multiple sources combined and leveraged effectively? • Were all relevant sectors of the research community engaged?	Would you characterize the CSRC's contribution to progress toward the research goals as: a. a major, necessary contribution (the progress would not have been achieved without the CSRC) b. an important contribution (facilitated progress toward the goal, but was perhaps not necessary) c. a minor contribution (helpful, but progress would have made without it), or d. no contribution or a hindrance to progress?
4.3.2 Vaccine development, toward the development of effective vaccines		
4.3.3 Therapeutics, toward the development of new or existing antivirals for SARS therapy		
4.3.4 Animal models for disease monitoring, treatment and vaccine testing		
4.3.5 Epidemiology and databases, developing an epidemiologic model of SARS outbreak		
4.3.6 Public health and community impact, examining of public health impacts and development of strategies for future action		

4.4 How successful was the CSRC in facilitating rapid and effective integration of research findings?

- How successfully did the CSRC facilitate effective communication among research groups, within Canada and internationally?
- How successfully did the CSRC facilitate rapid integration of emerging findings into subsequent research?

5. Overall effectiveness and efficiency

5.1 Has Canadian capacity for SARS research been enhanced and, if so, how? How has the CSRC contributed to this?

5.2 In your view, has the CSRC been able to translate knowledge into improved health for Canadians? If so, how? If not, why not? How could this be improved?

5.3 Overall, how efficient was the CSRC as a strategy for coordinating, promoting and supporting SARS research in Canada? Have the costs been reasonable in terms of outcomes generated? What alternatives might be more efficient?

5.4 From your perspective, what are the main lessons learned through the CSRC that you would want to see applied in future situations calling for a concerted national research response to a disease outbreak?