

Editorial: Realizing the Vision. The Canadian Longitudinal Study on Aging as a Strategic Initiative of the Canadian Institutes of Health Research*

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RÉSUMÉ

L'Étude longitudinale canadienne sur le vieillissement (ÉLCV) a progressé à partir d'une vision lancée par l'Institut du vieillissement des IRSC en 2001 à une plateforme nationale de recherche subventionnée par le fédéral en 2008. Le développement du protocole d'ÉLCV a été mis en valeur par une série d'examen internationaux par les pairs, un comité de coordination multisectoriel, et un comité des IRSC des questions d'éthique, juridiques, et sociales; chacun était essentiel à l'excellence de la science et à rendre l'ÉLCV pertinente aux secteurs multiples. L'équipe de recherche de l'ÉLCV, menée par trois chercheurs principaux (Kirkland, Raina, et Wolfson), a développé un protocole unique se concentrant sur le vieillissement de la cellule à la société – conçue pour suivre 50 000 personnes âgées entre 45 à 85 ans, sur une période de 20 ans années. Une association stratégique avec Statistique Canada a été cruciale au développement et au lancement de l'ÉLCV. L'ÉLCV contribuera à notre compréhension des transitions et de la trajectoire chez une population qui vieillit, et différera des études longitudinales du vieillissement dans le monde entier par rapport à l'ampleur de sa portée, le recrutement des moins âgés dans l'étude (âge 45), la diversité ethno-culturelle de la population du Canada, et au potentiel de lier des données rassemblées aux données administratives de santé au niveau provincial. L'étude d'IRSC est une étude novatrice longitudinale, basée sur la population, qui sera une ressource de recherche sans précédent soutenant la recherche multidisciplinaire et la prise de décision fondée sur des faits dans le domaine du vieillissement au Canada.

ABSTRACT

The Canadian Longitudinal Study on Aging (CLSA) has progressed from a vision initiated by the Canadian Institutes of Health Research (CIHR) Institute of Aging in 2001 to a federally funded national research platform in 2008. The development of the CLSA protocol was enhanced through a series of international peer reviews, a multisectorial Steering Committee, and a CIHR Ethical, Legal, and Social Issues committee; each was essential to the excellence of the science and to making the CLSA relevant to multiple sectors. The CLSA research team, led by three co-principal investigators (Kirkland, Raina, and Wolfson), has developed a unique protocol focusing on aging from cell to society, designed to follow 50,000 people aged 45 to 85, for 20 years. A strategic partnership with Statistics Canada has been crucial to the development and launch of the CLSA. The CLSA will contribute to our understanding of transitions and trajectories within an aging population, and will differ from longitudinal studies of aging worldwide through the breadth of its scope, the early age of recruitment into the study (age 45), the ethno-cultural diversity of Canada's population, and the potential to link collected data to health administrative data at the provincial level. The CIHR is a novel longitudinal population-based study that will be an unprecedented research resource underpinning multidisciplinary research and evidence-based decision making in aging in Canada.

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This special issue of the *Canadian Journal on Aging* represents an important milestone for the Canadian Longitudinal Study on Aging (CLSA), documenting the results and findings of some of the pilot studies that have informed the development of the CLSA. The CLSA is intended to be a national research platform that will provide important information about the health status of Canadians as they age, generating data that will inform many future research projects. While other articles in this issue describe the vision of the CLSA and detail the results of the scientific inquiries fundamental to its launch, this article focuses on the CLSA's process of development, and the various means by which this strategic, "big science" initiative was brought from vision to reality.

The Vision and the Process

In 2001, the vision for the CLSA was a national network of infrastructure across Canada to enable state-of-the-art interdisciplinary population-based research on aging. It originated with Réjean Hébert, the inaugural scientific director (2001–2003) of the Institute of Aging of the Canadian Institutes of Health Research (CIHR), with the support of the Institute's inaugural Advisory Board.¹ The CLSA would go well beyond common cohort approaches of focusing only on social aspects or on specific diseases. It would not focus on the aged only but on aging and adaptation, and on transitions to older age. Despite the existence of other longitudinal studies of aging worldwide, the CLSA would have a particular "niche," due to Canada's unique ethno-cultural diversity, national health care delivery systems (with the potential for linkage to health administration data); and particulars of climate, environment, geography, and retirement policy and pension programs.

In late 2001, the Institute of Aging, in partnership with Health Canada, sponsored an invitational workshop, "Healthy Aging: From Cell to Society-Planning Workshop for the CLSA," in Aylmer, Québec, Canada, that brought together a broad cross-section of the Canadian research community in aging, to discuss essential steps in mounting a Canadian longitudinal study in the area of aging, including protocol design, key partners, and steering committee membership. A request for proposals (RFP) to develop the protocol for the CLSA was launched in 2001.² Although the Institute of Aging was the lead CIHR institute on the RFP, 10 of the other 12

CIHR institutes as well as CIHR corporate were financial partners on this initiative, along with Health Canada. One application was received in response to the RFP, but the scope of the applicant team was truly national and multidisciplinary, which had been the hoped-for response when the RFP was launched. The team consisted of three co-principal investigators (Kirkland, Raina, and Wolfson), supported by theme leaders, senior science advisors, and senior institutional advisors; and included more than 200 co-investigators from across the country. Working under the rubric of eight theme areas, this team developed a draft research protocol over the period from 2002 to early 2004. A multisectoral steering committee³ was established, with a mandate to oversee the development and realization of the CLSA protocol. Chaired by the scientific director of CIHR's Institute of Aging, it included representatives from Health Canada, Statistics Canada, the Canadian Association on Gerontology, the Canadian Institute for Health Information, the Health Charities Council of Canada, Merck Frosst Canada, and the scientific directors of the CIHR institutes of Population and Public Health, Musculoskeletal Health and Arthritis, and Health Services and Policy Research. Other experts, such as the late Betty Havens, director of the Aging in Manitoba Longitudinal Study, were members of the Steering Committee. Consultation with key federal departments, such as Human Resources and Skills Development Canada, also took place.

By the time the draft protocol, along with a plan for the considerable development work, was submitted to the Steering Committee in early 2004, Anne Martin-Matthews had succeeded Réjean Hébert as scientific director of the Institute of Aging. In March 2004, the protocol as well as the plan and budget were reviewed by an expert international panel. This review was important to both CIHR and the CLSA, as the feedback would not only provide an assessment of merit but also recommendations that would strengthen the scientific and technical aspects of the draft protocol. The panel concluded that the applicant team had the necessary commitment and breadth to pursue the initiative and bring it to a successful launch, and also recommended that the draft protocol be revised and resubmitted based on their review comments. Their recommendations included adjusting the time lines to conduct additional key pilot studies, observations concerning governance

structure, and noted strong support for continuing to build a relationship with Statistics Canada.

The CIHR Context

While the CLSA research team laboured to revise and further develop the draft protocol, concurrent developments at CIHR helped to build a foundation of support for the initiative. A crucial event was the endorsement by CIHR's Scientific Council⁴ (composed of the 13 institute scientific directors, and vice-presidents and president of CIHR) of the CLSA as a "cross-cutting strategic initiative," along with a companion birth cohort study, under the umbrella of the Canadian Life Long Health Initiative (CLHI⁵). CIHR's 2004 Strategic Plan, *Investing in Canada's Future: CIHR's Blueprint for Health Research and Innovation*, identified the organization's commitment to develop national research platforms and initiatives. The CLHI was one of four major cross-cutting strategic initiatives identified in *Blueprint*, although it was well recognized that the implementation scale of these initiatives was contingent on the availability of funding from CIHR and partners. For much of its developmental history at CIHR, the CLSA was promoted and supported with the expectation that it would (in some way) be linked with a national birth cohort study under the CLHI umbrella, the goal of which was to facilitate the establishment of a research program to conduct large multicentered longitudinal cohort studies of Canadians. Such studies increase the understanding of the role and interaction of different genetic and environmental exposures involved in human development and aging processes over the life course, the multifactorial causes and evolution of common diseases, and the utilization of health care services.

Developmental Phase I: 2004–2006

In the spring of 2004, the report of the international peer review committee on the revised protocol was received. In addition to its review of the draft protocol, the committee provided important advice to CIHR on the commitment then required for the continuation of the developmental work necessary to mount a national cohort initiative, implying a minimum two years of development funding. The message was clear: the next development phase of the CLSA must proceed without delay, and funding should be uninterrupted.

A strategically significant turning point in the CLSA's history occurred at this time. The notable advancements of the CLSA, and its internationally recognized design and value, were acknowledged by CIHR. Resources well beyond the scope of the Institute of Aging (even with partner resources from other institutes) would be required for the CLSA's continued development, and CIHR's Governing Council was asked

for its funding support. In April 2004, the Executive Committee of the Governing Council approved an interim grant of \$250,000 to support the ongoing development of the CLSA, with a requirement for a full discussion at the Governing Council meeting in June. Keenly aware that they were working in an environment without precedent for the development and funding of this kind of initiative by CIHR at that time in its evolution, the co-principal investigators (co-PIs) produced an updated plan for the CLSA's development, including an extensive budget. Following review of these materials by external referees and by CIHR, the scientific director of the Institute of Aging and the then vice-president research at CIHR, Mark Bisby,⁶ presented the evidence for CLSA support at the Governing Council meeting where, in June 2004, a further \$1.7 million in CLSA developmental funding was approved.

The funded projects were expected to constitute methodological feasibility studies of relevance to, and utility for, other cohort initiatives at CIHR, in alignment with the CLHI, and not just the CLSA. All of the feasibility studies published in this special issue were funded at that time. With this Governing Council support, the CLSA had made a significant transition: from being primarily an Institute of Aging-based initiative, to one supported and resourced as a component of CIHR's strategic cross-cutting CLHI.

Developmental Phase II: 2006–2008

Two years later, the feasibility studies were complete, and funding support was now required to pilot the draft protocol and to move to launch the initiative. The international peer review panel was reconvened to review the report of the findings of the pilot studies (Phase I Development) and the Phase II Development funding request. The panel was positive about the improvements made to the original submission, noting that CLSA's approach to addressing both biological and social aspects of aging was well planned out, solid and extremely valuable, with the potential to lead to significant impacts on policy and practice. They noted that the CLSA will contribute to the science of aging in Canada and elsewhere by linking many disparate areas of research. It will also generate data that will inform public health and social policy in areas such as chronic disease management, health-related retirement transitions, and health care delivery; and will provide such benefits as new jobs, an increase in research capacity, the retention of scientists in Canada, and, ultimately, the improved health of aging Canadians.

In June of 2006, after considering the recent international review, CIHR's governing council approved additional funds of \$2.1 million for the period 2006–2008. These funds were directed specifically to content-

related pilot and feasibility studies to finalize the CLSA protocol, such as exploring attitudes of Canadians concerning long-term participation in the CLSA; and improving the informed consent process, with attention to such issues as cognitive impairment amongst study participants. The developing partnership with Statistics Canada (described later) was critical to securing this additional support from the Governing Council.

CIHR's commitment to the CLSA was demonstrated not only in its funding of CLSA's planning and feasibility phases, but also through the resources allocated within CIHR to an Ethical, Legal and Social Issues (ELSI) Committee (with a mandate to advise CIHR CLHI leaders on actions and best practices to address issues relevant to CLHI) and the creation in 2006 of the position of CLSA executive director. This appointment was another strategically important development for the CLSA, for it reflected CIHR's recognition of the importance of partnership development and oversight of large strategic initiatives (beyond the scope of the scientists' expected roles at that time). It was also strategically important to the collaboration being negotiated between the CLSA team and Statistics Canada with the proposal that the Canadian Community Health Survey 4.2 (CCHS 4.2) focus on aging and become the mechanism for recruitment of 20,000 people as the "inception (tracking) cohort" for the CLSA. The one-year secondment of a Statistics Canada executive to the CLSA executive director position within CIHR facilitated the relationship between the CLSA research team and Statistics Canada at a crucial time as the CLSA protocol was being adapted for use in the CCHS 4.2.

Securing Support for the Launch

The partnership with Statistics Canada became strategically important once again in the spring of 2008 as the CCHS 4.2 moved into its final planning stages. Additional funding would be required to lower the age range of the proposed CCHS sample, from age 55 to age 45, as this had long been the intended entry age group for the CLSA. In addition, Statistics Canada now required confirmation from the CLSA team that funding was secured for the proposed second wave of data collection with the 20,000 individuals aged 45–85 to be recruited to the CLSA. Without this confirmation, Statistics Canada could not provide data from those CCHS 4.2 participants who had indicated their agreement to have their identifying information shared with the CLSA for purposes of recruitment into the CLSA. With a rigorous set of policies and procedures now in place at CIHR for the consideration of such funding requests, the CLSA co-PIs and Institute of Aging staff worked assiduously through the spring of 2008 to secure CIHR's commitment of the \$3.85 million required to

solidify the partnership with Statistics Canada for the recruitment of the CLSA inception cohort.

Another challenge remained: the securing of funds to launch the "comprehensive cohort" involving recruitment of a further 30,000 people for clinical assessment over the CLSA's 20-year period. Several factors exacerbated the challenge. The CLSA and the development of a national birth cohort were now progressing at different speeds and somewhat independently of one another, with their linkage under the Canadian Lifelong Health Initiative increasingly unlikely in the short term (although CIHR is keeping abreast of developments and potential future collaborative opportunities). In the spring of 2008, a very large Canadian cancer cohort study was launched, and there was recognition that multiple large national cohorts, with distinct purposes but targeting somewhat similar age groups, might prove difficult to sustain in the longer term.

A number of other factors informed CIHR's support of the CLSA. In 2008, the Science, Technology and Innovation Council, reporting to the Minister of Industry, recommended four sub-priority areas of research within the "Health and related life sciences and technologies" priority area: among them, health in an aging population.⁷ The recommendations were accepted by the Minister of Industry in September 2008. This was a strategically very important development. In addition, the Institute Advisory Board of the Institute of Aging continued to demonstrate considerable support for the CLSA, through its creation in 2007 of a bi-annual CLSA Fellowship Program competition (this multiyear program aims to build and strengthen research capacity and expertise in Canada in health measurement studies with emphasis on the CLSA and similar longitudinal studies) and also through its May 2008 commitment of an additional \$2.5 million in supplemental funding support for research projects using CLSA data for the period 2011–2013. The ongoing support of partners on the initiative, especially the Public Health Agency of Canada, Health Canada, the Quebec Network for Research on Aging (funded by the *Fonds de la recherche en santé du Québec*), the BC Network on Aging Research (funded by BC's Michael Smith Foundation for Health Research)—and support from McMaster University, McGill University, and Dalhousie University to the three co-PIs since 2002—were critical to the success of partnering efforts for the CLSA.

In addition to these factors, three issues were particularly compelling for CIHR's funding decisions concerning the CLSA. First, Statistics Canada's commitment of significant in-kind contributions to the CLSA design and recruitment of the "inception" cohort signaled to CIHR the national importance of the study and its operational feasibility, as well as the level of interest

among other federal partners in longitudinal data on aging. Second, the value of the CLSA science and its potential impact on policy and practice was well established, as confirmed through successive rounds of international peer review. And finally, the tenacity and dedication of the core CLSA team over the six years of project development – through the multiple stages of rigorous peer review, the ebbs and flows of discussions concerning stand-alone or collaborative cohort initiatives, and their commitment over a significant period of their academic careers – were acknowledged throughout. On June 25, 2008, the Scientific Council of CIHR voted to award an additional \$19.65 million⁸ to launch the comprehensive cohort component of the CLSA across 10 sites throughout Canada. This funding commitment was finally approved in December 2008. The total CIHR commitment in support of the five-year implementation phase of the CLSA now totaled \$23.5 million, enabling the CLSA to establish itself solidly as a national, longitudinal research and data platform. The vision had become reality.

Realities, Risks, and Returns on Investment

The launch of the CLSA has signaled a new era of research on aging in Canada. Its magnitude, scope, and duration will change the way in which research on aging is conducted across the country. Its creation has already changed the way in which Canada is viewed as a major research player on the world stage, not only in its commitment to research on aging but also in its investment in a science initiative on this scale. In the few months since the funding award, the CLSA has been included in several international meetings focused on harmonization and cross-national comparability of data and access.

The funding of the CLSA also represents a different approach to the support of research in Canada. It is not an investigator-initiated research project but a strategically initiated research “platform,” which will provide data for many future research projects in aging and for relevant stakeholder groups. Its unique nature, coupled with its large scale, challenge traditional operating and financing models for research. Although it began as a dream of the Institute of Aging, the CLSA launch in 2008 was only possible because CIHR recognized, at a crucial juncture, that its development could only be assured as a transversal strategic initiative, with significant financial and resource investment.⁹

The process of bringing the vision of the CLSA to reality is also a history of risks recognized and risks incurred. Team members, and the co-PIs in particular, undertook risks in investing considerable scientific capital and commitment in a venture that took longer

to initiate than expected, was often uncertain in its outcome, and will take some years to be fully realized. For the Institute of Aging and for CIHR, there has been significant risk over time: risk in the investment of funds in 2002, 2004, and 2006 when the result of this investment, the launch of the CLSA, was not yet assured. Even now, with the CLSA having been successfully launched, it is well recognized that the sustainability of an initiative such as the CLSA goes well beyond the capabilities of CIHR alone.

Nevertheless, throughout the seven years from the initial meeting in November 2001 to the funding approval in December 2008, the benefits of this strategic initiative have been well recognized by researchers, governmental and non-governmental partners, funders, and community members: its potential to contribute to the identification of ways to prevent disease and improve health and social services for an aging population; and its capacity to develop a better understanding of the impact of non-medical factors such as economic and social changes on individuals as they age. The enormous bank of data collected will also generate new knowledge of the many interrelated biological, clinical, psychosocial, and societal factors that affect healthy aging. In addition, three strengths identified by international peer reviewers are highly relevant to the success in achieving support for this initiative: the beginning of the study at mid-life, its capacity to contribute to an understanding of aging in Canada’s diverse ethno-cultural context, and the potential to link the data provided by the study participants to provincial health administrative data.

With the launch of the CLSA, the vision has been realized. The goals that have driven the science are now within our reach, the applications of that knowledge now on a horizon that can be seen. Such an exciting and energizing opportunity! And with it, the really hard work begins.

Notes

- 1 Members of the inaugural Advisory Board of the Institute of Aging included the late Betty Havens, the principal investigator on the Aging in Manitoba longitudinal study; and several members with experience of the three waves of data collection of the Canadian Study of Health and Aging (1991–92; 1996–97; and 2001–02), including N. Chappell, P. Durand, R. Hébert, Y. Joannette, and K. Rockwood. Their experience with these studies and familiarity therefore with the challenges in mounting and sustaining longitudinal research were important factors in Institute of Aging Advisory Board discussions and support for the CLSA. A. Martin-Matthews was vice-chair of the IAB during the period of these deliberations.
- 2 The RFP is available at <http://www.cihr-irsc.gc.ca/e/4169.html>. The submission deadline was January 2002, and the funding amount available was \$462,024.

- 3 This steering committee oversaw the development of the protocol. Health Canada, Statistics Canada, the Canadian Institute for Health Information, the Canadian Association on Gerontology, the Health Charities Council of Canada, Merck Frosst Canada, and the other CIHR Institutes, as members of the CLSA Steering Committee between 2002 and 2006, joined in the planning and overseeing of the study's protocol development. This approach was essential in making the CLSA relevant to various sectors. This committee was officially disbanded in 2006, with its acceptance of the (then) CLSA draft protocol as having met the requirements of the 2002 RFP.
- 4 At various points in its history, this group has been known as the Research Priorities and Planning Committee (RPPC) of CIHR, and the Research and Knowledge Translation Committee (RKTC) of CIHR. It became the Scientific Council as of September 2008, but may be referred to by these other names in earlier documents and correspondence.
- 5 Four scientific directors were identified at the "cohort" champions at CIHR, and worked to advance a coordinated cohort initiative: John Frank (Institute of Population and Public Health), Michael Kramer (Institute of Human Development, Child, and Youth Health), Anne Martin-Matthews (Institute of Aging), and Rod McInnes (Institute of Genetics).
- 6 On behalf of the research community on aging in Canada, the authors of this article extend a heartfelt thanks to Mark Bisby for his support of the CLSA at several crucial junctures in the process of its development and in its requests for funding support from CIHR.
- 7 The report of the Science, Technology and Innovation Council may be found at http://www.stic-csti.ca/eic/site/stic-csti.nsf/eng/h_00007.html (retrieved 7 April 2009).
- 8 In approving this funding, the Scientific Council recognized that this represents approximately 86 per cent of the funding required for the first five years of the CLSA. It is expected that other funding partners will be attracted to this initiative.
- 9 Big science initiatives also require oversight of complex management, partnership, and governance structures. Recognizing this, CIHR has appointed Linda Mealing as associate director for the CLSA for the period 2009–2012.

Reference

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