Palliative and End-of-Life Care Initiative: Impact Assessment

Highlights and Conclusions

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Highlights of the Palliative and End-of-Life Care Initiative

What did the Initiative accomplish?

- Engaged 18 partners and focused considerable resources – and national attention – on a critical but historically neglected health need.
- Developed teams which have proven to be excellent models of effective integrated knowledge translation in action.
- Built major clinical research capacity, creating a community extremely young in research experience but wise in health care practice and decision-making.
- Increased both the quantity and quality of PELC research many-fold.
- Developed strong and effective partnerships with user communities, including decision-makers and patients.
- Is producing results that are being integrated into practice guidelines, health professional training, and policy discussions.

What did we learn?

- PELC research is highly applied, practice-oriented, and mostly undertaken by care providers, not academic investigators.
- Most PELC researchers are thus outside CIHR's normal sphere of funding or influence, but the NET structure is particularly effective for integrating key users, communities and collaborators from beyond mainstream academia.
- PELC trainees are mostly well-established health professionals - not young students - seeking to improve their own clinical, management and policy decision-making.
- Teams are a hugely rewarding and effective way to do PELC research, but take enormous time to build trust and make them work – time often not valued by employers.
- Funders and grantees both need to plan their exit strategy from day one, and start working to build a sustainable community which outlasts the strategic funding cycle.

What are the future opportunities?

- Capture and synthesize the research outcomes into a transferable, useable format.
- Hold a post-initiative meeting with the PELC community to launch processes to move those outcomes into practice and start planning for its own future.
- Create research release-time support and encourage the creation of jobs which support practice-based research clinicians, like PELC trainees, doing integrated KT.
- Capture and share lessons-learned from the rich experiences of the NETs in building partnerships, integrating KT and developing community-based research approaches.
- Define the desired outcomes of translational research and develop new metrics which assess achievement against such outcomes.

Conclusions about the Palliative and End-of-Life Care Initiative

The Palliative and End-of-Life Care (PELC) initiative was developed by the Canadian Institutes of Health Research's Institute of Cancer Research in collaboration with the 18 partners listed below. The objectives of the Initiative were to support infrastructure development, enhance interdisciplinary research collaboration, encourage the development of early career researchers and attract trainees to this emerging area. Since 2004, the PELC initiative has supported nineteen Pilot Projects, ten New Emerging Team Grants (NETs), one Career Transition Award and a Strategic Training Program (STIHR). With a total investment of $16.5 million over six years, the Initiative is the largest research investment in PELC research in the world.

Alberta Cancer Board	CIHR Institute of Health Services and Policy Research
British Columbia Cancer Agency	CIHR Institute of Human Development, Child & Youth Health
Canadian Breast Cancer Research Alliance	CIHR Institute of Neurosciences, Mental Health & Addiction
Cancer Care Manitoba	CIHR Knowledge Translation Branch
CIHR Institute of Aboriginal Peoples' Health	Health Canada
CIHR Institute of Aging	Heart and Stroke Foundation of Canada
CIHR Institute of Cancer Research	National Cancer Institute of Canada
CIHR Institute of Circulator and Respiratory Health	National Ovarian Cancer Association
CIHR Institute of Gender and Health	

Impacts on the research agenda

Palliative and end-of-life care (PELC) was receiving limited attention in the research and health care communities when the new CIHR Institute for Cancer Research (ICR) identified it in 2003 as its top priority. Respondents commended the Institute for its courage and leadership in championing PELC research, and making a compelling case that here was an ideal juxtaposition of great health need with significant research opportunity.

The Institute's budget for strategic research is a very small piece of Canada's large and complex cancer research funding; its Board felt that *"we needed something that was not just incremental but Big and Bold – as compared to investing in genomics or imaging, where ICR would have little added-value."* By investing a substantial portion of its strategic funds into palliative and end-of-life care, the Institute was able to have an enormous impact in this area.

PELC research presents significant unique methodological, logistical and ethical challenges. PELC research involves extremely vulnerable populations and thus needs highly-trained personnel, increasing its cost and complexity. The PELC practice community is itself nascent, and few health care practitioners in PELC have research training. For these reasons – and many more – Canada had only

a very small PELC research community. Respondents identified the decision to focus the majority of ICR's resources in this one initiative as both brave and risky. However, the Institute undertook a range of activities and events to maximize the impact of its investment in PELC research: its comprehensive approach to consultation, planning and execution interactions drew high praise from all we interviewed.

Impact on research productivity and quality

Since the launch of the Institute, CIHR's support for PELC research has increased sixty-fold, from less than $100,000 to almost $6 Million, invested in all four theme areas, with a preponderance of clinical research. Some 60% of CIHR funding comes from outside the Initiative. Pilot Projects attracted new researchers to PELC, tripled their productivity, and greatly exceeded expectations when 2/3 obtained follow-on CIHR grants. The Institute has clearly spurred considerable activity beyond its own budgetary limits, and PELC research is growing and competing in CIHR competitions.

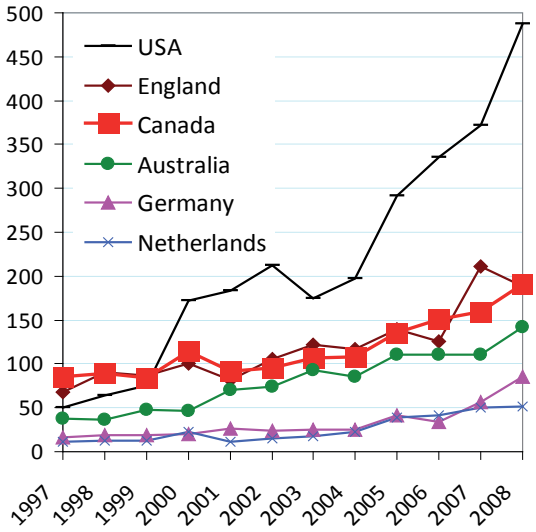
As a result, Canada almost doubled its world share of PELC publications between 2004 and 2009: at 8% it is almost twice Canada's overall world share of health research publications. NET funding has already enormously increased the productivity of the NET PIs: while doubling their productivity, they also moved from authoring 29% to authoring 37% of Canada's rapidly growing body of PELC publications. Overall, Initiative investigators (not just NET PIs) accounted for half of the all Canadian PELC publications between 2006 and 2008, and 70% of Canada's increased research productivity.

Citation measures show Canadian PELC papers have significant impact: for example, Canadians are consistently over-represented among the world's top 40 most-highly cited PELC papers.

NET PIs collaborated with 50% more investigators than Canada's average, and twice as many as the general PELC average. The PELC research community, previously isolated, is now well-connected internationally, with international co-authors on almost 40% of Canada's papers.

In Canada, PELC is strongly practice-based and implementation-oriented: *"there's virtually no such thing as a PELC researcher who is not also a care provider."* A UK study backs up this belief, identifying Canada's PELC research as the most "clinically-oriented" in the world.

Canadian PELC productivity (publications/ year) relative to that of other leading nations



Impact on research capacity

The primary objective of this initiative was to create research capacity. Peer reviewers, investigators and decision-maker partners all agree there have been substantive improvements in both the quantity and quality of PELC research in Canada. For example, the number of unique Canadian authors has doubled since the Initiative's launch (from ~540 to ~1090).

The "youth" of this community, in terms of research experience, is remarkable: although the initiative, as intended, drew some experienced researchers to focus their expertise on PELC issues, the majority of the added PELC capacity comes from new researchers. For example, half of today's top ten most productive Canadian PELC authors weren't yet publishing in *any* field in 2001-03. The vast majority of researchers today receiving CIHR funding for PELC research were not yet receiving *any* CIHR operating grants in 2001-03.

Another unanticipated finding is the extent to which the PELC research community existed – and is growing – outside of CIHR's traditional sphere of activity and influence. For example, despite its massive increase in PELC spending, and increase in absolute number of funded PELC researchers, the proportion of Canadian PELC authors receiving CIHR funding has actually declined since 2001 from 40% to 34% (from 218 /540 to 367/1090).

Respondents consistently depict most PELC research as implementation-oriented, undertaken primarily by active health professionals in the course of their clinical duties, and funded largely by internal or local resources. This description is consistent with our finding that the majority of publishing PELC researchers do so without benefit of CIHR support. However, we believe that through the NETs, CIHR is indirectly reaching many more people than official numbers show, and developing the research interests and skills of a wide range of health professionals - collaborators, partners, and trainees - who could not access CIHR funding as investigators but who are a substantial portion of that other 66% of authors. The cancellation of the open team grants competition eliminates a major support of mentoring, pilot funding and collaboration, and may significantly hinder the future productivity of these supposedly "non-CIHR funded" authors.

Impact of NETs and STIHR on training

NETs have proven to be fruitful training ground for students and young investigators. They provide a wide range of contacts and experiences, as well as mentors and research infrastructure, which can leap-frog training or new investigator development and provide added credibility and a competitive edge to job-seeking and grant and award proposals. Trainees all described their NET and STIHR

"I got clinician release time (6 months, but enough!); I'm the only nurse who ever got one of these CIHR awards, which led to my current grant." For this new investigator, a $25,000 CIHR investment in release time led to over $300,000 in funding from open grants.

training as *"a much bigger experience": "there were enormous differences between my training and what was available to the others [in my cohort], huge benefits for me."* However, team work can be detrimental to career development: *"I can get further faster by working in this group, but my Chair likes to see my name by itself on papers."*

The most striking aspects of the PELC trainees interviewed are their maturity and experience. A significant proportion of the trainees attracted to the NETs and STIHR were practicing health professionals - nurses, social workers, psychologists and others - many with decades of experience and leadership roles within the health system. These trainees seek a very different career path from typical new PhDs and post-docs.

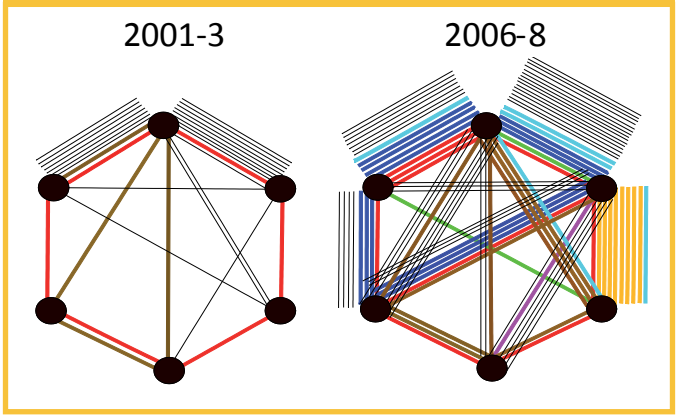
Rather than seeking the first steps of the tenure track, most wish to continue leading change in the health system, ideally splitting time between research and care so as to identify problems *and* be able to fix them. The PELC trainees have the credibility to engage health care providers and access populations, and the skills and reputation to get the results implemented: integrated KT in action. However, such positions are almost non-existent in the health care system, nor do salary awards provide protected time for this kind of part-time researcher. As a result, few PELC trainees were taking on posts in which they could put their training to use, that is, where they could both do research, and then implement it in practice.

"Collaboration is fantastically improved. The NET has enabled the hiring of staff and the travel for individuals to come together in ways never before possible." Net PI

Impact of NETworking

Investigators lauded the NET approach, agreeing their work was *"enhanced by the many perspectives brought to the table. The richness of research ideas and wide range of approaches to problem solving were largely due to this interdisciplinary culture."* NET participants agreed that individual operating grants would not have achieved a fraction of the same impact. Achieving true interdisciplinary team work requires trust, which can only be built through an enormous (the NETs would repeat, *enormous*) time commitment to communicating, especially face-to-face, which teams are uniquely able to fund. The NET structure is particularly well-

Co-publication among members of PELC NETs: each line represents a co-publication; each colour a different team.



"Interdisciplinary teams… keep you grounded in what you're trying to achieve, in what's really important to this population. When I work with this group, I know it will be highly relevant and able to be applied." NET New Investigator

suited to integrating knowledge users, and supports many important collaborators and user communities who on their own could not access CIHR funds or projects. Sadly, investigators still find these leadership activities count *against* tenure and promotion, and urge CIHR to do more to influence universities to value the kinds of research activity that CIHR wants them to pursue.

Impact on KT

Despite an RFA which included no KT requirements, all the NETs have substantively engaged user communities in their work, making the NET itself into the primary structure for integrated knowledge transfer. And though some PELC investigators still tend to think of the partner's primary role as end-of-grant dissemination, every partner we spoke with saw their time as best invested at the front-end, strategic phase of the research program. We are confident that the NETs have developed close linkages among investigators, health professionals, managers and policy makers, and user communities, and are investing in on-going knowledge translation to maximize the potential benefits of these innovations. NETs have already been prolific users of CIHR KT support, with over 30 funded KT grants among them.

Impacts on research-supportive infrastructure

CIHR created a dedicated PELC peer review panel, and although researchers agree this panel is extremely important, they are not yet using it in large numbers. Of ongoing concern is the widespread belief that certain kinds of research did not get appropriate review in this panel. Our extensive analysis suggests the panel is functioning well and free of systematic bias. Nonetheless, the persistent concern among both applicants and panel members themselves suggests on-going attention should be paid to panel composition and expertise.

Participants at the New Emerging Team Grants Mid-term Meeting, held Nov. 7/07 in Toronto

A variety of formal and informal attempts have been made by the Institute of Cancer Research, Health Canada, and the research community to network the PELC community. These efforts seem characterized by a wealth of good intentions but little follow-through by either sponsors or participants. Such efforts require committed leaders, and the nascent NETs had few resources to spare for anything not yielding immediate results. And while Initiative partners encouraged these networking efforts, ultimately there was no institutional support for the necessary resources. There is now a significant appetite for maintaining and enhancing connections across the new PELC community, but some fear the opportunity is already lost.

Maximizing the return-on-investment from the PELC Initiative

The PELC initiative has many impressive achievements to date, but its gains are fragile. The capacity built could be lost to health care practice or better-funded team opportunities and research areas – or just never quite make it through the next step to achieving CIHR competitiveness. The teams and partnerships so painstakingly built can disintegrate without ongoing nurturing. The community is still small and dispersed across Canada, and needs to be better connected to maximize synergy in research and knowledge exchange if potential health outcomes are to be realized. Finally, to have real impact on practice nationally, the outputs of the Initiative as a whole need to be collected and packaged for knowledge users.

A key next step could be an end-of-initiative forum to showcase synthesized results from across all the funded research and plan next steps for the PELC community. Knowledge users and researchers should work together to identify:

- *what was learned;*
- *who needs to know and what should be done with it;*
- *specific needs for a community-wide knowledge translation and exchange network; and*
- *next directions for a PELC research agenda.*

The Initiative created a cadre of "research-clinicians" seeking to improve health care in real-time by researching change and implementing what works. Mechanisms are needed to encourage and support integrated researcher/decision-makers (in all applied health areas), while open grants competitions should continue to adapt policies, procedures and review criteria to reward the behaviors CIHR seeks to encourage through interdisciplinary teams and KT. Mentoring and developmental grant approaches could help new researchers in nascent fields make the huge leap from strategic support to open competition. Reinstating the open team grants will be crucial to obtaining the benefits from CIHR's many strategic investments in new emerging teams.

Best practices in strategic initiatives

A clear lesson from many initiatives, and emphasized by many funders with whom we spoke, is that it's unrealistic to expect any field of research to move from small and fragmented to world-class in just five years. Nor is a single 5-year infusion of funding to a single cadre of investigators likely to result in a sustainable, self-renewing community. A successful initiative therefore needs to plan for the long term at the outset, and include continuous capacity strengthening and community building activities in throughout and beyond the primary funding cycle. Comparatively small investments in research-enabling activities add huge value.

Academic definitions of worthiness, excellence and success continue to dominate program design and peer review, and these are often incompatible with effective KT and

knowledge implementation. Research whose goal is to achieve health impacts must be judged by its ability to produce health impacts – not by its ability to produce academic outputs.

Given the large investments teams entail, it's in the funders' interest to help build better-functioning teams. The NETs' lessons learned, in creating and sustaining multidisciplinary, integrated KT teams, could be captured in a workshop, casebook and/or training module bringing together recent research findings with the practical experiences of team participants.

We believe large strategic initiatives need an explicit up-front KT strategy and dedicated KT resources. A knowledge broker assigned to a large initiative could expand the reach and enhance the outcomes of an initiative by working across individual teams, partners and KT staff.

Finally, CIHR has been innovative in trying out new tools or models of funding, in new areas of research, with new kinds of investigators and partners, and it is recognized internationally for its novel approaches, a number of which have been emulated by other agencies. There is enormous scope to share these experiences and best practices in more systematic ways.

Participants at the New Emerging Team Grants Mid-term Meeting, held Nov. 7/07 in Toronto

Integrated KT in Action

- VP-NET found misperception and distrust kept disabled patients from accessing effective palliative care. A NET post-doc with an English background developed a theatrical play to highlight issues and opportunities for collaborative problem solving to reduce suffering and untimely death.
- VPRN-NET turned their research findings about how skilled physicians effectively and compassionately communicate prognostication information to patients and their families into a series of DVDs called "Breaking Bad News," and are using them to train BC medical students, and physicians around the world.
- The Difficult Pain Net has widely shared lessons learned in PELC clinical trials, including: novel approaches to assess study feasibility; low-cost data transfer to a central repository (replacing $100k software); dealing with multiple REBs; validating methodologies and improving trial reporting.
- The Family Caregiving NET is creating book of advice based on letters written by bereaved caregivers to help other caregivers in similar circumstances.
- The Winnipeg Regional Health Authority has provided VP-NET with $5 million to operationalize *Dignity Conserving Care*, transforming the culture of health care throughout the authority.
- A key partner, the Canadian Hospice Palliative Care Association (CHPCA), *"takes the research findings and makes them more ready to use."* CHPCA incorporates initiative research findings into its conferences and public events, and synthesizes results into factsheets, websites, press releases and other materials.
- The Difficult Pain NET developed the world's first on-line palliative care research methods course, now mandatory or strongly recommended in most palliative medicine residency programs across Canada.
- To better talk to patients about where they want to die, a STIHR trainee developed decision-support tools and training which proved so successful in testing with nurses, pharmacists and social workers that the Registered Nurses' Association of Ontario asked the trainee to co-lead the development of decision-support Evidence-Based Best Practice Guidelines, and to sit on their panels to develop end-of-life practice guidelines; develop new criteria for the hospice palliative care exam; and the gerontology exam.
- A Cross-Cultural NET investigator developed KT products based on needs expressed by research participants: a booklet to share support-group experiences with new patients (distributed through the cancer agency); an article about prostate cancer misdiagnosis (in GP Review), recommendations to support group funders to improve their services.
- The New Interventions NET validated a simple instrument to assess pain in people with limited ability to communicate: participants experienced 95% relief from common catastrophic cancer complications.
- The New Interventions NET has established a national collaboration with CPAC and the Quebec Health agency to provide cancer navigators with working tools and training curriculum as part of a Canadian Navigator manual. They are also improving patients' continuity of care with a pilot intervention to increase interprofessional collaboration, particularly among family physicians and nurse navigators.
- VPRN NET has developed several web-based tools for physicians, including a web-based risk calculator and set of web-based prognostication tools, based on a database of over 10,000 anonymized palliative care patient records from Canada and the US.
- Policy planners and program/service managers are using a NET's survival estimates to inform policy changes around eligibility for palliative benefits plan enrolment and admission criteria to hospices and acute/tertiary palliative care units.
- Advance care planning (ACP) recently emerged as a major issue; regions are testing models, provinces are enacting legislation, and the federal government is developing national policy. The Cross-Cultural NET found that the relationships it had fostered with regional policy makers, managers, and clinicians allowed it to quickly develop a collaborative approach to researching and implementing ACP in its partners' organizations