RE-IMAGINING LONG-TERM RESIDENTIAL CARE
an international study of promising practices

Major Collaborative Research Initiative

Midterm Review Report

for the period April 1, 2010 to August 31, 2013

Principal Investigator: Pat Armstrong PhD

Prepared for the
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Objectives

"A society that treats its most vulnerable members with compassion is a more just and caring society for all" (WHO 2002:5).

Long-term residential care is where many of our most vulnerable members live and, in spite of moves towards aging in place, where many will continue to live in the future. It is also a workplace for thousands of paid and unpaid providers, most of whom are women and many of whom are from racialized communities.

The project seeks to identify:

a. approaches to care, to work organization, to accountability, and to financing and ownership in long-term residential care that offer the most promising practices when the goal is to treat both providers and residents with dignity and respect, to understand care as a relationship and to take differences and equity into account, especially those differences and inequities related to gender, racialization and age,
b. the contexts, regulations, funding and conditions that allow residents and providers to flourish.

The project focuses not on failures, but on identifying promising practices for conceptualizing and organizing long-term care, learning from and with other countries. It is a comparative and interdisciplinary project, involving those from the social sciences and humanities, medicine and architecture working in Norway, Sweden, Germany, the UK, the US and five Canadian provinces. It is developed in partnership with five unions in the health sector, an employer's organization and a seniors group. It involves multiple methods, combining quantitative and qualitative approaches. Central to the project is a 'methodology in development' – rapid, site-switching ethnographies involving large teams – and ongoing knowledge exchange with partners, the public and academe.

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The project's organizational structure is integrally related to its methodology. Under the entire team's guidance, members in the four theme areas (approaches to care, work organization, accountability, financing and ownership) began with mapping residential care in each jurisdiction, providing both a portrait and analysis. Each theme includes an international member, a partner, at least one student, and two leaders from different disciplines. A system for sharing and organizing all documents ensures cross-theme integration, as does our annual full team meeting. While mapping is ongoing throughout the project, this first layer (Layer I) provided the basis for key informant interviews and team development of protocols for site selection for our ethnographies and for primary data collection in Layer II (see Appendix 3 for details). This initial mapping exercise also created the material for a conference organized to share data with key stakeholders, a conference designed to offer a platform for feedback on our work. At this stage, half the theme members move to another theme, ensuring both cross-pollination and continuity. In Layer III, a Canadian-led team involving at least one local researcher conducts rapid ethnographies of foreign facilities. Similarly a foreign researcher, accompanied by a local one, leads sites visits in Canada, again with protocols and web-based systems ensuring data sharing across the team in a timely, rigorous manner. Although analysis is ongoing, Layer IV focuses mainly on an iterative analysis of our theory and data and a reflexive analysis of our method.

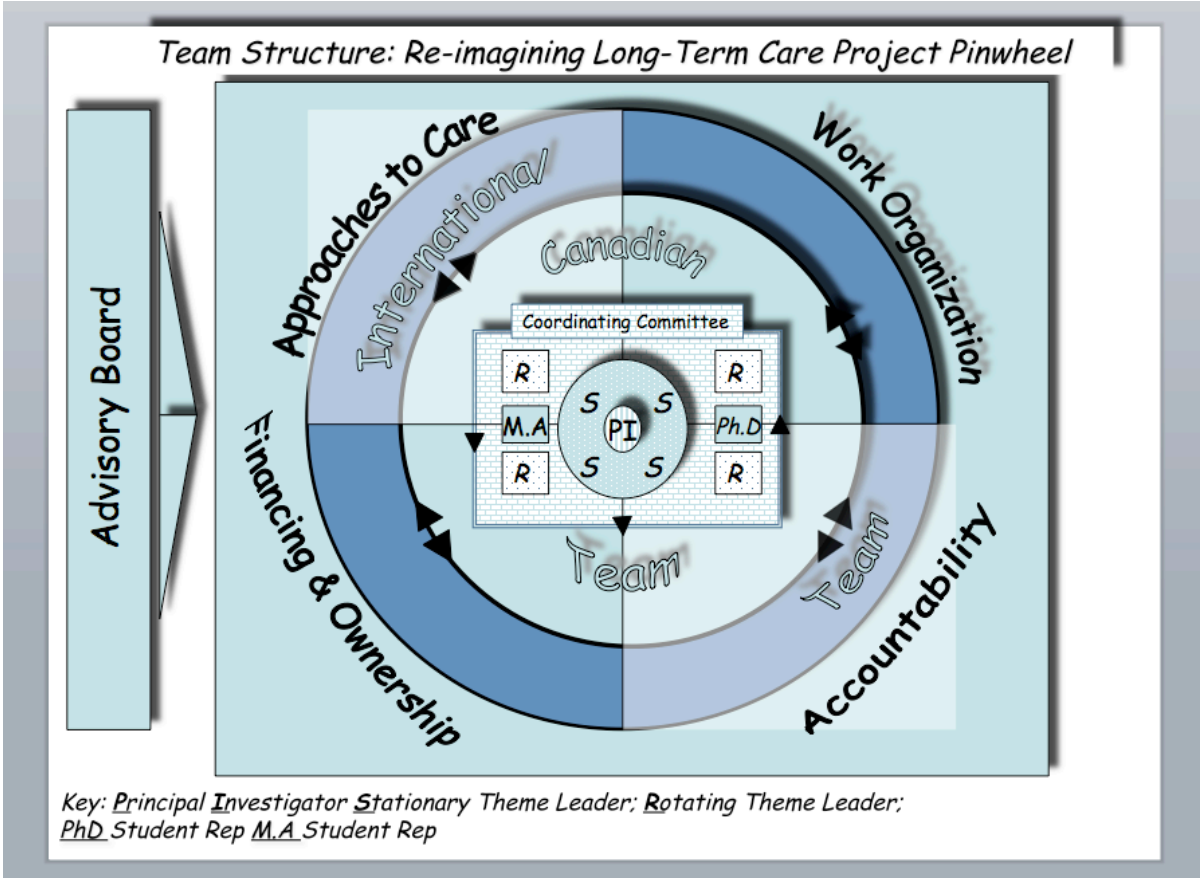
Both our organizational structures and methods are intended not only to build in interdisciplinary perspectives but also the perspectives of our partners, and to stimulate innovative thinking by constantly bringing fresh eyes to the study of long-term residential care in each jurisdiction. Our approach is designed to balance the need for comparison and rigour with openness to new insights and diverse contexts. The project allows academics and partners to think through the practical implications of theory and the theoretical implications of practices and processes. It creates conditions for new developments in theory, empirical results, processes of collaboration, policy and practices not only about conceptualization of care and their implications but also about ways of doing and sharing research, filling major gaps in knowledge about long-term care. The success of these strategies is evident in our book, in our multiple publications, events, and presentations, as well as in our proposal for a methods text.

Throughout the project we are engaging in knowledge translation at conferences, in journals and in books. We also produce plain language documents, as well as technical reports and presentations for the media, community groups, employers, policy-makers and unions.

Integration

When the SSHRC team visited at the beginning of our MCRI, they told us they were impressed by the extent of integration and interdisciplinarity described in our proposal — an aspect that set us apart from other MCRIs. This is why we kept the number of members manageable (adding only Susan Braedley, our initial project manager, to the team when she became a faculty member at Carleton) and we have worked very hard to put that integration into practice through a number of strategies.

a. The governance structure and organization is profoundly integrated. Our organizational chart below was singled out as particularly useful and appropriate by the SSHRC team. As planned, this spring each theme has one new leader and half of the membership is new to that theme in order to bring fresh eyes and new disciplinary mixes to each theme.



b. We have held a face-to-face full team meeting every spring and virtually the entire team has attended all of them. These meetings have spawned a host of spin-off projects, networks, and proposals. All partners have participated in these meetings and presented on a panel at them.

c. We have used the team meetings not only to share content, further specify our goals, and develop work plans for the coming year, but also to learn together. At those team meetings we have held a workshop on doing archival research in order to ensure everyone is familiar with how it is done and why it is critical. We have also organized a workshop on ethnography, so everyone is prepared to carry out such research. For both workshops, we received funding from CIHR. We visited a long-term care facility at another meeting in order to provide a basis for planning site visits, and organized two initial sessions and two follow-up sessions with community stakeholders where team members described residential care in their jurisdictions. Based on these meetings, we formed a knowledge network connected through our website. At our most recent meeting, we presented our shared work at a public forum and an invitation-only conference (see Appendix 2 for details on knowledge sharing) before spending two days finalizing our plans for site visits and collectively considering research on ownership.

d. We have ensured students are full participants not only in team and theme meetings, but also in all aspects of our research. Unusually, faculty and students work side-by-side in primary data collection and analysis, exposing students and faculty not only to the accumulated knowledge of faculty but also to other disciplines.

e. In addition, students have published with faculty members, with one such publication named the CIHR IHSPR 2012-13 article of the year Award Winner (see Appendix 1 for full details).

f. We organized a year-long seminar series for faculty and students that resulted in a book with contributions from the humanities, social sciences and medicine. Seven students have chapters under their names. Another seminar series is planned for 2013-14.

g. Our theme groups that bring together faculty and students from multiple disciplines meet regularly through Skype and conference calls. The emerging work from themes has been shared with the entire team – including partners – both at full team meetings and through webinars.

h. Our coordinating committee, made up of theme leaders, has been able to meet more frequently than planned and is regularly in contact through email about decisions that need to be made between team meetings. Students frequently attend these meetings and one of our post-doctoral fellows is a theme leader.

i. Our O3 (https://reimagineltc.othree.ca/) architecture has proven to be an effective means of sharing information on a daily basis. The site is visited regularly by team members, partners and students. A second layer provides password protected access to primary data — yet another matter that required collective development of protocols. Our shared bibliography (https://sites.google.com/site/reimagineltc/) has been particularly valuable to all team members and has been made available to other stakeholders.

j. Themes have focused on the mapping exercises, while members from across themes participated both face-to-face and electronically in planning our pilot project and site visit. The two completed site visits have involved a total of eighteen team members, including national and international students, faculty and post-doctoral fellows. All but two of our team members will participate in the site visits planned for 2013-14. In addition, there are some cross-theme projects underway that integrate material from approaches to care, financing and ownership, work organization and accountability.

k. Annual reports from each theme, along with a host of other material submitted by members, are shared through O3 and through our newsletters.

l. Our Advisory Committee members (Pat Evans, Carleton; Nancy Guberman, UQAM; Paul Lovejoy, York; Leah Vosko, York) have all held major research grants. The Committee has access to our shared website and is sent our newsletters. In our annual conference call, they have been unanimous in approving our progress and our methods. They have indicated that, given our other means of communicating, the Committee did not need to meet more regularly.

m. Dr. Karen Messing, an internationally recognized expert both on observation methods and on the gendered analysis of health and safety, came for a month as a visiting scholar to the project. During that time, she conducted two seminars for students, met with them individually and presented a webinar on observation methods to the entire team. The webinar is available on O3. She also co-wrote, with Pat Armstrong, an article on the importance of gender analysis.

n. We organized four webinars which allowed students and faculty to present their papers-in-progress to the entire team. These papers then became the basis for our conference on regulation in the spring of 2013. In addition to providing an international forum for feedback on specific team papers, the webinars allowed us identify a coherent theme for our conference.

Adjudication Committee Comments

We received the following comments from the committee: "The team should keep in mind that the overall goals of the project will need to be clarified. Also, the research objectives should be made more interdisciplinary."

As we indicated in the proposal, the goals of the project are being increasingly clarified as our interdisciplinary team and theme groups work out how to put them into practice. As our newsletters,

coordinating committee minutes and annual theme reports along with the minutes of theme meetings make clear, interdisciplinary teams are continually clarifying and acting on goals. Our team meetings have focused on content and methods in ways designed to ensure interdisciplinary integration. By conducting workshops on archival and on ethnographic research that involved all team members, we have shared research strategies. Our site visits have not only involved interdisciplinary teams working together on primary data collection but have also involved regular meetings before, during and after the visits to clarify and share both methods and goals.

Progress as Set Out in the Milestone Report

Overall, we have made significant progress in the Layer I mapping of residential care, going beyond our initial proposal to produce a number of studies. A Masters student is working with our post-doctoral fellow and the PI to identify gaps, based on our mapping work to date, and our plan for 2014 is to fill in as many gaps as possible (see additional detail under Responsibilities, Roles and Results below).

The Layer II pilot study has been completed. It involved:

a. archival and ethnographic workshops,
b. Baycrest visit by entire team to provide a basis for protocol development,
c. site selection interviews with key informants in all jurisdictions to get advice on what homes, based on what criteria, we should use as a way of studying promising practice,
d. webinar for project members on observation techniques, given by our visiting scholar Dr. Karen Messing-an internationally recognized expert,
e. negotiations to gain access to a home and institutional ethics approval,
f. determination of background documents required and their procurement,
g. development of interview and observation guides, and protocols for student and faculty involvement,
h. pre-interviews and background document development,
i. organization of week-long site visit by 12 members (4 students, 8 faculty),
j. developing a system for organizing, sharing and analyzing data,
k. reporting back to the home,
l. meetings to analyze materials, propose publications.

As planned, our pilot study involved establishing templates that have been applied in a second site visit. Our pilot project was a success in developing protocols and templates (see Appendix 3 for more details) that, as our second site visit demonstrated, are effective but will need adjustment for different jurisdictions. In the process, we have developed a proposal for a methods book based on this work.

Layer III has been organized, with a site visit planned for Texas in December 2013, followed by site visits in Norway, Sweden, the UK and Germany in spring 2014. The remaining Canadian site visits are planned for 2015.

Below we set out what we have done according to the Milestone Report product categories, indicating in brackets the numbers from the milestone report. The categories are to some extent artificially separated and overlap significantly with dissemination milestones. Further detail on the content of publications and presentations are provided in the theme reports and more complete lists can be found in Appendix 1. It should be clear that we have gone well beyond our promised output.

a. Thesis and Dissertations (5): At least 8 students involved in the project have theses specifically on long-term care. One is completed.

Completed:

Banerjee, Albert	On the Frontlines: Structural Violence in Canadian Long-Term Residential Care
In process:	
Campbell, Andrea	Invisible women, invisible work, invisible hazards: an examination of injury and illness among direct care workers in long-term care facilities in the 'new' global economy
Day, Suzanne	LTC workers decision-making processes
Kehoe MacLeod, Krystal	Regional organization of home care
Laxer, Kate	Mapping the LTC Labour Force
Meyn, Christina	Psychosocial Health in Workplaces – Workplace Health Promotion using the example of Long-term Care
Seeley, Morgan	Falling Through the Cracks: Conditions of Care and Non-Senior Adults with Disabilities in Long-Term Care Homes
Twomey, Amy	The Politics of Long-term Care Reform in Ontario and Manitoba, 1970-2000

b. Conference papers – 52 (14)

c. Academic Publications – 46 (4)

   In addition we produced a book, *Troubling Care: Critical Perspectives on Research and Practices* which includes articles individually authored by seven students, as well as by seven faculty members. (http://www.cspi.org/books/troubling_care)

d. Mainstream/ Stakeholder Presentations – 70 (17)

e. Mainstream/ Stakeholder Publications – 10 (5)

f. Internet Reports/Articles/Updates: Our shared website O3 (https://reimagineltc.othree.ca/) is now updated almost daily, with all members able to post news and share data on the password protected portions.

g. Newsletters (six completed, one in production), O3 updates including publishing, presenting and grant opportunities (constant by staff, students and faculty)

h. Student/Postdoctoral Fellow Involvement: One of our post-doctoral fellows was successful in obtaining an OTC post-doctoral fellowship and a CIHR fellowship, extending his work with us as a theme leader. Both fellowships are supervised by Pat Armstrong. He has published five articles and presented for the project on more than a dozen occasions. Some are with faculty in the project, while others are sole authored. Our other post-doctoral fellow has played a central role in developing templates for our site visits, is writing a chapter for our methods book and is working to identify gaps in our mapping project. She is presenting a paper at an international conference in October based on our primary data, and has co-authored with two faculty members. In addition, she is sharing responsibility with the PI for the development of the methods book and is working with a Masters student on identifying gaps in our mapping.

   Forty-eight students from Canada and abroad have been engaged in the project (11 Bachelors, 10 Masters, 27 PhDs). This has involved full participation in team meetings, seminars, publications, mapping, grant applications, ethnographic work and conference presentations. They have also been involved in developing protocols about ethics, authorship, payment and participation for students, all of which are available on O3.

   Twelve social science, medical and humanities students, working under the direct supervision of faculty, have prepared or are preparing bibliographies. Three students from the joint York-Sheridan program on design have worked with the project managers, the administrator and the PI on planning and developing the public website. An undergraduate student from York's Faculty

of Health has worked on the bibliography for our book and on our shared bibliography, while others from the work-study program have been involved in some of the planning work for our meetings.

Our mapping exercise has involved students in quantitative data analysis as well as in the study of policy and regulations. Working with the PI, one doctoral student in sociology is documenting the international labour force in long-term residential care, building on collaborative work they are doing for the Comparative Perspectives Database (CPD). Another health studies student co-authored a publication with one of our physicians on verified complaints about long-term residential care. Yet another is documenting the regulations on health care workers while a fourth has investigated health and safety policies, providing the basis for the chapter in her thesis on personal support workers in long-term residential care. Our partners have also assisted her in identifying workers to interview for her thesis. A German student, working with our faculty member in that country, has used long-term care as an example for promoting workplace health.

Our 2011-12 York Seminar series, funded by York University, involved presentations and full participation by students in a series that included multiple disciplines. In the resulting book, seven of them have articles under their own names. The process has contributed to their understanding of how a book is negotiated and developed.

Students have the unique experience of participating as full team members in our rapid site switching ethnographies that involve them working on primary data collection and analysis with senior academics. Four students were full participants in the planning and development of our pilot site visit, working side by side with the full professors to construct interview schedules and to conduct interviews, as well as carrying out both observations and analysis. Three of them have written an article on their experience of doing ethnographic research in this manner and what they have learned in the process. It was presented at a conference and one version will be submitted for publication while another will be included in the methods book. Two of the student participants are using the primary data as the basis for their theses while the other two are working with faculty on writing papers out of the materials. Our second site visit included one of the Swedish students participating in the pilot and a second Norwegian student who shared his experiences of doing ethnographic research in Egypt for his Masters work. Our post-doctoral fellow was part of both site visits, bringing her experience of working alone on an ethnographic study for her doctoral thesis.

Students have presented posters and papers at our team meetings, at university seminars and at 16 conferences, both under their own names alone and with faculty. They have worked with partner organizations as part of our project, and have been involved in our public events. At least a half a dozen students are using the data in their theses. A number of these presentations will be submitted for publication.

These are some examples of the ways students are learning with and from faculty and partners in our project. More details can be found in Appendix 1. In keeping with our philosophy, their contributions to publications and presentations are included with those of faculty. Our emphasis has been on total integration, although students have informally met together at our team meetings and through a reading group organized at York. With students, we have developed protocols for student payment and research engagement.

Dissemination

Our dissemination has gone according to plan.

a. We established a secure site – O3 (https://reimagineltc.othree.ca/) – very quickly. It is frequently visited by team members and is supplemented regularly by collective emails, with their content also posted. It has layers of password protection, with the most secure being the primary data on site visits. We have collectively developed polices and protocols around access and use. It has been even more useful and more used than we anticipated.
b. Both the coordinating committee and theme groups have met more often than planned. Minutes are shared on O3 and important decisions highlighted. Our webinars have allowed us to share content across themes.
c. Our on-line library (https://sites.google.com/site/reimagineltc/) took time to develop as we established systems for organization, access and use, but it is now fully stocked and continually upgraded. Our partners, as well as the knowledge network of stakeholders, make use of this resource.
d. Our public website (www.yorku.ca/reltc) is frequently accessed, and in August will have new, livelier visuals. It includes the information as set out in milestone – a description of the project and the team including student and partners, updates, events, media reports, contact information, publications by members and relevant links. We also have a twitter account, with a student managing the tweets.
e. Our milestone report sets out categories which, to a large extent, overlap with our products. To avoid repetition and in order to provide an overview, we have produced the charts found in Appendix 1. It is important to note that virtually all of the categories listed in the milestone report exceed our expectations.
f. We have engaged in a wide variety of knowledge exchange activities, including media interviews and commentaries. For example the paper on scandals will b highlighted for press and media coverage by the International Journal of Sociology and Social Policy (see Appendix 1 for details).

Additional Activities

In collaboration with ECHO, we held two meetings with stakeholders in Toronto to consult on our research agenda and plans. Similar meetings were held in Ottawa, and with Baycrest senior management in Toronto. We organized a Café Scientifique for the public with CIHR funding on gender in long-term care. We organized an event for stakeholders on how long-term care is structured internationally, and held a public forum on changing the long-term care conversation. These three events were scheduled in conjunction with project team meetings to avoid additional costs and time commitments. Our invitational conference on regulation was carried out as planned (see Appendix 2), allowing us to get feedback from policy makers, unions, community groups and researchers on our work related to regulation.

We have published a book *Troubling Care: Critical Perspectives on Research and Practices* and have proposed an electronic methods book. We have developed a collaboration with another researcher in Norway as a result of our additional and fully integrated grant on Healthy Active Aging in Residential Places — a project funded in Canada by CIHR and in Norway, the UK and Sweden by their national research agencies. A special section of a journal is in process based on our conference papers. We have cooperated with our partner, the Canadian Union of Public Employees, in their production of a film on long-term residential care. *Time to Care* includes interviews with many of our investigators.

Explain Delays

We have not experienced any significant delays in our project plans.

Significant Changes

There have been no significant changes to our plans as set out in the proposal and milestone report. As explained in our proposal, ethnography is an evolving process and thus the forms of our ethnographies are developing as we assess each site visit. As a result of our experience with a full-team session at a long-term care facility and of our experience with the resources involved in site visits, we have decided to make a few visits shorter than week-long ethnographies and use these to develop a new version of ethnography.

Roles, Responsibilities and Results of Each Member

It should be noted that we are committed to working as a team, rather than as individuals, in order to promote collaborative work among disciplines as well as among faculty and students, with at least one student on each theme ((S) indicates student). The emphasis is on combining fresh eyes with experience. Therefore we are reporting on the roles, responsibilities and results of each theme, naming individual members involved.

Approaches to Care

1st leaders: Sally Chivers, James Struthers; **1st members:** Katie Bausch (S), Susan Braedley, Megan Davies, Suzanne Day (S), Monique Lanoix, Joel Lexchin, Tone Elin Mekki (S), Amy Twomey (S)

2nd leaders: Albert Banerjee, Sally Chivers; **2nd members:** Annmarie Adams, Susan Braedley, Paul Leduc Brown, Megan Davies, Frederika Eilers (S), Monique Lanoix, Liz Lloyd, Morgan Seeley (S)

Work-in-progress

The overarching goal within the 'Approaches to Care' theme group is to investigate the way ideas about long-term care and assumptions about rights to care influence what long-term care looks like. Such ideas can be found in history, advertisements and films, in policies and in the ways we treat both residents and care providers. The mapping projects encompass media, policy, professions and philosophy, as all of these play a role in the shaping of long-term care. Dementia, as a theme, is explored, including the historical development of geriatric psychiatry and practices around residential care for the elderly with dementia in Ontario and British Columbia. Of particular concern are the current perspectives on dementia and mental health which connect past, present, and future policies and practices. A connecting focus is on pharmacology and chemical restraint usage in this population. The separation of mental health from dementia in both theoretical and practical domains is also a topic explored.

As a basis for this research project, 'care' as a conceptualized, modeled and/or theorized term, was mapped by reviewing the body of relevant literature and developing an extensive bibliography. Understanding how approaches to care have evolved over time is also critical in the investigation. A review of the historical literature on welfare states and care models was carried out and an additional bibliography was developed (Struthers, 2012). Struthers (2013) also analyzed the final reports of two Special Senate Committees on Aging between 1963-1966 and 2006-2009, to show how old age was framed differently as a policy problem in these two eras. Poverty among the elderly was the central concern in the 1960s (e.g., the Guaranteed Income Supplement was created in 1967 for those in need), and later the focus was on promoting healthy aging and developing a national caregiver strategy. Struthers (2013) examined the reasons for the differences, and the impact of the reports. He also explored the changing social, economic, and demographic contexts and the ways in which they have consequently shaped approaches to population aging. In a complementary fashion, Twomey's (2013) book chapter in *Troubling Care: Critical Perspectives on Research and Practices* explores

long-term care reform in Japan and Germany. By collecting and summarizing reports on senior care from various sources including Health Canada, group members mapped the Canadian governments' concerns regarding elder care, both at federal and provincial levels (Ontario, Manitoba, British Columbia, Nova Scotia, and Quebec), from 1985 onwards. This included the National Advisory Council on Aging and media coverage, as well as provincially specific reports and academic publications. Similarly, the group compiled data on government worries related to senior care from California, Texas, Germany, and Sweden. This compilation of literature provides a vivid picture of the scope of the problem, from hospital bed shortages due to the lack of long-term care beds, the closing of psychiatric hospitals, and the lack of community support services to the fragmented health system. In order to identify the challenges that arise for residents, staff and managers, another study (Braedley, 2013) contrasted the design standards of residential care homes (in conjunction with other government regulations such as staffing requirements) for their influence on approaches to care.

In another study, the depiction of long-term residential care in Sarah Polley's film *Away from Her* (2007) was compared to its real-life hospital setting in Kitchener, Ontario, as a way to suggest that architectural devices, in particular daylighting and wayfinding, occur neither in isolation nor as a fabricated fiction (Adams & Chivers, 2011). Rather, they are actively engaged in the production of social and cultural values and norms associated with healthcare and aging, depicting late life as a time of impending darkness and disorientation. "Home Pages: Domesticity and Duplicity in Images of Architecture for Aging" is a further forthcoming publication in this area of research (Adams & Chivers, 2013).

This group continues to focus on dementia care as a theme, examining the evolution of dementia care within the social, economic and political contexts across countries.

- One group member is examining emerging dementia plots in cinema.
- Another is investigating a historical site that was originally intended for dementia research and care.
- Another connecting focus is on differences and similarities in structural designs of residential homes across jurisdictions and the impact on dementia care.
- Yet another is exploring is the lack of standardization with new drugs used in long-term residential care.

The section above describes how this theme has clarified their goals, and highlights both the content of some publications and plans for publications that are part of the mapping exercise in this theme (see Appendix 1 for details). Various presentations from theme members add dimensions (see Appendix 1). For example, Monique Lanoix has explored the importance of dance and care ethics while Susan Braedley and others have emphasized the importance of gender analysis in academic presentations. In presentations to more public audiences, Susan Braedley has talked about how difficult it is to dare to dream about this kind of care.

Work Organization

1st leaders: Donna Baines, Tamara Daly; **1st members:** Annmarie Adams, Frederika Eilers (S), Oddvar Forland, Monika Goldmann, Kate Laxer (S), Kathryn McPherson, Christina Meyn (S), Marta Szebehely

2nd leaders: Tamara Daly, James Struthers; **2nd members:** Malcolm Doupe, Monika Goldmann, Frode Jacobsen, Kate Laxer (S), Christina Meyn (S), Dee Taylor (S), Amy Twomey (S)

Work-in-progress

The work organization theme group examines how work is organized within long-term care and shaped by forces outside it. Specific questions include 'who does what for whom,' with 'what kind of training,' with 'what recognition' and 'to what extent is there the right to decide about care' and, 'what kinds of work organization and rewards are most promising in meeting the needs and balancing the rights of residents, providers, managers, families and communities?'

At the first group meeting, it was agreed that a priority was the development of an overall map of what work organization in long-term residential care involved. Macro/meso/micro level indicators of work organization were mapped under the temporal, spatial, regulatory, social, administrative, instrumental and financial dimensions to facilitate cross-jurisdiction comparisons and to determine gaps in the research. The template was taken to a community/policy meeting for feedback and revised on that basis. Theme members collectively gathered an extensive amount of information on, for example, forms of employment (full-time, part-time), employee retention rates, types of contracts, minimum care standards, regulation of staff/residents, skill requirements, training systems, occupational health and wellbeing, models of leadership, degree of privatization of ownership, etc. Particular attention is being paid to the mapping of informal care, including the work of families, private companions, volunteers, spiritual advisors, and the unpaid work that is carried out by various employees of facilities. For example, a connected ongoing study, entitled "Invisible Women: Gender and the Shifting Division of Labour in Long-term Residential Care Facilities" explores the informal paid and unpaid care provided within this context.

Thus far, health and safety in long-term care across jurisdictions in Canada has been mapped. A review of the related academic and grey literature focused on such aspects as workplace health and safety approaches, regulatory and enforcement practices (Campbell, forthcoming 2014), health and safety concerns in long term care (i.e. violence, injuries, stressors) and strategies and/or interventions to address safety in these settings (Sousa, 2011). Occupational health and safety in elder care in Germany has also been mapped (Meyn, 2012). Journal publications include an analysis of survey data on care workers' experiences in Canada and Sweden, which were linked to the broader economic and organizational contexts. In this study, Daly and Szebehely (2012) found a high degree of differentiation among jurisdictions regarding work organization, with Canada's highly differentiated, more demanding task-oriented work organization contrasted to Sweden's integrated relational care model.

Experiences of working conditions in long-term care were examined in three Canadian provinces and four Scandinavian countries using an iterative mixed methods approach. The researchers found there was a normalized culture of "structural violence" (Galtung, 1969), an indirect form of violence that is built into social structures and that prevents people from meeting their basic needs or fulfilling their potential (Banerjee, Daly, Armstrong P, Armstrong H & Szebehely, 2011). Canadian frontline care workers were found to be six times more likely to experience daily physical violence than their Scandinavian counterparts. The poor quality of the working conditions and inadequate levels of support experienced by Canadian care workers constitute a form of structural violence (Banerjee, Daly, Armstrong P, Szebehely M, Armstrong & Lafrance, 2012). Gender in particular has been highlighted in two publications on how skills are defined, taught and rewarded (Armstrong, 2013; and forthcoming). Kate Laxer (2013) has used comparative international data to develop a portrait of the long-term care labour force, while also identifying the inadequacies of existing data sources. Work continues on the aging of this labour force and on cross-country comparisons.

Work within this theme group is geared towards mapping completion, filling in research gaps as outlined in the 'work organization indicators' chart through data collection at site visits, continuous

review of current literature in these areas, and ongoing interconnected research projects. Several team members are involved in the Nordic Research Network on Marketisation of Eldercare (Normacare). The overall aim of the network is to strengthen the Nordic research on the ongoing marketisation of eldercare services, in particular to support younger scholars and to encourage comparative research.

This section indicates only content in the publications, with detailed titles provided in Appendix 2. The presentations in academic and in non-academic setting indicate a host of other work in progress. For example, Armstrong and Laxer have been documenting the aging of the LTC labour force and examining factors contributing to the high rates of work absences in the sector. Donna Baines has presented on managerial strategies, as has Tamara Daly. Kate McPherson has stressed the importance of history in her examinations of nursing work.

Accountability

1st leaders: Albert Banerjee, Jacqueline Choiniere; **1st members:** Andrea Campbell (S), Charlene Harrington, Frode Jacobsen, Robert James, Nasreen Khatri, Liz Lloyd Morgan Seeley (S), Isabel Sousa (S)

2nd leaders: Hugh Armstrong, Jacqueline Choiniere; **2nd members:** Gudmund Agnotes (S), Suzanne Day (S), Robert James, Ruth Lowndes, Krystal Kehoe MacLeod (S), Margaret McGregor, Pauline Vaillancourt Rosenau

Work-in-progress

The overarching goal of the accountability theme group is to identify those strategies which help promote conditions of work and care that make residential care facilities places where people want to work and live, while encouraging the best use of resources. This group also recognizes that care which promotes dignity and respect for both residents and care providers requires some kind of standards and some means for guaranteeing that these standards are met. Accountability is viewed by the group as a relationship, as multi-directional and democratizing rather than the traditional one-way financial accountability. The focus for mapping is on the mechanisms of accountability and current quality measures in long-term care, putting the resident at the core of accountability concerns. Mapping also includes historical overviews such as the genealogy of accountability, beginning at the decline of Fordism in the early 1970s.

In year one, mapping and census work included the gathering of selected accountability mechanisms across different jurisdictions and a range of levels in order to identify gaps, underlying principles, discourses, tensions and contradictions, and promising practices. Collection of data from various sources included surveys, appeals/lawsuits, resident and family council documentation, labour contracts, contracting out/P3 provisions, workplace practice/care guidelines, assessment tools (e.g.RAI-MDS), certification and accreditation mechanisms, state legislation and regulations, free-trade agreements (e.g. EU, NAFTA, WTO, GATS, TRIPS), professional association regulations, organizational record keeping, and arrangements for contracts between residents and service providers. The data served as starting points to map out such aspects as bylaws, regulations and quality indicators, best practice guidelines, and skill mix and resident-provider ratios for nursing homes and retirement homes across jurisdictions.

A review of the accountability literature in long-term care, largely within the Canadian context, was undertaken at the outset to inform this study (Falvo, 2010). An annotated bibliography of literature focusing on mechanisms of accountability as perceived by family members of residents in long-term care facilities was also developed (Seeley, 2011). Additionally, a review of the literature on strategies to improve quality of care in long-term care settings through education or training

interventions, and/or changing practice guidelines/models of care was conducted (Banerjee, 2012). Based on group-defined goals, numerous publications and presentations have been developed. For example, within the USA, one study had researchers estimating the cost of regulating quality care in 1168 nursing homes using data from Medicare cost reports, the denominator file, the Minimum Data Set, and a survey of States' certification and licensing offices. It found that those located in states with stringent regulations incurred increased costs (Mukamel et al., 2011). A further study found that rigorous quality regulations lead to better quality of care in some, but not all, dimensions (Mukamel et al., 2012).

Nursing home staffing standards and staffing levels were also compared across six countries, including the United States, Canada, England, Germany, Norway and Sweden. Wide variations in both were found within and across countries (Harrington et al., 2012). The staffing standards and levels were found to be lower than the recommended levels in all countries except Sweden and Norway, which the researchers emphasize, has implications for quality of nursing home care (Harrington et al., 2012). Harrington, Olney, Carrillo and Kang (2012) compared staffing levels and deficiencies of 10 of the largest U.S. for-profit nursing home chains both before and after purchase by private equity companies. They found that in comparison to government funded and regulated facilities, such facilities had lower registered nurse and total nurse staffing hours, 36% more deficiencies and 41% more serious deficiencies. They also reported serious deficiencies in some of those purchased by private equity companies in comparison to the period prior to purchase. Choiniere (2011) conducted semi-structured interviews with registered nurses working in public health, long-term care, home care, and acute care hospitals across Canada, and found that instead of a providing a more accountable, effective, or efficient system, 'managed care' is jeopardizing nurses' ability to provide care within supportive and healthy work environments. Scandals in long-term care reported in the media in Canada, United States, United Kingdom, Norway and Sweden were also mapped, along with government responses. They found that these responses tended to avoid addressing structural conditions (Lloyd, Banerjee, Harrington, Jacobsen & Szebehely, 2013), and that for-profit care provision, lack of consensus on the state's role in care delivery, international trends in ownership and financing, and investigative reporting all contributed to the emergence of scandals. Other research (Seeley and Smele, 2013) has focused on younger people in long-term care and the ways person-centered policies fail to address their needs.

Publications currently being developed include a comparison of nursing home audit/inspection processes in six jurisdictions (Choiniere et al.), a study of the effects of regulation and litigation on a large for-profit nursing home chain (Harrington et al.), and a narrative analysis of governmental white papers regarding public elderly care policy in Norway (Jacobsen). Additionally, ongoing mapping and analysis of accountability mechanisms such as RAI-MDS, transition practices into and between long-term care facilities, and medical/administrative positions in long-term care are being carried out in collaboration among various team members.

Further details on publications can be found in Appendix 1. Here, too, presentations indicate a range of other work in progress. For example, Banerjee, Taylor and Wahl have looked at relational accountability and at communications across workplace hierarchies. Choinere presented a paper on audits and inspections as part of our conference, Daly presented on MDS-RAI to the team and Harrington, along with Jacobsen presented on nursing home accountability in the US and Norway.

Financing and Ownership

1st leaders: Hugh Armstrong, Martha MacDonald; **1st members:** Paul Leduc-Brown, Malcolm Doupe, Krystal Kehoe MacLeod (S), Margaret McGregor, Justin Panos (S), Allyson Pollock, Saskia Sivananthan (S), Pauline Vaillancourt Rosenau

2nd leaders: Donna Baines, Martha MacDonald,; **2nd members:** Charlene Harrington, Joel Lexchin, Kathryn McPherson, Justin Panos (S), Allyson Pollock, Marta Szebehely

Work-in-progress

This theme group's focus is on determining the patterns and consequences of financing and ownership of long-term care facilities, seeking to identify those which meet the goals of dignity and respect for both workers and residents in these settings.

Thus far, this group has collected data and mapped the continuum of long-term care in the USA (Rosenau, Harrington, Stockdale, & Joseph, 2011), highlighting the various types of housing and support services, the lack of integration of services, the failure of the system to support the vulnerable elderly population, and the resulting high reliance on informal care (Harrington & Roseneau, 2011). The private and public spending across Canada on residential care has also been mapped, along with an overview of home care, nursing homes and resident demographics, lengths of stay, and health status indicators in particular jurisdictions such as Nova Scotia (MacDonald, 2011), and across countries. Further, the daily/annual rates for basic, semi-private and private rooms, as well as adjustments according to level of income across Canada (MacDonald & Panos, 2011) and the US (Rosenau et al., 2011) were identified. Funding models and ownership patterns for long-term care in particular jurisdictions such as Ontario (Panos, 2013) and Nova Scotia (MacDonald, 2012) are currently being outlined. Grids have been developed to allow comparisons of these models and patterns across the countries in the project (MacDonald & Panos, 2012). Within each ownership type various characteristics such as contracting out and/or centralization of services, regulations, approval processes, governance and collective rights and action have also been reviewed.

Based on the collectively determined research goals, the group members have developed a number of publications and presentations (see appendix 1). In one Canadian study, for example, publicly available data were used to compare the type of facility ownership with verified complaints as one performance indicator (McGregor et al., 2011). The researchers showed that significantly more verified complaints were documented in for-profit homes than in those with other ownership types, including non-profit, charitable, and publicly owned long-term care homes. Marketization in eldercare and childcare within England, Sweden and Australia was also explored (Brennan, Cass, Himmelweit & Szebehely, 2012). Although marketization is claimed to be the most cost-effective and efficient means of increasing quality and lowering costs of services, there is no evidence to support either of these claims in the case of for-profit eldercare and childcare.

Other questions being addressed within the group include:

- the size of public expenditure on long-term care, allocation of funds for long-term care within jurisdictions (federal, provincial/state and district/municipality), the types of transfers used (e.g., block grants and cost-sharing), the number of funding departments such as health and community services, operating funding (activity based and per diem allotments), and investigations of capital funding and staffing,
- contracts with service providers, whether they are private or public, and the differences between for-profit and not-for-profit funding and contracts,
- resident charges/expenses according to the type of institution (types of user fees or co-payments, income and/or asset testing, deductions from public pensions, role of private health insurance),
- ownership patterns in long-term care (the mix of ownership types and market share such as number of beds, facilities and trends), and the differences in ownership types including location, size of facilities, socio-economic and/or health status of residents, staffing ratios, staff retention rates, unionization rates, contracting out of services,

- the use and limitations of MDS-RAI (Minimum Data Set – Resident Assessment Instrument) applications,
- the analysis of 'medical loss ratio' data,
- the impact of homecare arrangements for long-term care across jurisdictions,
- medication approval and usage patterns,
- the construction and use of comparative official statistics such as CIHI, Statistics Canada, OECD, and WHO.

The financing and ownership group has also been active in presenting at academic and non-academic conferences, looking for example at security in old age and financial accountability.

Cross Theme Work

While theme groups are where much of the mapping has been organized, a cross-theme group is also organized and many presentations by team members have provided overviews of the project as well as papers that integrate material from all themes (see Appendix 1). We have also done work and made presentations on theoretical framing and on scandals. A team that crosses themes is focusing on RAI-MDs and another on ethics for research.

Future Work and Grant Completion

Our ethnographic work takes us beyond and across themes, allowing us to develop a new set of related issues. We decided on two approaches: 1) writing papers now on issues that are more general but based on our mapping, current site visits and interviews and 2) drafting papers that will provide a basis for focusing our subsequent site visits. We initially identified the following topic areas, and anticipate many more as the international site visits develop:

1. the social organization of food
2. the structural context for food
3. safety and risk
4. the division of labour and staffing levels
5. physical structures and care
6. gender relations/racialized relations
7. community involvement and precarity
8. clothing

Based on our experience, we are planning what we have tentatively called a 'growing electronic workbook' on methods, one that will be updated for subscribers as we move into other countries. Focused on research dilemmas as well as promising practices, the workbook would include sections on:

1. context and theory
2. novice eyes – by the students involved
3. photo-voice
4. field notes as a basis for thinking through multiple eyes, shifting frames and interdisciplinarity
5. interviewing – how to encourage, process etc.
6. similarities and differences between individual and team ethnography
7. technical aspects such as organizing data
8. conducting collective analysis
9. ethical challenges

Our mapping will continue and result in multiple publications which will fill critical gaps in the literature on what long-term care looks like across jurisdictions and what lessons on promising practices can be learned from other countries. While this analytical mapping has tended to reveal more problems than promising practices, we are identifying some that we anticipate will be further developed as we conduct our site visits. The second half of our project involves intensive work on site visits. Our initial visits have produced rich and thick data that will be further explored as we complete our site visits over the next two years, leaving us plenty of time to analyze these data in ways that move us well beyond problems to new ways of seeing, designing, organizing and practicing long-term residential care. Our dissemination will also continue as we work with our partners and knowledge network to link theory to practice. We plan to return to our sites to report on our findings, to organize a final conference, and to continue publishing and presenting in a variety of venues, including a popular media series on what everyday life in long-term residential care looks like in various countries.

Notes on the Budget

York, other universities, and our partners, have provided us with the support as promised. We have been very successful in raising additional funds. This has allowed us to save money in the first three years that means we can conduct and extend our site visits in the next few years and hire the students, as well as the post-doctoral fellows and administrative staff, we need to make a critical contribution to long-term residential care theory and practice.

Support to September 2013:

Source	**Amount**	**Source**	**Amount**
Cash		**In-kind**	
Support as per application (all delivered):			
York University	135,942	York University	70,175
		Trent University (45,000 to students)	102, 421
		McMaster University	10,889
		Carleton University	11,575
		University of Manitoba	5,250
		McGill University	1,575
		St. Mary's University	1,575
		University of British Columbia	1,575
		Université du Québec en Outaouais	1,575
		Partners: CAW, CFNU, COA, CUPE, NUPGE, OANHSS, SEIU	73,504
Total cash and in-kind support (as per application)			**416,056**
Additional support - students:			
Bruyere Research Institute	28,313	York University	9,250
		CHSRF/CIHR Chair (York University)	91,445
		McGill University	2,812
		Carleton University	10,848
Additional support - other:			
		York University	23,450
		CHSRF/CIHR Chair (York University)	38,681
		U of Manitoba; Appalachian, Bergen U	4,007
Total additional cash and in-kind support			**208,806**