

# Supervisor & Project Information Form

Please complete and return via email ONLY to [gdip.hres@utoronto.ca](mailto:gdip.hres@utoronto.ca) by **Monday September 30, 2019**

## Supervisor Information

*MUST have unrestricted SGS appointment (appointment to supervise graduate students)*

<b>Name:</b> Dr Meredith Giuliani Radiation Oncologist, Princess Maragret Cancer Centre; Associate Professor Department of Radiation Oncology, UoFt & Dr Janet Papadakos Assistant Professor, Institute for Health Policy, Management & Evaluation, University of Toronto	<b>Email:</b> <a href="mailto:Meredith.Giuliani@rmp.uhn.ca">Meredith.Giuliani@rmp.uhn.ca</a> ; <a href="mailto:Janet.Papadakos@uhnresearch.ca">Janet.Papadakos@uhnresearch.ca</a>
<b>SGS Department:</b> Institute of Health Policy, Management and Evaluation (IHPME)	<b>Field of Research:</b> Health Literacy & Education
<b>Research Institution affiliation (if applicable):</b> Princess Margaret Research Institute	<b>Location of Work:</b> Princess Margaret Cancer Centre
<b>Student contact time (number of hours per week YOU are available to the student for any concerns or to review progress:</b> 1-2 hours for standing meetings. Research associated 2 hours per week. All available daily over email.	

**Project Information (will be posted on GDipHR website for student access)**

**TITLE:**

Evaluation of the Online Education and Skills Development Program for Informal Caregivers of Cancer Patients: Caregiver Accessible Cross-Continuum Education & Skills System for Cancer (Caregiver ACCESS)

**DESCRIPTION (MAX 500 WORDS):**

**Background:**

Unpaid Caregivers (CGs) are defined as, “individuals (e.g., adult child, spouse, parent, friend, or neighbour) who provide care which is typically uncompensated and usually at home, which involves significant amounts of time and energy for months or years, and which requires the performance of tasks that may be physically, emotionally, socially, or financially demanding”. CG ability to manage the symptom(s), treatment regimes, physical, psychosocial consequences and life-style changes inherent with caring for a loved one living with cancer is critical however very few opportunities to build this necessary foundation and skills exist. Digital interventions hold significant potential for promoting CG self-management skills but there is a paucity of interventions that have been tailored for cancer CGs that are focused on holistic competency development. CG SMS initiated early in the cancer continuum has the potential to build caregiver resilience and cancer health literacy, improve their ability to problem-solve, monitor and manage patient symptom burden.

**Significance of the Research:**

CGs are tasked with navigating increasingly complex and fragmented health care systems and in recent years, cancer CG responsibilities have increased dramatically. This is primarily due to the use of toxic treatments in outpatient settings, the decline in available health care resources, and a shortage of HCP. Recent government reports, editorials and publications acknowledge the urgent need for CG support and training program. As cancer rates continue to grow, and as more people survive cancer, the burden on CGs increases. The cancer care system needs proactive and practical interventions to support CGs, and digital education and training in SMS have demonstrated efficacy. There is need for more holistic CG SMS programs that are tailored to the specific needs of cancer CGs and we hope that Caregiver ACCESS will advance what is known about supporting CGs.

**Project Aim:**

To obtain a holistic understanding (qualitative and quantitative data) of the essential CG SMS program content inclusive of features and functionality.

**Methods:**

This is an exploratory, sequential, mixed method study aimed at obtaining a holistic understanding (qualitative and quantitative data) of the essential CG SMS program content inclusive of features and functionality.

In **Phase 1**, qualitative descriptive methods and data sources (interviews and focus groups) will be used to understand the CG experience. This will be followed by a cross-sectional needs assessment survey of a larger population of patients and CGs from across Ontario. The needs assessment survey will include quantitative surveys to understand CGs experience and comfort with digital technology and to assess priority of CG learning needs. We anticipate that with consideration of maximal variation in our sample, 30 patients, 30 CGs and between 10-20 clinicians, data saturation will be met for the interviews and focus groups. For the survey, 150 patients and 150 CGs will be recruited. This sample size is adequate to meet assumptions for descriptive analysis of cross-sectional survey data.

In **Phase 2**, user-experience design testing will be conducted to assess acceptability of the high fidelity prototype Caregiver ACCESS. Sample target is 12 participants in the initial usability testing; and n=6 in the second iteration.

If human subjects are involved, have the appropriate Research Ethics Board approvals been obtained?

Yes       No       Application Submitted (Approval anticipated January 2020.)

Do you expect this work will be published within the 20 months?

Yes       No       Uncertain / Other

***Student Roles & Responsibilities (please be as specific as possible)***

The student will report to the research associate on the project for day-to-day supervision and will have weekly meetings with the co-supervisors Drs Giuliani and Papadakos. The student will be engaged in the conduct of the study, data capture, analysis and knowledge translation activities.

