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OCT. 2020 | VOL.

# CARER-INCLUSIVE PG NETWORK

GENDER, HEALTH, AND CAREGIVER FRIENDLY  
WORKPLACES – STREAM B



## Upcoming Events

Canadian Hospice Palliative Care  
Association Learning Institute  
Virtual Event: Nov. 12-13, 2020

**9<sup>th</sup> International Community, Work and  
Family Conference, 2021**  
Location and date TBA

Know of any other events? Send them to  
[kaplar1@mcmaster.ca](mailto:kaplar1@mcmaster.ca) with the Name,  
Date(s), Location, Registration date,  
Abstracts Due

### Quick-Study Guides available in English and French available here:

#### English

<https://ghw.mcmaster.ca/app/uploads/2020/08/Quick-Start-Implementation-Guide--Carer-Friendly-Workplace-Standard-Final-FINAL-ua.pdf>

#### French

[https://ghw.mcmaster.ca/app/uploads/2020/09/Quick-Start-Implementation-Guide-Carer-Friendly-Workplace-Standard-French\\_Final\\_FINAL-ua.pdf](https://ghw.mcmaster.ca/app/uploads/2020/09/Quick-Start-Implementation-Guide-Carer-Friendly-Workplace-Standard-French_Final_FINAL-ua.pdf)

## Important Reminders

Please remember to cite as follows in all your dissemination mediums including KM tools, research outcomes, and presentations:

CIHR/SSHRC Healthy Productive Work Partnership Grant “Scaling up the Career Inclusive Accommodating Organizations Standard” FRN: HWP-146001 (CIHR); 890-2016-3018 (SSHRC)

If you have any project updates or news items for the newsletter, please send them to [kaplar1@mcmaster.ca](mailto:kaplar1@mcmaster.ca)

When sharing information about the project on social media, we suggest using the following hashtags to connect to our posts:

#careremployee  
#CarerStandard  
#PGProject



# Trainee Network

## September 11, 2020- PG Trainee Network

The trainee network met virtually for the first time on September 11<sup>th</sup> in an informal setting, where trainees across all projects were able to meet and play introductory icebreaker games. The focus of these meetings is to build rapport and social support between trainees across the various PG projects. Next meeting to be held in November. Stay tuned.

## Recent Publications

Dr. Allison Williams' article recently published by The Conversation has generated great exposure for the PG. The Article highlights the need for, and how to nurture a caregiver friendly workplace, and can be found here: <https://brighterworld.mcmaster.ca/articles/covid-19s-silver-lining-creating-a-caregiver-friendly-work-culture/>

Congratulations to Sue Yeandle on the publication of "[Caring and COVID-19: Financial wellbeing](#)". Click title to read full report.

Congratulations to Dr. Sethi on the publication of her article in The Conversation, which focused on racialized Personal Support Workers (PSWs) experiences within healthcare that initiated multiple media responses. Read full article here: [Personal support workers are the backbone of health care but the bottom of the power structure](#)

Dr. Sethi and Dr. Williams were interviewed on September 5, 2020 with 980 CKNW, following her article publication. Listen to the radio segment here: [CKNW Weekend Mornings](#)

Congratulations to Chloe Ilagan on the publication of [Use of Photovoice Methods in Research on Informal Caring: A Scoping Review of the Literature](#). Click title for full article.

Congratulations to Dr. Diane-Gabrielle Trambly on several recent publications. Click links below to read full articles:

- i) The importance and challenges of caregiving in an aging society. E-Journal of International and Comparative Labour Studies. [http://ejcls.adapt.it/index.php/ejcls\\_adapt/article/view/704](http://ejcls.adapt.it/index.php/ejcls_adapt/article/view/704)
- ii) La proche aidance : nouveau défi du vieillissement des sociétés ! Professionalità Studi, Diritto delle Relazioni Industriali. <https://moodle.adaptland.it/course/view.php?id=21#2020>
- iii) Concilier emploi et famille en temps de pandémie : les résultats d'une recherche au Québec. <http://www.lespolitiquessociales.org/>

## We're in the news!

Over the past few months there has been lots of exposure for the PG! click the link below for a list of links and recently published articles

<https://ghw.mcmaster.ca/were-in-the-news/>

### Helpful Links

- Canadian Government resources for seniors and their caregivers  
<https://www.canada.ca/en/public-health/services/diseases/coronavirus-disease-covid-19/resources-older-adults-caregivers.html>
- Statistics Canada released "[Caregivers in Canada, 2018](#)". Click to read report.

## New Developments

- The Carers' Standard **Quick-Study Guide** is now available in English, French, and in accessible formats through Able Docs.
- This fall, a social media campaign will be led by the Canadian Centre for Occupational Health and Safety (CCOHS) to disseminate the **Quick-Study Guide**
- Happy to share that Dr. Williams will be presenting a poster presentation titled, "**The CSA Carer-inclusive and Accommodating Organizations Standard: Helping Carer-Workers Balance Caregiving and Paid Work**" at the Canadian Hospice Palliative Care Association Learning institute on November 12-13.m
- Sophie Geffros, who is a doctoral trainee involved in **Project 8- Coming Out to Care** has been shortlisted for the **Vanier Scholarship** in the School of Earth, Environment and Society and will go on to the next level of competition within the University. Congratulations Sophie, and best of luck moving forward!
- Dr. Williams and the work of the PG is represented in the **Caregivers 4 Change network**. See more info on the organization's website <https://www.caregivers4change.com/>

## Spotlight on Regina Ding

"Last year, I had the pleasure of attending the 2019 International Medical Geography Symposium (IMGS), that took place in Queenstown, New Zealand. As a smaller sized conference with approximately 200 international attendees, this conference offered a smaller and more intimate atmosphere for knowledge exchange, critical discourse, and presentation of research findings.

In a small breakout room on the last day of the conference, I presented my research to my largest audience yet, having only attended local and smaller conventions prior to IMGS. My topic was on carer mental and physical health, and the results of a longitudinal intervention study that had concluded the previous year. This was a presentation that I had done many times before, and so, was so ingrained in muscle memory that everything down to the questions asked were routine to me.

What was surprising was when, not even an hour after my session ended, my presentation was selected for best oral presentation at the closing remarks of the conference. It was the first year that the IMGS committee had decided to award trainee presentations; with two graduate level awards and one post-doctoral level award given to a total of three trainees. To say I was honored by this award was an understatement, considering the depth and breadth of topics covered by the presenters. Regardless, it would not be accurate to say that I won the award on my own. My presentation that I made on that day in New Zealand, represented 3 years of work – from planning, to data collection and analysis, assisted by a vast collection of researchers, statisticians, post-doctorate fellows, and other fellow graduate students. And perhaps most importantly, I would like to extend my acknowledgements to all my research participants, who's experiences and stories are the very foundation of the research presented."



*Regina Ding, PhD Candidate*  
*Gender, Work and Health*  
*McMaster University*

The paper from the conference is now published in the Journal of Occupational and Environmental Medicine and can be found here [here](#). The article Abstract follows:

## **Evaluation of a Caregiver-Friendly Workplace Program Intervention on the Health of Full-Time Caregiver Employees**

*Regina Ding*

### **Abstract**

**Objective:** To evaluate effectiveness of a workplace educational intervention at improving health-related outcomes in carer-employees.

**Methods:** A pre-post test design compared the health of a sample (n=21) of carer-employees before (T1) and after (T2) a workplace intervention, as well as a final timepoint (T3) 12 months after T1. An aggregate health score was used to measure health and consisted three scales; depression (CES-D), psychosocial (CRA), and self-reported health (SF-12), where higher scores indicated higher frequency of adverse health symptoms. Three random-slope models were created via the linear mixed modeling method (LMM) to illustrate changes in reported health.

**Results:** All three LMM models reported a reduction in participants' health score, particularly between T1 and T2, indicating a decrease in reported adverse health symptoms.

**Conclusion:** The intervention was successful in improving the health of carer-employees. The results of this paper demonstrate evidence of the effectiveness of an education-based workplace intervention at improving the overall health of carer-employees. Building on existing literature, this adds to the business case for employers to uptake similar educational interventions within their own workplaces.

# Carergivers 4 Change: Creating a transformational social movement for caregivers by caregivers across Canada.

The objective of the Transformation stream is to support large-scale, Canadian-led interdisciplinary research projects that address a major challenge with the potential to realize real and lasting change. The challenge may be fundamental, leading to a scientific breakthrough, or applied, with a social, economic, environmental or health impact. Projects are expected to be world-leading, drawing on global research expertise, when relevant.

Dr. Hsien Seow (Associate Professor, Dept of Oncology) is the lead PI and the application is called, Caregivers4Change: Creating a transformational social movement for caregivers by caregivers across Canada . The overarching goal is to build and mobilize a national caregiver network of change agents, transform how individuals support caregivers in their diverse communities, and sustain the energy for change for the longer term. The substantial change that will result is the spread and adaptation of co-designed solutions that will be implemented rapidly across Canada by caregivers.

See the full press release below:

## **A Declaration of Family Caregiver Rights and Responsibilities Affirms the Role of Family Caregivers as an Essential Component of Care**

**OTTAWA, October 6, 2020** - In response to inconsistent and in some cases extreme restrictions on end-of-life visitations across Canada during the COVID-19 pandemic, Caregivers4Change in collaboration with Plan Well Guide and numerous provincial and national organizations, to release a Declaration of Family Caregiver Rights and Responsibilities affirming that family caregivers are more than just visitors.

The Declaration calls upon all Canadians to adopt and promote caregivers' rights and responsibilities designed to realize, maintain, and strengthen the role of family caregivers as an essential component of a caring and compassionate society.

1 in 4 Canadians are caregivers who provide care and support to those living with disease, disability or frailty due to aging. 75% of care is provided by family members who are often the care recipient's closest, holistic, and involved care partner; family caregivers deserve to be regarded as critical members of the health care team. Daren Heyland, critical care physician and creator of the Plan Well Guide and lead author of the Declaration, says "In no way do we suggest or imagine that the rights of the family caregiver supersede those of a patient. Family caregiver rights are consistent with the needs and desires of the people they care for and should complement, not conflict with patient rights".

There have been too many stories of family caregivers who were unable to perform their caregiver's duties due to extreme restrictions on end-of-life visitations. The Declaration affirms certain caregivers' rights and responsibilities and maintains that these rights are reflected in constitutional and human rights and international standards. "We aim to influence policy and practice so that family caregivers are never

excluded from their essential role as part of the health care team except at the behest of a competent care recipient” says Hsien Seow, Associate Professor from McMaster University and lead of the Caregivers4Change network.

Caregivers4Change is urging decision makers and elected officials to deliver on the following key asks:

- Adopt the Declaration in the programs and organizations, they lead or fund;
- Find ways to give voice to family caregivers to ensure they have representation at the decision making councils;
- Implement a strategy that allows for grievances to be rapidly assessed and addressed.

Sharon Baxter, Executive Director Canadian Hospice Palliative Care Association, says “We acknowledge that previous work has attempted to formulate a “rights-based’ approach for family caregivers. However, these efforts were pre-COVID-19 and this pandemic has exposed new challenges resulting in unconscionable harm to patients by restricting and often excluding family caregivers from the bedside where they could fully participate in care. These are not new problems, but they have been intensified and made more obvious during this pandemic. The Declaration is meant to have application to both now and, we hope, in a less exceptional future”.

Health care providers and organizations are encouraged to become leaders for change in their organization by signing on this declaration and supporting the implementation of a family caregiver policy, separate from a visitor policy, that respects the rights and responsibilities outlined in the Declaration. Plan Well Guide Caregivers4Change

Caregivers4Change invites Canadians to sign this petition supporting the Declaration and use the hashtag #NotJustAVisitor on social media to advocate for the adoption of the rights in the Declaration. For more information, please visit [www.caregivers4change.com](http://www.caregivers4change.com)

Read the full Declaration of Family Caregiver Rights and Responsibilities here

Caregiver4Change is a growing network of people passionate about improving the lives of caregivers. This includes caregivers, researchers, clinicians, and organizational partners across Canada. The movement aims to inspire individuals and communities to support family caregivers.

Plan Well Guide is an online tool, created by Dr. Daren Heyland. The goal behind the Plan Well Guide is to help prepare people to make decisions with doctors when seriously ill by helping them learn about medical treatments and by helping communicate important values and preferences.

For media enquires:

Aia Raafat

Communications Officer,

Canadian Hospice Palliative Care Association (CHPCA)

# Project Updates

## Project 1- Internationalization of the Standard

The International Standards Organization (ISO) TC 314 Working Group 3 is running on schedule which final publication slated for January 2022. The ISO Plenary meeting is scheduled for November 23, 2020.

## Project 2- Knowledge Mobilization

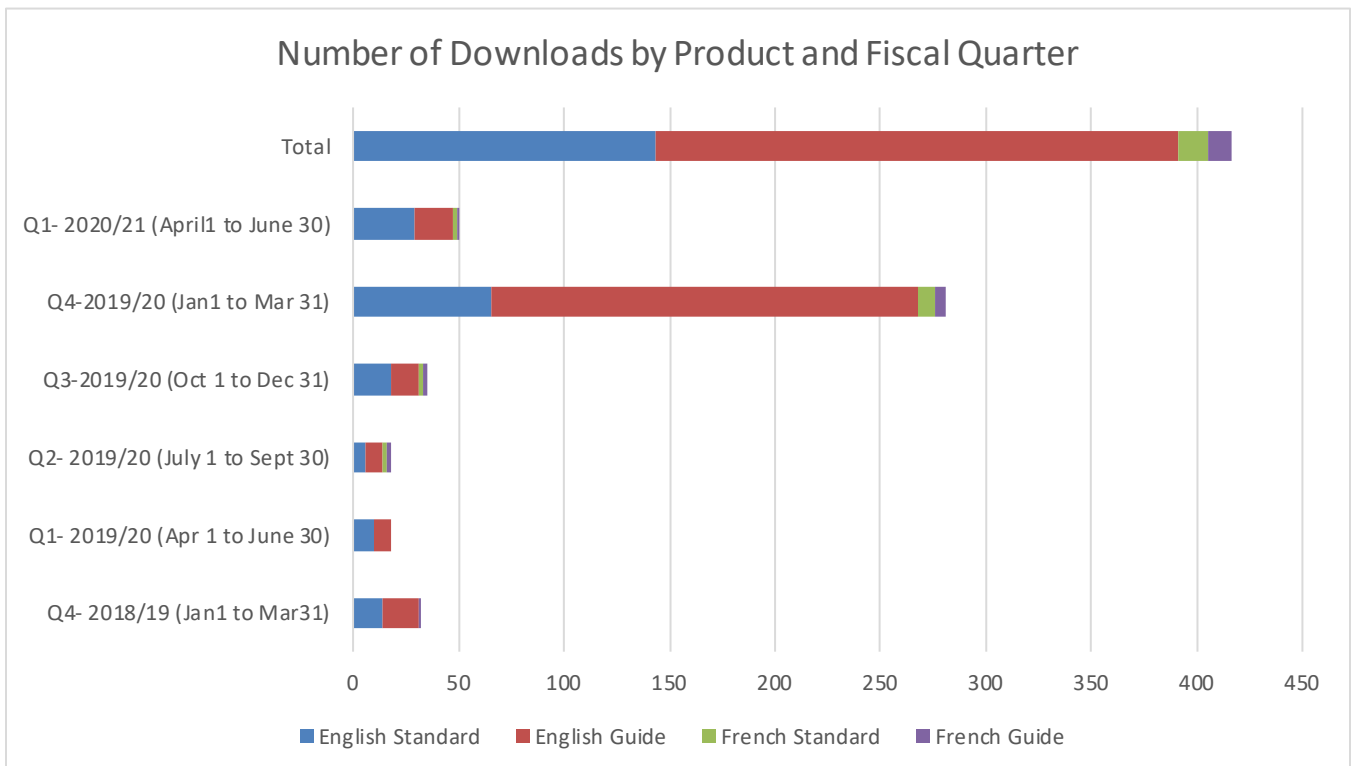
The Quick-Study Guides have been made available in English and French, and made accessible through Able Docs.

**Quick-Study Guides available in English and French available here:**

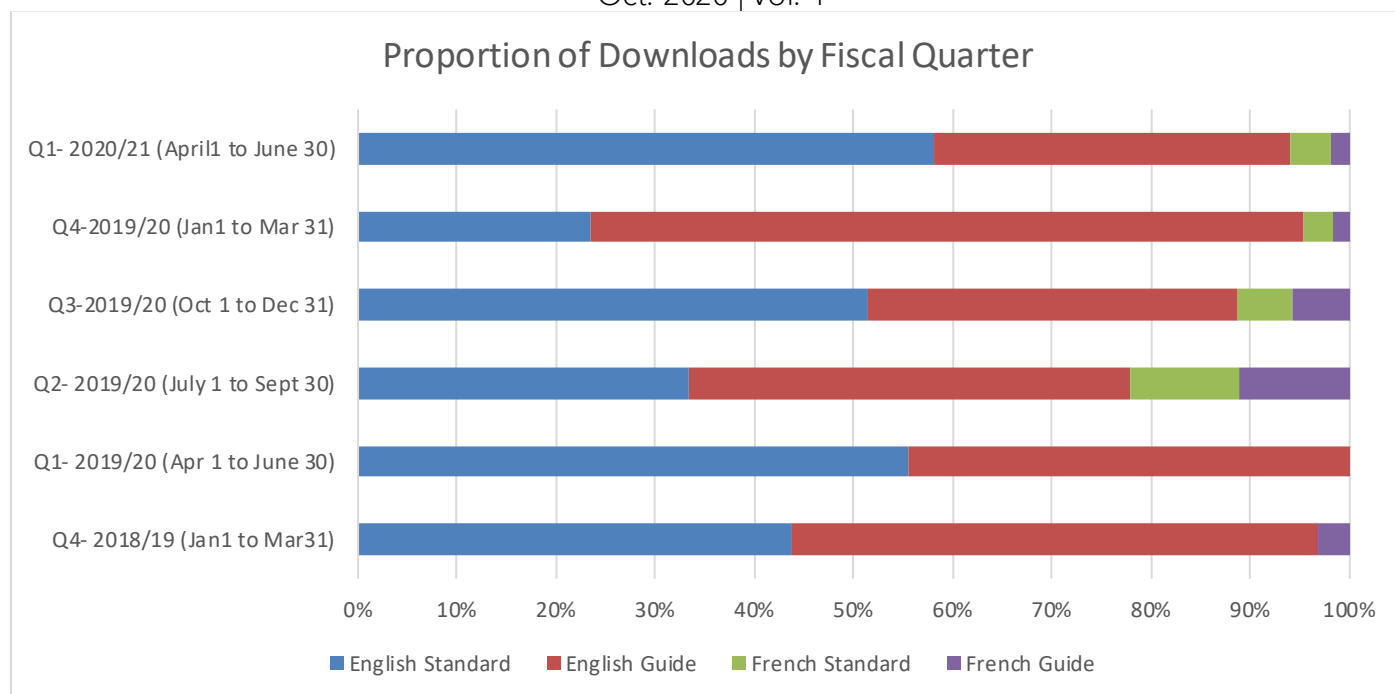
**English-** <https://ghw.mcmaster.ca/app/uploads/2020/08/Quick-Start-Implementation-Guide--Carer-Friendly-Workplace-Standard-Final-FINAL-ua.pdf>

**French-** [https://ghw.mcmaster.ca/app/uploads/2020/09/Quick-Start-Implementation-Guide-Carer-Friendly-Workplace-Standard-French\\_Final\\_FINAL-ua.pdf](https://ghw.mcmaster.ca/app/uploads/2020/09/Quick-Start-Implementation-Guide-Carer-Friendly-Workplace-Standard-French_Final_FINAL-ua.pdf)

## Evaluation Metric: Carer Standard and Handbook Downloads







## Project 3- Readiness for Change

Led by Dr. Duxbury at Carlton University, [Key findings](#) can be found on the PG website under Stream B, Project 3. Dr. Duxbury is currently working with the Conference Board of Canada on a new survey addressing work-life balance during the COVID-19 pandemic.

## Project 4- Feasibility and CBA of the Standard as an Intervention

Under the supervision of Dr. Allison Williams, PhD Candidate and PG Trainee Regina Ding is making good progress on a mixed-method study evaluating the implementation of the Carer Standard as an intervention in the workplace. Regina is currently writing up a data that considers the impacts of COVID-19. Ethics approval and soft recruitment have been completed, with an Advisory Council underway and data completion planned for April 2021.

## Project 5- Informing the Standard's Cultural Competency

We have also strived to ways to build relationships while working digitally. A culturally responsive method we are using for Indigenous Peoples is to send medicines to our Indigenous Participants before their virtual interview. We are working closely with our Advisory Committee members and meeting with them quarterly to ensure that we are including our stakeholders' needs in our research. We are very grateful for the support of our advisory team during these challenging times.

The Project 5 team also welcomes Alexis Kydd, who will be part of our team looking into our Indigenous population. Welcome, Alexis!



## Project 6- Indigenous Perspectives and Experiences with Caring

The collaborative partnership between Brock University and the Fort Erie Native Friendship Centre (FENFC) is led by co-investigators Dr. Eva Jewell (Ryerson University) and Dr. Andrea Doucet (Brock University). Our progress to date includes securing Karen Hilston from the FENFC as a peer researcher and hiring Jessica Falk as an MA student researcher from Brock University. We completed two ethics applications: one to Brock University's Research Ethics Board (REB) and one to the Ontario Federation of Indigenous Friendship Centers (OFIFC). We completed two focus groups at the FENFC in 2019 and we began team data analysis in spring 2020. After writing our report throughout the spring and summer of 2020, we will present our results to the FENFC community for feedback and create a press release at Brock University this fall 2020. Finally, we will produce two articles for peer-reviewed journals and at least one Op-Ed in 2020 and will present 1-2 conference papers in summer of 2021.

## Project 7- Disseminating the Standard in Quebec, Canada

Dr. Diane-Gabrielle Tremblay has conducted an online survey with firms, as well as interviews with HR managers in Québec. The focus of study is on how they are managing carers' requests for accommodations arrangements for caregiving. The online survey has a little over 100 respondents, and the team is trying to pursue the interviews with HR managers, but they are all quite busy with COVID issues since the spring. Several recent articles can be found on page 2.

## Project 8- Coming out to Care

This new project, which is examining the implementation of the Carer Standard for 2SLGBTQ+ carer-employees, is being led by PhD Candidate and PG Trainee Sophie Geffros, under the supervision of Dr. Allison Williams. This project aims to understand the experiences of LGBTQI2S carer-employers (CE's) and how their identity impacts their comfort in accessing workplace accommodations, as defined by the Carer Standard. The current timeline aims for this project to be completed by 2023, with data collection to begin January 2021.

## Project 9: Aging Caregivers: An Analysis of Employment Health, Life Satisfaction and Financial Well-Being using the Canadian Longitudinal Study on Aging (CLSA)

This project aims to fill the data gap with respect to aging carers, and specifically carer-employees through the Canadian Longitudinal Study on Aging (CLSA). Led by new investigator, Dr. Li Wang, in collaboration with Dr. Peter Kitchen and Dr. Allison Williams, a summer Research Assistant (Chris Ji) assisted with the submission of a paper from this study, which has been accepted for publication in **The Canadian Journal of Public Health**.

# For Our Knowledge Mobilization Partners

To help you support the Knowledge Mobilization campaign, we have provided a list of channel-specific links for you to use with your social media efforts or e-newsletters, when applicable.

## How to Use the Links

If you want to tweet a link to the Standard or the Implementation Guide, in either English or French, please use the appropriate social media or e-newsletter link. This way, the CSA can track where the hits/downloads are coming from, helping reach the 'evaluation of reach' element of the CHCA project.

In all cases other than social media or e-newsletter, use the standard links:

### Links to the Standard

English: <https://www.csagroup.org/article/b701-17/>

French: <https://www.csagroup.org/fr/article/b701-f17/>

### Links to the Guide

English: <https://www.csagroup.org/article/b701hb-18/>

French: <https://www.csagroup.org/fr/article/b701hb-f18/>

### Links to the Quick-Study Guide

English:

### Regarding Social Media Use

If each project lead could share partners'

- Twitter handles
- Facebook pages
- Webpages outlining/promoting your project

This information could be distributed to all partners so we can follow, re-tweet, and support all your media efforts.

Please forward to:

Rebecca Kaplan at [kaplar1@mcmaster.ca](mailto:kaplar1@mcmaster.ca)

Catherine Suridjan at [csuridjan@cdnhomecare.ca](mailto:csuridjan@cdnhomecare.ca)

Link to new and improved website