

---

**CONFERENCE ABSTRACT****Improving CARE Together – Building Partnerships with Family Caregivers**18<sup>th</sup> International Conference on Integrated Care, Utrecht, 23-25 May 2018Jacobi Elliott<sup>1</sup>, Carol Riddell-Elson<sup>1</sup>, Roy Butler<sup>1</sup>, Karen Perkin<sup>1</sup>, Michelle Mahood<sup>1</sup>,  
Dana Borrie<sup>1</sup>, Jody Glover<sup>1</sup>, Harpreet Bassi<sup>2</sup>, Elizabeth McCarthy<sup>1</sup>

1: St. Joseph's Health Care London, Canada;

2: The Change Foundation, Canada

---

**Background:** An estimated 8 million people in Canada are family caregivers and save the health care system over \$31 billion annually 1. Yet, family caregivers are often referred to as “the silent partners” in care. Recognizing the importance of the family caregiving role and engaging families in decision-making and healthcare planning is an important aspect to improving care. St. Joseph’s Health Care London, a multi-site health care organization in Ontario, Canada aims to ensure patients and families are full partners in their care and in the design, measurement and improvement of care. Guided by St. Joseph’s Care Partnership Framework 2017, this project aims to improve family caregiver experiences and engagement through partnering with patients, families and health care providers in decision-making and health care planning.

**Methods:** This project follows best practices for experience-based co-design 2 which includes three major steps. Step 1: a discovery phase to learn about current health care experiences. Focus groups and individual interviews were conducted with patients n=15, family caregivers n=73 and health care providers n=141. Ethnographic observations were also completed. Data were analyzed using line by line emergent coding techniques 3. Step 2: Experiences, represented in broad themes, were shared in co-design workshops involving health care providers, patients and family caregivers. Together, priorities were identified. Step 3: Working groups developed resources and strategies that were implemented to improve family experiences and engagement in decision-making. Qualitative e.g. interviews and quantitative measures e.g. experience measure were used to evaluate the work.

**Results:** Several themes emerged from the discovery phase, including: the issue of time, caregiver involvement in care planning, the need for better communication, and better involvement in care transitions. These themes were discussed at a co-design event with patients and families. Resources were co-created including: a resources for better patient, family caregiver and provider communication following best practices for engagement; b tools to recognize and assess family caregivers; and c educational materials to provide community and self-management information to patients and families. Family caregiver and provider outcomes were positive following implementation.

**Discussion & Conclusions:** New resources and care processes were implemented to improve family caregiver engagement and experiences. Patients and family caregivers were involved in

all stages of this work, including patient and family caregiver representatives who worked directly with the project team and patient and family caregiver advisors who guided this work through a steering committee.

**Lessons Learned:** Important insights about patient and family engagement emerged including: taking time to build a trusting relationship; involving families in every aspect of co-design and care planning; and engaging health care providers and leaders in education around the importance of family engagement.

**Limitations:** This work is limited to two areas of the health care organization, geriatrics and rehabilitation. Learnings will be applied to other areas of the organization over the next two years.

**Future Research:** Future work should focus on patient and health system outcomes as a result of improved family caregiver experiences.

1. The Change Foundation, 2016
2. Point of Care, 2016
3. Lofland et al., 2006

---

**Keywords:** co-design; family caregivers; older adults; patient and family caregiver engagement

---