EXECUTIVE SUMMARY

Context
Patient safety has become a national and international area of priority following the release of the Institute of Medicine’s report *To Err is Human* in 1999 (IOM, 1999) and the release of the Canadian Adverse Events Study in 2004 (Baker et al., 2004). Traditionally, patient safety efforts and patient engagement have focused on the acute care setting, with incidence rates of adverse events in care delivery ranging from 5-10%. Decreasing capacity for care delivery in hospital has driven an exponential rise in the demand for home care, and the need to study patient safety in home care. The release of the *Safety at Home: A Pan-Canadian Home Care Safety Study* report in 2013, findings supported the need for patient safety efforts focused in the home care sector with 10% of home care patients experiencing an adverse event (Doran et al., 2013a; Doran et al., 2013b; Blais et al., 2013). Common adverse events in home care, including falls, wound infections, and medication errors, speak to the need to address safety in home care, and to support patients and family caregivers in mitigating incidents. Furthermore 56% of adverse events in the study were found to be preventable, and that greater coordination of care and patient education and involvement could help to reduce this incidence rate. Armed with these findings one of the next steps is to develop tools to support providers and patients and families in making the delivery of home care safer for all involved. To do this we proposed the development of a tool to bridge the gap between patients and providers, and to support both groups in delivering the best care possible. This study had six objectives:

1. Identify current practices that aim to improve patient and caregiver safety and continuity of care at the interface of primary care and home care
2. Describe safety concerns for patients and caregivers during the transfer between primary care and home care for patients Describe current ways patients and caregivers are involved in bridging gaps between primary care and home care
3. Caregivers and health care providers
4. Develop a strategy to enable patients and caregivers to become empowered as knowledge brokers during these transitions of care
5. Identify strategies for health care providers to use patient safety tools that better engage patients and caregivers as knowledgeable team members
Methods

Qualitative methods and content analysis methodology were used to address the study objectives (Hsieh & Shannon, 2005; Zhang & Wildemuth, 2009). Methods included conducting: (1) an environmental scan of current tools and strategies, (2) a secondary analysis to identify implementation strategies for patient safety tools in primary care, (2) interviews and focus groups with health care providers, and (4) interviews with patients and family caregivers. Interviews and focus groups were conducted with health care providers who were identified as stakeholders in primary care and home care delivery, including (1) family physicians, (2) home care nursing staff (RNs and LPNs), (3) Nurse Practitioners (NPs), and (4) home support workers (HSWs). Participants were recruited in both the greater Halifax and Toronto areas. Both primary care and home care providers were eligible to participate if they were in their current position for at least six months and were providing direct care to patients receiving home care. Interviews were also conducted with patients and family caregivers who were receiving home care services from VON Canada for at least six months. VON nursing staff identified potential patients and family caregiver participants who met inclusion criteria. All interview and focus group data were audio recorded, transcribed verbatim and collated into one complete dataset for analysis. Data analysis of health care provider and patient and family caregiver interviews and focus groups was conducted using content analysis. Finally, a secondary analysis of a narrative review of patient safety tool implementation in primary care was completed to identify common strategies for implementation.

Key Findings

Environmental Scan/Implementation Strategies

A number of patient journal tools were identified after conducting an environmental scan. For the most part, these tools originated from health care organizations and were often paper-based and tailored to that particular setting. A number of electronic tools were also examined. However, some of these platforms require that patients be invited by health care professionals to use the portals, thereby reducing patient access to these tools. Through our review of the broader literature on the implementation of patient safety tools, we identified the following barriers to implementation: time (n=6), workflow/workload (n=4), staff acceptance/awareness (n=4), and training/usability (n=4). The most common implementation strategies included creating teams (n=11), providing training/educational workshops (n=11), and integrating into workflow/workload (n=9). While there was a paucity of patient-oriented patient safety tools (n=2) included in the articles, implementation strategies for these tools included creating reminders and utilizing mass marketing/newsletters to improve patient awareness and use.

Interview/Focus Group Analysis

Muddling Through
Participants routinely spoke to a lack of coordination in care and the issues that can arise when there is poor communication among health care providers. Underpinning the discussion of patient safety concerns was a dichotomy of what patient safety meant. While providers often saw issues stemming from continuity of care and medication safety, patients/family caregivers viewed patients’ safety concerns as much more personal.

**Assuming New Roles**

Patients and family caregivers are already playing important roles in the health care system by helping to keep and transfer knowledge between their health care providers. Both providers and patient/family caregivers saw the need for patient/family caregivers to play significant roles in the health and delivery of health care. Providers spoke to the importance of having patients/family caregivers as members of the health care team, while patients/family caregivers spoke to how they are already navigating the system by keeping a record of their health care experience and sharing this with other providers.

**Supporting Patient/Family Caregiver Involvement**

Many patients/family caregivers are already actively involved in ensuring safe transitions of care occur. However, many patients/caregivers spoke to the importance of their ability to communicate with their health care providers as being important to their involvement, as well as not treating patients as objects in their health care treatment or during decision-making as this can often lead to patients not wanting to be involved in their care. Likewise, providers spoke to the importance of involving patients/family caregivers as members of the care team from the first encounter.

**Articulating/Recording the Need to Know**

Participants spoke to the need to have a patient’s complete medical history available to ensure that transitions are safe and can share important information among their health care providers. Providers were able to articulate in detail the types of information that should be included in a patient’s medical history, whereas patients/family caregivers spoke to the need to have space to write down information that they think is important.

**Conclusions**

Study findings provide support for the engagement of patients/family caregivers during transitions between primary care and home care. Through discussion with health care providers, patients, and family caregivers, it was clear that the majority of providers value patient/family caregiver involvement in their care and see them as important keepers of health care information and bridges to continuity of care. The creation and implementation of the patient journal tool Canada-wide provides an opportunity to establish a dialogue among health
care providers and patients/family caregivers to move forward in shaping team-based and patient-centred health care in the community setting.