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3 **Patient and caregiver experience in the transition from hospital to home: results from a**  
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5 **province-wide consultation**  
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35 **Author contributions**  
36

37 TK conceived of the study. TK, DW, AL, and PO designed the study. TK, DW, and AL recruited  
38 participants and supported data collection. TK, DW, KO, CK, KD, GM, LP, and PO analyzed the  
39 data and interpreted the results. TK drafted the manuscript and all authors critically reviewed it.  
40  
41  
42  
43  
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49 **Competing interests**  
50

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## Abstract

**Background:** In many health systems, the transition from hospital to home has been identified as an area where quality of care could be improved. However, few jurisdictions have engaged broadly with patients and caregivers to understand what most affects their experience transitioning home.

**Methods:** A provincial health quality agency partnered with healthcare and community organizations to recruit patients, and caregivers of patients, who had a lived experience transitioning from hospital to home in Ontario, Canada in the last three years. We asked patients and caregivers to respond to a single focal prompt: “When leaving the hospital for home, some thing(s) that affected the experience were: \_\_\_\_\_.” Participation was by on-line survey or facilitated group discussion over ten weeks.

**Results:** 1113 individuals (44% patients, 56% caregivers) completed the on-line survey and 71 individuals participated in one of eight group discussions. Participants most commonly reported challenges with home care including timeliness, reliability, consistency, and sufficiency of publicly-funded services. Many relied on family, friends, private services or charities to fill the gap. The second most notable theme related to the discharge process including the involvement of patients and caregivers in discharge planning. The largest proportion of positive experiences related to the kindness and caring of the healthcare team in hospital.

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3 **Conclusions:** Patients and caregivers from across Ontario noted a range of issues affecting  
4 their experience transitioning from hospital to home, most notably challenges with home  
5 care. Our findings will be used to inform a provincial quality standard on the transition from  
6 hospital to home.  
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Confidential

## Introduction

Improving the transition from hospital to home is an important health system priority. Care after hospital discharge is often fragmented and patients are at high risk of experiencing adverse events (1-4). Length of stay has decreased substantially (5-7), making effective communication between hospital and community providers more important, yet this type of communication is often suboptimal (8). Support at home and in the community after discharge becomes even more critical.

Much of the research about the transition from hospital focuses on reducing readmission, partly as a strategy to reduce costs (9). But, interventions to reduce readmissions have had mixed success (10, 11) and there is debate about whether readmissions can be prevented through better care (12, 13) or whether readmission is an outcome important to patients (14). Focusing efforts on understanding and improving the patient experience may be a more fruitful approach to improving the quality of transitions from hospital to home.

Engaging patients in healthcare design can improve service delivery and quality of care (15, 16). Many organizations are trying to enhance patient engagement in direct care (17, 18) or have engaged patients to inform organizational-level interventions. For example, researchers have recently sought patient perspectives on transitions from hospital to home, although often with a specific goal of understanding how readmissions can be prevented (19-21). In contrast, few

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3 policy-makers have consulted with patients about what matters most to them and what areas  
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5 they would prioritize for health system improvement.  
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10 We describe a partnership between a provincial health quality agency and researchers to  
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12 engage patients –and caregivers of patients—with a lived experience of a transition from  
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14 hospital to home in Ontario, Canada. We sought to understand what affected the patient and  
15  
16 caregiver experience during the transition from hospital to home to inform the development of  
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18 a “quality standard” that will be used as a foundation for quality improvement.  
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## 25 **METHODS**

### 26 27 28 29 30 ***Setting and context***

31  
32 The research was conducted in partnership between Ontario’s health care quality agency,  
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34 Health Quality Ontario (HQO) and a team of researchers to inform development of a provincial  
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36 quality standard on the transition from hospital to home. Ontario is Canada’s most populous  
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38 province with an estimated population of 14.1 million people in 2017. Physician and hospital  
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40 services are fully insured under the provincial health insurance plan that covers all permanent  
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42 residents, but there are recognized gaps in coverage including gaps in dental care, home and  
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44 community care, and medications (22). Home and community care services are organized and  
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46 delivered at the level of the health region (Local Health Integration Network, LHIN).  
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### 54 ***Study design and participants***

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3 We used concept mapping methods to engage people with lived experience as a patient, or  
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5 caregiver of a patient, discharged home after being admitted overnight to an Ontario hospital  
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7 within the last three years. Concept mapping is a research method ideally suited to gather input  
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9 from a large number of stakeholders to inform planning and evaluation (23, 24). More recently,  
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11 the method has been used to engage patients in clinical quality improvement (25). Concept  
12  
13 mapping involves engaging participants in generating ideas, prioritizing emerging concepts, and  
14  
15 interpreting results (Appendix, Exhibit 1). We report on the first phase of concept mapping,  
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17 brainstorming, which engages participants in generating ideas relevant to the research question.  
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25 Our intent was to capture the perspectives of patients—and caregivers of patients—who were  
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27 discharged after an inpatient hospital admission. We defined home broadly to include  
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29 community residences, such as an apartment or house, but also includes shelters, supportive  
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31 housing, long-term care, rehabilitation and chronic care facilities. Caregivers could include  
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33 family members or unpaid friends. The protocol was reviewed and discussed with the St.  
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35 Michael’s Hospital Research Ethics Board and deemed not to constitute research under the Tri-  
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37 Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS), Article 2.5.  
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#### 45 ***Data collection***

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47 Participants were asked to provide responses to a single focal prompt: “When leaving the  
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49 hospital for home, some thing(s) that affected the experience were: \_\_\_\_\_.” Participants  
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51 could respond through an anonymous, on-line survey hosted on HQO’s website or via a  
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53 facilitated group discussion. In some cases, a team member supported patients to complete the  
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3 on-line survey. We clarified that participants could report both positive and negative  
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5 experiences and encouraged participants to be specific in their descriptions. After the focal  
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7 question, participants were asked to complete a short demographic survey. Demographics were  
8  
9 linked to individuals' responses in the on-line survey but not for group sessions. On-line survey  
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11 responses were anonymous and exported into Excel for analysis. HQO received group  
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13 responses without any participant identifiers and entered these manually into Excel without  
14  
15 any group identifiers. The survey included introductory questions to confirm respondents met  
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17 inclusion criteria; we relied on the group facilitator to communicate the inclusion criteria to  
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19 potential participants.  
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### 28 **Recruitment**

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30 We undertook both broad and targeted outreach efforts to recruit participants over  
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32 approximately 10 weeks. This included 1) communication to the public via HQO's website and  
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34 social media channels and 2) leveraging HQO's networks of patient groups and partners  
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36 including the HQO Patient Advisors Network, comprised of over 500 patients, families, and  
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38 members of the public from across the province. Patient groups and partners were provided  
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40 with material to support recruitment. HQO also provided support to patient, community, and  
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42 health care organizations interested in directly facilitating discussion through two live webinars  
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44 and a facilitation guide. On request, HQO staff facilitated brainstorming sessions for  
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46 organizations, in-person or via videoconferencing. Further details on broad outreach and  
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48 recruitment materials used can be found in Appendix A.  
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6 Targeted outreach was focused on recruiting participants from patient groups that we  
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8 hypothesized *a priori* as having unique perspectives but suspected were difficult to reach. We  
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10 formed a Community Advisory Group (CAG) composed of patients, caregivers, and  
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12 representatives from select community and health care organizations to help with targeted  
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14 engagement (Appendix, Exhibit 3). Target populations included children, long-term care  
15  
16 residents, rural residents, those living with mental health issues, newcomers, people who did  
17  
18 not speak English, individuals who were homeless or experiencing housing housing instability,  
19  
20 and members of the LGBTQ2S community. CAG members served as liaisons between the  
21  
22 project team and their communities. Members supported their community groups to engage in  
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24 live discussions or complete the on-line survey, for example, providing language interpretation  
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26 as needed.  
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### 35 ***Analysis***

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37 We aimed to identify 35 to 50 unique concepts that summarized the breadth of responses from  
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39 participant engagement. These statements would be used in future phases of concept mapping.  
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41 Eight team members, including researchers and HQO staff, used modified thematic analysis to  
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43 develop the unique statements. We used an iterative, consensus based process that included  
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45 several cycles of team members independently reviewing responses, discussing discrepancies  
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47 with another team member, and discussing emerging themes and concepts as a group. As a  
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49 final check, the principal investigator re-reviewed all responses and modified or confirmed the  
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51 final concepts.  
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### ***Patient involvement in the research***

Members of HQO's Patient and Family Advisory Council identified that improving transitions from hospital to home was a priority and were involved in the initial study design. They informed the engagement approach, participant inclusion criteria, and brainstorming question. The Community Advisory Group (CAG) for our study supported targeted participant outreach, informed study design, and helped with interpretation of results. Finally, we reviewed study design, proposed outreach, and preliminary results with the Transitions from Hospital to Home Quality Standard Advisory Committee (QSAC). The QSAC includes people with lived experience as well as clinicians, administrators, and policy experts who advise HQO on the development of the quality standard. A brief summary of preliminary results from the brainstorming were shared with all participating individuals and organizations and posted on the agency website.

### **RESULTS**

1113 individuals (44% patients, 56% caregivers) completed the on-line survey and 71 individuals participated in one of eight group discussions. Groups were facilitated in 5 different Local Health Integration Networks and were organized by a LHIN, hospitals, primary care centre, and patient advocacy organizations (Table 1). The majority of survey participants reported the patient being discharged to an apartment, house, or other community residence (86%) with 6% going to a long-term care home and 6% a rehabilitation facility or chronic care hospital. Self-reported demographics of the patient participants and patients being cared for are reported in Table 2. Figure 1 depicts the geographic distribution of survey respondents.

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6 Most responses to the focal question described negative experiences (approximately 85%). We  
7  
8 identified six themes and 52 related concepts summarized below (Figure 2 and Table 3).  
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10 Themes and example quotes were shared with people with lived experience who were on our  
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12 advisory groups or participated in this or later engagements; themes resonated as reflective of  
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14 their experience.  
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### 20 ***Home and community care and supports***

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22 The largest number of participant responses were related to home and community care, and  
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24 most of these described negative experiences. There were many comments about the poor  
25  
26 quality of home care including the timeliness and sufficiency of services and the consistency  
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28 and reliability of home care staff. Many described home care not being in place for weeks or  
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30 days once home, sometimes contrary to what they were told in hospital. Home care staff  
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32 changed frequently and often cancelled with short notice. Many described not having enough  
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34 care, particularly for bathing and dressing, and some specifically noted that patients and  
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36 caregivers needed to advocate to get the care they needed. Some mentioned challenges with  
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38 coordination and staffing when patients moved between two Local Health Integration  
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40 Networks.  
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50 Participants discussed challenges accessing a range of community supports. Participants  
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52 specifically discussed inadequate outpatient mental health support. Experiences with home  
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54 palliative care were mixed. Participants expressed that there was often a long wait for publicly  
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3 funded physiotherapy and rehabilitation supports and the publicly-funded care eventually  
4 provided was insufficient to meet their need. Participants also noted that housecleaning,  
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6 laundry and other support services were not covered by the home care agency and that  
7  
8 arranging these was challenging. Many described the important role their family and friends  
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10 played in supporting their recovery at home while others described how difficulties in living  
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12 alone after discharge with no family support. Some commented on the minimal respite services  
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14 for caregivers.  
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### 22 ***Medical follow-up after discharge***

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25 Participants reported both positive and negative experiences accessing their family doctor  
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27 and/or specialist after discharge in a timely way. Some appreciated having a trusted family  
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29 doctor while others noted they had no family doctor and were not given help to find one. Some  
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31 participants left hospital with specialist appointments clearly arranged while others expressed  
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33 frustration at having to arrange these themselves sometimes without clear direction.  
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38 Participants noted whether their family physician or living facility had information about the  
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40 admission. Participants also recounted challenges getting to follow-up appointments because  
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42 of challenges with mobility, distance, and related transportation/cost, with some wishing their  
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44 doctor made house calls.  
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### 49 ***Discharge process***

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52 Several participants described negative experiences related to the timing of discharge. Many  
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54 described feeling that they or their loved one was discharged too early, before they had  
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3 recovered, with some thinking this contributed to a subsequent emergency department visit or  
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5 readmission. Some described the discharge process as rushed, in some cases noting that  
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7 someone else was waiting for the bed. At the same time, others said there were unnecessary  
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9 delays in the expected discharge due to paperwork. Experiences relating to communication and  
10  
11 shared-decision making were mixed. Some described being involved as a patient or caregiver in  
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13 the discharge process while others, particularly caregivers, discussed being left out in planning  
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15 although they would be caring for the patient at home. Participants described not being given  
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17 enough notice about the discharge time and in some cases this resulting in logistical challenges  
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19 for caregivers. Participants specifically commented on not being able to see the doctor at the  
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21 time of discharge. Some also expressed challenges with transportation home.  
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### 30 ***Patient education***

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32 There were mixed experiences with receiving a written discharge summary that included  
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34 instructions. Many mentioned they were uncertain who to call if there was a problem after  
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36 discharge although some participants were given the number of a doctor or other staff. Some  
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38 participants noted receiving clear information about self-care and recovery once home while  
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40 others described not having information on how to care for themselves or use new equipment.  
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### 47 ***Medications***

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49 Some participants had medication effects, side effects, and schedules explained clearly to them  
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51 before discharge while others did not. Several described challenges managing complex new  
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53 medication regimens at home and not having sufficient instruction or support to do so. Some  
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3 participants mentioned the high out-of-pocket costs for medication. A few noted difficulty  
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5 filling their prescription in a timely way after discharge.  
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### 10 ***Kind and caring of healthcare team in hospital***

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12 Many participants recounted how doctors, nurses, and other hospital staff were kind and caring.  
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14 Others described staff being rude or inattentive. Many noted whether their doctor or nurse  
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16 took time to listen and answer their questions. A few described not having accommodations for  
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18 people with specific physical health needs (e.g. visual or hearing impairment) or not having  
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20 language or cultural needs met. For many, how they were treated in hospital directly impacted  
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22 their recovery at home.  
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## 30 **DISCUSSION**

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35 We consulted with a diverse group of patients and caregivers, across a vast geographic area,  
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37 who had a lived experience of transitioning from hospital to home. We used several different  
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39 recruitment strategies including partnerships with health care and community organizations  
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41 who were supported to facilitate engagement sessions. Patients and caregivers highlighted  
42  
43 several areas that affected their experience in the transition from hospital to home. The most  
44  
45 commonly reported challenges related to home and community care with many participants  
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47 reporting that publicly-funded home care services were not timely, sufficient, reliable, or  
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49 consistent. Many relied on family, friends, private services or charities to fill the gap. The  
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51 second most notable theme related to the discharge process including timing, communication,  
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3 and involvement of patients and caregivers in the planning process. The largest proportion of  
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5 positive experiences related to kindness and caring of individual physicians, nurses, and hospital  
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7 staff.  
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13 The gaps we found in the availability and quality of home care echo concerns raised in the final  
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15 report from Ontario's Expert Group on Home and Community care published in 2015 (26). In  
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17 2017, home care delivery in Ontario underwent significant reforms, with responsibility  
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19 transferring from regional agencies to the Local Health Integration Network itself (27). A year  
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21 after these reforms, patients and caregivers in our study continued to report numerous  
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23 challenges with home care services. Implementing more recent recommendations to ensure a  
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25 consistent and transparent level of service may address some of these concerns (28).  
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32 Our findings build on a few other studies that highlight how home and community supports  
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34 affect patient and caregiver experience and hospital readmissions. Other Canadian studies,  
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36 done at a single site (21) or region (29), have described patient challenges with managing at  
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38 home (29) and noted limited access to home care services as a potential reason for avoidable  
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40 readmission (21). Post-discharge interventions to reduce rehospitalization have historically  
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42 focused on enhancing medical supports (10), but a recent review noted that more successful  
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44 interventions enhance patients' capacity for self-care (30). A large qualitative study conducted  
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46 at multiple academic medical centres in the US identified several patient-centred readmissions  
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48 factors and concluded that future transitions interventions should focus on enhancing patient  
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50 self-management and provision of clinical and social support after discharge (19).  
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6 Our findings underscore the importance of shared decision-making and clear communication  
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8 during the transition from hospital to home. Patients and their caregivers wanted to be  
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10 involved in discharge planning, have their questions answered, understand their medications,  
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12 and know how to perform self-care once home. Lack of patient and caregiver involvement in  
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14 discharge planning is a known gap (31-33). Other studies have found patients attribute  
15  
16 readmissions to being discharged too early and not having their concerns addressed (20, 34).  
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18 Informational continuity between hospital, patients and families, and outpatient settings is  
19  
20 another known challenge (8, 35, 36) that was echoed in our findings and is the subject of  
21  
22 interventions under evaluation (37). Like us, others have also noted how kindness and caring by  
23  
24 care team in hospital can impact the transition from hospital to home (38).  
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32 Our study highlights the limits of Ontario's public health insurance and how these conflict with  
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34 patient and caregiver expectations. Policy experts have long noted that Canada has deep public  
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36 coverage for a narrow basket of services, specifically hospital, diagnostic, and physician services  
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38 (39). Our study revealed challenges even within this narrow basket including patients with no  
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40 family doctor and a pressure on hospital beds leading to people feeling pushed out. Bigger  
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42 challenges related to out-of-pocket costs for medications, equipment, transportation, and  
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44 home support services such as meal preparation and house cleaning. People noted limited  
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46 coverage for services like physiotherapy and home care but in these circumstances, challenges  
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48 could be mitigated with paying privately for services.  
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3 Our study has both strengths and limitations. The research was conducted in partnership with a  
4 health care quality agency and was designed to influence priority-setting. Patients were directly  
5 involved in study design, execution, and validation of results. The health care quality agency  
6 took a unique approach to recruiting a broad cross-section of respondents. Participants came  
7 from varied geographic, medical, and social backgrounds but we had limited success recruiting  
8 newcomers and people who did not speak English or French. Our initiative was not specifically  
9 designed to understand or address the unique needs of Ontario's Indigenous communities;  
10 Indigenous health experts we spoke with advised that the provincial quality agency partner  
11 with Indigenous communities separately to focus on the impact of transitions in care on  
12 Indigenous health. The unique concept mapping methodology made it feasible for us to gather  
13 open-ended responses from a large number of participants but also meant our responses were  
14 not as rich as qualitative data from semi-structured interviews or focus groups.  
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35 In summary, our consultation with over 1000 patients and caregivers from diverse communities  
36 across the province highlighted 6 key areas affecting their experience of transition from  
37 hospital to home: home and community care, the discharge process, medical follow-up after  
38 discharge, medications, patient and caregiver education, and the kindness and caring of the  
39 healthcare team in hospital. Most notable were challenges with publicly-funded home care  
40 services being timely, sufficient, reliable, and consistent. The second phase of our concept  
41 mapping work will engage patients and caregivers to prioritize areas for health system  
42 improvement and inform a provincial quality standard on transitions from hospital to home.  
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## References

1. Coleman EA, Mahoney E, Parry C. Assessing the quality of preparation for posthospital care from the patient's perspective: the care transitions measure. *Medical care*. 2005;43(3):246-55.
2. Forster AJ, Murff HJ, Peterson JF, Gandhi TK, Bates DW. The incidence and severity of adverse events affecting patients after discharge from the hospital. *Annals of internal medicine*. 2003;138(3):161-7.
3. Institute of Medicine (US) Committee on Quality of Health Care in America. *Crossing the quality chasm: a new health system for the 21st century*. Washington DC: National Academies Press; 2001.
4. Krumholz HM. Post-hospital syndrome—an acquired, transient condition of generalized risk. *New England Journal of Medicine*. 2013;368(2):100-2.
5. Bueno H, Ross JS, Wang Y, Chen J, Vidán MT, Normand S-LT, et al. Trends in length of stay and short-term outcomes among Medicare patients hospitalized for heart failure, 1993-2006. *Jama*. 2010;303(21):2141-7.
6. Kalra AD, Fisher RS, Axelrod P. Decreased length of stay and cumulative hospitalized days despite increased patient admissions and readmissions in an area of urban poverty. *Journal of general internal medicine*. 2010;25(9):930-5.
7. Verma AA, Guo Y, Kwan JL, Lapointe-Shaw L, Rawal S, Tang T, et al. Patient characteristics, resource use and outcomes associated with general internal medicine hospital care: the General Medicine Inpatient Initiative (GEMINI) retrospective cohort study. *CMAJ open*. 2017;5(4):E842.
8. Kripalani S, LeFevre F, Phillips CO, Williams MV, Basaviah P, Baker DW. Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care. *Jama*. 2007;297(8):831-41.
9. Health Policy Brief: Care Transitions. *Health Affairs*; September 13, 2012.

- 1  
2  
3 10. Hansen LO, Young RS, Hinami K, Leung A, Williams MV. Interventions to reduce 30-day  
4 rehospitalization: a systematic review. *Annals of internal medicine*. 2011;155(8):520-8.  
5  
6
- 7  
8 11. Naylor MD, Aiken LH, Kurtzman ET, Olds DM, Hirschman KB. The importance of  
9 transitional care in achieving health reform. *Health Affairs*. 2011;30(4):746-54.  
10
- 11  
12 12. Joynt KE, Jha AK. Thirty-day readmissions—truth and consequences. *New England*  
13 *Journal of Medicine*. 2012;366(15):1366-9.  
14  
15
- 16  
17 13. Krumholz HM, Wang K, Lin Z, Dharmarajan K, Horwitz LI, Ross JS, et al. Hospital-  
18 Readmission Risk—Isolating Hospital Effects from Patient Effects. *New England Journal of*  
19 *Medicine*. 2017;377(11):1055-64.  
20  
21
- 22  
23 14. Soong C, Bell C. Identifying preventable readmissions: an achievable goal or waiting for  
24 Godot? *BMJ quality & safety*. 2015:bmjqs-2015-004484.  
25  
26
- 27  
28 15. Bombard Y, Baker GR, Orlando E, Fancott C, Bhatia P, Casalino S, et al. Engaging patients  
29 to improve quality of care: a systematic review. *Implementation Science*. 2018;13(1):98.  
30
- 31  
32 16. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family  
33 engagement: a framework for understanding the elements and developing interventions and  
34 policies. *Health Affairs*. 2013;32(2):223-31.  
35  
36
- 37  
38 17. Backman C, Chartrand J, Dingwall O, Shea B. Effectiveness of person-and family-  
39 centered care transition interventions: a systematic review protocol. *Systematic reviews*.  
40 2017;6(1):158.  
41
- 42  
43 18. Commission J. Transitions of care: Engaging patients and families. *Quick Safety*.  
44 2015;18:1-3.  
45  
46
- 47  
48 19. Greysen SR, Harrison JD, Kripalani S, Vasilevskis E, Robinson E, Metlay J, et al.  
49 Understanding patient-centred readmission factors: a multi-site, mixed-methods study. *BMJ*  
50 *Qual Saf*. 2017;26(1):33-41.  
51
- 52  
53 20. Howard-Anderson J, Lonowski S, Vangala S, Tseng C-h, Busuttil A, Afsar-manesh N.  
54 Readmissions in the era of patient engagement. *JAMA internal medicine*. 2014;174(11):1870-2.  
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21. Jeffs L, Dhalla I, Cardoso R, Bell CM. The perspectives of patients, family members and healthcare professionals on readmissions: preventable or inevitable? *Journal of interprofessional care*. 2014;28(6):507-12.
  22. Naylor CD. Health care in Canada: incrementalism under fiscal duress. *Health Affairs*. 1999;18(3):9-26.
  23. Trochim WM. An introduction to concept mapping for planning and evaluation. *Evaluation and program planning*. 1989;12(1):1-16.
  24. Velonis AJ, Molnar A, Lee-Foon N, Rahim A, Boushel M, O'Campo P. "One program that could improve health in this neighbourhood is \_?" using concept mapping to engage communities as part of a health and human services needs assessment. *BMC health services research*. 2018;18(1):150.
  25. LaNoue M, Mills G, Cunningham A, Sharbaugh A. Concept mapping as a method to engage patients in clinical quality improvement. *The Annals of Family Medicine*. 2016;14(4):370-6.
  26. Bringing care home: Report of the Expert Group on Home & Community Care March 2015 [Available from: [http://health.gov.on.ca/en/public/programs/lhin/docs/hcc\\_report.pdf](http://health.gov.on.ca/en/public/programs/lhin/docs/hcc_report.pdf)].
  27. Ministry of Health and Long-Term Care. Update: Health System Integration April 7, 2017 [Available from: [http://health.gov.on.ca/en/news/bulletin/2017/hb\\_20170127\\_10.aspx](http://health.gov.on.ca/en/news/bulletin/2017/hb_20170127_10.aspx)].
  28. Thriving at home: a levels of care framework to improve the quality and consistency of home and community care for Ontarians June 2017 [Available from: [http://health.gov.on.ca/en/public/programs/lhin/docs/loc\\_report\\_2017.pdf](http://health.gov.on.ca/en/public/programs/lhin/docs/loc_report_2017.pdf)].
  29. Neiterman E, Wodchis WP, Bourgeault IL. Experiences of older adults in transition from hospital to community. *Canadian Journal on Aging/La Revue canadienne du vieillissement*. 2015;34(1):90-9.
  30. Leppin AL, Gionfriddo MR, Kessler M, Brito JP, Mair FS, Gallacher K, et al. Preventing 30-day hospital readmissions: a systematic review and meta-analysis of randomized trials. *JAMA internal medicine*. 2014;174(7):1095-107.

- 1  
2  
3 31. Dyrstad DN, Testad I, Aase K, Storm M. A review of the literature on patient  
4 participation in transitions of the elderly. *Cognition, Technology & Work*. 2015;17(1):15-34.  
5  
6  
7  
8 32. Hahn-Goldberg S, Jeffs L, Troup A, Kubba R, Okrainec K. "We are doing it together"; The  
9 integral role of caregivers in a patients' transition home from the medicine unit. *PloS one*.  
10 2018;13(5):e0197831.  
11  
12  
13 33. Jeffs L, Saragosa M, Law M, Kuluski K, Espin S, Merkley J, et al. Elucidating the  
14 information exchange during interfacility care transitions: Insights from a Qualitative Study.  
15 *BMJ open*. 2017;7(7):e015400.  
16  
17  
18  
19 34. Kangovi S, Grande D, Meehan P, Mitra N, Shannon R, Long JA. Perceptions of readmitted  
20 patients on the transition from hospital to home. *Journal of hospital medicine*. 2012;7(9):709-  
21 12.  
22  
23  
24 35. Dhalla IA, O'Brien T, Ko F, Laupacis A. Toward safer transitions: how can we reduce post-  
25 discharge adverse events. *Healthc Q*. 2012;15:63-7.  
26  
27  
28  
29 36. Hesselink G, Schoonhoven L, Barach P, Spijker A, Gademan P, Kalkman C, et al.  
30 Improving patient handovers from hospital to primary care: a systematic review. *Annals of*  
31 *internal medicine*. 2012;157(6):417-28.  
32  
33  
34 37. Hahn-Goldberg S, Okrainec K, Damba C, Huynh T, Lau D, Maxwell J, et al. Implementing  
35 patient oriented discharge summaries (PODS): a multi-site pilot across early adopter hospitals.  
36 *Healthcare Quarterly*. 2016;19(1).  
37  
38  
39  
40 38. Mitchell SE, Laurens V, Weigel GM, Hirschman KB, Scott AM, Nguyen HQ, et al. Care  
41 Transitions From Patient and Caregiver Perspectives. *The Annals of Family Medicine*.  
42 2018;16(3):225-31.  
43  
44  
45  
46 39. Martin D, Miller AP, Quesnel-Vallée A, Caron NR, Vissandjée B, Marchildon GP. Canada's  
47 universal health-care system: achieving its potential. *The Lancet*. 2018.  
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**Table 1. List of facilitated group sessions conducted across Ontario**

<b>Name of organization</b>	<b>Geographic location of session</b>	<b>Facilitation</b>	<b>Number of attendees</b>
<b>Country Roads Community Health Centre</b>	<b>Portland, Ontario</b>	<b>Facilitated by member of Community Advisory Group</b>	<b>8</b>
<b>Waterloo Wellington LHIN PFAC</b>	<b>Waterloo, ON</b>	<b>Facilitated by HQO Staff</b>	<b>20</b>
<b>North East LHIN PFAC</b>	<b>North Bay, ON</b>	<b>Facilitated by HQO staff through OTN</b>	<b>16</b>
<b>Ottawa Cancer Foundation</b>	<b>Ottawa, ON</b>	<b>Facilitated by local member</b>	<b>5</b>
<b>One More Thing</b>	<b>Online (Facebook group)</b>	<b>Facilitated by HQO Staff</b>	<b>6</b>
<b>Powerhouse Project</b>	<b>St. Catherine's Ontario</b>	<b>Facilitated by local member</b>	<b>5</b>
<b>St Michael's Hospital PFAC</b>	<b>Toronto, Ontario</b>	<b>Facilitated by hospital staff member</b>	<b>5</b>
<b>Champlain LHIN</b>	<b>Ottawa, ON</b>	<b>Facilitated by member of HQO Patient and Family Advisors Committee</b>	<b>6</b>

**Table 1.** Self-reported demographics of respondents who completed the optional demographic portion of the survey (954 of 1113 respondents). Caregiver participants reported demographics of the person they were caring for

	On-line survey	
	n	%
<b>Patient age, (n = 611)</b>		
0-5	10	1.6
6-18	24	3.9
19-25	14	2.3
26-49	99	16.2
50-64	139	22.7
65-79	186	30.4
80+	139	22.7
<b>Patient gender (n = 617)</b>		
Female	360	58.3
Male	250	40.5
Other*	7	1.1
<b>Discharge destination (n = 925**)</b>		
Apartment, house, other place of residence	809	85.8
Nursing or long-term care home	55	5.8
Short-term rehab facility or chronic care hospital	55	5.8
Other	24	2.5
<b>Other demographics (n = 601)</b>		
Patient lives in a community that is parallel to or north of Sudbury	59	9.8
Patient lives in a community that has 30,000 or fewer residents	150	25.0
Patient would take more than 60 minutes by car to get to the hospital where they were last admitted	85	14.1
Patient has been admitted to hospital more than once in the last year	201	33.4
Patient does not have a family doctor or nurse practitioner to attend to their regular medical needs	32	5.3
Patient does not have family and/or friends who can help when needed	33	5.5
Patient lives alone	151	25.1
Patient sometimes has difficulty making ends meet at the end of the month	78	13.0



Patient does not have a college diploma or university degree	172	28.6
Patient came to Canada as an immigrant within the last 10 years	12	2.0
Patient came to Canada as a refugee within the last 10 years	1	0.2
Patient identifies as Indigenous	13	2.2
Patient is most comfortable speaking a language other than English with their health care provider	46	7.7
Patient identifies as a member of the LGBTQ2S community	17	2.8
Patient has a physical, sensory, or developmental disability	125	20.8
Patient admitted to hospital because of a mental health condition	35	5.8
Patient has dementia	55	9.2

\*Some respondents reported "other" because they were responding based on the experiences of more than one person (e.g. two different patients)

\*\*925 unique respondents indicated discharge destinations. Caregivers, who were also patients, responded with more than one location to indicate the discharge location for themselves and the patient, if they were different.

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**Table 2. Thematic summary of responses from patients and caregivers to the focal question “when leaving hospital to home, some things that affected the experience were \_\_\_\_\_”**

Unique concept	Respondent quotes
<b>Theme 1: Home and community care and supports</b>	
Home care support being in place when arriving home from hospital	<p>“After moving home it took over 3 weeks before we were linked to any home support services”</p> <p>“My father received home care after a week not 24 hours as indicated by hospital discharge staff”</p>
Consistency of home care staff	<p>“No consistency of care...too many different psw's, at one point my mother with dementia had 8 different psw's in one week”</p> <p>“My mother didn't have enough home care support that was consistent she had dementia and she had 14 different workers in seven days”</p>
Reliability of home care staff	<p>“Several days after coming home case workers started to arrive to access the my husband to determine what I will be needing for home care help. Finally got some help coming to house but not enough hrs..as well as numerous NO shows as well as No phone calls to say they are not coming. Just because my husband cannot talk does not mean that his caregiver cannot talk to him”</p> <p>“Three times a PSW never showed up to help , and no call was sent to let us know they could not make it”</p>
Sufficiency of publicly-funded home care	<p>“We had to offset home care with private and family support”</p> <p>“Limited hours offered by CCAC to support a failing 90 year old woman in her own apartment.”</p> <p>“After leaving the hospital, my loved one did not have enough care for both their morning (wake/ bathe/ dress) and evening (dinner preparation, cleanup, undress/hygiene/bed clothes) routine.”</p>
Having to advocate to get enough home care	<p>“Had little to no help from ccac coordinators. Had to 'fight' to get help”</p> <p>“Patients who cannot express themselves well due to cognitive or other barriers are roughly treated and if there is no advocate, it doesn't get addressed”</p> <p>“It took a lot of work to access the home care services my loved one required and multiple phone calls”</p>
Consistent coordination and/or level of home care between communities	<p>“There was a gap with CCAC because there were two LINs involved but once the communication was done we were contacted”</p> <p>“Home care is based on geography. when my relative moved from home to respite care back to her apartment, her care coordinator kept changing”</p>
Consideration of home safety and/or accessibility during discharge planning	<p>“There was no consideration whether the home environment was safe to go back to. It wasn't but the hospital didn't care. They said it wasn't their problem.”</p> <p>“When I took my brother home his apartment was not accessible and I had to make all the necessary changes to help in”</p>
Medically-necessary equipment being in place at home when discharged	<p>“I was not given enough time to arrange how to get my necessary equipment”</p> <p>“CCAC did not have the equipment ready for us when we arrived home. It took 2 days to receive a crucial piece of equipment.”</p>

1 2 3 4 5 6 7	Cost of medically-necessary equipment	<p>“All the needed equipment, canes, walkers, raised toilet seats and bath seats were bought by the patient's family.”</p> <p>“Beds, support equipment free for 28 days. Is it expected that a person is back to normal in 28 days???? ADP does not cover all the equipment”</p>
8 9 10	Availability of community mental health supports	<p>“Mental health support was not considered or offered”</p> <p>“A suicidal child was discharged home, community agency connection but 1 year wait time for intensive therapy”</p>
11 12 13	Availability of community palliative care supports	<p>“Lack of community resources for palliative patient”</p> <p>“Palliative care doc was accessible and responsive. He came late at night, explained everything. He answered texts directly and quickly”</p>
14 15 16 17 18	Timeliness of publicly-funded community-based physiotherapy, occupational therapy and/or other rehabilitation supports	<p>“Community therapy services were only available on a fee for services basis while waiting for 10 weeks for an OHIP funded program”</p> <p>“On returning home, 6 weeks after my hospital discharge I still had to wait 3 weeks for CCAC OT &amp; PT”</p>
19 20 21 22 23	Sufficiency of publicly-funded community-based physiotherapy, occupational therapy and/or other rehabilitation supports	<p>“Need PT only once per week is not enough for someone who could perhaps learn to be mobile and more self-sufficient. Again we are lucky to afford our own support, but this shouldn't be necessary.”</p> <p>“Only rehab was 5 1 hour visits paid for be OHIP in 2nd month after surgery”</p>
24 25 26	Availability of support services such as housecleaning, laundry, and/or meals	<p>“for people who need more supportive care are given restricted - only 'bathing' or extremely minor assistance. Of no real help to keep people housed independently, their home is left unclean and no help with food I needed someone to help with some cleaning”</p>
27 28 29 30	Arranging support services such as housecleaning, laundry, and/or meals	<p>“the need to figure out where to find support services for services beyond what CCAC would provide e.g.. house cleaning; laundry for someone with very limited income”</p> <p>“Community services were not in place and support such as: CCAC, Wheel trans, patients are expected to organize”</p>
31 32 33 34 35	Reliance on family and friends to provide care after discharge	<p>“No one is available to get my Mom to bed at night so we have to do it. We go from 6:30 to 10 or 11 at night and get up for work at 5:30 a.m.”</p> <p>“After leaving hospital, my family member didn't have enough home care support to help them bathe and dress, so my spouse had to take time off work to assist his father”</p>
36 37 38	Living alone without family and friend support	<p>“I live alone and had no support with meal preparation”</p> <p>“Great concern for people sent home without family to advocate for and help them”</p> <p>“I lived alone and was scared to be by myself”</p>
39 40 41	Assumptions about family and friend support during discharge planning	<p>“Disheartening. It is unfair to assume family members could just drop everything to be home with their loved ones, especially after long unexpected illness”</p>

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	“no questions about home environment - it seemed to be assumed I'd be there 24/7. (I was)”
Respite for caregivers	“My dad and mom moved into my sister's house as qualified help was not available on a consistent basis (not even private care). My sister received daily calls of no care available. In three months she has received respite twice so she could buy groceries.” “Respite care has been meager. It's a struggle to get one day away from the house to be able to travel out of town for shopping, business, etc.”
<b>Theme 2: Medical follow-up after discharge</b>	
Timely follow-up with family doctor, nurse practitioner, and/or specialists	“My family doctor, who is a member of [primary care organization], called to arrange a follow up appointment” “My family doctor knew my daughter was admitted to hospital because I phoned to let her know. I knew that if we ran into trouble after discharge, our doctor would fit us in to be seen” “Told to call his office (which was stated on a form they gave me) in 6 weeks. When I called the nurse laughed and said he hadn't seen patients that he had operated on for more than 6 months prior to my operation. I kept calling and it took over a year to see him”
Having a trusted family physician	“No attempt to connect me with a family physician was made by [hospital]” “I had a trusted family doctor that I could consult if I was uncertain about anything”
Having specialist follow-up arranged or being able to arrange it	“Discharge summary listed two critical follow-ups needed within 1 week: cardiology and nephrology clinics – NEITHER appointment was made when we left hospital” “Clear, concise written instructions were given for follow-up appointments with various Doctors were given., so that it was a handy guide”
Family physician receives complete and timely information about hospitalization	“I wish that my primary care physician had received notification about my hospitalization. When I phoned about constipation issues and the bed sore they had no idea what had happened or care that had been provided in the hospital and would have liked to have been more proactive on these issues” “Family dr received nothing from hospital to allow a seamless transition home”
Information transfer between facilities	“Lack of transitional support for journey from home to hospital to retirement home which was a bridge to LTC. Information transfer was lacking at each stage so needs were not able to be met initially at each stage. A case manager seemed to be lacking” “Detailed notes and test results were sent to the rehab hospital”
Challenges getting to and from appointments once discharged	“Routine visits to clinic were very difficult post-stroke, but were not offered through telemedicine” “having to follow up with a doctor whose office was out of town and I do not drive” “The hospital parking for follow up was poor. The garage with elevators and easy access is reserved for staff. It's not just the cost of parking – it's also the ease of use”
Having a doctor who does home visits	“Family Doc doesn't make house calls, so totally lost contact with a doctor. How can a person in bed with discomfort in a wheelchair get an assessment from a doctor. Totally a huge logistical challenge and exhausting

	and painful for patient to use wheelchair taxi to go to physician office”
<b>Theme 3: Discharge process</b>	
Being discharged too early	<p>“None of us felt he was ready to leave the hospital but felt he was being pushed out to free up a bed”</p> <p>“Discharged too early. I felt I hadn’t healed and was afraid of re-injuring”</p> <p>“Reason for mental health crisis had not been resolved, although the person was no longer in an suicidal state, they still had suicidal ideation”</p>
Discharge being delayed	<p>“Long wait to be discharged”</p> <p>“On the discharge day (Saturday), we waited several hours for the doctor to sign the discharge papers. By the time she did, the pharmacy was closed, so they had to give us enough for 24 hours, and we had to make another trip (20 minutes each way) the next day to fill the prescription”</p>
Discharge process being rushed	<p>“Felt a little rushed to leave room as someone was waiting for bed but staff made sure I understood my discharge papers”</p> <p>“I had almost no preparation time to leave, it was like “get out of bed, you’re going home”</p> <p>“rushed process, nurse run ragged and info passed on in 3 minutes”</p>
Receiving clear and consistent communication about health status in preparation for going home	<p>“I was nervous as they still didn’t know what caused the horrible leg infection he had”</p> <p>“the doctors were not honest about her prognosis – they glazed over it and the patient did not fully understand what was happening”</p>
Being involved in discharge planning	<p>“Discharge planning was well done. My mother was involved in her discharge planning, as were her caregivers”</p> <p>“Family/caregiver was not involved in persons care plan or discharge plan, though expected to support outside hospital and provide housing during crisis”</p>
Having short notice of discharge time	<p>“I was notified that same day that my spouse was being discharged and had to arrange to leave work and pick him up”</p> <p>“No warning was given that she was being discharged one day it was a week away the next day it changed to that day”</p>
Seeing the doctor at time of discharge	<p>“Did not see the dr at time of discharge leaving many many unknowns and adding to fear”</p> <p>“None of the doctors took the time to tell me anything on discharge. The only doctor who did explain anything was not present the day of discharge. He had explained a further test I needed before discharge. I never got the test.”</p>
Having challenges with transportation home	<p>“The person I care for was unable to get into the car and was unable to afford to transfer back “home” in an ambulance”</p> <p>“My caregiver wasn’t given a wheelchair to put me in to take me to the car. She had to go down to the lobby to get one and come all the way back up.”</p> <p>“I did not have anyone to pick me up or any money to get home. So I had to walk, it was a five mile walk”</p> <p>“Had to drive over 200 km to my home. Travel grant doesn't cover the full cost of an overnight stay. Very</p>

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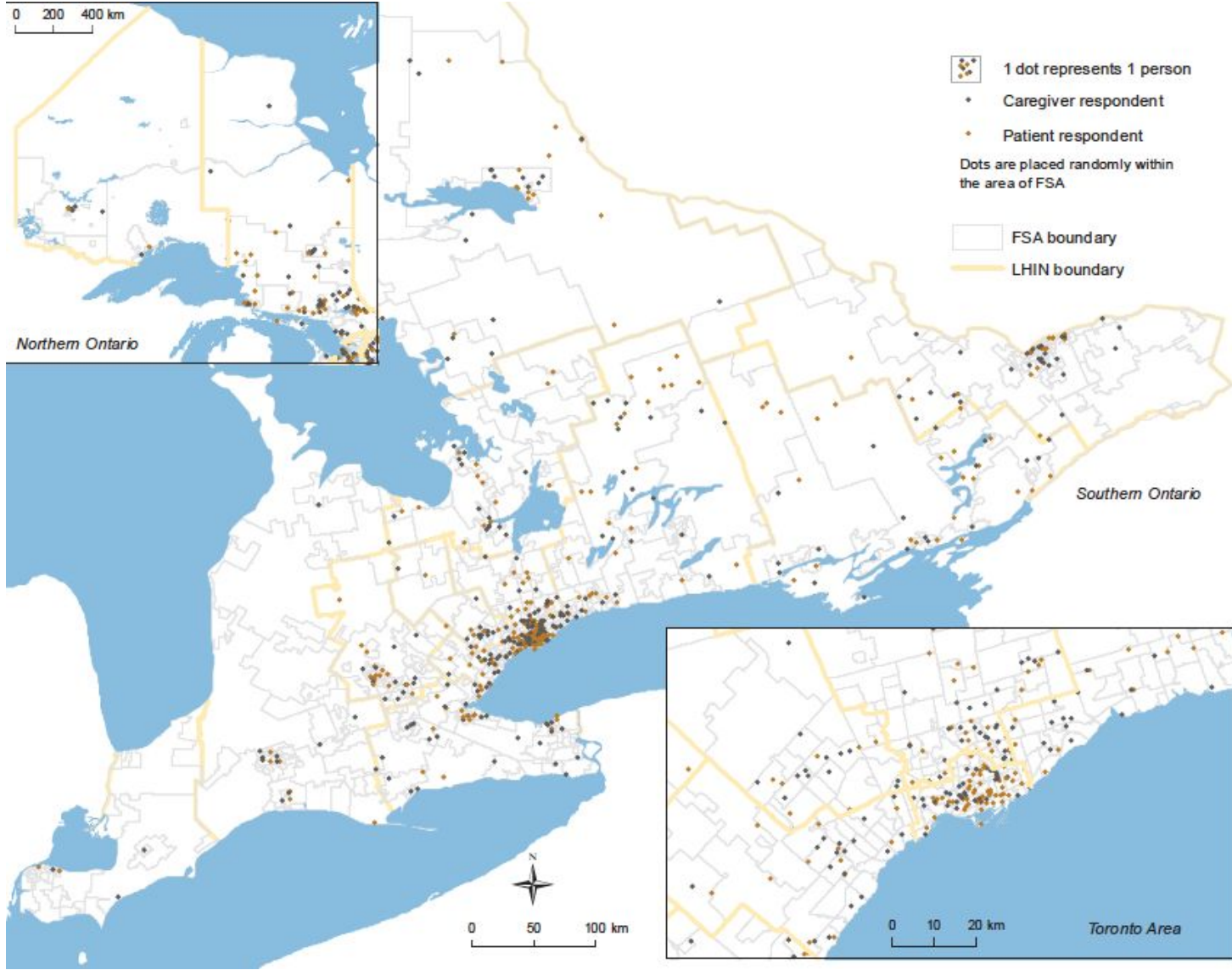
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<b>Theme 4: Patient education</b>	
Receiving a written summary of the hospital admission at discharge	“After getting a hospital discharge, my father received no discharge instructions” “We were provided with a detailed discharge summary that included ‘next steps’, including follow ups, medications, and signs to look for re: common complications”
Having contact number(s) of someone to call if there is a problem once home	“There was no one I could call once discharged home for the first time to talk about my symptoms which might have sent me to the ED earlier thereby avoiding some undue suffering and optimizing my recovery process” “The doctor made sure I had his contact information so that if I experienced any complications or had concerns I could call him. I did have complications from a procedure he performed and being able to contact him helped me get readmitted to the hospital and treated faster”
Being prepared by hospital staff to manage symptoms and/or care at home	“There was a good booklet provided about recovery from cardiac surgery but it would have been great if the most important details were highlighted or individually detailed” “paucity of information on how to manage care at home (what to watch for in changes, improvement or deterioration)” “There was little discussion or instructions with family or LTC about how to care differently for our loved one upon return to LTC”
<b>Theme 5: Medications</b>	
Medication effects, side effects, or schedule explained clearly before leaving hospital	“My medication schedule was explained clearly to me before I left the hospital” “The person I care for did not understand how to take the medications and no one spent the time explaining”
No training and/or support on how to manage complex medication needs once home	“Managing the meds was extremely complex when your loved one is dying - more nursing care is required at home” “Having to inject medication for yourself is a big responsibility.”
Errors about medications on the discharge summary and/or prescription	“After one discharge, the medications on the discharge summary were not correct” “When I left I was given two inhalers (one ventalin and another bronchial powder inhaler). I was a bit surprised but only noticed a month later that they were both addressed to someone else.”
Having challenges filling a prescription soon after discharge	“not able to get discharge prescriptions prior to discharge, no offer to fax to drug store so by time I got him home and the analgesic picked up he was at least 2 hours late in getting!” “My family member's medications were not readily available at any pharmacy and she was sent home on a Saturday evening so hospital outpatient pharmacy closed.”
There is no plan for pain management once discharged	“Alternate treatments other than pain meds not considered or offered” “before leaving - a plan for pain management was not adequately addressed, dosage ranges to accommodate movement at home vs hospital”
Pain medications prescribed at	“My 11 year old was prescribed morphine for pain. After the first night at home she had a reaction so I switched

1 2 3 4 5 6	discharge are too strong or not strong enough	to Childrens Advil and she was fine. Why an opioid for a child?" "My father has been on prescription pain medications for too long. Need support getting him off these druges given to him by doctors"
7 8 9	Having to pay out-of-pocket for medications and medical supplies	"Cost of medicine or supplies out of pocket are high "The staff on the floor 'forgot' to return patient's Rx medications that we brought in to use -- because they were not on their formulary... necessitating extra expense/money to replace these."
10	<b>Theme 6: Kindness and caring of healthcare team in hospital</b>	
11 12 13 14 15 16	Hospital staff being kind and caring	"Once home, I recalled each day the words of encouragement and advise I had received while in the hospital, to my benefit" "Some of the hospital physios were just going through the motions – did not seem to care" "The doctor was amazing. Caring and kind and treated my 92 year old Dad the same way he would treat a 25 year old"
17 18 19	Health care team in hospital respecting and listening to caregivers	"The nurses, doctors and specialists taking our concerns seriously since we know our child best" "Not enough weight was given to the concerns of the relatives of the patient. They weren't always included and the patient being 85 did not advocate for the support needed"
20 21 22 23	Doctors and nurses taking the time to listen and answer questions in hospital	"Doctor took time to answer questions and ensure I was equipped to manage on my own" "The doctor and nurses did not answer all my questions and were not helpful with things like what to expect post-surgery"
24 25	Physiotherapy/occupational therapy support being provided in hospital	"No physio, OT or discharge planning on the weekends" "Physio made sure I could safely move enough before I was discharged"
26 27 28	Speech, hearing, visual, and/or mobility needs being accommodated in hospital	"We felt that the staff did not make sure that their message was heard and understood by our parents. Their lack of hearing was not recognized by the hospital staff" "There is no accommodation for someone with Aphasia, which is contrary to the AODA"
29 30 31 32	Dementia being accommodated and managed appropriately in hospital	"Every new nurse working with him had no idea he was demented and little notion how to accommodate care. Care plan was inadequate or not read" "Nurses at hospital had parent in hospital for over 1 week and did not recognize there were cognitive deficits"
33 34 35	Providing culturally safe and appropriate care for Indigenous people in hospital	"...this was a First Nations patient and there are unique needs to consider with the history of FN distrust for the healthcare system"
36 37 38	Being able to communicate in preferred language in hospital	"When I was translating for my data, the doctor was losing patience with me as I tried to find the right words" "No translations services were provided for patient who did not speak English"



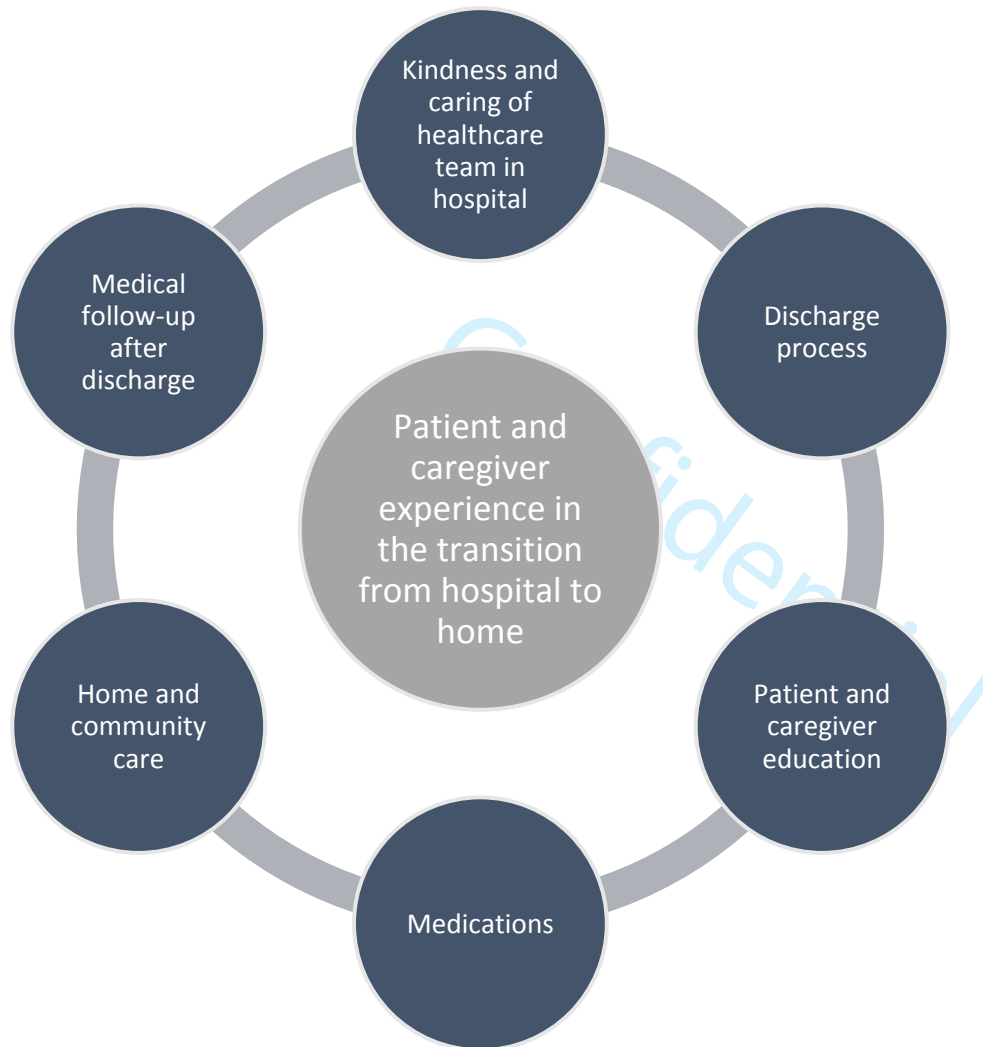
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**Figure 1.** Geographic distribution of patients (n=275) and caregivers (n=304) who responded to the on-line survey and provided the first three digits of their postal code. Caregivers reported postal codes of the person(s) they were caring for.





**Figure 2.** Thematic overview of Issues affecting patient and caregiver experience in the transition from hospital to home



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**Appendices**

Exhibit 1. Stages of concept mapping

Exhibit 2. Recruitment materials prepared by Health Quality Ontario

Exhibit 3. Community Advisory Group membership

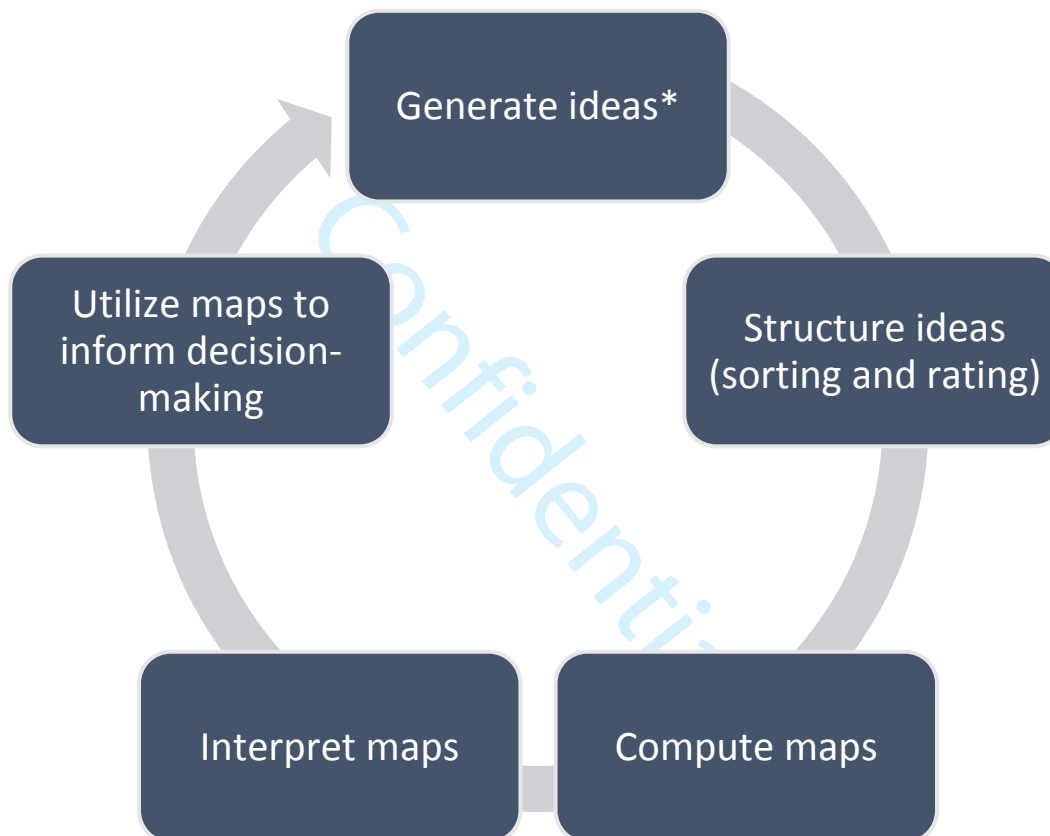
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### Exhibit 1. Stages of concept mapping

Our study reports on the first phase of concept mapping, idea generation, where we consulted with patients and caregivers across Ontario to understand what affects their experience in the transition from hospital to home. Final results of concept mapping will be used to inform what is prioritized in Health Quality Ontario's quality standard on the transition from hospital to home.

Figure adapted from William M.K. Trochim

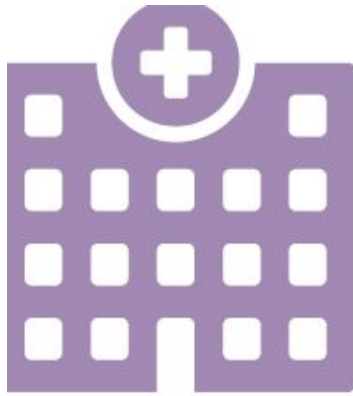
(<http://www.socialresearchmethods.net/kb/conmap.htm>)



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3 **Exhibit 2. Recruitment materials prepared by Health Quality Ontario**  
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6 Broad outreach included communication to the public via Health Quality Ontario’s website,  
7 newsletter, blog (ref), and social media channels (Twitter, Facebook, LinkedIn). Emails were also  
8 sent to Health Quality Ontario’s Patient Advisors Network, comprised of over 500 patients,  
9 families, and members of the public from across the province. Health Quality Ontario provided  
10 patient groups and partners such as the Ontario Hospital Association, Association of Family  
11 Health Teams of Ontario, and Ontario Association of Residents Councils with communications  
12 material to distribute to their members to recruit participants. Recruitment materials included  
13 poster images, email text, and suggested social media posts. These materials were also  
14 available on Health Quality Ontario’s website to encourage the public to spread the word  
15 through their networks. Examples of these materials are provided below  
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Have you been admitted to the hospital within the last three years?



# How was your transition home?

**Health Quality Ontario wants to hear from patients and caregivers about this experience.**

Your input will help organizations across Ontario to better support patients as they recover at home after a hospital stay.

**To learn how you can get involved, visit: [HQOntario.ca/Transitions](https://www.hqontario.ca/transitions)**

**Health Quality Ontario**  
*Let's make our health system healthier*

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# Health Quality Ontario

*Let's make our health system healthier*



## TRANSITIONS IN CARE : GET INVOLVED

Please tell patients and caregivers in your community that we want to hear about their experiences transitioning from hospital to home.

To get you started, here is newsletter / website copy you can use to let people know about this opportunity and how to participate:

### Sample copy

Have you or your loved one been admitted to hospital overnight in the last three years? How was the transition home?

[Health Quality Ontario](#) welcomes you to share your experiences with them by completing this survey before March 15, 2018: <http://bit.ly/2F3COe0>

Or join [INSERT YOUR ORGANIZATION NAME HERE] in a conversation about transitions, at [INSERT DETAILS ABOUT YOUR NEXT PATIENT, FAMILY OR CLIENT MEETING]. We will then share our learnings with Health Quality Ontario.

Your input will inform health care quality initiatives across Ontario about how to better support patients in their journey home after a hospital stay.

For more information, visit [www.HQOntario.ca/Transitions](http://www.HQOntario.ca/Transitions).



# Health Quality Ontario

*Let's make our health system healthier*



## TRANSITIONS IN CARE : GET INVOLVED

Please tell patients and caregivers in your community that we want to hear about their experiences transitioning from hospital to home.

To get you started, here are a number of social media posts you can use to let people know about this opportunity and how to participate:

### Sample Tweets

.@HQOntario wants to hear from patients and their caregivers who have transitioned from hospital to home in the last 3 years. What made the experience a good one? What made it difficult? Complete this survey by March 15: <http://bit.ly/2F3COe0> #TransitionsInCare

Patients who see a doctor within 7 days of a hospital discharge varies widely in #Ontario. If you were in the hospital in the last 3 yrs, please share your #TransitionsInCare. Complete this survey before March 15! <http://bit.ly/2F3COe0>

Calling all those who have been discharged from the hospital in the last 3 yrs: What would have helped in your transition back home? Share your experience with @HQOntario by completing this survey before March 15: <http://bit.ly/2F3COe0> #TransitionsInCare

What supports would you need to feel comfortable when going home after a hospital stay? @HQOntario wants to hear about your experience before March 15. <http://bit.ly/2F3COe0> #TransitionsInCare

Are you caring for someone who has been discharged from the hospital and is now living at home? Tell @HQOntario how the transition went. What is currently working? What isn't? Deadline is March 15: <http://bit.ly/2F3COe0> #TransitionsInCare

Have you been in the hospital in the last three years? How was your transition home? @HQOntario wants to hear about your experience. <http://bit.ly/2F3COe0> #TransitionsInCare

.@HQOntario wants to hear from patients/caregivers what makes a good transition home from the hospital. Feedback will inform projects aimed at better supporting people as they recover at home after a hospital stay. Get involved! [www.HQOntario.ca/Transitions](http://www.HQOntario.ca/Transitions) #TransitionsInCare

.@HQOntario wants to hear from patients and caregivers about their experience transitioning from hospital to home – get involved and help spread the word within your community: [www.HQOntario.ca/Transitions](http://www.HQOntario.ca/Transitions) #TransitionsInCare

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4 **Sample Facebook post**

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7 Being discharged from the hospital can be a stressful experience for patients and caregivers.

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9 [Health Quality Ontario](#) wants to hear from patients and caregivers about their experience when  
10 transitioning from hospital to home.

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12 What worked for you and your caregivers? What didn't?

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14 Your feedback will inform organizations across Ontario about how to better support patients as they  
15 recover at home after a hospital stay.

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17 Learn how you can get involved:

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19 [www.HQOntario.ca/Transitions](http://www.HQOntario.ca/Transitions)  
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## EVIDENCE TO IMPROVE CARE

Home > Evidence to Improve Care > Quality Standards > View all Quality Standards > Transitions in Care

Share   

EVIDENCE AND HEALTH  
QUALITY ONTARIO

HEALTH TECHNOLOGY  
ASSESSMENT

### QUALITY STANDARDS

- [View all Quality Standards](#)
- [Frequently Asked Questions](#)
- [Ontario Quality Standards Committee](#)

### TRANSITIONS IN CARE : GET INVOLVED

Patients and caregivers tell us that the journey home after hospital admission is tough. Poor transitions put a strain on Ontario's health system and increase the risk of complications.

Together with Dr. Tara Kiran at St. Michael's Hospital, we want to hear from patients and caregivers about their experience transitioning from hospital to home.

Feedback will inform health care quality initiatives across Ontario about how to better support patients as they recover at home after a hospital stay.

#### Fill Out Our Survey

Have you or your loved one been admitted to hospital overnight in the last three years? How was the transition home?

Share your experiences with us by filling out this survey by February 28, 2018.

[\[purple button\] Survey](#)

#### Host a Conversation in Your Community

Are you a health care provider or patient?

Would you like to host a discussion where patients and caregivers can share their experiences of recovering at home after a hospital stay?

Learn more about this project and how to lead a conversation by attending a webinar or downloading a [facilitator guide](#).

[\[purple button\] Webinar Sign-Up](#)

[\[add under the purple button\]](#) Webinar ID: 571-116-251

#### Help Spread the Word

their experiences transitioning from hospital to home.

To get you started, here are a number of communication tools you can use to let people know about this opportunity and how to participate:

[Social Media Posts](#)

[Newsletter / Website Copy](#)

[Poster](#)

[Image 1](#)

[Image 2](#)

[\[after the 3 accordions\]](#) For more information, contact [Transitions@hqontario.ca](mailto:Transitions@hqontario.ca).

**Exhibit 3. Community Advisory Group membership**

Member name	Role, Organization	Target population supported by outreach
Toby Stewart	HQO Patient and Family Advisors Council	Rural, multiple admissions
Lucie Allard	HQO Patient and Family Advisors Council	Francophone, multiple admissions
Cathy Bachner	HQO Patient and Family Advisors Council	Multiple Admissions
Samira Chandani	HQO Patient and Family Advisors Council	New immigrant and refugee, socially isolated, Multiple Admissions
Julio Santas	Patient Advisory, Health Links	Multiple Admissions
Hanaa Elkalza	Regional Patient and Caregiver Engagement Coordinator, Health Links	Multiple Admissions
Chantal Bohemier	Planning and Community Engagement Office, RMEFNO	Francophone
Karen Sappleton	Senior Manager, Child and Family-Centred Care & Health Equity, Sickkids Hospital	Pediatrics
Dee Lender	Executive Director, Ontario Association of Residents' Councils	Long-term care
Sharron Cooke	President, Ontario Association of Residents' Councils	Long-term care
David Kent	Vice-President, Ontario Association of Residents' Councils	Long-term care
Lisa Morris	Communications and Outreach Manager, Lived Experience and Recovery Network	Mental Health
Kari Sterling	Regional Director, Lived Experience and Recovery Network	Mental Health
Devon McFarlane	Director, Rainbow Health Ontario	LGBTBQ2ST
Karen Okrainec	Physician, UHN	Multiple Admissions

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Mary Salmon	Discharge Planner/Patient Flow, North Bay Regional Health Centre	Rural
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