

# Supporting conversations about patient safety in the home

**Am I Safe?**



#### ABOUT CANADIAN HOME CARE ASSOCIATION

The Canadian Home Care Association (CHCA) is a national not-for-profit membership association dedicated to ensuring the availability of accessible, responsive home care and community supports to enable people to safely stay in their homes with dignity, independence, and quality of life. Members include government policy planners, administration organizations, service providers, researchers, educators and others with an interest in home care. The CHCA, as the national voice of home care, promotes excellence through leadership, advocacy, awareness and knowledge.

Visit [www.cdnhomecare.ca](http://www.cdnhomecare.ca) for more information.

#### ABOUT CANADIAN PATIENT SAFETY INSTITUTE

The Canadian Patient Safety Institute was established in 2003 as an independent not-for-profit corporation, operating collaboratively with health professionals and organizations, regulatory bodies and governments to build and advance a safer healthcare system for Canada. The Canadian Patient Safety Institute would like to acknowledge funding support from Health Canada. The views expressed here do not necessarily represent the views of Health Canada.

Visit [www.patientsafetyinstitute.ca](http://www.patientsafetyinstitute.ca) for more information.

## EXECUTIVE SUMMARY

Home care is an essential component of an integrated health care system that enables individuals to remain safely in their homes with dignity, independence and quality of life. Building on the findings of the 2013 pan-Canadian report, *Safety at Home: A Pan-Canadian Home Care Safety Study* (Doran, Blais et al), the Canadian Patient Safety Institute (CPSI) co-hosted with the Canadian Home Care Association (CHCA) an expert roundtable in June 2014 to identify actions, outcomes and next steps to advance safety in the home.

One of the actions identified at the roundtable was the need for resources to guide safety conversations between health care providers, patients and family carers. These conversations promote informed decision-making and care planning to minimize risk associated with the provision of care in the home setting. Utilization of these resources would result in the following outcomes:

- Increase patients and their carers<sup>1</sup> awareness and understanding of the importance of safety and the need to make informed decisions that consider elements of safety.
- Support health care professionals in their interactions and conversations with patients, specifically in the areas of safety, risk management in the home setting.
- Enable community organizations and disease-specific associations to facilitate conversations about patient safety.

As a preliminary step in the development of potential resources, the CPSI commissioned the CHCA to conduct an environmental scan of tools and resources available in Canada. The scan included care providers within the health care system in three targeted areas:

- Acute care discharge planning,
- Primary health care
- Home care service providers

Drawing on the findings of the environmental scan and E-Delphi consultation, the following framework and approach is recommended.

<sup>1</sup> Carers, also referred to as caregivers or family caregivers, are individuals (family members, neighbours, friends and other significant people) who take on an unpaid caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness.

**REFRAME THE CONVERSATION – FOCUS ON SAFETY:** The concept of ‘patient risk’ should be reframed to that of ‘patient safety’ in the home. Patient risk can be viewed negatively by patients, their carers and the health care team. Subsequent management strategies can be viewed as punitive or having negative impacts on a patient’s quality of life. Focusing the conversation on patient safety positively frames the discussion and will likely lead patients and their carers to embrace change resulting from safety management and mitigation strategies.

**RECURRENT CONVERSATIONS IMPROVES SAFETY:** Safety conversations must take place often and involve many health care providers across various settings of care. The environmental scan identified a clear gap in this area. Patients and their carers are the one constant between providers and across care settings. Empowering patients and carers to engage health care providers in conversations and become vested parties in their own safety is critical. This approach will ensure the conversations about patient safety are a priority and always take place no matter where or who is providing care. A proposed communication model builds on these two concepts: patient and carers are stewards of their own safety and safety is a continuous conversation.

**CUSTOMIZED, FLEXIBLE TOOLS :** Resources and tools to facilitate safety conversations need to meet the unique needs for the variety of individuals involved in ensuring safe and effective patient care in the home and community. Tools to support appropriate language and messaging about safety will likely increase engagement and achieve sustained behaviour change among patients, caregivers and health care providers. Resources and information should address three critical areas (at a minimum): communication, decision-making, and ethical or moral distress.

**BUILD ON EXISTING PRACTICES:** A suite of tools is the most appropriate approach to supporting conversations about patient safety at home and should reflect the context and setting of care where providers, patients and carers are being engaged. A variety of risk assessments are currently a routine component of frontline health care provider and patient interactions therefore the resources should support the key areas that are evaluated.

Model of patient centric safety conversations **Am I Safe?** (see pag 11)

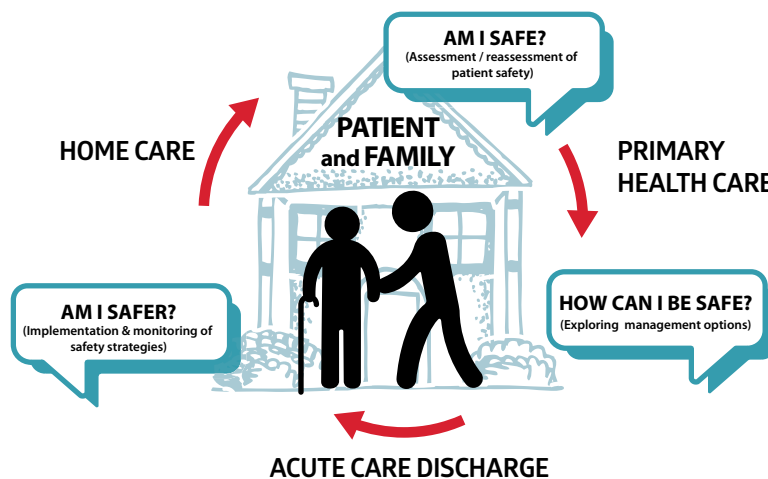


Figure 1

Model of patient safety conversations where patients and carers drive iterative conversations about safety in the home. Key features of the model include:

- Patient and carer are the focal point of the model, representing their lead role in conversations about patient safety.
- Home care services, primary health care and acute care discharge planning inform patient conversations and decision making.
- Patient safety conversations occur in a continuous cycle of safety evaluation, education, implementation and monitoring.
- Patients and carers are empowered and capable of making informed choices about risk and safety with the assistance of the health care team.

## AM I SAFE?

### Supporting conversations about patient safety in the home

Home care is an array of services for people of all ages, provided in the home and community setting, that encompasses health promotion and teaching, curative intervention, end-of-life care, rehabilitation, support and maintenance, social adaptation and integration, and support for carers. The goals of home care are to:

- Help people maintain health, well-being and personal independence in their homes and community.
- Prevent, delay or substitute for acute or long-term care alternatives.
- Facilitate appropriate use of community-based services including health and social services and residential care options.
- Recognize and supplement the care provided by family, friends and other community-based services.

As the setting of care shifts from acute care to the home, the acuity and complexity of patients receiving care in the home has increased. The element of risk and potential for adverse events increases as more complex care is provided in an unpredictable and / or inconsistent home setting.

Supporting an individual's choice to live at risk in their home is a complex and challenging issue for frontline care providers, patients and their carers. Defining risk and acceptable risk are difficult tasks. Understanding and accepting "what is safe" requires achieving balance between the patient and family's concept of risk and the health care provider's knowledge and perception of acceptable risk. Living at risk is fundamentally an informed decision and requires health care providers to engage patients and their carers in candid conversations about identifying, managing and mitigating risk. Conversations contribute to establishing rapport and trust, exchanging and imparting knowledge, relaying support for one another and communicating the safety needs of all parties.

Further support for conversations about patient safety among providers, patients and their family carers can be found in the 2013 report, *Safety at Home: A Pan-Canadian Home Care Safety Study*<sup>1</sup>, which recognized that patients and caregivers sometimes make decisions that put their health at risk leading to the occurrence of adverse events. These findings highlighted the clear need to engage patients and their families in conversations that address and draw attention to the presence of patient safety concerns in the home.

To help address this challenge, the Canadian Patient Safety Institute (CPSI) commissioned the Canadian Home Care Association (CHCA) to conduct an environmental scan and E-Delphi consultation to identify tools and resources available in Canada that could help guide conversations about patient risk among providers, patients and families in the context of care provision in the home setting. In scope for this scan was identifying the assessment of patient risk by care providers and use of tools by providers to support conversations with patients and families about risk. It was not the mandate of this scan to define, qualify or quantify patient risk, or identify, evaluate and recommend risk assessment tools.

## METHODOLOGY

Accurately assessing current practice and the needs of health care providers with respect to a tool to support conversations with patients and carers about risk in the home, requires careful evaluation of when, where and how these conversations occur. In exploring the opportunities for conversations between frontline care providers, patients and family caregivers and the resources where providers would look for tools, four key audiences were identified:

1. Primary health care teams
2. Acute care discharge planners
3. Direct service providers
4. Professional associations and regulatory bodies

A variety of tactics were employed to engage each of the four identified target groups:

- Online survey of service providers, discharge planners and care coordinators.
- Structured interviews of primary care teams and professional associations and regulatory bodies.

To ensure a comprehensive environmental scan of tools and resources available to frontline care providers in Canada, an internet search of openly available tools and resources to support conversations about patient risk in the home setting was conducted.

More detail of the methodology can be found in Appendix 1.

### E-DELPHI CONSULTATION

To further articulate and refine the findings of the environmental scan, a two-round E-Delphi consultation was conducted with participants invited from the surveys and interviews. The purpose of the E-Delphi consultation was to solicit the expertise of participants and achieve convergence of opinion on statements (identified in the initial scan) regarding the elements and features of a suite of tools to support conversations between frontline health care providers, patients and family carers about living at risk in the home setting (Reference Appendix 1 for the amalgamated feedback.).

### WEBSITE SCAN

A scan of websites for openly available materials was undertaken using popular internet search engines (Google, Bing), the scan included Canadian and international websites. The websites examined included Canadian and international health professional associations and regulating bodies, health care/health system related sites, patient and carer sites, disease/illness based sites and organizations outside of the health care.

### Limitations of Scan and Future Opportunities

The scope of the environmental scan was limited to including care providers within the health care system in three targeted areas (acute care discharge planning, primary health care and home care service providers). Potential for future work in this area lies in exploring care interfaces among emergency services (including ambulance, fire and acute care emergency departments) and a more focused outreach to community support and volunteer services.

<sup>1</sup> Family caregivers are individuals (family members, neighbours, friends and other significant people) who take on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness. (Canadian Caregiver Coalition, 2014)

## FINDINGS

An iterative approach was used to explore the availability, use and potential opportunity for tools and resources to help guide conversations about safety and risk with health care providers, patients and their carers.

All three interfaces of care (primary health care, discharge planners and care coordinators, frontline home care providers) provide opportunities to engage patients and carers in conversations about living at risk and ensuring a safety in the home setting. Health care providers in each of these areas connect with patients and their carers in the planning and provision of care, ensuring that the care needs of an individual are met. During these interactions patients, carers and providers exchange information about risk tolerance, consequences and potential outcomes of continued or unaddressed risk, patient and carer values, as well as management and mitigation strategies. Stakeholders in each of the areas overwhelming expressed the need for a comprehensive suite of tools and resources to assist them in engaging patients and carers in conversations about safety and living at risk in the home setting.

Despite the widespread use of risk assessment instruments, only 32 percent of survey respondents indicated the use of a tool or resource to support conversations with patients and caregivers about risk. On further examination, the tools and resources were often organizational policies to support having the conversations and not a specific tool to support the facilitation of a conversation.

Participants shared that conversations with patients and carers about risk can be potentially difficult and uncomfortable to have. Often, patients perceive these conversations as punitive and worry about loss of independence and the inability to remain in their home. Health care providers identified the value of a tool to initiate and guide these difficult conversations, particularly for situations where patients may feel threatened, un-empowered and uncomfortable.

Continuing the risk and safety conversation is essential as patients transition between care settings, health care providers or services because conversations can be lost or forgotten.

HEALTH CARE PROVIDERS EXPRESSED A CLEAR **NEED FOR TOOLS** TO ASSIST THEM IN ENGAGING PATIENTS AND CARERS **IN SAFETY CONVERSATIONS.**

### ASSESSING RISK

The environmental scan identified an array of patient risk and safety assessments are currently performed by the care providers. In some instances (e.g. cognitive assessments), specific standardized tools were widely employed, while in other instances (e.g. falls risk), a variety standardized or adapted tools and assessments are in use. The diversity of the target areas (discharge planning, primary health care teams and home care service providers) dictates the variety of assessment tools utilized. Selection and customization of tools is influenced by a provider's or organization's culture, goals for care, assessment needs and approach.

Risk and safety assessments evaluated a broad range of situations and elements. Respondents across all target areas were asked to identify which specific patient risks were included in their assessments. Four distinct risk themes (including specific risk considerations) were identified and confirmed through the E-Delphi process:

### **1. LIFESTYLE AND SOCIAL ELEMENTS**

- Smoking
- Substance abuse (prescription, over the counter, illegal drugs and alcohol)
- Nutrition (e.g. availability of food, nutritional habits)
- Physical activity (e.g. activity level, exercise, driving)
- Social isolation-social disconnectedness/support networks
- Physical/emotional/sexual abuse
- Financial considerations

### **2. PHYSICAL WELL-BEING, COGNITIVE AND/OR MENTAL HEALTH FACTORS**

- Cognitive impairment (e.g. memory loss, poor judgement, dementia, confusion)
- Sensory impairment (e.g. vision, hearing)
- Impaired mobility (e.g. balance, strength, range of motion)
- Falls
- Dysphasia
- Aphasia and other communication impairments
- Functional abilities (e.g. Instrumental Activities of Daily Living, incontinence)
- Co-morbidities
- Mental health disorders (e.g. Depression, Schizophrenia, Bi-polar disorders)

### **3. ENVIRONMENTAL CONSIDERATIONS (HOME SETTING AND GEOGRAPHIC LOCATION)**

- Clutter and hoarding (e.g. fire risks, emergencies, electrical cords, unstable furnishings)
- Physical layout, home furnishings and maintenance (e.g. stairs, multi-storey, flooring surface, lighting, snow clearing)
- Appropriate assistive devices in place (e.g. lift bars, raised toilet seat, wheelchair)
- Weapons
- Pets
- Essential utilities (e.g. heating, water, electricity)
- Geographic location (e.g. proximity to health and support services, emergency services, support network, community resources)

### **4. CARE IMPLICATIONS (E.G. INTERVENTIONS, THERAPY OR TREATMENT)**

- Medication safety (e.g. medication adherence, administration)
- Wounds
- Infection prevention and control
- Indwelling or implanted devices (e.g. urinary catheters, central/peripheral venous access devices, pacemaker)
- Medical devices (e.g. infusion pumps, oxygen supplies, home ventilator, home dialysis)



## ACCEPTABLE AND UNACCEPTABLE RISK

When a potential risk is identified, health care providers involve patients and their carers in determining whether or not the identified risk is acceptable or unacceptable. In evaluating risk, consideration is given to the individual's perception and tolerance of risk, and capacity to make informed decisions.

Through the E-Delphi process, participants were asked to indicate their agreement with a standard definition of acceptable and unacceptable risk from the World Health Organization (2001). The following modified definitions were agreed upon by participants:

- An **acceptable risk** is a situation where the benefits of the action / circumstance outweigh or are greater than the possible occurrence of a safety incident or negative outcome or impact.
- An **unacceptable risk** is one where the occurrence of a negative outcome or safety incident is likely and outweighs any benefit of the activity or circumstance.

CONSIDERATION MUST BE GIVEN TO THE PATIENT'S **UNDERSTANDING AND TOLERANCE OF RISK** AND CAPACITY TO MAKE **INFORMED DECISIONS.**

## PASSIVE AND ACTIVE COMMUNICATION

Having identified a potential risk, health care providers employ a variety of approaches to communicate with patients and carers, providing them with education and information to manage and mitigate patient risk in the home setting. Commonly, a combination of both passive and active forms of communication are employed.

- **Passive communication** refers to the provision of reading or visual materials or referral to a secondary resource (e.g. website, community service or remote falls monitoring service provider) to patients and caregivers by frontline care providers. This involves a one-way flow of information and does not necessarily ensure that the information presented is understood by the patient and carer.
- **Active communication** of patient risk involves a rich and deliberate engagement of patients and carer by the health care professional, in a dialogue about patient safety in the home. This type of communication consists of a two-way flow of information, and works to ensure that there is an understanding of the information and risk communicated to the patient.

The use of either form of communication is highly dependent on the level of risk identified (acceptable versus unacceptable risk), patient and carer capacity to understand and comprehend the information being communicated, and the availability of time and resources.

## REFRAMING THE CONVERSATION

Reframing the focus from conversations about patient risk to that of patient safety is a change that will impact patient and caregiver perception and potentially the implementation of management and mitigation strategies. Patients often fail to see themselves at risk in their home environment due to the fact that identified risks are ever-present in an individual's day-to-day life. Despite failing to see themselves at risk, patients have a desire to be safe and would likely be willing to implement strategies that would maintain or add to their personal safety.

REFRAMING  
CONVERSATIONS  
WILL **CREATE A**  
**CONSTRUCTIVE**  
**ENVIRONMENT** THAT  
ENCOURAGES PATIENTS  
AND CAREGIVERS TO  
BE ENGAGED

The notion of risk and risk-taking is often regarded in a negative light. As a result, patients and caregivers may perceive the management strategies as punitive or an attempt to negatively impact on one's life choices. Repositioning the conversation to one of patient safety approaches the topic from a positive angle, creating a constructive environment that nurtures patients and caregivers to be engaged in collaborative conversations about safety and thereby increasing receptivity for interventions.

## A SUITE OF CUSTOMIZED TOOLS

There is no "one size fits all" solution for a tool to support conversations with patients and caregivers. Rather, the recommended approach is the development of a suite of tools. The environmental scan has identified that conversations about patient safety involve several distinct elements. A suite of tools would assemble the necessary information and resources together in a single package or location.

Recognizing and managing patient safety rests on all parties achieving an understanding of the risk, agreement on the magnitude of risk and implementing management strategies that align with patient, caregiver and provider goals for care. The key components of a suite of tools would, at a minimum, need to address communication, decision-making and ethical or moral distress related to patient safety in the home.

The following key considerations have been identified to support conversations about patient safety:

### COMMUNICATION

- Recognize barriers that prevent or limit patient and carer understanding of safety in the home.
- Strategies to facilitate 'difficult' conversations. Health care providers acknowledge that conversations about patient risk may be difficult and uncomfortable for all parties involved and help is needed to initiate and improve the engagement of patients and carers.

### DECISION-MAKING

- Making informed decisions. Providers, patients and carers require information about care options and the importance of informed decisions and consent.
- Determining capacity and competency. Scan informants identified the need for information regarding capacity determination, legal processes and tools to assess capacity / competency.
- Awareness of available options in the presence of limited capacity or incapacity. Providers, patients and carers lack an awareness of the resources, options and services available to them when the patient or caregiver is determined to be incapable of making a competent, informed decision.

## **ETHICAL OR MORAL DISTRESS**

- Identifying health care provider bias and understanding patient perception and tolerance for risk. Health care providers identified the importance of recognizing the influence of personal bias and values on conversations with patient and caregivers. Materials to guide providers in eliminating personal bias and recognizing patient and caregiver values and goals is needed.
- Navigating conflict between provider, patient and/or caregiver values. Ethical or moral distress arises among providers when they are unable to act on their ethical choices or when actions to mitigate risk are constrained by a patient's right to choose. A provider's ethical distress may be grounded in their recognition of professional accountability<sup>ii</sup>. Resources are required to support providers in resolving ethical and moral conflict.

The target audience for a suite of tools to support conversations with patients and carers about patient safety in the home is broad and diverse. Members of the target audience should include:

- Physicians
- Nurses
- Allied health professionals<sup>2</sup>
- Personal support workers
- Patients and carers

Within the identified audience exists a wide range of knowledge, scope of practice, clinical experience and understanding of safety issues. A suite of tools will need to be contextualized for each audience group to reflect the different conversations that occur informed by the scope of practice, expertise and experience of the health care professional, care provider, personal support worker or individuals engaging in discussion.

## **AM I SAFE? A CONTINUOUS PROCESS**

The process of assessing, communicating and managing patient risk is one where continuous feedback and engagement is supported through repeated conversations. A continuous process can be supported across transitions in care settings and providers. As risk management actions are implemented, it is necessary to continually evaluate whether or not the action has been effective in improving or maintaining patient safety. Over time, patients will experience changes in health status that may introduce new elements of risk or compound existing risk in their home setting.

E-Delphi participants agreed that risk assessments and the accompanying conversations with patients and caregivers cannot be a onetime event and depending upon the determined level of risk, be revisited after a specified period of time.

Effectively sustaining conversations about patient safety across transitions and ensuring accountability of continuing the conversation was clearly identified as a priority throughout the environmental scan. Patients are the one constant across the system and care transitions. Empowering patients and carers to engage the health care provider in conversations and become vested parties in their own safety will ensure discussions are not forgotten, dropped or ignored across care transitions.

**EFFECTIVELY SUSTAINING CONVERSATIONS ABOUT PATIENT SAFETY ACROSS TRANSITIONS WAS IDENTIFIED AS A PRIORITY THROUGHOUT THE ENVIRONMENTAL SCAN.**

<sup>2</sup> Allied health care professionals include respiratory, occupational and physical therapists, social workers, dieticians, speech and language therapists,

The following graphic (Figure 1) outlines a patient and caregiver driven model of communication supporting iterative conversations about safety in the home. The patient and caregiver are the focal point of the model, representing their lead role in conversations about patient safety. The three supporting areas (discharge planning, primary health care and home care) provide the patient and carer with the necessary information to make informed decisions.

Patient safety conversations are continuous and include safety evaluation, education, monitoring and re-evaluation. Resources for the patient encourage and empower them to engage health care professionals by asking “Am I Safe?” or “How Can I Be Safe?” Patient safety becomes a collaborative process. Patients, carers and providers partner to plan, implement change and evaluate safety in the home.

### Model of patient centric safety conversations AM I SAFE?

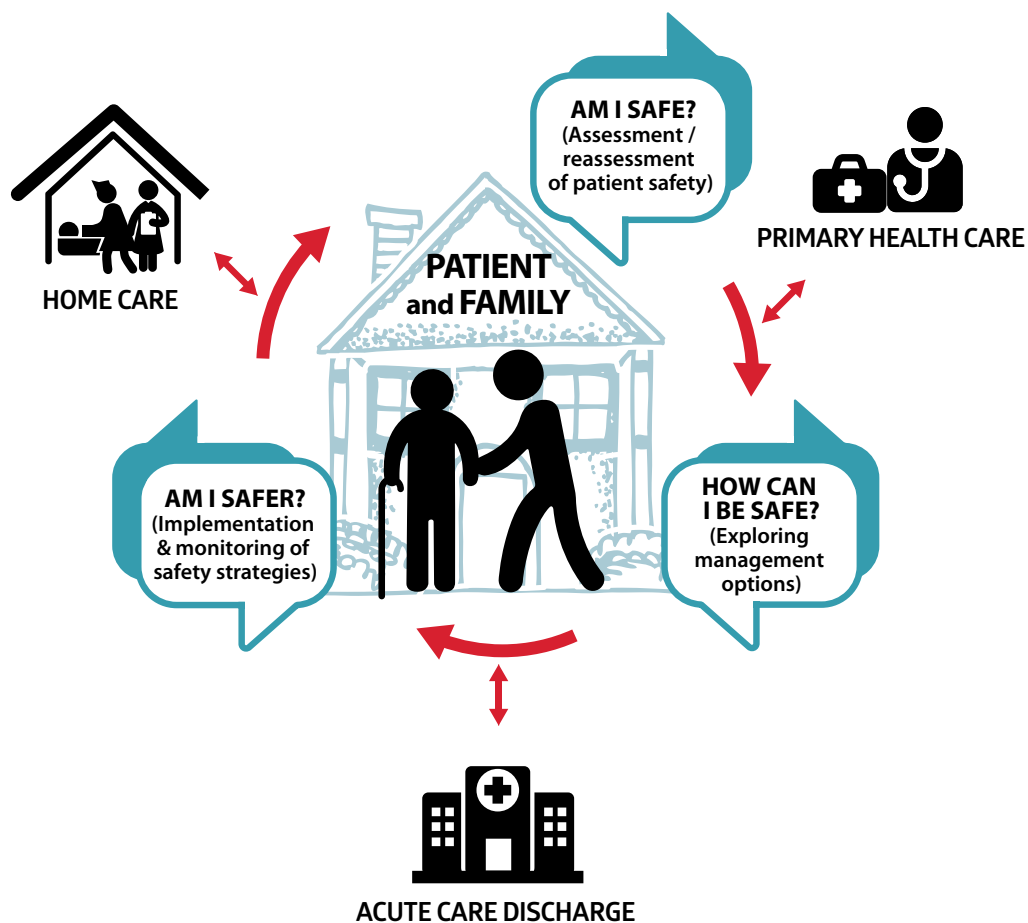


Figure 1

Model of patient safety conversations where patients and carers drive iterative conversations about safety in the home. Key features of the model include:

- Patient and carer are the focal point of the model, representing their lead role in conversations about patient safety.
- Home care services, primary health care and acute care discharge planning inform patient conversations and decision making.
- Patient safety conversations occur in a continuous cycle of safety evaluation, education, implementation and monitoring.
- Patients and carers are empowered and capable of making informed choices about risk and safety with the assistance of the health care team.

Empowering patients and carers to lead conversations about safety in the home is only one component of a successful model. Frontline health care providers need to be supported and equipped with the knowledge to stimulate conversations. Appropriate communication skills will support the engagement of patients and carers. Health care providers also need to understand patient safety and risk in the home and offer management and mitigation strategies. Patients and carers are empowered to ask questions and receive answers.

## **SUSTAINABLE IMPLEMENTATION**

Adoption and implementation of a suite of tools to support safety conversations would be best accomplished by aligning patient safety conversations with current risk assessment processes. Safety conversations among patients, their carers and providers need to become embedded in risk assessments and be seen as the next step in the process once an element of patient risk has been identified. Ensuring that patient safety conversations become part of the practice and not a separate entity is key. The first step in improving patient safety in the home is recognizing the need for safety conversations.

To achieve widespread dissemination and uptake of this suite of tools, users must have ready access. Respondents involved in the environmental scan indicated this would be best achieved through free, online or electronic access. Tools that could be electronically downloaded, presented online or studied virtually would meet the learning needs and styles of the current health care workforce. Availability of the tools should be made through a variety of sources. Incorporating the contextualized suite of tools into professional or health care curricula would secure the widest dispersal and incorporate the learnings into future generations of health care providers

## **CONCLUSIONS**

The vast majority of health care providers lack awareness of, or utilize tools and/or resources to support conversations about safety in the home. Respondents clearly identified a need for tools to support patient safety conversations among frontline health care providers, patients and caregivers. Assessment tools are widely employed to guide patient risk assessments, similarly, a suite of tools to support safety conversations among patients, their carers and providers is needed.

At a minimum, the tools need to address communication, decision-making and ethical distress considerations of patient safety in the home setting. Further consultation with physicians, nurses, personal support workers, allied health professionals, patients and family caregivers is required to customize and contextualize the suite of tools to meet each group's individual needs.

Widespread knowledge translation of the tools would be best achieved using free, online and electronic access to resources. Beyond the development and dissemination of a suite of tools, a critical component is ensuring the utilization and sustainability of the tools. It is key that the use of tools supporting safety conversations be linked and align with current patient safety assessments and processes. The acceptance and uptake of a suite of tools to support safety conversations will be dependent upon coupling safety conversations to risk assessments. Patients, carers and providers need to recognize that safety conversations are another component of the risk assessment process and one should not occur without the other.

## RECOMMENDATIONS

1. The concept of patient risk in the home setting should be reframed to that of patient safety in the home. “Patient risk” infers negative connotations for patients and caregivers and may carry the fear of punitive management strategies. A positive approach towards patient safety in the home may be more likely to cause patients and caregivers to embrace change resulting from safety management and mitigation strategies.
2. Ensuring the uptake and implementation of tools is critical. Integrating the use of a suite of tools to support safety conversations with current practices (risk assessments) is key to ensuring that the tools will be utilized and adopted. This measure will ensure the sustainability and longevity of a suite of tools.
3. A suite of tools to support conversations about patient safety in the home among health care providers, patients and caregivers should address the following key items:
  - a. Communication:
    - i. Identification of barriers and solutions to patient and caregiver understanding of patient safety in the home
    - ii. Facilitation of ‘difficult’ conversations
  - b. Decision-making:
    - i. Patient and caregiver capacity limitations to making informed decisions
    - ii. Tools for assessing capacity
    - iii. Resources to support decision-making in the absence of patient or caregiver capacity
  - c. Ethical and moral distress:
    - i. Recognizing and balancing provider, patient and caregiver perception and tolerance for risk
    - ii. Resources to support frontline providers in navigating ethical or moral distress
4. Tools with key considerations need to be customized to meet the scope of practice and unique needs all members of the health care team, including patients and caregivers.
5. Knowledge translation of a suite of tools to support patient safety conversations would be best achieved through the use of free, online or electronic (electronic download, webinars, virtual learning) platforms.
6. Consider a communication model that empowers patients and caregivers to share the responsibility of driving conversations about their safety in the home. Identifying the patient and caregiver as stewards of safety, provides a vehicle to facilitate conversations across care transitions, settings and time.

THE KEY COMPONENTS OF A SUITE OF TOOLS WOULD BE **COMMUNICATION, DECISION-MAKING AND ETHICAL OR MORAL DISTRESS.**

## REFERENCES:

- i Doran, DM., R. Blais, M.B. Harrison, J.P. Hirdes, G.R. Baker, A. Lang and M. Macdonald. 2013. “Safety at Home: A Pan-Canadian Home Care Safety Study.” Edmonton: Canadian Patient Safety Institute.
- ii [https://www.cna-aiic.ca/~media/cna/page-content/pdf-n/ethics\\_pract\\_ethical\\_distress\\_oct\\_2003\\_e.pdf?la=en](https://www.cna-aiic.ca/~media/cna/page-content/pdf-n/ethics_pract_ethical_distress_oct_2003_e.pdf?la=en)

# APPENDIX

## METHODOLOGY

Three primary audiences were included in the review of available tools and resources to support conversations between frontline care providers, patients and carers:

1. Primary care team interactions
2. Acute care discharge planning
3. Direct service provision in the home.

During each of these interfaces, there are opportunities for health care providers to identify, educate, manage and mitigate risks in the home with the patient and carer. These also present opportunities for patients and families to bring forward their safety and risk concerns for discussion. The scan also included professional associations and regulatory bodies in addition to an internet search of openly available tools and resources that frontline care providers may consult as potential knowledge resources. A variety of tactics were employed to engage each of the target groups.

## KEY INFORMANT SURVEYS & INTERVIEWS

*(Survey tools are available upon request)*

### Home Care service providers:

Surveys were distributed to over 200 home care programs across Canada, with a 10 percent response rate. The surveys were sent to program administrators, policy developers and the executive leadership of home care service providers. The survey addressed:

- The existence of organizational policies regarding patient choice to live at risk;
- strategies used to mitigate risk in the home setting; and
- tools/resources used to support conversations about patient risk.

### DISCHARGE PLANNERS:

In surveying discharge planners, the objective was to determine the availability and utilization of tools to support conversations (during discharge planning) about patient risk in the home setting. The transition of care from the acute care setting, back into the home and community is often accompanied by new or increased levels of pre-existing patient risk. Twenty responses were received from the survey. The organizations who responded included: Alberta Health Services (Alberta), Winnipeg Regional Health Authority (Manitoba), Champlain Community Care Access Centre (Ontario), Horizon Health Network (New Brunswick), Capital District Health Authority (Nova Scotia), Hay River Community Health Board (NWT).

### PRIMARY CARE TEAMS:

The primary care teams involved in the scan included multidisciplinary teams providing health care services to a community population. The teams varied in their diversity and included physicians, nurses, social workers, physio- and occupational therapists and dietitians. Primary health care teams were engaged by means of team interview focused on risk identification in the home setting and addressing identified risks. Four teams were included in the interviews from Alberta, Ontario and Nova Scotia.

### Professional Associations and Regulatory Bodies:

Health care providers often rely on the guidance and resources provided through professional associations and regulatory bodies of their profession. The focus of inquiry for the interviews was the scope of practice with respect to the mitigation of risk and support for respective professional membership through the provision of tools and resources to guide them in practice.

Associations:

- Canadian Nurses Association
- Canadian Medical Association
- College of Family Physicians of Canada
- Canadian Family Practice Nurses Association
- Canadian Physiotherapy Association
- Canadian Society of Respiratory Therapists
- Royal College of Physicians and Surgeons of Canada
- Canadian Association of Social Workers
- Community Health Nurses of Canada
- Canadian Association of Occupational Therapists

## E-DELPHI CONSULTATIONS

*(Survey frames available on request)*

The E-Delphi consultation (2 rounds) sought participant feedback and confirmation on the findings of the environmental scan and interviews. Input on the following key areas of a suite of tools was solicited: risk foci and sub-elements; risk qualification; risk communication and conversations about risk. Eleven organizations were involved in the E-Delphi:

- Canadian Family Practice Nurses Association
- Canadian Forces Health Services
- Canadian Physiotherapy Association
- Champlain Community Care Access Centre
- College of Family Physicians of Canada
- McMaster Family Practice Team
- Red Cross Canada
- Safety First Consulting
- SCA Personal Care
- Taber Medical Clinic (participated in round one only)
- VHA Home Health Care

**The following is a summary of the E-Delphi feedback:**

### ASSESSMENT OF RISK - KEY FOCI

The respondents confirmed risk assessments were completed for home care clients, the four key areas are examined: (a) lifestyle risk (b) physical/cognitive risk (c) home environment risk (d) risk related to care interventions/therapy/treatment.

The participants provided input and recommendations on the specific components that should be reviewed within each foci:

#### Lifestyle/Social Risks

- Smoking
- Illegal drug use
- Alcohol
- Diet
- Exercise
- Social Isolation
- Physical/Emotional Abuse
- High risk neighborhoods

#### Physical/Cognitive Health Status Risks

- Dementia
- Hearing Impairment
- Vision Impairment
- Impaired Mobility
- Dysphasia
- Aphasia

#### Home Environment

- Clutter/hoarding
- Physical layout of home
- Assistive devices
- Weapons in the home
- Pets

#### Risk related to medical treatment/intervention/therapies

- Fall risk
- Medication safety
- Wounds (surgical)
- Wounds (pressure ulcer)
- Infection Prevention and Control

### RISK QUALIFICATION

Participants recommended the following concepts in regards to evaluating patient risk:

Following the completion of a risk assessment health care providers involve patients and caregivers in determining acceptable or unacceptable risk, consideration must be given to:

- The patient's perception and tolerance of risk.
- Patients' capacity to make informed decisions (formally assessed if required).
- A way to moderate biased in regards to 'acceptable' through a framework or tool.

There was general agreement on the definition of acceptable and unacceptable risk, with one recommendation - change "adverse event" to "safety incident" (An event or circumstance which could have resulted, or did result, in unnecessary harm to a patient [WHO, 2009]). Modified definitions:

- **Acceptable risk** is defined as risks where the benefits of the action / circumstance outweigh or are greater than the possible occurrence of a safety incident or negative outcome or impact.
- **Unacceptable risk** is one where the occurrence of a negative outcome or safety incident is likely and outweighs any benefit of the activity or circumstance.



## RISK MITIGATION – COMMUNICATION

When an area of client risk in the home is identified, health care providers employ a variety of strategies to manage and mitigate client risk. One strategy utilized is to provide information to clients and family caregivers. Participants provided the following suggestions regarding communications:

- Information is generally provided to patients and caregivers.
- Both passive and active communication is used depending on level of risk, patient capacity, resources.
  - Passive communication of risk involves the provision of reading materials to the patient and family caregiver or referral to secondary resources or services.
  - Active communication of risk involves engaging patients and family caregivers in conversations and ensuring understanding of the risk.
- Risk conversations with patients and caregivers are seen as potentially difficult ones.
- Following up with the patient and caregiver is important to ensure increased understanding of risk

## TOOLS TO SUPPORT RISK CONVERSATIONS

Participants agreed that a suite of tools to support conversations among frontline health care providers, patients and family caregivers about patient risk in the home setting is needed. These tools could include Simple algorithms may be useful for quick reference and should be customized to support the needs of frontline health care providers in the following areas (as a start):

- Discharge planning
- Primary Health Care
- Home care providers

Within each target area, the specific elements of the tools will be tailored to meet the needs of:

- Physicians
- Nurses
- Personal Support Workers
- Allied health professionals (respiratory, occupational and physical therapists, social workers, dieticians, speech and language pathologists)
- Patients
- Family caregivers (family members, neighbours, friends and other significant people who take on a caring role to support someone with a diminishing physical ability, a debilitating cognitive condition or a chronic life-limiting illness)

The tools should address (at a minimum):

- **Communication** with the patient / caregiver
  - user friendly with appropriate language / literacy (include pictures)
  - support facilitating difficult conversations
- **Engagement** (empowerment) of the patient / caregiver
  - tools to support assessing the patient's ability to make informed decisions
  - consequence/outcome of choices are clear to client/caregiver
- **Ethical & Legal aspects**<sup>1</sup>
  - understanding and balancing provider and patient / caregiver risk perception and tolerance

## MODEL FOR APPLYING THE TOOLS

The suite of tools should include a follow-up component to support continuous risk evaluation and promote behaviour change. The model should include: Risk detection - Classify severity of risk for prioritization purposes (time-line for action/others that may require involvement) - Engagement of client/family - Identification of contributory factors - Evaluation - Development of mitigation strategies; safety solutions/care modification - Monitor effectiveness/outcome.

The approach must be realistic across the continuum of home care. Within discharge planning there is limited ability to follow-up with the patient. The process / model should follow the patient across the continuum with providers being able to pick up the "conversation" at various touch points of care. Accountability for continuing the conversation will be key.

<sup>1</sup>To further explore and refine the ethical and moral themes identified through the E-Delphi process, patient and ethics resources of the Toronto Central Community Care Access Centre were consulted. Their expertise helped to clarify and distinguish the themes of professional accountability and liability relating to ethical and moral distress that were presented during the initial surveys and interviews as well as the E-Delphi process.

## **DISSEMINATION AND UPTAKE OF THE TOOLS**

Recommendations to support the introduction and uptake of the tools to support conversations among frontline health care providers, patients and caregivers about patient risk in the home setting:

- On-line access through professional regulatory bodies / associations
- Incorporation into professional / educational curriculums
- Virtual learning
- Professional education sessions
- Simulation workshops
- Communities of Practice
- Dissemination by social media such as Twitter can be very effective
- YouTube videos