Loud and Clear
Seniors and caregivers speak out about navigating
Ontario’s healthcare system

This report is about their stories, experiences, and ideas.
The Change Foundation

The Change Foundation is an independent policy think tank, intent on changing the healthcare debate, healthcare practice and healthcare experience in Ontario.

A charitable foundation established in 1996 and funded through an endowment, The Change Foundation leads and leverages research, policy analysis, quality improvement and strategic engagement to enable a more integrated healthcare system in Ontario, designed with individuals and caregivers top of mind.

Goal

The goal of our strategic plan is to improve the experience of caregivers and individuals as they move in, out of, and across the healthcare system over time.

Vision

To be Ontario’s trusted advisor advancing innovative health policy and practice.

Mandate

To promote, support and improve health and the delivery of healthcare in Ontario.

Mission

• To make caregivers and individuals in need of healthcare part of the healthcare discussion about how to find solutions to improve their experiences.
• To stimulate new ways of thinking, behaving and interacting to foster improved healthcare for people, especially when they are in transitions.
• To generate robust and independent research and policy analysis of healthcare issues related to improving the experience of individuals and caregivers as they navigate the healthcare system.
• To lead informed discussion and strategic engagement with the stewards, stakeholders and users of the healthcare system.

Values

Excellence – we strive for excellence in all we do. Innovation – we take innovative approaches in developing new ideas. Collaboration – we work in partnership with others to achieve success. Inclusivity – we strive to include all voices and views.

About this report

In the fall of 2011, The Change Foundation engaged seniors with chronic health conditions and their informal caregivers. We asked them to describe their experiences at transition points in Ontario’s healthcare system. What happened when they switched settings, services or providers? And how did it affect their lives? We went into communities and learned from people face-to-face; we listened to their stories on a webinar; and captured their experiences and reflections online. This report gives voice to their healthcare experiences as a first step in improving them.
Acknowledgements

The Change Foundation would like to recognize and thank each of our host partners for supporting our engagement work and for showing their commitment to including seniors and caregivers in healthcare discussions:
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- Timmins and District Hospital
- Toronto Community Housing

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- Dryden Regional Health Centre
- Golden Manor Home for the Aged in Timmins
- Peterborough Regional Health Centre
- Primary Health Care Services of Peterborough
- Regent Park Community Health Centre in Toronto
- Support Enhance Access Service Centre in Toronto
- Timmins Family Health Team
- York Central Hospital in North York

We acknowledge as well the advice and support received from the North West, North East, South West and South East Local Health Integration Networks.

The Loud and Clear project was led by The Change Foundation’s Communications and Community Engagement Director Sine MacKinnon and Andrew MacLeod, Project Lead, Strategic Engagement and IT, with the expertise and support of public engagement specialists Ascentum Inc.
Dedication

We dedicate this report to the seniors and their family members and friends across Ontario who shared their experiences and stories with us. They spoke forcefully and thoughtfully, with both emotion and measure, about where the system has failed them and how it could serve them better. They spoke loud and clear.
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At The Change Foundation, our goal is to improve people’s healthcare experience as they move in, out of, and across Ontario’s healthcare system. Our strategic plan focuses on the quality of that experience because we believe it is the lens which can lead us most clearly and quickly to practical patient-and-family-centred solutions, based on lived realities. We are looking in particular at seniors with chronic health conditions and their informal caregivers. This is because they generally have the most frequent interactions with the healthcare system and with a wide array of providers from different parts of it – interactions that offer rich and instructive stories.

It is fitting, then, that we started to roll out our strategic plan by going first to the source: seniors and caregivers. Late last fall, Foundation staff travelled across Ontario in search of stories. From the province’s north in Dryden to the south in London, our team found out what’s happening as seniors and their informal caregivers navigate transitions in the health system; we learned what problems they’re facing and what we might do to make things right. *Loud and Clear* captures people’s voices and views, and offers new data and unique insights into the big and small changes that might make a difference to their health, their lives – and the quality and sustainability of our system.

Such changes as: greater predictability – advance notice when home-care staff or shift
They spotted areas where no one seems to be responsible or accountable – not surprising since our system wasn’t designed as a whole, and is still thought of as having discrete “parts.”

They spoke loud and clear, and their message is – in short – connect, communicate, include. “Connect the Docs” – connect all healthcare providers and services to, for, and with patients and caregivers. Clarify and simplify the process. Communicate early, often and well – provider to patient/caregiver, provider to provider, system to system. Include patients, families and caregivers in decisions that affect their lives and health. Don’t let people who are facing barriers fall behind.

Our engagement brought to light an encouraging finding that augurs well for the future: seniors and their caregivers are willing and eager to share their stories to improve our collective system. Their evaluations showed that 97.5% of the seniors and caregivers we engaged valued being part of the discussion, and over 90% thought that by sharing their stories they could help change Ontario’s healthcare system for the better. Let’s not let them down.

Cathy Fooks
President and CEO
The Change Foundation
Project, purpose, people.

We believe that the lived realities and personal stories of people’s healthcare experiences are legitimate sources of information; these experiences provide evidence that helps tell us how well our system delivers on the promise of patient-centred healthcare. At The Change Foundation, our goal is to improve people’s experience as they move in, out of, and across Ontario’s healthcare system over time. We are looking in particular at seniors with chronic health conditions and their informal caregivers, zooming in on what happens – or doesn’t – before, during, and after they leave one service or provider and await or seek out another, and another.

What is the nature of those myriad interactions and transitions, and how do they affect the health and quality of life of seniors and their caregivers? What is the relationship between their experience, the quality of their care and the cohesion of our healthcare system – and its efficiency and sustainability?

Those questions were in our minds late last fall as we began to implement our strategic plan by engaging with Ontario seniors and caregivers in all regions, face-to-face and online, in settings ranging from a small city in northwestern Ontario to one of Toronto’s most diverse neighbourhoods. People’s stories about healthcare experiences flowed...
freely during these interactive engagement sessions, as did their insights about how to improve the system. The sessions were finely focused on healthcare transitions – those smooth and stormy spots in system navigation. Using real-time keypad voting technology, we also asked 10 closed-ended questions. The voting results complement the qualitative data from the open, story-sharing process. We share both in this report.

Seniors with chronic health conditions – and their caregivers – are uniquely positioned to explain in concrete, compelling terms what happens during myriad multi-directional moves: between hospital, home, assisted living, long-term care, etc., as they are banded about from family doctor to specialist, from lab to clinic to rehabilitation centre and sometimes back. What makes those moves easier or worse for the people living through them? The health and social care needs of seniors with chronic health conditions and their caregivers are often complex; reorienting healthcare services and practices to address their realities will also deal with many of the gaps and dead ends that inhibit improvements system-wide.

**This report**

In *Loud and Clear: Seniors and caregivers speak out about navigating Ontario’s healthcare system*, we explain our rationale for the timing and target of our engagement, describe our methodology, present our findings and how we plan to use them, and share the Foundation’s next steps and how they fit, feed into, and even blaze the way for patient-centred healthcare in Ontario.

The engagement that fueled this report was the first step in a trajectory that will take The Change Foundation into one Ontario community to support a two-year experiment that we believe will improve transitions in healthcare and introduce to Ontario the benefits of building patient and caregiver participation into the re-design of health services. That’s the essence of our project called PATH – Partners Advancing Transitions in Healthcare: a first with Ontario patients.

From the stories and experiences of seniors and caregivers in Ontario emerge ideas about what adds value to our healthcare system, what needs fixing, and what’s missing.
The top five themes
Absorbing and analysing what we heard from seniors and caregivers across the province, we saw certain themes rise to the top. In the appendices, you can see the number of references made to specific issues; we have bundled them here under five themes, starting with the most oft-cited one:

1. **THE PRIMACY – AND PROBLEMS – OF PRIMARY CARE**
Stop the dead ends; make primary care accountable for guiding people’s transitions.

2. **THE IMPORTANCE OF CONNECTIONS AND CLARITY ABOUT NEXT STEPS**
“Connect the Docs.” Connect all healthcare providers and services to, for, and with patients and caregivers. Clarify and simplify the processes.

3. **THE COMMUNICATION DEFICIT**
Communicate early, often and well – provider to patient/caregiver, provider to provider, system to system.

4. **THE INCLUSION FACTOR – HEY, WHAT ABOUT US?**
Include patients, families and caregivers in decisions that affect their lives and health.

5. **ISSUES OF EQUITY**
Don’t let people who are facing barriers fall behind.

A disconnect at the primary care level was a leading factor in people’s transition problems.

What we heard:
Connect. Communicate. Include.

**FIGURE 1**: I have had problems navigating a transition in the healthcare system. (N=95)

“I don’t know what’s happening next, but where do you go to find the answers? Seems like there are roadblocks set up in the system that make it hard.”
Ontario senior

Our findings, based on results of participants’ closed-ended keypad voting as well as our analysis of the qualitative research, indicate that seniors and caregivers in Ontario are experiencing problems navigating transitions from one part of the healthcare system to an-
other. Figure 1 shows that the majority (55%) of the participants in our in-person and online engagements told us that they had experienced such problems, and less than one-fifth (16%) said that they had not.

Seniors and caregivers don’t want the moon; they don’t necessarily even want more. Their most frequent calls for change revolve around coordination and communication. A disconnect at the primary care level was a leading factor in people’s transition problems. This disconnect appeared to be due to communication breakdown and/or lack of coordination and/or barriers between primary care physicians and other providers involved in seniors’ care. People frequently cited problems associated with access to their up-to-date records and lack of follow-up on referrals. Figure 2 shows that over half of participants said they had experienced a disruption in their care because of poor communication between health workers.

In addition, poor communications between care facilities was a barrier to successful transitions, with patients – and their records – falling through the cracks. We heard stories of elderly patients simply being “lost” during the discharge from hospital back to long-term care. When their caregivers called for an update, neither the hospital nor the long-term care facility could confirm the patient’s location. In one case, a senior with dementia was dropped at the wrong long-term care facility and could not be identified.

Many people recounted being unsure or confused about the next steps in their care, and some were fearful of what would happen to them next in their journeys. Indeed, less than half of participants (45%) said they leave their appointments with a clear sense of what comes next. This finding suggests that significant challenges exist in the navigation of transitions – in fact, even in knowing what the transition is or will be.

The struggle often starts at the primary care stage. Seniors and their caregivers are affected by communication and collaboration breakdowns between primary and specialty care providers and between health facilities. Most importantly, they encounter communication problems in their own interactions with healthcare providers. The system, the practice, and the culture – all three are failing seniors and their caregivers, leaving them confused about what comes next and feeling lost in a complex system that is hard to navigate. We’ve heard that there’s no map to help them find the services they need. We’ve heard that even providers only seem to understand their own part of the system, and lack “the big picture.”
In addition, during their attempts to navigate what seems to be a very complex and fragmented system, many seniors and caregivers believe their providers aren’t adequately listening to them. Many participants told us they had little confidence that their voices were being heard or taken seriously – when they said what kind of care they would prefer, for example, or complained about a negative healthcare experience, or even when they described their symptoms.

People also felt that they weren’t adequately involved in making decisions about their care, and perceived a lack of transparency in how these decisions were being made.

Due to all the above, caregivers believe they must advocate on behalf of the seniors they care for; they see advocacy as an essential part of their role. This in addition to providing physical care. As advocates, they arrange and manage appointments and records, “push back” against roadblocks and take whatever steps they feel are necessary to get their loved ones the desired or required care.

The caregiving role already places a significant financial, emotional and temporal burden on seniors’ loved ones – a burden that they feel goes largely unrecognized and unappreciated by providers and governments.

“I’ve never been asked as a caregiver, ‘What’s convenient for you?’ or ‘How would this work in your family?’ Instead, it’s ‘This is what we’re going to do for you.’ There’s no discussion of collaboration.”

Ontario caregiver

And seniors who don’t have a family member or friend to act as caregiver or advocate are even more vulnerable – and more so again if they have any cognitive deficits or mental health problems. We even heard stories from participants who had seen seniors with these problems being treated less respectfully by healthcare providers and staff.

The stories that seniors and caregivers shared at our engagement sessions reinforce calls from The Change Foundation – and many others – for change: change in how primary care and specialist healthcare providers communicate and collaborate with one another and with their patients and families; change in how patient health information is coordinated and shared;
WE NEED CHANGES:

• in how primary care and specialist physicians and providers communicate and collaborate with each other and with patients and caregivers;
• in how patient health information is coordinated and shared;
• in how health facilities transfer or move patients; and
• in how both seniors and caregivers are informed about care options and then actually involved in making the decisions.

change in how health facilities transfer or move patients; and change in how both seniors and caregivers are informed about care options – and then involved in making the decisions.

Pointing out the positives – a willing nod to providers and pockets of excellence

Despite the significant challenges many participants described in their stories, some reported positive experiences – especially with team-based care and the growing use of Nurse Practitioners, and with the support and clarity and coordination they received after a being diagnosed with certain conditions such as stroke or Alzheimer’s disease. One wry senior said he had to have a stroke to get that kind of response – musing that maybe the stress of trying to sort out his health caused it! Seniors and caregivers cited times when they felt understood and respected – as well as safe and assured. They credited the dedication, professionalism and compassion of individual providers – people who took the time to connect with them, and their families and friends, to explain in accessible ways, what’s likely to lie ahead, and who will be there to help them along the way.

Next steps – we’re just getting started

The engagement that fueled this report was the first step in a trajectory that will take The Change Foundation into one Ontario community, starting this summer, to support a two-year experiment that we believe will improve transitions in healthcare and introduce to Ontario the benefits of building patient and caregiver participation into the re-design of health services.

That’s the essence of our project called PATH – Partners Advancing Transitions in Healthcare: a first with Ontario patients. PATH, which will involve a broad-based coalition of service providers and seniors and caregivers, will be launched in May when the selected PATH community is announced. Meanwhile, you can learn more about PATH on our website – www.changefoundation.com.

The Change Foundation will hold another round of engagements with seniors and caregivers in 2014 – similar to the Loud and Clear engagements reported on here. These will run parallel to our second set of consultations with health system leaders and practitioners about patient experience and patient-centred care; (results from our first round of these consultations will be released in late June).

Our goal in the consultations is to discuss and determine answers to the following questions: Has the yardstick moved? Is it getting easier to navigate across our system? Is the experience improving for seniors and caregivers? Do
policymakers understand what people need to successfully navigate across and between services? Have the thinking, discourse, practice and policies begun to change, to reflect a more responsive understanding?

In 2015, The Change Foundation will wrap up our current strategic plan, Hearing the stories, changing the story. First, we’ll host a culminating summit to bring together all the players who’ve brought the plan to life – healthcare’s stewards, stakeholders, and users who have engaged with us to improve people’s healthcare experience in Ontario. Together, we’ll discuss the recommendations and advice that emerge from our collective efforts and lessons: recommendations for government and other audiences involving healthcare practice, process, policy, design and governance. That advice will include – must include – the voices, views, and ideas of people who are truly in-the-know but whose knowledge is often overlooked: patients and caregivers.

In the meantime, the Foundation is not sitting silent on the engagement front. We are forging ahead so that we can continue our multi-directional conversations with health-system users in Ontario, via various formats. In particular, we are now in the midst of developing a Public Engagement Panel which we will launch in the fall.

And the timing couldn’t be better – for our upcoming and ongoing projects and for the release of this Loud and Clear report. Right now, the province is considering how to respond to the Drummond Report on public services and how to make good on Ontario’s Action Plan for Health Care and to get the most out of the Excellent Care for All Act. From the stories and experiences of seniors and caregivers in Ontario emerge ideas about what adds value to our healthcare system, what needs fixing, and what’s missing.

We began this engagement with the belief that the lived realities of people who rely on a host of healthcare services and supports are worth listening to. Their experience is their expertise and our evidence – an essential element in understanding the efficacy and impact of our healthcare system.

Our first round of engagements with seniors and caregivers benefitted from the support of community-based healthcare and service organizations from across Ontario. We acknowledge and appreciate their invaluable contribution, and would welcome more collaboration in the future.

However, we save the dedication of this report for the seniors and caregivers across Ontario who shared their healthcare stories with us and suggested ideas for change. Loud and Clear captures their voices and views and offers fresh data and unique insights into the big and little things that will make a difference – if we heed their voices – to people’s health, people’s lives and the quality and sustainability of Ontario’s healthcare system.

Seniors and caregivers don’t want the moon; they don’t necessarily even want more. Their most frequent calls for change revolve around coordination and communication.
1. Introduction

The knowledge of experience experts

The Change Foundation’s strategic plan, *Hearing the stories, changing the story,* and its implementation plan, *The Storyboard,* explain our underlying imperative for engaging so-called “non-experts” in healthcare discussions, shared decision-making, and co-design of services.

To achieve our goal of improving people’s experience in Ontario’s healthcare system, we need to examine the system through the eyes of those who use it. Especially those who use it most. We need the participation of people who can talk first-hand about healthcare transitions. The Foundation is focusing on transitions because research shows that’s where things often go awry, the place where people’s health is put at risk due to delays and gaps in care and communication.

Seniors with chronic health conditions and their informal caregivers – our current population of focus – are uniquely positioned to relate the ins and outs and in-betweens of healthcare. So we began to roll out our strategic plan last fall with an engagement project to learn from their experiences, over time, at key transition points in the system. Which service arrangements worked best for them? Did their health information follow them from appointment to appointment? How were they treated before, during and after their care? At what points did things go well? Or badly? Clearly, seniors and caregivers are the experts here.

We tapped into their expertise in the fall of 2011, when we asked them to identify troublesome transitions and describe how these have affected their experience, health and quality of life. *Loud and Clear* is a summary of the stories they shared and ideas they proposed during this province-wide engagement. It also includes a set of original data tables derived from their answers to standardized questions and – for those interested in the process of public engagement – an account of our strategy, methodology, design, and lessons learned.

Essential knowledge – essential now

The stories and experiences of health system users such as seniors are an essential resource in The Change Foundation’s engagement and research, which also includes consultations with health system leaders and program managers. The findings we present in *Loud and Clear* will inform our work on PATH (Partners Advancing Transitions in Healthcare: A first with Ontario patients), our seminal signature project. PATH will transform healthcare transitions in one Ontario commu-
nity by bringing seniors and their caregivers to the table as full partners with healthcare providers from all sectors. Together, they will re-design healthcare delivery to improve transitions in care.

As we said in *The Storyboard*, there is “increasing evidence of a positive association between the experience of individuals and clinical outcomes, and between quality and financial performance.” For the quality of healthcare to improve in Ontario, we need to learn how best to incorporate people’s lived experience and their views directly into improvement methodologies.

While looking through the lens of patient and caregiver experience, The Change Foundation always takes a systems perspective too, to argue for those changes in thinking, practice and policy which are needed to create an integrated patient-centred healthcare system. The timing couldn’t be better. Right now, the province is considering how to respond to the Drummond Report on public services, make good on Ontario’s Action Plan for Health Care and get the most out of the Excellent Care for All Act.

If we can get the changes right – by pooling the expertise of both traditional and non-traditional “experts” and taking action on it – we can make real progress in improving the quality and sustainability of our healthcare system. Not only for our growing population of seniors and caregivers, but for all.
2. Loud and Clear

A province-wide engagement

The people

We needed to hear from a broad range of seniors and caregivers to reflect the diversity of Ontario’s older population – people from different age groups, geographic regions, and linguistic and cultural communities.¹

Age and perspective

Participants ranged from young and middle-aged caregivers to seniors in their 90s. Definitions of a senior vary, but, taking the threshold to be 60 years of age, over three-quarters (77%) of participants were seniors. This included near-equal numbers of people in their 60s, 70s and 80s, giving our research team access to a wide range of healthcare and transition-point experiences.

Participants at several engagement events included multi-generational family members. This allowed us to hear stories about transitions the whole family had been through, but from different perspectives.

¹ Note: Demographic information from participants was collected from the five core engagement events and online Storyboard tool. Consequently, the demographics presented in this report do not include those who participated in our pilot events (held in Ottawa and via webinar).

ENGAGEMENT / PUBLIC PARTICIPATION CORE VALUES

- Public participation is based on the belief that those who are affected by a decision have a right to be involved in the decision-making process.
- Public participation includes the promise that the public’s contribution will influence the decision.
- Public participation promotes sustainable decisions by recognizing and communicating the needs and interests of all participants, including decision makers.
- Public participation seeks out and facilitates the involvement of those potentially affected by or interested in a decision.
- Public participation seeks input from participants in designing how they participate.
- Public participation provides participants with the information they need to participate in a meaningful way.
- Public participation communicates to participants how their input affected the decision.

Source: International Association of Public Participation (IAP2)
Nearly half the participants (48%) indicated they had at least one chronic health condition, and a quarter (25%) were caregivers for a senior who had at least one chronic health condition. Just under a quarter (23.9%) indicated that they were both. Most frequently, these were spouses – a senior couple with one or both partners acting as caregiver for the other. This shows that the popular image of a caregiver as a younger and healthier friend or family member isn’t always the case. A significant proportion of our sample were seniors caring for a loved one while also trying to manage and access care for their own chronic health condition(s).

Finally, some participants said they didn’t fit any of the three main perspectives. These were younger people, not seniors, who had at least one chronic health condition of their own and were also providing care for a senior with at least one chronic health condition.

**Chronic health conditions**

As noted in the Introduction, we targeted seniors with chronic health conditions because they interact often with the healthcare system, and with a wide array of providers from different parts of it. The range and richness of the stories we heard certainly backs this up: some participants told us they had to make weekly visits to healthcare providers, while others had to keep straight recurring appointments with a host of different specialists. Participants were invited, but not required, to describe any chronic health conditions they had when registering for the in-person conversations. Many did, and some chose not to. Among the conditions referenced:

- autoimmune diseases, including Crohn’s disease
- cardiovascular diseases including heart failure
- chronic osteoarticular diseases such as osteoarthritis
- chronic respiratory diseases, including asthma and chronic obstructive pulmonary disease
- diabetes
- neurodegenerative diseases such as Alzheimer’s and Parkinson’s
- osteoporosis.

2 Demographic information on chronic health conditions was not collected at all in the online engagement tool.
Diversity

Many of the engagement events reflected Ontario’s cultural and linguistic diversity and included people with a range of incomes with varying levels of financial and human resources available to them. In Timmins and Ottawa, for example, we heard from seniors whose first language was French. And the Toronto engagement, held in partnership with Toronto Community Housing in the Regent Park neighbourhood, drew new Canadians and participants from Vietnamese, Bengali, Mandarin and Cantonese language communities (simultaneous interpretation was used). In Dryden and Peterborough, members of First Nations communities took part – with the help of a whisper translator in Dryden. All of this gave us additional perspectives – a look at how language and culture can shape people’s experience as they navigate transitions in healthcare.

The places

The in-person events (small group discussions) were held in six locations, which include a small city in the province’s northwest, a larger one in its northeast and a downtown neighbourhood in its largest urban centre. They were chosen to reflect geographic, linguistic, cultural and socio-economic diversity, and we also consulted census data about the proportion of seniors in the local population. Other engagement channels – online and webinar – added a broader range of participants from elsewhere in Ontario.
The process

Project design and development

Public engagement projects take a systematic approach to gathering and analyzing data that come in the form of contributions from participants. Our goal was to gather stories and input from demographically diverse seniors who have lived with various chronic health conditions, and caregivers for that population. Our team began by designing an engagement strategy that used a blend of in-person, online and webinar tools. The aim was to explore the same set of research questions through multiple channels.

As noted in Table 1, the Ottawa in-person event and cross-province webinar session were pilots. We conducted them early in 2011 to test our methodology and instruments; we then refined them to finalize the design of the project.

We took a step-by-step approach based in part on a methodology developed by the International Association for Public Participation (IAP2) – from our Strategy and Planning through to Analysis and Reporting and, finally, Evaluation and Lessons Learned. This was done in collaboration with external public participation practitioners and based on best practices in public engagement in healthcare. For an overview of the steps we took and further details on our project design and implementation, please see Appendix B, Engagement Methodology.

At the heart of our project design was a combination of three engagement instruments tailored to elicit broad and deep participation:

<table>
<thead>
<tr>
<th>Engagement Instrument</th>
<th>Description</th>
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<tbody>
<tr>
<td>1 In-person conversation</td>
<td>A series of six in-person events, organized with local partner organizations, to bring together groups of 15–25 seniors and caregivers to describe, share and explore their experiences</td>
</tr>
<tr>
<td>2 Webinar dialogue</td>
<td>A webinar dialogue, linking participants through web and phone conversations to share and explore their experiences</td>
</tr>
<tr>
<td>3 Online engagement</td>
<td>A specially designed website where seniors or caregivers could share their stories and ideas when it best suited them</td>
</tr>
</tbody>
</table>

We targeted seniors with chronic health conditions because they interact often with the healthcare system.

A partnership approach

We worked with local health, seniors’ and service agencies across Ontario to plan and host the six in-person conversations. These partner organizations – listed under Acknowledgements – helped us understand the local healthcare context, service innovations and challeng-
es; and helped us recruit 15 to 25 participants for each conversation. They included community health centres and family health teams, seniors’ clubs, hospitals, retirement homes and long-term care facilities, and other community-based organizations such as Toronto Community Housing. Local Health Integration Networks (LHI�) and community leaders provided helpful advice in connecting with these partners.

**The research questions**

These were based on literature about healthcare reform and patient experience, and were also informed by initial results from our pilot event in Ottawa and feedback from our Board of Directors. Questions were grouped under two closely related themes: people’s experience navigating transitions in the healthcare system; and how that experience was affected by their relationships with healthcare providers and others they encountered along the way.

1. Your experience navigating the healthcare system:
   • How was your experience moving from one part of the healthcare system to another, across one or several of these “transition” points?
   • And, what could have made your experience better?

2. How your relationships with people affected your experience:
   • How were you treated as a person through your healthcare journey – moving from location to location (or within locations), provider to provider, service to service?

**The in-person engagements**

The team decided on a 2.5 hour process: two hours for introductions and conversation followed by a 30-minute social for less formal discussion. The conversation component was experiential – an open, plenary, stories-sharing process where participants could listen and relate to experiences together as a group. The local healthcare leaders respected the process and were not present for any of the discussions. Keypad technology was used to pose close-ended questions and provide real-time voting results based on the anonymous responses of the people in the room. That helped frame the issues, instigate discussion, and capture data.
We used two engagement tools – a Conversation Guide and electronic voting keypads – to foster deep and informed dialogue:

**Conversation Guide**

We developed the guide to explain the issues and stimulate creative thinking, and distributed copies to participants in advance of each in-person event. The guide:

- helped people understand the policy issues around transitions in healthcare
- used straightforward visuals and accessible plain language
- featured one case study – a story from a senior and her caregiver – and discussion questions to help people think about their own stories in advance, and come ready to share
- provided background on The Change Foundation and its activities
- explained that people’s stories would be kept anonymous, and how they would be used.

**Electronic voting keypads**

This is a relatively new engagement tool – and a promising one. Participants’ evaluations, including written comments, showed that they believed the keypad voting enriched and advanced the discussions.

Before posing the two sets of research questions, the facilitator posed a short series of baseline questions for keypad voting. These were closed questions (i.e., participants were asked to indicate their level of agreement or disagreement with a given statement) about healthcare experience. The results were subsequently used for analysis, but there was also an on-the-spot benefit: they could be tallied and shared with the participants right away. This provided quantitative data that added another layer of context and understanding to the story-sharing that came next.

The statements that participants voted on via the keypads are shown – along with results – in the next section, Findings, and can be found in Appendix D. More details about our electronic keypad voting process can be found in Appendix B, Engagement Methodology.
The online engagements
A user-friendly website allowed for broader participation; people from anywhere in Ontario could log on and share their stories and ideas about healthcare transitions. This means of engagement was streamlined and efficient, could be done at the senior’s and/or caregiver’s convenience, and took only 15 to 20 minutes in all.

From the site, www.changefoundation.ca/mystory, people could launch an online “Storybook” tool. After entering basic demographic information, they were invited to respond to the same baseline-experience voting questions that were used for keypad voting during the in-person events. They were then invited to enter their stories. The Storybook was easy to use, and all participant data was stored safely and securely on Canadian-based server infrastructure.

Webinar engagement
Using a commercially available hosting platform, the addition of this means of engagement was designed to broaden the reach of our discussions in an efficient and accessible way. People from anywhere in Ontario could join the webinar and participate in a discussion session which mirrored the in-person process design.

The hybrid use of both internet and telephone-only connections meant that there were limited barriers to participation. Seniors and caregivers could participate from the comfort of home or join a small gathering hosted by a local health or social service provider.

For those with a full internet and telephone connection, the technology platform allowed for both verbal and written contributions to the dialogue and response to close-ended questions as well as the display of visual materials.
Data analysis and reporting
Once the field research had concluded, our team carefully reviewed all the stories they had gathered from participants – from the pilot event and webinar, the core in-person events and online engagements. Following leading practices in social research, they systematically reviewed and analyzed the data.

Their qualitative analysis was conducted using QSR NVivo, a specialist software application that allows researchers to organize and code qualitative data, identifying common threads and recurring themes and incorporating “hidden gems” such as key strategic comments that occur less frequently. (See Appendix E, Qualitative Data Coding Frequencies Using NVivo, for details.)

Participants and community organizations involved in our engagement will receive copies of *Loud and Clear*, following best practice in public engagement and fulfilling our commitment to the seniors and caregivers to share what we heard and found from our research and to explain how it feeds into efforts to improve the healthcare experience in Ontario.

Evaluation
Participants evaluated all aspects of the engagement through questionnaires at each of the core in-person events and in the online Storybook. The Change Foundation will conduct a more formal evaluation of the project and plans to conduct a series of key informant interviews with participants and staff – in keeping with our commitment to evaluate our work and share the lessons we learn in the growing field of public engagement.

Meanwhile, we encourage you to see Appendix F, Evaluation Data Table, for participants’ feedback; and Appendix G, Process Design Learning, for our preliminary account of what worked well – and what could have worked better – based on people’s feedback and our own reflections.
This section describes in detail what we learned from participants about their transition experiences: problems they encountered, how these could have been prevented, and also about times when the system worked well for them and met their health – and human – needs.

The text is drawn from qualitative data (people’s stories), while the graphs show the results of the 10 baseline-experience questions they answered online or through keypad voting. We flag within the text some specific and concrete suggestions that seniors and caregivers made during the engagements – ideas for change that they believe would help improve people’s healthcare experiences.

The majority (55%) of people in our core in-person and online engagements said they had experienced problems navigating a transition in the healthcare system, and less than one-fifth (16%) said they had not experienced any such problems.

We identified five key themes:
1. The primacy – and problems – of primary care
2. The importance of connections and clarity about next steps
3. The communication deficit
4. The inclusion factor – hey what about us?
5. Issues of equity

The themes are interrelated and frequently overlap, but we have collapsed the findings into these five themes for the sake of brevity, starting with the issue mentioned most often by participants – primary care. We then close the Findings section on a positive note: Pointing to the Positive, what people praised about the healthcare system.

Note that full details on the coding and topic categorization of the qualitative data, together with the number of “mentions” for each theme, are contained in Appendix E, Qualitative Data Coding Frequencies Using NVivo.
1. THE PRIMACY – AND PROBLEMS – OF PRIMARY CARE

Loud and Clear: Stop the dead ends; make primary care accountable for guiding people’s transitions.

A disconnect at the primary care level was a leading factor in people’s transition problems.

This disconnect appeared to be due to communication breakdown and/or lack of coordination and/or barriers between primary care physicians and other providers involved in seniors’ care. People frequently cited problems associated with access to their up-to-date records and lack of follow-up on referrals. Over half of participants said they had experienced a disruption in their care because of poor communication between health workers.

It was here at the primary care level that problems with transitions most often began, with basic services that were uncoordinated and not patient-centred.

Problems starting at step one

People’s problems often began with their first interaction to report a health complaint – be it with their family physician, nurse practitioner or other provider.

Other participants felt that the provider didn’t take their health complaint seriously, and said they were told to wait until the problem solved itself. We even heard from some seniors, who said they were experiencing either physical pain or emotional discomfort, that providers had told them there was no health problem and that they were simply imagining it.
No follow-up, or ineffective follow-up, on referrals

Participants valued seeing the right health provider and described positive experiences once they actually did see a specialist – but it was here, at the referral process, where transition often broke down.

We heard about referrals that never happened because the request wasn’t received. The patient or caregiver only learned that the appointment had fallen through the cracks when they called on their own to follow up, after waiting a long time with no contact or direction. One suggestion was for closer coordination around the hand-off from one provider to another, WITH THE PATIENT BEING CONTACTED BY BOTH PROVIDERS’ OFFICES to ensure a successful transition.

A related challenge was the transition from a specialist back to the original primary care provider. Many people said they didn’t hear from their primary care provider after their specialist appointment. This left them worried that any advice, or any test results that might indicate a problem, had been misplaced or not reported back. What they told us they want: a call from the primary provider’s office to complete the transition, even if only to tell them that everything is fine and there is no need for concern.

“Our doctor sent us for an appointment with a specialist. We waited five months and never heard anything, so I called and they had no record of the appointment. It would be a good idea if someone from the doctor’s office called the patient once an appointment is made to confirm.”

Ontario senior

Liz, a senior and caregiver from the London area, describes the difficulties she and her husband have had with transitions in healthcare, especially hospital to home.
Long wait times for transitions to and from primary care

People understood that wait times were inevitable, given specialists’ case loads, but they believed the wait times were too long – and worried that their health could worsen or be compromised in the interim. They also described other ways in which long wait times could contribute to unsuccessful transitions during the referral process: long periods seemed to increase the likelihood of their health information not being transferred ahead of them, and of associated test results not being received and incorporated into their medical records.

Mistakes, or disagreement with diagnosis or treatment course

We heard numerous stories in which people described what they believed were mistakes in their care, or disagreements they had had with their primary care providers about diagnoses or appropriate courses of treatment. In some cases, they said the provider had overlooked symptoms or results – their health status was actually much better, or much worse, than the provider had indicated. Many of these stories involved prescription drugs. People talked about noticing mistakes in medications that were dispensed to them, and getting little or no support from either their pharmacist or family physician. This left them frustrated – they felt abandoned by the system and were left with serious concerns about how their health may have been harmed.

In the words of one woman, a caregiver for her senior husband: “My husband went into the hospital for knee surgery. He came home but got sick and had to go back to hospital. His blood pressure was sky high. The hospital was looking for a knee infection but it turned out that he had pneumonia. We only found that out because a neighbour was a doctor and noticed discrepancies in our tests. The process was so difficult that he just wanted to go home! ... At times, we just felt forgotten by the health system.”

“One morning, we were both taking our medications. I looked down and saw a medication I didn’t recognize. I asked my husband what it was. It turns out that the pharmacy had been giving my husband my own pills for 32 days. I didn’t know what to do. I called and asked what to do but the pharmacy just said, ‘What do you want us to do about it.’ My family physician wasn’t there to help either.”

Ontario senior and caregiver
Short appointments that leave patients with outstanding health complaints

Some participants said they were frustrated that appointments with their regular primary care providers were too short for them to adequately discuss their health complaints. They pointed out that seniors with chronic conditions often have multiple, interrelated health issues that need to be managed. They suggested... PROVIDERS SHOULD ALLOCATE ENOUGH TIME TO DISCUSS THESE IN A SINGLE APPOINTMENT. Some even reported being told that they could only discuss one health issue during each appointment – if they had more, they’d need to book multiple appointments. This was clearly inconvenient and problematic for seniors, and also for their caregivers who might, for example, have to book time off work to accompany them.

Duplication and wasteful use of resources

Some participants believed that primary care providers sometimes use resources wastefully for diagnostic purposes. They said providers often refer seniors for blood work or other tests as a matter of course, even when the senior may have recently completed similar tests, the results of which should be in their record. It may sound easy from a provider’s perspective, but travelling to a clinic for tests can be challenging and taxing.
2.
THE IMPORTANCE OF CONNECTIONS AND CLARITY ABOUT NEXT STEPS

Loud and Clear: “Connect the Docs.” Connect all healthcare providers and services to, for, and with the patients and caregivers who need them. Clarify and simplify the process.

Across participants’ stories, we heard that many seniors are confused or uncertain about the next steps in their care journeys. This appears to be the result of the system being hard for them to navigate, the lack of an accessible map or user guide, and frequently poor communication between providers and patients, particularly at the point of discharge.

Confusion about what happens next

As indicated above, we heard a broad range of stories. The next step, and what’s required to take it, may seem clear to the healthcare worker or provider, but our findings (see figure 6) suggest that a large proportion of seniors leave appointments without a clear sense of what’s happening next in their care. If the senior is left feeling confused, lost and anxious, the transition eludes them. As the graph below shows, only just over a third of participants (35.2%) agreed or strongly agreed that they could easily navigate to the next step.

“What I see these seniors going through, I wonder if I’ll be suffering as well when I become a senior.”

Ontario caregiver
Fear, from not knowing what happens next

Some seniors described feeling afraid about what was going to happen to them. This seemed related to the same vulnerability that they and their caregivers feel when trying to navigate a system with roadblocks that make it hard to find the care they need. Some caregivers even expressed concerns on their own behalf – would they experience the same challenges tomorrow that their loved ones were having today?

Need for a health system map or guide

One woman said a map or guide should be developed for seniors and their caregivers, to help them navigate through the system. This idea was popular with other participants, many of whom described the system as hard for patients to use and as seeming extremely complex. They thought a map or guide could assist them with transitions by helping them understand where they were going for their next step, and where to find the care they were looking for.

Confusion about home care

Some people described challenging transitions involving home-care services coordinated by Community Care Access Centres (CCACs). In general, we found that seniors were often confused about which home-care services were available, at what price, and coordinated by which agency. Specific to CCACs, people related times when they’d been unhappy with the level of support from the CCAC and with the quality of services provided by the partner agency the CCAC had employed.

“I got confused about what help CCAC, VON, Rehab, and all the other services could provide. Home-care services were hard to use. The professional home care caregivers were bad. I had to call different agencies and call my friends for help and advice about who to call.”

Ontario senior
**Need for better information at discharge**

Some participants suggested more detailed communication between patient and provider before a discharge from a healthcare facility. They said this would have improved their own transition outcomes and experiences. **MORE INFORMATION, EXPLAINED IN MORE ACCESSIBLE WAYS, would have increased their understanding of the next steps and of their own role in making the transition a success in terms of booking follow-up care. One person WISHED THE ATTENDING PHYSICIAN HAD BEEN THERE AT DISCHARGE TIME TO ANSWER QUESTIONS – many of which went unanswered – and another wondered if hospitals could provide DISCHARGE HANDOUTS FOR CAREGIVERS.**

**Need for patients to be updated about their own files**

As figure 7 shows, only about half of the respondents felt they were kept abreast of what was in their own health information files.

“**When my sister had her stroke (in)Sept 2010 she was in hospital then in rehab, then in a nursing home, and she had the residence doctor. When she was released because ..I decided to take care of her 24/7, we had no doctor because the nursing care doctor does not follow the patient outside of the place. Her previous doctor (secretary) told us she was discharged and she was the nursing home doctor’s patient. Well I took it upon myself to find a doctor and found one but then her family doctor said that she was her patient and that she HAD to return to him. My sister was very stressed out about that because she was happy to get a lady doctor and her family doctor is not compassionate and does not follow up on blood work and is very cold. She is stressed from one visit with him and is exhausted from the trip to see him.**

Ontario caregiver via the online “Storybook”

**FIGURE 7: My healthcare workers do a good job of communicating and sharing my health information with me (and my caregiver).** (N=90)
3. THE COMMUNICATION DEFICIT

Loud and Clear: Communicate early, often and well – provider to patient/caregiver, provider to provider, system to system.

Communication involves everything from specific information to the most general. As one participant stated, “What would have helped me is a guide on how to find my way around the system.” The government, she said, should send a guide to everyone on their 65th birthday.

And there's the question of how information is conveyed.

We heard stories about communication problems and communication breakdown at all levels – person to person, facility to person, system to system.

One of the most frequent themes in participants’ stories was unsatisfactory communications they had with healthcare providers. What they wanted from their healthcare experience was to be treated with respect, to have their preferences about care options taken seriously, and their feelings acknowledged.

A perception, among patients, that their healthcare providers aren’t listening

This was the most frequently mentioned communication problem, contributing to many people’s negative transition experiences. It crossed different locations and types of transitions, ranging from one participant whose requests for pain relief seemed to go unheeded in hospital, to another whose doctor didn’t seem interested in her views on what kind of care should come next.

If providers fail to listen adequately when patients request a healthcare preference or describe their symptoms, needs or goals, how can we expect healthcare transitions to be positive, or even successful? What’s required is respect, and acknowledgement of people’s rights as patients. As one participant suggested, “What’s missing is a list of patients’ rights!”

“More explanation of my medical condition would have greatly improved my experience at both of these hospitals. The handbooks prepared by the Heart and Stroke Foundation (or by other organizations for other diseases) need to be given to caregivers and patients immediately at the various transition points.”

Ontario senior via the online “Storybook”
“My cardiologist recommended that I not take Tylenol 3’s but when the surgeon came to see me before discharge, I told him this and in front of his medical students he disagreed and said there was no reason I couldn’t take it. He ignored me, didn’t listen and didn’t change my discharge notes to reflect what I’d told him.”

Ontario senior

The following story comes from London, Ontario:

“My husband has had a problem for the last year and a half: an infection in his legs. He’s on a drug that wrecks his immune system to treat his leg infection, so it means he often gets sick. He’s had three major infections in the last year, the last time with a bladder infection. As a result, all of a sudden he found he couldn’t get up. He was in the bathroom much of the night, frequently having to pee; but he couldn’t get up in the morning. I took a urine sample to the doctor and she confirmed that it was a bladder infection. The next day, he was walking to the bathroom to pee but fell over. He’s too heavy for me to lift, so I had to call an ambulance.

“The hospital called next day to discharge him despite my requests to keep him at least 24 hours for observation. That same night, he couldn’t get up again, and when he tried, he fell over. There were two ambulances in 24 hours because the hospital didn’t listen to me and what my husband and I wanted for our care! This time, they kept him in for a while, but then sent him home again! I said you’ve got to keep him for more than four hours because his symptoms come and go! Eventually, he got better by himself and the medication he received.”

More respondents felt listened to than not, but figure 8 also shows that less than half of them (46.9%) agreed or strongly agreed that their healthcare workers were listening to them to understand their unique needs.

FIGURE 8: My healthcare workers listen to me to make sure that they understand my needs. (N=81)
**Reports of rude or insensitive communication**
Some participants said they’d been spoken to rudely by a provider or by staff at a facility or physician’s office. This contributed to their feeling of isolation and of not being supported by those they turned to for help.

**Desire to be treated “as a human being”**
People said there were times when they simply wanted to feel treated “more like a human being” – like a vulnerable person looking to others for care and support. For some, this meant a human touch with more empathy and compassion – a nurse responding quickly to requests for help, for example, or a family physician taking a few extra minutes to explain what was happening and to address some of their concerns.

“Hospital professionals should have provided me with more reassurance and more understanding, especially as it pertains to the possible ‘incontinence’ after a stroke.”

“My doctor told me, ‘if you don’t get better, you’ll have to go to ...’, which made me scared. I thought it was a place people go to die. I wish I had had a brochure [on the facility] at that time because it would have reassured me and helped me understand that it’s not that bad.”

**Poor communication between healthcare workers**
The results of our baseline-experience voting (figure 9) illustrate the potential size and scope of healthcare system communication problems at the individual level as well as at the institutional. Over half of participants (52.2%) responded that they had experienced a disruption in their care because of poor communication between healthcare workers and/or providers. Only one-fifth (21.1%) said they had not experienced such a disruption.

**FIGURE 9: I have experienced a disruption in my care because of poor communication between health care workers. (N=90)**

![Graph showing the percentage of participants experiencing disruptions in care due to poor communication between healthcare workers.](image)
Given that communication problems are closely linked to other problems – and are sometimes a source of them – the voting results shown in figure 10 may not be surprising. Only 36.7% of respondents agreed or strongly agreed that all the healthcare workers involved in their care were working together well.

**FIGURE 10:** All the different healthcare workers involved in my care work together well. (N=89)

<table>
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<th>Percentage</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>I don’t know</th>
</tr>
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<td>21.3</td>
<td>22.5</td>
<td>28.9</td>
<td>7.8</td>
<td>2.2</td>
<td></td>
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</tbody>
</table>

*Problems with record-and information-sharing among providers*

Healthcare transitions are often hampered by poor information-sharing across the system, particularly the transfer of patients’ medical records.

Many people described instances where their personal health information had not been transferred from one provider to another at the time they needed it – often between a family physician and a specialist. We heard of them waiting several months for a referral – then arriving to discover that the records the specialist needed for their assessment had not been transferred from the family physician, or had somehow “got lost” between the two offices.

We heard of similar records-management breakdowns occurring between healthcare facilities, when a patient was transferred from one to another – often between hospital and long-term care. Seniors arriving back to their long-term care facilities after a short stay in hospital sometimes found that the records about their treatment and discharge had not arrived with them. This left staff at the facility unaware of any changes in the senior’s health status or care needs.

*Some people carrying their own medical records through the system*

In frustration, some seniors and caregivers have decided to simply try to manage their own health information. They create packages that they update – with recent test results,
medications lists and personal health history — and carry them from one facility or provider to another, instead of relying on the system to transfer their information. As one woman said, “EVERYBODY SHOULD BE ISSUED THEIR OWN MEDICAL FORMS TO TAKE WITH THEM.”

However, we heard of providers who refused to give people the copies of test results or other documentation that they asked for. Patients found this lack of cooperation hard to fathom.

We also heard of regrettable instances where providers overlooked the information even though it had been given to them for reference. In one participant’s case, providers reviewed a list of his current medications, but then gave him another medication that led to a foreseeable adverse drug interaction, causing serious health complications.

**Need for a coordinated electronic health records (EHR) system**

To solve problems with the transfer of patient records, many participants called for wider use of electronic records by providers and facilities across the healthcare system. They knew the technology was readily available — many were aware of electronic medical records (EMR) in their family doctors’ offices — and couldn’t see why it wasn’t being used to manage and transfer records on a system-wide basis.

“In the past four years with my husband I’ve made 11 transitions. About the third transition, my daughter put together a sheet with all the medical information about my husband. That made such a big difference. When I give people that sheet, they have the RIGHT health history. Everybody should be issued their own medical forms to take with them. They get everything right, including the medications. When I give this to nurses they say, ‘Oh, that’s great!’”

Ontario senior
THE INCLUSION FACTOR – HEY, WHAT ABOUT US?

Loud and Clear: Include patients, families and caregivers in decisions that affect their lives and health.

Transitions can have a significant impact on seniors’ and caregivers’ lives. But participants believed this was often overlooked by the health system and individual providers when decisions were being made.

Lack of consideration for the impact transitions can have on quality of life

Successful transitions can lead seniors to the healthcare services they need. But just making those transitions can have a negative impact on their quality of life. Some people said they struggled to adjust to new medications and deal with side effects, struggled to adjust to new service arrangements such as home care, and found travelling to appointments a challenge because of mobility issues. People were grateful for the care they received. They just wished that the system – and providers and workers in it – better recognized the difficulties that sometimes come with accessing this care and making care transitions – difficulties that can affect other aspects of seniors’ lives.

Resource burden placed on caregivers

Navigating transitions can also place a disproportionate burden on caregivers. We heard from many of them, from across Ontario, that their roles involve significant sacrifice of time – including other family time – and money. They’re often required to take time off work regularly to transport seniors to and from appointments, as well as managing their records and medications and providing a range of services from cooking and cleaning to actual health services. Many caregivers told us their role requires financial resources, whether to pay for home care, medications, etc., or due to unpaid time away from work.

Caregivers understood that their role meant making sacrifices. Some said they would appreciate some financial assistance from government, and one participant said communities
should provide training COURSES, SEMINARS OR PAMPHLETS TO HELP CAREGIVERS and educate them in navigating the system. But most important, according to the caregivers we heard from, was this: that healthcare providers appreciate that caregivers’ circumstances can be difficult, and make greater efforts to accommodate them during transitions.

This comment is from a caregiver in Dryden: “Our doctor was very good, but she did her rounds with patients at 5:00 to 6:00 a.m. and I can’t be there to ask questions. The whole time my mother was in hospital, I couldn’t get two minutes with the doctor. I was involved in her care but that role wasn’t recognized or valued. Because of the privacy issues, the nurses were reluctant to give me information about my mother’s care and rationale for decisions. One suggestion from a nurse was to put a note on her chart asking that information be passed to me too.”

Disruptive changes in home-care support staff and schedules
Some seniors told us that changes in their home-care services made transitions even more challenging. They said they valued continuity in their home help, with the same worker coming consistently. They developed relationships of trust and understanding through these regular visits, and coordinated other aspects of their lives around the worker’s schedule.

Frequent shift changes and personnel changes, then, were hard – and led participants to believe that their convenience and quality of life was not an important consideration for the service agencies. People wanted greater predictability and, when change had to happen, notice in advance.

Feelings of pressure to leave hospital
Transitions involving hospital discharge – these can be particularly difficult. And even more so when one feels pressured to leave prematurely. We heard of some seniors calling their caregivers in distress because providers had threatened to start charging them fees if they didn’t leave.

“I’ve been having community care for two years. I’m supposed to have two hours every other day. The shift times are often changed by the service providers without even telling me. Sometimes they come late or early. It makes me want to pull my hair out. I call to complain and they tell me not to worry and that the time change has been approved. But it’s not convenient for me!”

Ontario senior
“Medication dosage and medication prescribed was sometimes changed without my real understanding as to what was being prescribed and why.”

Ontario senior

**Need for greater involvement in making care decisions**

Across participants’ range of experiences, there was an expressed need to be more included in decision-making about care options. For seniors, this meant having a voice and a say in when, where and how they would receive care. For caregivers, it meant having a greater say in care decisions that would affect their lives too. Some told us they had never been asked whether a particular care option would be convenient, or even possible, for them, based on their own personal circumstances.

Despite the voting results in figure 11, seniors’ and caregivers’ stories and shared experiences strongly indicated that they did not feel adequately involved when decisions were being made – for example, about their next treatment or care placement. Both seniors and caregivers often found that decisions about health services were made without their input, or even their knowledge, and weren’t transparent to them.

![FIGURE 11: Healthcare workers involve me in making important decisions about my care. (N=86)](image-url)
Lack of transparency about how decisions are made
Participants told us they often don’t understand how decisions are made about their care – who gets to make them, based on what criteria and using what information. As patients, seniors want to understand what medication or treatment they’re receiving and, if it is changed, why.

One area of significant dissatisfaction: wait list management for long-term care and other services. Many believed that these lists were not managed transparently, and pointed to instances where they felt they’d been treated unfairly by others “jumping ahead” of them in line.

“My wife was here in long-term care in the hospital for a year. She was supposed to be transferred to the Manor nursing home. I assumed that the hospital was managing a waiting list fairly for admission to the Manor home. But I know there are five couples who have bypassed my wife for admission to the home. This lack of knowing about a timeline makes me feel insecure because we don’t know when the transition is going to happen. I don’t know where I stand. Am I 35th in line? Second in line? Am I even in line?”

Ontario senior and caregiver
5. ISSUES OF EQUITY

Loud and Clear: Don’t let people who are facing barriers fall behind.

People expressed concerns about healthcare transitions for the most vulnerable – i.e., seniors without caregiver support and those with cognitive deficits or mental health problems. They told stories in which these seniors faced greater barriers than others when navigating transitions, and, in some concerning instances, appeared to receive lower-quality care.

Concerns about seniors with cognitive and mental health challenges

These seniors face additional barriers as they navigate the health system. They rely on their caregivers – some of whom we heard from – to accompany them through every step, being on hand to give vital information to providers.

Some of the caregivers described a situation when they weren’t available or present; the senior made a transition alone, resulting in confusion and uncoordinated care. These caregivers speculated – as did other participants – that transition challenges of this type might increase as the province’s population ages.

We also heard stories from participants who had seen seniors with these health conditions receiving what seemed to be

“My mother also can’t remember what health workers tell her so she can’t pass that on to me, her caregiver. One time, I wasn’t allowed to travel to Thunder Bay with my mother and when she arrived, she couldn’t remember what was wrong with her, so she couldn’t tell the hospital staff and I wasn’t there to help!”

Ontario caregiver
lower-quality care. Participants recognized that these seniors may present unique challenges, but there was a belief among many that they weren’t treated with the same degree of respect from staff. In some stories, these seniors were left in distress longer, after requesting assistance; in others, they were spoken to in a patronizing tone, as though they were children.

**Double vulnerability – alone, and with cognitive or mental health challenges**

People wondered how seniors with capacity deficits would cope with transitions if they didn’t have a caregiver or family or friend support. Who would coordinate their care, take them to appointments and advocate on their behalf?

**Advocacy – linked to better transitions for all seniors**

Caregivers told us that advocacy was the most important aspect of their role in trying to ensure a positive transition experience. This meant arranging and managing appointments and records, “pushing back” against roadblocks, and taking whatever steps they felt were necessary to get their loved ones the desired or required care. Seniors without a caregiver echoed the importance of advocacy.

“**In long-term facilities, as long as people are cognitively capable they get respect from health workers. When they aren’t capable they aren’t treated with respect, and get patronizing treatment from staff. There seems to be a line there, about capacity and respect, and that seems to be a real concern. It’s when people are at their most vulnerable that the level of care gets lower, as well as the treatment as a human being.”**

*Ontario caregiver*

**Worries about consequences of complaining**

We heard of more than one situation where the caregiver of a vulnerable senior – i.e., one with cognitive or mental health challenges – was unhappy with the senior’s treatment but didn’t complain for fear of making it worse. In a troubling observation, these participants told us they were worried about repercussions, especially when they weren’t present to observe things first-hand.

“**My mother ... I don’t know what she would have done without me as an advocate and helper to navigate through the system. We had to explain her care and what was going to happen to her next. At the end of the day, seniors with chronic health conditions need to have an advocate in order to make it through.”**

*Ontario caregiver*
They suggested that those who don’t have a support network must be prepared to advocate on their own behalf.

There was broad consensus that advocacy – whether a caregiver’s, or one’s own – leads to a better transition experience. It helps ensure that steps will be explained to you, and helps bring problems to a providers’ attention to get solved.

But some people cautioned that providers can be uncomfortable with strong advocates, especially caregivers. They said providers aren’t used to people who ask questions, express disagreement and try to manage a senior’s transition on behalf of the healthcare system.

**Seniors advocating on their own behalf**

This meant taking greater ownership over their own healthcare journey – following up on referrals and test results instead of assuming it was being done for them; asking questions; voicing disagreement if a provider proposed a care option they didn’t like; and speaking up when unhappy with the quality of care received.

“Caregivers have to be relentless, organized and an advocate both for yourself and the person you’re caring for all the time.”

**Ontario caregiver**

But some people cautioned that providers can be uncomfortable with strong advocates, especially caregivers. They said providers aren’t used to people who ask questions, express disagreement and try to manage a senior’s transition on behalf of the healthcare system.

**“Patients need to BE PROACTIVE. Don’t sit back and wait. Advocate on your own behalf. Be informed, learn the options.”**

**Ontario senior**

**Barriers to care**

Some participants said seniors with chronic health conditions face more barriers than other patients do when navigating transitions. Some barriers are obvious, such as physical accessibility issues, but participants told us that financial barriers were more difficult for them to overcome.
For example, travelling alone to appointments can be expensive, whether it involves taxi fare or parking fees at a facility.

Some people, including providers, may see these costs as acceptably low. But participants reminded us that seniors with chronic health conditions are often on very modest incomes. Any additional or unexpected costs can be hard for them to afford.

Caregiver challenges around legal issues
Caregivers spoke of legal complications that had created communication problems for them at transition points. Even some with documented Powers of Attorney were refused convenient access to information – instead of getting it over the phone, they had to travel to the facility and see the provider in person.

This represented a needless barrier in their attempts to help their loved ones get the best care and experience and to balance their caregiver roles with social, work and other commitments.

Geographical and cultural challenges
Participants in northern Ontario said they often have to drive three or four hours each way for an appointment. And seniors and their caregivers in small communities spoke about another challenge: finding a family physician who will stay there long enough to get to know them and help them through ongoing transitions.

At the Toronto multilingual dialogue, people spoke of linguistic and cultural obstacles to navigating transitions. Language barriers between patients and providers can be challenging, but some facilities are making effective use of translation machines and human interpreters. However, cultural barriers may remain. Some seniors told us they don’t feel respected by providers who don’t speak their language.
POINTING TO THE POSITIVES

Our main goal in *Loud and Clear* was to learn more about the challenges faced by seniors with chronic health conditions and their caregivers when navigating transitions in Ontario’s healthcare system. But we also wanted to know what went well. Despite the challenges, seniors and caregivers acknowledged and celebrated the people and processes that made for a good transition experience. These stories were often marked by the compassion, professionalism and dedication of healthcare providers.

**On navigating transitions**

Some participants said it seemed as if the health system was mobilizing and wrapping around them to provide the services they needed, and taking them step by step on their care journey. One man said that after he suffered a stroke, the system “sprang into action” and provided him with integrated, high-quality care.

**On treatment from health providers**

A positive experience with a health provider can make all the difference to patients trying to find their way through the healthcare system. It may be a moment of compassion, or a few extra minutes a provider spends to help them feel reassured. It may well be the part of the healthcare experience that they remember most. The positive experiences we heard about usually included a feeling, on the senior’s or caregiver’s part, that their voice and opinions had been heard. In short, that they had been treated like a human being. This engendered feelings of trust, as conveyed in the voting results in figures 12 and 13:

**FIGURE 12: I trust the healthcare workers involved in my care.** (N=86)

**FIGURE 13: People in the healthcare system do a good job of treating me as a human being.** (N=84)
**On team-based care**

People were especially positive about nurse practitioners and nurse practitioner-led clinics. To quote one participant in Dryden: “Seeing nurse practitioners works really well. It’s been a really big help for us. We can always get in to see one and they call a doctor right away if they need to.” To quote another participant, in Timmins: “Some people think that nurse practitioners are a solution for the problems in the healthcare system.”

“In my journey, my workers have been great. I was recently diagnosed with [early stage] melanoma. Because of my great relationship with my providers, I had surgery within 24 hours so I could still go on a pre-booked vacation. I feel respected. Perhaps because they listened to me and what I wanted. I love the healthcare that I get when my problems are relatively minor. A doctor recently took a lot of time to explain cancer to me so I don’t worry as much. Wish I’d had this seven years ago when I first learned I had cancer!”

*Ontario senior*
4. Next Steps

Following up on the findings

We’re not done listening – not by a long shot.

The engagement that fueled this report was the first step in a trajectory that will take us further. It will take us into one Ontario community, starting this summer, to support an experiment that we believe will improve transitions in healthcare and introduce to Ontario the benefits of building patient and caregiver participation into the re-design of health services. That’s the essence of The Change Foundation project called PATH – Partners Advancing Transitions in Healthcare: A first with Ontario patients. One of the first things we’ll do is elicit the views of local seniors and caregivers, as well as healthcare providers, to help us identify the most pressing healthcare transition issues in the community. That way, we’ll know which ones to tackle together.

Before we get there, we will have heard from health system leaders – the stewards and stakeholders of Ontario’s healthcare system – about their perceptions of the state and future fate of patient-centred healthcare. A separate report on those perspectives will be released before the fall.
At the same time, The Change Foundation plans to continue our multi-directional conversations with health-system users in Ontario via various formats, but principally through a Public Engagement Panel we’ll launch in the fall. It will allow us to keep listening to – and learning from – Ontarians about what hastens or hinders a good healthcare experience. We expect to engender dialogue between our PATH community partners and our panel, and will turn to our panel to debate the value and practicality of the latest thinking and initiatives emerging from system leaders. We will frame relevant and timely questions for discussion and deliberation – questions to which we genuinely want answers.

We will bring together all the players who’ve brought our strategic plan to life – healthcare’s stewards, stakeholders and users – for a capstone summit to discuss the merit and meaning of our work and to arrive at recommendations for change. But first, we’ll once again go back to seniors and caregivers in Ontario to engage with them about navigating the province’s healthcare system. Has the yardstick moved? Has the journey improved?

Is the destination different? We will also check in with the health system leaders to see if progress has been made in how our healthcare system serves those who spend a lot of time working their way across it.

We began our engagement with the belief that the lived realities of those who rely on a host of healthcare services and supports are worth listening to. Their experience is their expertise and our evidence – an essential element in understanding the efficacy and impact of our healthcare system.

To those experts – the seniors and caregivers who gave us their time, energy and stories so that together we could learn how to improve people’s healthcare experience in Ontario – we offer our thanks. As we carry their Loud and Clear messages into future projects and add it to our bank of healthcare-system and public-engagement knowledge, we promise that their stories and insights will be shared widely. They have become part of our evidence to incite change.
5. Appendices

Appendix A.
List of Events and Locations

A full explanation of the criteria used to select event locations can be found on page 19.

<table>
<thead>
<tr>
<th>Event</th>
<th>Location</th>
<th>Venue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pilot</td>
<td>Ottawa</td>
<td>Bruyère Continuing Care</td>
</tr>
<tr>
<td>Conversation Guide Focus Test</td>
<td>Ottawa</td>
<td>The Palisades Retirement Residence</td>
</tr>
<tr>
<td>Core Engagement Event 1</td>
<td>Dryden</td>
<td>Patricia Gardens Supportive Housing</td>
</tr>
<tr>
<td>Core Engagement Event 2</td>
<td>Timmins</td>
<td>Timmins and District Hospital</td>
</tr>
<tr>
<td>Core Engagement Event 3</td>
<td>Peterborough</td>
<td>Canterbury Gardens Retirement Residence</td>
</tr>
<tr>
<td>Core Engagement Event 4</td>
<td>London</td>
<td>Kiwanis Seniors Community Centre</td>
</tr>
<tr>
<td>Core Engagement Event 5</td>
<td>Toronto</td>
<td>Community Room, Residence, Regent Park</td>
</tr>
</tbody>
</table>

Clockwise from top left:
Dryden, Timmins, Ottawa, Peterborough, Toronto, London
Appendix B.
Engagement Methodology

Strategy and planning
We reviewed and considered different engagement instruments, ranging from large-scale town hall meetings to targeted key informant interviews, but decided on an approach using a complementary blend of in-person community-based conversations, a webinar dialogue and online engagement. This approach, using these instruments, provided the team with multiple channels for gathering data, and participants with differing options for sharing their stories.

Pilot events
To test our engagement approach, early designs of the research instruments and, indeed, the underlying assumptions of our overall strategy, we held pilot events with seniors and caregivers. First, an in-person conversation pilot, held in Ottawa in partnership with Bruyère Continuing Care, which offers rehabilitation, long-term and palliative care at facilities in Ottawa; and, second, our webinar held in conjunction with several healthcare organizations in different parts of Ontario.
While the pilots allowed us to gather participants’ stories and ideas about transition experiences, they also offered some important process learnings about where, when and how to effectively engage seniors with chronic health conditions and their informal caregivers. We learned or confirmed that:

- the preferred engagement timing was immediately following the lunch hour. This was identified as the most accessible and user-friendly time of day for participants – whether caregiver friends or family, or seniors.
- the maximum duration for engagements was 2.5 hours. The pilot went slightly longer, and some seniors with chronic health conditions struggled to stay actively involved to the end.
- a community-based care facility, with meeting rooms and appropriate accessibility features, was a highly suitable venue for the event. Participants familiar with the building are comfortable in an environment they know.
- an informal atmosphere that is open and accessible is best – it helps participants feel welcome and relaxed.
- due to some participants’ hearing problems or reduced ability to speak loudly, microphones proved to be essential for both participants and facilitators. This ensured that everyone could take part equally in the dialogue.
- a medium-sized group of 15–25 participants is large enough to provide an adequate range of perspectives and experiences, but small enough to allow everyone to participate and to maintain an intimate environment.

Each of these findings from pilot events was incorporated into the process design for the core engagement events.

**A partnership approach**

In identifying and inviting potential participants, we worked closely with our partner organizations (listed under Acknowledgements) to develop a “reflective sample” – one which, while not based on a randomized, representative approach, would provide a group of participants that reflected the age, language and cultural diversity of each location. This gave us an overall sample of participants that similarly reflects the diversity of the senior and caregiver populations in Ontario.

**Design and development**

As described in the report, we created and/or used various research instruments to gather data in the form of participant views and stories.

**Electronic voting keypads**

The voting keypad is a relatively new and innovative engagement tool, the use of which can use a brief explanation here. We asked participants to respond to ten statements (listed, with results, in the Findings section of the report and in Appendix D.). They could indicate their level of agreement or disagreement, on a Likert scale, or choose an “I don’t know” option. All voting was optional and anonymous.

**Implementation**

With pre-launch strategy, planning, design and development activities completed, the core in-person engagement events were held and the website opened for participation.
The timing was planned to hold the in-person events in the late autumn to allow for participant recruitment after the summer vacation period, and to ensure that subsequent events were held before winter weather arrived that would have acted as a potential barrier to physical participation for seniors with chronic health conditions.

### Analysis and reporting

As noted in the report, our qualitative analysis was conducted using QSR NVivo. See Appendix E, Qualitative Data Coding Frequencies, for details.

### Evaluation and lessons learned

The seniors and caregivers engagement is the first in the Foundation’s engagement series, initiating the strategic plan’s implementation; other phases and projects will follow and continue through to the end of the plan, in 2015. We are committed to evaluating our work and to sharing our lessons with the growing field of engagement.

As noted in the report, our team involved participants in evaluating all aspects of the engagement, and the Foundation will also be conducting a more formal evaluation of the project and plans to conduct a series of key informant interviews with participants and staff.

For results of participant evaluations, see Appendix F, Evaluation Data Table; for our initial thoughts on the project’s successes and lessons, drawn from participant evaluations and our own reflections, see Appendix G, Process Design Learning.

<table>
<thead>
<tr>
<th>Timeline</th>
<th>Research Steps</th>
</tr>
</thead>
<tbody>
<tr>
<td>September and October</td>
<td>Participant identification and recruitment</td>
</tr>
<tr>
<td>November and early December</td>
<td>Core in-person engagement events held (Dryden, Timmins, Peterborough, London and Toronto), Engagement website launched</td>
</tr>
<tr>
<td>January</td>
<td>Field research concluded, Quantitative and qualitative data analysis</td>
</tr>
<tr>
<td>February</td>
<td>Development of engagement reports</td>
</tr>
</tbody>
</table>
Appendix C.
In-Person Event Agenda

Note that start and end times varied slightly across events based on meeting-place availability.

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>12:15 - 12:30</td>
<td>Arrival and registration</td>
</tr>
<tr>
<td>12:30 - 12:45</td>
<td>Welcome and introductions</td>
</tr>
<tr>
<td>12:45 - 12:55</td>
<td>What do we mean by “transitions” in the healthcare system?</td>
</tr>
<tr>
<td>12:55 - 1:45</td>
<td><strong>Discussion Topic 1:</strong> Your experience finding your way across the healthcare system</td>
</tr>
<tr>
<td>1:45 - 2:25</td>
<td><strong>Discussion Topic 2:</strong> How your relationships with people affected your experience</td>
</tr>
<tr>
<td>2:25 - 2:30</td>
<td>Closing</td>
</tr>
<tr>
<td>2:30 - 3:00</td>
<td>Tea Party Social (optional)</td>
</tr>
</tbody>
</table>

Appendix D.
Keypad Voting Data

<table>
<thead>
<tr>
<th>I have had problems navigating a transition in the healthcare system.</th>
<th>I can easily navigate through the healthcare system to find the answers I need to take the next step in my care.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strongly Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>6.3%</td>
<td>22.7%</td>
</tr>
<tr>
<td>Disagree</td>
<td>Disagree</td>
</tr>
<tr>
<td>9.5%</td>
<td>26.1%</td>
</tr>
<tr>
<td>Neutral</td>
<td>Neutral</td>
</tr>
<tr>
<td>24.2%</td>
<td>9.1%</td>
</tr>
<tr>
<td>Agree</td>
<td>Agree</td>
</tr>
<tr>
<td>24.2%</td>
<td>28.4%</td>
</tr>
<tr>
<td>Strongly Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>31.6%</td>
<td>6.8%</td>
</tr>
<tr>
<td>I Don’t Know</td>
<td>I Don’t Know</td>
</tr>
<tr>
<td>4.2%</td>
<td>6.8%</td>
</tr>
</tbody>
</table>

(N=95) (N=86)
<table>
<thead>
<tr>
<th>My healthcare workers do a good job of communicating and sharing my health information with me (and my caregiver).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strongly Disagree</strong></td>
</tr>
<tr>
<td><strong>Disagree</strong></td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
</tr>
<tr>
<td><strong>Agree</strong></td>
</tr>
<tr>
<td><strong>Strongly Agree</strong></td>
</tr>
<tr>
<td><strong>I Don't Know</strong></td>
</tr>
</tbody>
</table>

(N=90)

<table>
<thead>
<tr>
<th>I have experienced a disruption in my care because of poor communication between healthcare workers.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strongly Disagree</strong></td>
</tr>
<tr>
<td><strong>Disagree</strong></td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
</tr>
<tr>
<td><strong>Agree</strong></td>
</tr>
<tr>
<td><strong>Strongly Agree</strong></td>
</tr>
<tr>
<td><strong>I Don't Know</strong></td>
</tr>
</tbody>
</table>

(N=90)

<table>
<thead>
<tr>
<th>All the different healthcare workers involved in my care work together well.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strongly Disagree</strong></td>
</tr>
<tr>
<td><strong>Disagree</strong></td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
</tr>
<tr>
<td><strong>Agree</strong></td>
</tr>
<tr>
<td><strong>Strongly Agree</strong></td>
</tr>
<tr>
<td><strong>I Don't Know</strong></td>
</tr>
</tbody>
</table>

(N=89)

<table>
<thead>
<tr>
<th>People in the healthcare system do a good job of treating me as a human being.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strongly Disagree</strong></td>
</tr>
<tr>
<td><strong>Disagree</strong></td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
</tr>
<tr>
<td><strong>Agree</strong></td>
</tr>
<tr>
<td><strong>Strongly Agree</strong></td>
</tr>
<tr>
<td><strong>I Don't Know</strong></td>
</tr>
</tbody>
</table>

(N=84)

<table>
<thead>
<tr>
<th>I trust the healthcare workers involved in my care.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strongly Disagree</strong></td>
</tr>
<tr>
<td><strong>Disagree</strong></td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
</tr>
<tr>
<td><strong>Agree</strong></td>
</tr>
<tr>
<td><strong>Strongly Agree</strong></td>
</tr>
<tr>
<td><strong>I Don't Know</strong></td>
</tr>
</tbody>
</table>

(N=86)

<table>
<thead>
<tr>
<th>My healthcare workers listen to me to make sure that they understand my needs.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Strongly Disagree</strong></td>
</tr>
<tr>
<td><strong>Disagree</strong></td>
</tr>
<tr>
<td><strong>Neutral</strong></td>
</tr>
<tr>
<td><strong>Agree</strong></td>
</tr>
<tr>
<td><strong>Strongly Agree</strong></td>
</tr>
<tr>
<td><strong>I Don't Know</strong></td>
</tr>
</tbody>
</table>

(N=81)
Appendix E.
Qualitative Data Coding Frequencies Using NVivo

<table>
<thead>
<tr>
<th>Themes and sub-themes, by frequency</th>
<th># of mentions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary care disconnect: broad challenges with transition experiences.</strong></td>
<td><strong>SUM = 59</strong></td>
</tr>
<tr>
<td>a) Mistakes, disagreement with diagnosis or treatment course</td>
<td>14</td>
</tr>
<tr>
<td>b) Health system map or guide for seniors and caregivers</td>
<td>7</td>
</tr>
<tr>
<td>c) Transition problems associated with primary care</td>
<td>6</td>
</tr>
<tr>
<td>d) Short appointments leave patients with outstanding health complaints</td>
<td>6</td>
</tr>
<tr>
<td>e) Absence of or ineffective follow-up on referrals</td>
<td>4</td>
</tr>
<tr>
<td>f) Wait times...</td>
<td>4</td>
</tr>
<tr>
<td>• At the emergency department</td>
<td>7</td>
</tr>
<tr>
<td>• For long-term beds in the community</td>
<td>2</td>
</tr>
<tr>
<td>• To see specialists</td>
<td>6</td>
</tr>
<tr>
<td>g) Duplication and wasteful use of resources</td>
<td>3</td>
</tr>
<tr>
<td>h) Suggestion for case managers to support transitions</td>
<td>2</td>
</tr>
<tr>
<td>Patient records and information sharing among providers</td>
<td>SUM = 44</td>
</tr>
<tr>
<td>-------------------------------------------------------</td>
<td>----------</td>
</tr>
<tr>
<td>a) Need for better information sharing among providers</td>
<td>12</td>
</tr>
<tr>
<td>b) Communications between healthcare facilities</td>
<td>11</td>
</tr>
<tr>
<td>c) Some seniors and/or caregivers bring their own health records as they move through the system</td>
<td>8</td>
</tr>
<tr>
<td>d) Challenges with legal issues that face caregivers in caring for their loved ones</td>
<td>7</td>
</tr>
<tr>
<td>e) A need for a coordinated electronic health records system</td>
<td>6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Communication with patients</th>
<th>SUM = 34</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Patient perception that they are not being listened to by providers</td>
<td>20</td>
</tr>
<tr>
<td>b) Desire to be treated more as a “human being”</td>
<td>7</td>
</tr>
<tr>
<td>c) Reports of insensitive communication from providers</td>
<td>6</td>
</tr>
<tr>
<td>d) Need for better information made available at discharge</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Concerns over transitions and quality of care for the most vulnerable seniors</th>
<th>SUM = 24</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Concerns about the experience of seniors with cognitive &amp; mental health challenges</td>
<td>11</td>
</tr>
<tr>
<td>b) Those with no caregiver</td>
<td>7</td>
</tr>
<tr>
<td>c) Worries about consequences of complaining</td>
<td>4</td>
</tr>
<tr>
<td>d) Concerns among some seniors and caregivers that relate to seniors’ vulnerability and associated reluctance to complain about particular healthcare experiences</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Confusion facing seniors on the next steps in their care journey</th>
<th>SUM = 21</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Fear from not knowing what’s happening next</td>
<td>12</td>
</tr>
<tr>
<td>b) Confusion about what happens next in seniors’ care journeys</td>
<td>7</td>
</tr>
<tr>
<td>c) Uncertainty about care options available</td>
<td>2</td>
</tr>
</tbody>
</table>
### Positive experiences with transitions and care services received

<table>
<thead>
<tr>
<th>Positive experiences with transitions and care services received</th>
<th>SUM = 20</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Positive experiences navigating transitions</td>
<td>11</td>
</tr>
<tr>
<td>b) Positive experiences with provider treatment</td>
<td>9</td>
</tr>
</tbody>
</table>

### Impact of transitions on the lives of caregivers and seniors

<table>
<thead>
<tr>
<th>Impact of transitions on the lives of caregivers and seniors</th>
<th>SUM = 17</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Changes in home-care support staff and schedules are disruptive to seniors</td>
<td>3</td>
</tr>
<tr>
<td>b) Feeling pressured to be discharged before ready</td>
<td>3</td>
</tr>
<tr>
<td>c) Lack of consideration of the impact transitions can have on seniors’ quality of life</td>
<td>2</td>
</tr>
<tr>
<td>d) Resource burden placed on caregivers and seniors</td>
<td>1</td>
</tr>
<tr>
<td>• Financial resources</td>
<td>6</td>
</tr>
<tr>
<td>• Lack of sensitivity to circumstances of seniors and caregivers</td>
<td>1</td>
</tr>
<tr>
<td>• Time</td>
<td>1</td>
</tr>
</tbody>
</table>

### Involving seniors and caregivers in decision-making about transitions

<table>
<thead>
<tr>
<th>Involving seniors and caregivers in decision-making about transitions</th>
<th>SUM = 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) A lack of transparency about how decisions are made and what to expect</td>
<td>3</td>
</tr>
<tr>
<td>b) Communication between providers and caregivers</td>
<td>3</td>
</tr>
<tr>
<td>c) Little attention paid to caregivers’ experience and knowledge</td>
<td>2</td>
</tr>
<tr>
<td>d) Need to involve seniors &amp; caregivers more in making care decisions</td>
<td>2</td>
</tr>
</tbody>
</table>

### Challenges in accessing the desired experience from Community Care Access Centres (CCACs)

<table>
<thead>
<tr>
<th>Challenges in accessing the desired experience from Community Care Access Centres (CCACs)</th>
<th>SUM = 9</th>
</tr>
</thead>
</table>

### Advocacy associated with better transition experiences

<table>
<thead>
<tr>
<th>Advocacy associated with better transition experiences</th>
<th>SUM = 8</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Advocacy linked to better transition experiences</td>
<td>7</td>
</tr>
<tr>
<td>b) Seniors advocating on their own behalf</td>
<td>1</td>
</tr>
</tbody>
</table>

### Barriers to care

<table>
<thead>
<tr>
<th>Barriers to care</th>
<th>6</th>
</tr>
</thead>
</table>
Specific geographical and cultural challenges  |  SUM = 6
--- | ---
a) Minority languages  |  2
b) Northern Ontario  |  3
c) Physical barriers to care  |  1

### Appendix F.
**Evaluation Data Table**
Immediately following each engagement session, participants were asked to evaluate the event by indicating their agreement or disagreement with a short series of statements. Aggregate results across all sessions are provided in the table below.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>I Don't Know</th>
</tr>
</thead>
<tbody>
<tr>
<td>I valued being part of today’s discussion.</td>
<td>60.5%</td>
<td>37.0%</td>
<td>1.2%</td>
<td></td>
<td></td>
<td>1.2%</td>
</tr>
<tr>
<td>I had enough information about The Change Foundation before our event today to understand why we are here.</td>
<td>33.3%</td>
<td>43.2%</td>
<td>6.2%</td>
<td>9.9%</td>
<td>2.5%</td>
<td>4.9%</td>
</tr>
<tr>
<td>The Conversation Guide was helpful in preparing me for the discussion.</td>
<td>42.0%</td>
<td>44.4%</td>
<td>6.2%</td>
<td>3.7%</td>
<td>1.2%</td>
<td>2.5%</td>
</tr>
<tr>
<td>The discussion questions were clear and helped me tell my story.</td>
<td>46.9%</td>
<td>45.7%</td>
<td>6.2%</td>
<td>1.2%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>The facilitators did a good job of managing the discussion so that I could share my story.</td>
<td>63.0%</td>
<td>32.1%</td>
<td>2.5%</td>
<td></td>
<td>2.5%</td>
<td></td>
</tr>
<tr>
<td>I understand why The Change Foundation wants to hear my story.</td>
<td>44.4%</td>
<td>53.1%</td>
<td>1.2%</td>
<td></td>
<td>1.2%</td>
<td></td>
</tr>
<tr>
<td>I think that by sharing their stories, patients and caregivers can help change Ontario’s healthcare system for the better.</td>
<td>39.5%</td>
<td>50.6%</td>
<td>3.7%</td>
<td>2.5%</td>
<td>3.7%</td>
<td></td>
</tr>
</tbody>
</table>
Appendix F.
Process Design Learning

Drawing from participants’ feedback from their written evaluations and our own reflections, this final section offers some thoughts on process successes and lessons.

What worked well from the participants’ point of view
Participants’ written feedback (completed immediately following the events) on what they liked most about the event clustered around two key response categories:

<table>
<thead>
<tr>
<th>Theme</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing: contributing their own stories and hearing other participants’ experiences</td>
<td>“Listening to others’ stories; opportunity to share, fact that your Foundation cares about improving the ‘system’” (Peterborough participant)</td>
</tr>
<tr>
<td></td>
<td>“The sharing of events in the journey of aging … knowing that we are not alone in these events” (London participant)</td>
</tr>
<tr>
<td>Learning /increasing understanding about Ontario’s healthcare system</td>
<td>“very interesting and informative” (Dryden participant)</td>
</tr>
<tr>
<td></td>
<td>“greater understanding of the Ontario healthcare system” (Toronto participant)</td>
</tr>
<tr>
<td></td>
<td>“… learning time” (London participant)</td>
</tr>
</tbody>
</table>

Other positive process elements identified by the participants:
Conversation Guide: useful aid in preparing participants for their dialogue
In addition to the two key points in the above table, participants (over 96% of those completing the evaluation) found the Conversation Guide to be helpful in preparing them for their discussion. When participants were asked if they had reviewed the document prior to the session, most replied affirmatively – and their familiarity with the transition concept bore this out. Their pre-review of the guide contributed to a more informed dialogue.

Electronic voting keypads: an effective tool to engage participants and focus discussion
Seniors and caregivers responded well to the use of electronic voting keypads to probe key questions. The keypads proved to be an effective method of quickly gauging the views of the room and focusing discussion on issues that elicited divergent and/or strong perspectives. Concerns about this demographic’s capacity to interact with keypad technology proved to be unfounded. As one participant noted in the evaluation form: “The question and answer with the remotes saved a lot of time in getting input.”
Social tea at the close of the session
While feedback on this feature was not solicited in the participant questionnaire, the large number of seniors and caregivers who participated in the social is a good indication of their interest in the topic and comfort with the session. Though the tea was scheduled for 30 minutes, typically participants remained beyond this time and continued to share perspectives and stories about their transition experiences.

Suggestions for improvements
In response to the evaluation question – What could have made today’s event better? – seniors’ and caregivers’ feedback clustered around two main points. The first was their desire to have had an even larger group of seniors participating in the session (though some did recognize that a larger group would have made it harder for all voices to be heard in plenary). The second point was about having more time to discuss the key issues in smaller groups. In particular, some expressed a desire for additional time to provide “more input about ideas about how to improve the system.”

Session duration is always a challenging issue in planning process design – and this was especially so with this demographic. Mindful of the geographic realities and physical and mental constraints facing seniors with chronic health conditions, the decision was made to host a two-hour session with a social afterwards. Upon reflection, this was ideal for many but not all of the seniors and caregivers. Some would have preferred a longer session with a break in the middle. On the other hand, some who were frail felt that the session was an optimal length – and still others found it to be worthwhile but taxing. In designing processes for this demographic, organizers will have to strive to find a reasonable balance between these perspectives.

Implications for public engagement practice
• Importance of narrative as an input to policy and program planning
Seniors and caregivers were eager to share their knowledge and experience through the channel of personal stories. Listening respectfully to their lived realities in all their diversity helped illuminate what works and what does not work so well in the implementation of policy, planning and practice related to the care of seniors with chronic health conditions. Threaded through their stories were insights about the disconnects in their transition journeys and practical ideas on how to overcome some of these failings. Their contributions constitute a type of evidence that should be taken into account in designing policy, program and practice solutions for seniors with chronic health conditions.

• Structured process
In designing the session, it was important to respect participants' time, and focus on the engagement objectives. Working in close collaboration with Ascentum Inc., we developed a clear structured process with well thought-out and carefully crafted questions. The design and questions were tested in a pilot session to make sure the process worked.
• **Importance of face-to-face events**

Having the opportunity to connect with peers (whether caregivers or seniors, friends or strangers) face-to-face, elbow-to-elbow, helps create a supportive and safe environment within which stories can unfold. While the availability of the website allowed for greater reach, this project confirmed that in-person contact is essential for this demographic.

• **Working with local partners**

Working with local partners to secure a convenient and comfortable location; to recruit participants and to understand the local context was invaluable in setting the stage for a successful engagement. Given the huge diversity of Ontario’s communities (north and south, newcomer and multi-generational Ontarian), tapping into local partners’ knowledge of regional and community healthcare services and support was critical. These relationships also lend credibility to the dialogue events.