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PRACTICE GUIDE

How can we better understand and meet the needs of

PATIENTS & CAREGIVERS?

CREDITS

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FOREWORD

Four practice guides for Ontario Health Teams

Four practice guides were prepared for Ontario Health Teams (OHTs). The guides are relevant for any group of providers and organizations aiming to implement a connected health care system centred around patients, families and caregivers. Each of the four guides focuses on a different aspect of a more connected and better integrated approach to care and has a slightly different emphasis and target audience. The guides can be read independently but achieving the overall implementation of OHTs will require attention to all dimensions presented.

This is the second guide which focuses on what it means for care to be centred around patients, families and caregivers and highlights 6 essential attributes of patient and family/caregiver-centred care. Two case vignettes are presented that characterize when a care system is well organized around a patient, and when the care system is fragmented. Achieving the well-coordinated system is a common thread that runs through all of the guides with specific mention in 3. This guide is central to the overall focus of Ontario Health Teams and is relevant to all leaders, providers, patients and the public.

The first guide focuses on essential aspects of implementation. It outlines key activities that are necessary at the organizational and inter-organization levels and activities required of senior management across organizations in order to enable managers and providers to reorganize around patient and family/caregiver-centred care. The implementation of OHTs will not be successful unless organizations think differently about care and set parameters so that providers and managers realign their care to think across organizational lines to encompass the patient's journey. The primary audience for this guide is organizational leadership.

The third guide focuses on the activities of providers and managers that are necessary to achieve patient and family/caregiver-centred care. The activities are organized around the 6 attributes and specific vignettes are provided that demonstrate what providers and managers have to do to enable the well-organized system in contrast to the fragmented case. The audience for this guide is primarily providers and managers though it is relevant to senior leadership that need to create the context that enables providers and managers to focus on these new activities and to create the space and time required for change.

The fourth guide focuses on governance. This guide outlines the internal and external changes that have to occur to create sustainable systems of connected care. The audience for this guide is organizational leadership and governors.

While there are many important aspects to implementing integrated care, this starter set provides a basis for understanding important new ways of working and fundamental shifts in collaboration across health and social care providers. Many more topics are important including population-based management, co-design, human resources and workforce transformation to name just a few. The most important guidance is to retain a focus on what is important to patients and caregivers; gather together the people you need to work with; agree to a common vision and principles that support your planning and implementation work; and build and support trusting relationships with all your team members. These essential ingredients, blended with courageous action, will accelerate your success.

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2 PRACTICE GUIDE SUMMARY

How can we better understand and meet the needs of patients and caregivers?

In this practice guide, we describe 2 key things: what matters to patients and caregivers and how to engage them in their care.

What matters to patients and caregivers?

Patients and caregivers told us that they want to:

1/ Be heard, appreciated and comfortable

2/ Have someone they can count on

3/ Know how to manage health and what to expect

4/ Easily access health and social care

5/ Be independent

6/ Feel safe

The practice document describes these things in greater detail, using the words of patients and caregivers.

How can we engage patients and caregivers in their care?

Patient and caregiver engagement in care is influenced by their:

1/ Perception of services

2/ Comfort in asking for things

3/ Beliefs about roles

4/ Access to resources

This practice document describes how to consider these barriers in practice.

What are the 3 key takeaways?

1 The things that matter most to patients and caregivers include relationships (how they feel when they interact with providers) as well as activities that make them feel human (hobbies), not just having medical needs addressed.

2 Taking the time to get to know patients and their caregivers will not only help them feel heard, it will help providers and teams understand the things that get in the way of them managing their health and participating in their care.

3 Activities to support self-management of care needs to consider the context of the patient and family (where they live, their comfort in their surrounding community and accessibility to health and social activities) as well as their ability to access resources (finances, etc.) to supplement care.

INTRODUCTION

Why this is important

Efforts to improve care delivery and optimize experiences require understanding what is most important to people, particularly patients with complex health and social care needs and their family and friend caregivers. A precursor to understanding experience is effective engagement (i.e., partnership). Patient and caregiver engagement activities can range from providing input into care plans, to co-designing services, and setting organizational priorities (Carman et al., 2013). A recent systematic review demonstrated that engaging people in their care (at these various levels) can enhance care experiences and outcomes (Bombard et al., 2018).

While there is a critical role for patient and caregiver engagement at the leadership and governance level, this practice brief focuses on patient and caregiver experiences and engagement at the micro level—the care interactions that people and their caregivers have with front-line staff and care teams. Not only do we look at what an optimal experience entails, but outline how providers engage patients and caregivers in care to optimize their experiences.

We focus on people with complex care needs as well as family and friend caregivers. People with complex care needs tend to have multiple health and social care needs and are poorly understood despite using health care more than the general population (Wodchis et al., 2016). Importantly, some people with complex care needs are not connected to the health care system and are at risk of decline and poor outcomes. Caregivers (typically unpaid family members and friends) shoulder a huge burden, often making enormous sacrifices as they provide care (in their personal and work lives). Caregiving is often met with financial challenges (stemming from lost days at work and through the cost of equipment, medication, home modifications and services not covered through Medicare or other insurance schemes. Caregivers report feeling unrecognized, excluded from the care team, and have few breaks even when services are in place (Kuluski et al., 2018).

How this relates to Ontario Health Teams

This practice guide will provide Ontario Health Teams (OHTs) with practical guidance on how to 1) address the things to matter most to patients and caregivers and 2) engage with patients and caregivers to enhance their relationships with them and improve their care. Through practical activities at the end of this document, OHTs can review their own strategies to engage patients and families (and that of their partner organizations) and outline barriers and facilitators to effective patient and caregiver engagement.

This practice guide provides concrete examples of what matters most to patients and caregivers in their care along with specific details of how things look when they work well. While some of these things may be known (or implemented) by your care team, some examples may offer new ideas on how to enhance people's experiences in your practice.

INSIGHTS

How we uncovered what matters to patients and caregivers

We draw our examples from a multi-jurisdiction study including 173 ethnically diverse older patients with complex care needs and their caregivers (mostly family), from Ontario, Quebec and New Zealand. These patients and caregivers participated in one-to-one in-person interviews to share their experiences and care needs. Patients and caregivers were using an array of services including primary care, home and community care, specialist care, hospital, emergency rooms and rehabilitation services. Many patients and caregivers relied on community and social services to manage transportation, food, housing and social activities in addition to health services.

Following in-depth analyses of interview content, the things that mattered most to patients and caregivers across these multiple jurisdictions of study were synthesized and described. We learned not only what mattered most to patients and caregivers but about the activities that supported these things. We also looked at the things that get in the way of people engaging (i.e., participating). It is critical to understand barriers to engaging patients and caregivers to ensure that steps are taken to create a comfortable environment for patients and caregivers, from all generations, cultures and linguistic groups, to participate in a way that is meaningful to them.

We understand that your target populations will include other groups, aside from older adults with complex care needs, including children with medically complex care needs, people with developmental disabilities, episodic acute care needs, etc. While we suspect that core attributes of care will be similar as to what is detailed below, as an OHT it will be important to determine other things that matter to patients and caregivers, which can be determined through the strategies and examples provided below.

What matters most to patients and caregivers in their care

Patients and caregivers want to be heard; have someone they can count on; know how to manage health and what to expect; easily access health and social care; be independent; and feel safe.

What matters most to patients and caregivers is that they...

1/ Be heard.

2/ Have someone they can count on.

3/ Know how to manage health and what to expect.

4/ Easily access health and social care.

5/ Be independent.

6/ Feel safe.

1/ Being heard captures the relational aspects of care and is characterized by many activities including:

- Treating patients and caregivers like equal partners (having a friendly demeanor, using a neutral tone of voice, creating a comfortable space to interact)
- Not rushing them
- Asking about non-health care related things (social activities, family members, etc.)
- Listening intently
- Understanding (and asking about) their preferences and incorporating this knowledge into care planning

Patients and caregivers are more likely to feel heard, appreciated and comfortable if their provider(s) and care team is consistent over time. Having consistent care providers will enhance familiarity and foster trust. Empathy is also an important trait that is required of all parties in the care interaction (patient, caregiver and provider). While it's not possible to completely relate to another person's experience until you have walked in their shoes, exercising empathy (trying to understand and acknowledge the feelings of another) can enhance the relationship and support the management of expectations.

For example, in getting to know a patient, you may come to understand that self-care is difficult given the stresses felt in other parts of their life. In response, recommended self-care strategies can be adapted to suit the unique needs of the patient, and if applicable, their families or care partners. Likewise, when a patient recognizes your constraints (as a provider), they may adjust their expectations, so long as they feel that you care about them and are doing what's possible to meet their needs.

2/ Having someone to count on helps patients and caregivers get access to the broader system. This "counted on" person is typically a paid provider who serves a coordinating function and has access to a broader interdisciplinary team with whom they regularly interact and can contact with questions. The trusted go-to person is:

- Easily accessible to the patient or caregiver by text, phone or email
- Can get resources/questions answered from other team members in a reasonable amount of time (and manages expectations around response times)
- Keeps track of appointments, sends reminders and determines if the patient is able to get there

This 'go-to person' connects patients to needed community based resources including primary care to avoid unnecessary hospital and emergency room visits. This role can also alleviate caregiver stress, by getting timely responses to care related questions and concerns.

3/ Knowing how to manage health and what to expect. Patients and caregivers want clear information on their health status and know what they might expect in the future regarding their care, symptoms and needs (even if things are uncertain). Key supporting activities include:

- Using lay language (avoiding the use of complex medical jargon)
- Teaching patients and caregiver's skills to self-manage by providing a written list of steps, or 'how-to' guides, exercises, etc. that take into consideration their contexts and capabilities
- Accepting (and preparing patients and caregivers for) a 'trial and error' approach to health management (trying different treatment/medication regimens, and working closely with them by checking in continuously and modifying the plan as needed)
- Providing clear explanations as to why certain treatment options are being recommended and what to expect
- Working with caregivers to anticipate and prepare for a patient's future trajectory (e.g., stages of dementia and decline)

Managing expectations through dialogue such as, "we might not get it right the first time, but let's try this first and I'll follow-up with you" helps patients and caregivers understand that complex care management requires 'continuous tweaking' as opposed to a silver bullet solution.

4/ Easily accessing health and social care that is meaningful is activated through the 'go-person' described earlier. Access to health care resources (doctor's and specialist visits, homecare) as well as social care resources (such as getting to the grocery store with ease, participating in social activities and hobbies) is typically required. At times, access is only met 'half way' — for example, a specialist appointment may be booked but transportation is not arranged or an assistive device is delivered to the patients home but not installed. Example activities in support of access include:

- Offering different methods of service provision to accommodate patient function (home visits, videoconferencing, etc.)
- Allowing patients and caregivers to easily change appointments if not feeling well
- Providing health and social care services under one roof or within a similar neighborhood

- Coordinating medical appointments and transportation
- Spanning boundaries (having food available at the primary care clinic or organizing a community group to offer programs in spaces where patients get medical care)
- Ensuring that resources offered can be fully utilized (e.g., knowing all the steps required to get someone to their appointment)

5/ Being independent is a top priority for patients and something that caregivers try to honour as much as possible, even as patients decline physically or cognitively. Being independent is supported by:

- Assistive devices inside and outside the home to support easy navigation and mobility
- Opportunities for patients and caregivers to participate in enjoyed activities (traveling, hobbies, visits with friends)
- Caregivers getting a "true" break (e.g., respite) by having a trusted and familiar provider available that the patient feels comfortable with so the caregiver can get away and not worry about the patient
- Giving patients and caregivers choices in their care plan

Being independent is intricately connected to (and sometimes trades off with) safety. As noted above, caregivers try hard to preserve patient independence for as long as possible but at certain points (typically as patients approach the latter stages of functional decline or onset of dementia) they become more concerned about safety. Caregivers, at times, feel distressed as they try to determine the right balance between independence and safety. Patients continue to prioritize independence and do not always understand why activities are restricted.

6/ Feeling safe (minimizing risk) both inside and outside the home is important to patients and caregivers. Activities that support feeling safe include:

- Training patients and caregivers on how to use mobility aids inside and outside the home
- Ensuring that caregivers can safely perform transfers and personal care without putting their health at risk (may require training, equipment or help from an extra person)
- Getting someone to go to the patient's home and working with caregivers to address care needs (such as behaviours and unpredictable events that typically arise with dementia or complex medical treatment)
- Providing caregivers with additional supports to offer peace of mind so they are able to attend appointments or social outings and know the patient is safe

The things that matter to patients and caregivers overlap, intersect and sometimes trade-off (see Figure 1).

Figure 1/ The intersection of the things that matter most to patients and caregivers.

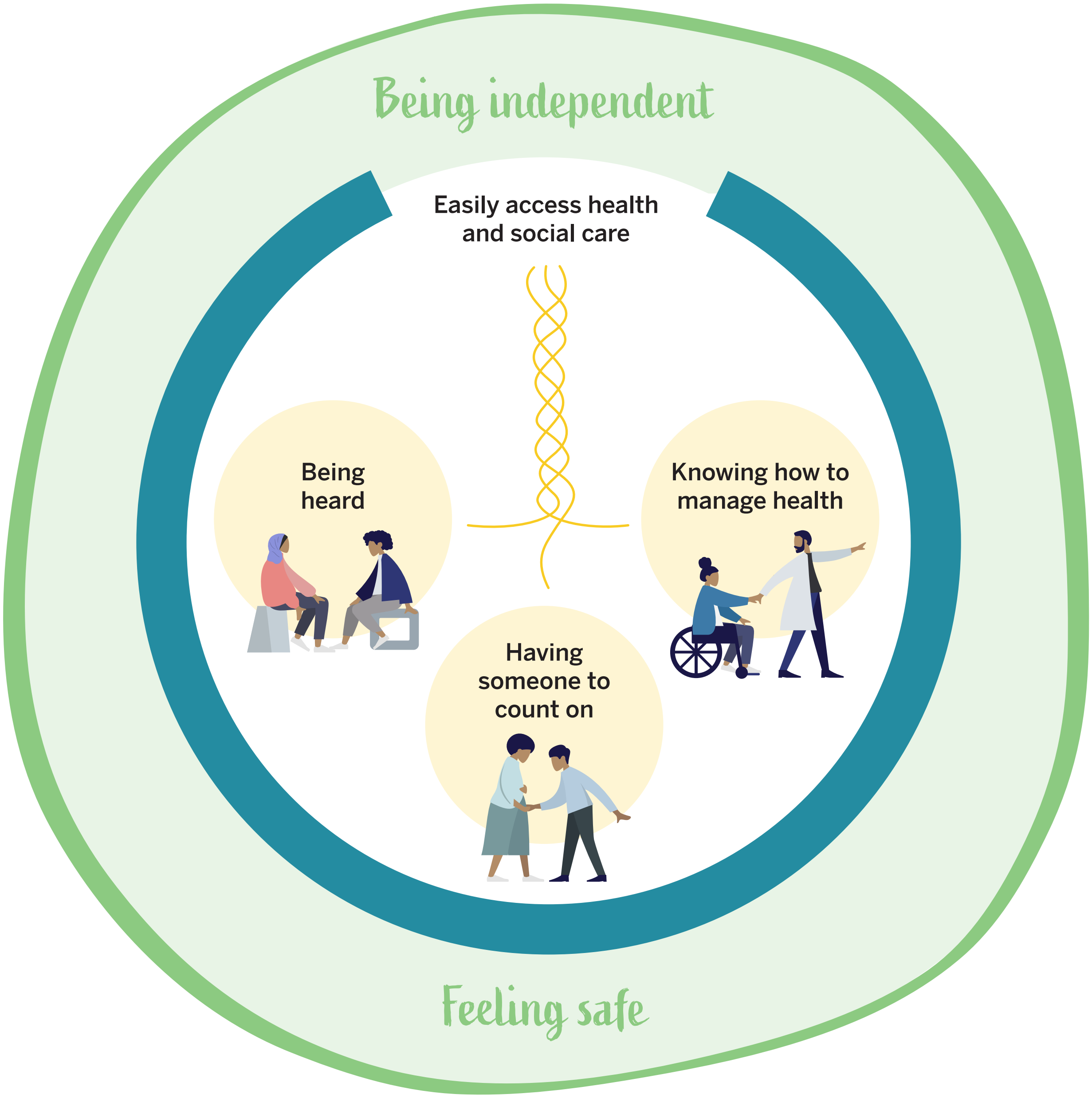

Figure description: Being heard, having someone to count on, and knowing how to manage health can be thought of as three key attributes of a care delivery model when patients and caregivers access health and social care (three inner circles linking to the fourth at top).

While health care includes medical and professional supports (in a clinic or home setting such as nursing, occupational therapy and physician care), social care includes both instrumental activities of daily living (supports with housecleaning, meals, medication management) as well as the social determinants of health (housing, financial support, food security, etc.).

Core attributes such as independence and safety (outer circle) can be thought of as outcomes (patients and caregivers feeling as safe and independent as possible). Finding the appropriate balance between independence and safety is key and will require priority-setting between patients, families and care teams.

Factors that influence patient and caregiver engagement in their care

In addition to understanding what matters most to patients and caregivers, there are a number of factors that influence patient and caregiver engagement in care. These include their perception of services; their comfort in asking for things; their beliefs about roles; and their access to resources.

Patient and caregiver engagement is influenced by their...

1/ **Perception of services.**

2/ **Comfort in asking for things.**

3/ **Beliefs about roles.**

4/ **Access to resources.**

More specifically, patients and caregivers are reluctant to use what is available or offered to them if they perceive the quality of care to be poor. These perceptions of poor quality are shaped by previous experiences or their observations of others experiences.

Patients and caregivers are reluctant to ask for things if they feel the 'system' is not able to respond to them or if they fear being reprimanded for voicing unmet need.

Role beliefs such as perception of whether or not it is appropriate to question care providers or relinquish personal responsibilities (such as caregiving duties) also plays a role. For example, cultural or generational factors may influence a patient's willingness to question their care team or engage in goal setting activities.

Finally, factors such as a common language, adequate health literacy and access to financial resources influence the extent to which patients and caregivers can meaningfully participate in their care.

These factors that influence engagement relate to the core attributes of care. For example, patients and caregivers are more likely to feel comfortable asking for things if they are working with a provider (or team) that they know and trust. Furthermore, the 'go-to' person is often the person who connects patients and families with tools (financial resources, translators, information, and self-management resources) to enhance engagement.

Three key takeaways

1

The things that matter most to patients and caregivers include relationships (how they feel when they interact with providers) as well as activities that make them feel human (hobbies) not just having medical needs addressed.

2

Taking the time to get to know patients and their caregivers will not only help them feel heard, it will help providers and teams understand the things that get in the way of them managing their health and participating in their care.

3

Activities to support self-management of care needs to consider the context of the patient and family (where they live, their comfort in their surrounding community and accessibility to health and social activities) as well as their ability to access resources (finances, etc.) to supplement care.

EXERCISE: SELF-ASSESSMENT

We now ask you to reflect on the types of resources and tools that your practice has regarding patient and caregiver engagement (with a focus on addressing barriers to engagement).

Does your practice have...

☐ A point person that patients and caregivers feel comfortable contacting with questions or making complaints?

☐ Translation services/interpreters available for patients and caregivers who don't speak the same language as their providers?

☐ Self-management/educational resources available in the preferred language of patients/caregivers?

☐ A point person to assess additional resources required (such as financial support, volunteer services) that might be required for patients and caregivers to manage care?

☐ An understanding of the preferences/expectations/capabilities of the patients and caregivers regarding their role (e.g., is the family comfortable having strangers coming into the home to provide personal care)

☐ Opportunities for patients and caregivers to participate in various modes of engagement (such as co-design of care services or sitting on organizational planning committees?)

☐ Resources and supports to orient staff and managers to the philosophy of patient engagement (e.g., training for staff)?

As an OHT, we recommend that you connect with your partner organizations to see what kinds of strategies they have in place to engage patients and caregivers. What works and what needs to change from their point of view? Taking note of this will help you leverage the strengths of your partners and build a common approach together. We recommend building in an in-person, brainstorm session to share strategies.

SCENARIOS

We now share two scenarios to illustrate a real-world example of what it looks like when the needs and preferences of the patient and caregiver are understood and addressed versus not.

A Poor outcomes

Needs and preferences of patient and caregiver are NOT understood or addressed.

One day...

Mrs. Lee woke up feeling unwell. She's an 87-year-old widow and lives alone in her apartment. Her daughter, Laura, just returned from a short vacation and tries to reach her Mom by phone, and after several tries there is no response. She drives over to check on her. When she arrives, her Mom appears confused and tells her daughter that she feels dizzy.

There have been several coordinators involved in her Mom's care and she is unsure who to contact. She doesn't feel comfortable calling the primary care doctor directly so she calls 911 and her Mom is taken to the emergency room where she waits for several hours. Laura and her mother meet with several people where they have to repeat their story over and over again.

They decide to keep her overnight to run tests. Due to a lack of rooms she is in a stretcher in a hallway where it's noisy and unfamiliar. Laura is exhausted and frustrated at the lack of timely response to her Mom's needs. Her Mom is scared and eats very little, making her feel increasingly tired and weak. She misses another dose of her medication as she waits and is feeling increasingly dizzy.

On her way to the washroom she has a fall and fractures her hip and is now waiting for surgery. Given the lack of operating rooms she waits for several days and then catches pneumonia which further delays her surgery. Laura, the sole family caregiver is exhausted, confused, frustrated and takes several days off work without pay so she can be there to advocate for her Mom who doesn't speak English.

SCENARIOS

We now share two scenarios to illustrate a real-world example of what it looks like when the needs and preferences of the patient and caregiver are understood and addressed versus not.

B Good outcomes

Needs and preferences of patient and caregiver are understood and addressed.

One day...

Mrs. Lee woke up feeling unwell. She's an 87-year-old widow and lives alone in her apartment. Her daughter, Laura, just returned from a short vacation and tries to reach her Mom by phone, and after several tries there is no response. She drives over to check on her. When she arrives, her Mom appears confused and tells her daughter that she feels dizzy.

Their care coordinator, Sandra, whom Mrs. Lee and Laura have gotten to know quite well over the years, always encourages them to call if they need something. Mrs. Lee doesn't feel comfortable asking for help, but her daughter knows to contact Sandra when something is wrong. She rings Sandra and she answers quickly and listens to Laura's concerns. During this phone call her Mom starts to feel better but is very tired.

Sandra is in regular contact with Mrs. Lee's primary care team and is able to arrange a home visit with her primary care provider that afternoon. During the home visit Mrs. Lee has her vitals checked and blood work done and later it's determined that she needs to adjust her medication. The primary care doctor calls the pharmacy and arranges for the new medication to be dropped off.

During this visit it's also clear that Laura is feeling burnt out and is concerned about leaving her Mom alone for long periods of time during the day while she is at work. The primary care doctor shares this with Sandra who connects back with Laura to tell her about a Day Program that caters to the Chinese population. Since the day program is with her Chinese speaking peers, Mrs. Lee agrees to go, and her daughter, who gets to know the staff, feels comfortable knowing that her Mom is happy and safe. Attending the program also helps Mrs. Lee feel independent as she does not want to move into a long-term care facility.

SCENARIO QUESTIONS

If faced with the scenario (in bold, above), what tools and approaches would your team use to respond to Mrs. Lee and Laura (her caregiver)?

1/ For example, would Mrs. Lee and her caregiver know who to call on your team?

2/ Who would be responsible for responding to the needs of Mrs. Lee and her caregiver?

3/ What types of tools or approaches would your team use to address the needs of Mrs. Lee and her caregiver?

4/ What barriers would you anticipate in meeting the needs of Mrs. Lee and her caregiver?

5/ How would you/your team continue to engage with Mrs. Lee and her caregiver if you wanted to draw on their experience to design improvements in your practice?

6/ Regarding Mrs. Lee and her caregiver, what engagement barriers do you anticipate and how would you address them? (hint: Laura, the caregiver, has a very busy work schedule and Mrs. Lee does not speak English)

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NOTES

Use the space below to capture your thoughts and reflections.