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# Twelve principles to support caregiver engagement in health care systems and health research

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## Twelve principles to support caregiver engagement in health care systems and health research

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### Abstract

Family and friend caregivers (i.e., unpaid carers) play a critical role in meeting the needs of people across various ages and illness circumstances. Caregiver experiences and expertise, which are currently overlooked, should be considered in practice (such as designing and evaluating services) and when designing and conducting research. In order to improve the quality of health care we need to understand how best to meaningfully engage caregivers in research, policy and program development to fill this important gap. Our study aimed to determine principles to support caregiver engagement in practice and research. A pan Canadian meeting brought together 48 stakeholders from research, policy and practice and lived experience (caregivers) to share perspectives on caregiver engagement and co-design. Several presentations from each stakeholder group were shared, followed by discussion and report back sessions. Extensive notes were taken and members of the research team synthesized the findings into categories and presented them back to participants for verification. 12 core principles to support caregiver engagement in practice and research were identified and validated by attendees: use policy levers and incentives, make blunt structural changes, face fears, recognize caregivers and increase opportunities to engage, define what quality means, be mindful of whose experience is being represented, address language and power, engage early, clarify roles and expectations, listen and act on what you hear, measure, and create a community of learning. These principles provide a foundation to guide curriculum development, core competency training, future research and quality improvement activities in health care settings.

### Keywords

Caregivers, carers, engagement, co-design, health services, quality improvement, health care

### Description of the issue

Family and friend caregivers (i.e., unpaid carers) play a critical role in meeting the health, social, emotional and practical care needs of millions of people worldwide<sup>1</sup>, ranging from children with complex care needs to older adults with multiple chronic conditions. Their often-unpaid role saves health care systems billions of dollars annually<sup>2,3,4</sup>, but at a personal cost to the caregiver, including depression and stress, lost time from work, compromised social relationships and loss of other valued activities<sup>5,6,7,8</sup>. As caregiver strain increases so does risk of mortality<sup>9</sup>. While caregiving is also characterized by positive experiences<sup>10</sup> including strengthened relationships with the people who are being cared for<sup>11</sup>, it is important to highlight the significant contributions and self-sacrifices that require more societal attention and resources. Despite their contributions and unique knowledge of the people

they care for, caregivers are seldom recognized as members of the care team<sup>12,13</sup> and too often are not offered appropriate supports to help them in their role<sup>12,14</sup>.

Tailoring services to meet the needs of the user (patient or caregiver) is the intention of engagement activities such as co-design work, where users share their experiences and create programs and services alongside care providers to meet their specific needs. Currently most of the engagement work has focused on *patients* including how to better engage them in their care<sup>15,16</sup> ranging from care delivery activities such as shared decision making, the elicitation of treatment goals, to systems design such as co-design of care programs or setting of organizational priorities<sup>17</sup>. While increasing patient engagement in these types of activities is an accomplishment, family and friend caregivers are too often left behind, or are merely an assumed extension of efforts to engage patients. While the value of engaging both patients *and* caregivers in their care in a meaningful way is difficult to dispute, acting

on this can be challenging. There is a growing body of evidence to support the idea that in order to improve care and outcomes, we need to involve patients *and* families in various engagement activities<sup>18</sup>. Levels of engagement may include sharing their stories and perspectives, deliberating with care teams on their care plans and setting priorities for health systems generally<sup>16</sup>. Needless to say, across all levels of engagement, strategies need to be in place to gather this information meaningfully and to transparently respond to the perspectives captured<sup>19,20</sup>.

This paper focuses on the caregiver, unpaid family members and friends as it is this particular group that has received little attention in the engagement literature. Given health system trends toward ‘aging at home,’ growing reliance on caregivers to provide support, and the critical knowledge that caregivers hold of patients, it is important to engage them in a meaningful way if health systems are truly looking to embrace a person-centered ethos. Given that health care systems are primarily oriented to the patient, and often fall back on paternalistic, provider driven approaches to care delivery, it is important to unpack core activities that support better engagement of caregivers.

In April 2018, we hosted a Pan-Canadian meeting of 48 stakeholders—caregivers, program planners, executive directors, care providers and researchers who are actively engaging with caregivers in their respective organizations and research projects. The goal was to understand their experiences and lessons learned and engage in a discussion on how to advance engagement and co-design activities in the future so others (i.e., health care organisations or research teams) can benefit.

### How we addressed the issue

Over the two-day meeting, several presentations from research, practice, policy and lived experience (caregivers) were shared, followed by discussion groups and report back sessions. Each participant was sought out as a key stakeholder in supporting better care for caregivers within their organizations. All speakers shared perspectives on caregiver engagement and co-design in a series of panels. After each panel, participants engaged in discussion and shared their impressions broadly with all in attendance. The session was facilitated by the Lead for Strategy at an Organization called the Change Foundation, an Ontario, Canada based think tank which has prioritized improving care for caregivers in health systems.<sup>21</sup>

Extensive notes were taken during the meeting by four note takers and reviewed by two members of the research team (KK and AP). The notes were reviewed line-by-line and text was divided into similar categories to capture core ideas. Initially 16 categories (i.e., principles) were identified and presented back to the participants. The participants

suggested additional details for the 16 categories and validated what was shared (noting that it was an accurate description of the presentations and discussions). Participants noted that these principles were a useful foundation from which to launch future activities such as curriculum development, core competency training (for all stakeholder types from patients to policy planners) and represented areas that can be explored further through dedicated research projects. The 16 principles were later reduced to 12 to eliminate redundancy and for ease of presentation. These 12 principles are presented in three categories: structures and policies; culture and mindset; and procedures. While many examples are tailored to caregivers, the principles are relevant to a range of stakeholders- including patients. (Table 1)

## Outcomes

### *Policies and Structures*

#### **1. Use Policy Levers, Incentives and Tools**

Policies (the rules and tools of an organization or funding body), have an effect on the nature and extent of engagement activities. One participant referred to policies as a “game changer” for creating the needed infrastructure for engagement. Given the Canadian context of the meeting, participants spoke about relevant policies in Canada that support engagement with specific attention to the province of Ontario (location of meeting). Accreditation Canada as well as Legislation in Ontario (Excellent Care for All Act, 2010 and the Patients First Act, 2016), are examples of institutions that have created opportunities and incentives for health care organizations to engage patients (and caregivers) in various activities. For example, each of Ontario’s regions, called Local Health Integration Networks are required to have patient and caregiver advisory committees and hospitals must report on a set of standard indicators which include user engagement.

Other examples of tools to support engagement were shared at the meeting. For example, a caregiver participant suggested that a new billing code for doctors may incentivize them to identify and address the needs of caregivers. Another example, which would presumably be easier to implement in the shorter term was a ‘prescription pad’ – currently used in primary care practices in British Columbia which has the contact information for the provincial caregiver organization and list of services available for caregivers. The notepad is available in GP offices as an easy ‘one page tear off’ information sheet. This type of tool can quickly direct caregivers to needed resources without a major policy shift or practice change to accompany it.

**Table 1. Summary of 12 Principles**

Categories	Principles	Examples
Policies and Structures	Use Policy Levers, Incentives and Tools	Implement incentives to change behaviors in support of engagement
	Make Blunt Structural Changes	Add a third chair to the care providers office
Culture and Mindset	Face Fears	Don't wait for perfection, just try something
	Recognize Caregivers and Increase Engagement Opportunities	Implement a formal approach to caregiver identification (such as through an assessment tool) and reduce barriers to engagement (e.g., flexibility in approach, reduce language and financial barriers)
	Define What Quality Means	Make sure stakeholders are on the same page (quality as defined by a manager is likely different than as defined by a caregiver)
	Be Mindful of Whose Experience is Being Represented	Avoid tokenism and the inclusion of the 'usual suspects.'
	Address Language and Power	Create a comfortable space for caregivers to open up. Be sure that what is captured is not unintentionally filtered through a non-caregiver lens.
Procedures	Engage Early	Engage during the problem identification stage
	Clarify Roles and Expectations	Continually re-visit role preferences and expectations (of caregivers and other stakeholders) given that circumstances will inevitably change through any 'cycle' of engagement.
	Listen and Act on What you Hear	Listen with kindness and be honest about how (and if) what is needed can be addressed
	Measure	Don't survey people to death, capture their stories too. Capture the impact of engagement on experience and outcomes.
	Create a Community of Learning (Training and Education)	Establish a set of learning competencies for all stakeholders (not just caregivers). For example, learning how to be reflexive— in tune with how ones presence, actions, behaviors and approaches influence others is an important skill.

## 2. Make Blunt Structural Changes

*"We need to add a third chair"*

While policies and practical tools provide an enabling function and incentive for engagement activities, changes in practice are often slow to catch up. However, when 'blunt' changes are made to the environment it creates an immediate space for engagement. A participant raised the concept of the 'third chair.' In any health care environment (such as a doctor's office) a third chair provides a space and expectation for the participation of a third party, such as a close friend or family member. Another caregiver participant shared an example about his local hospital's intensive care unit (ICU). The ICU door, which was always locked, prevented families from both visiting loved ones and participating in their care. When the door to the ICU was physically removed families could immediately participate more fully and be with their loved ones at times that worked for them. While many policies and organizational changes are typically quite lengthy due to the need for buy-in, negotiation and implementation, minor structural changes (blunt changes) can have huge impacts in a short time period.

### Culture and Mindset

## 3. Face Fears

*"Don't wait for it to be perfect, just try and do."*

Engagement activities with patients and especially caregivers are uncharted territory for many organizations

and research teams. Feelings of uncertainty and fear of failure may stall engagement efforts or prevent them entirely. A manager in a hospital setting encouraged people to: *"take a chance, some ideas will fall flat, some will come to fruition or birth something else."* However, a hospital quality improvement participant cautioned that, in doing so, one needs to be *"mindful of frightening the elephant."* Too much too soon may be actively resisted by others, particularly those who hold decision making authority within organizations that are newer to engagement activities. Starting small was recommended. A small scale engagement project may be the catalyst for a broader organizational culture shift<sup>20</sup>. Another participant highlighted the need to move away from a culture of blame to a culture of trial, one that supports the notion of 'learning as you go.' A 'storming phase' characterized by confusion, risk taking, and some conflict between parties involved should be expected and encouraged.

## 4. Recognize Caregivers and Increase Engagement Opportunities

Many caregivers don't recognize themselves as *caregivers* but as family members or friends that are simply doing what family and friends do<sup>21</sup>. They may not view themselves as individuals who deserve a place at the care planning table or as individuals 'worthy' of support<sup>22</sup>. While some caregivers prefer not to participate in engagement activities (such as care planning with the care team or co-designing service improvements) others may appreciate

opportunities to be involved. In this case, caregiver engagement is contingent on providers understanding the value of caregiver contributions and incorporating strategies to identify caregivers (such as through assessment tools) or other deliberate outreach activities.

Recognizing and reducing barriers to engagement may enable better representation of diverse perspectives. Barriers may be related to language, health literacy, physical and financial limitations, timing of activities, poor past experiences and negative perceptions of engagement. Some caregivers may wonder; *Will I be listened to? Will it make a difference? How will I know? Do I know enough to be helpful?* Among those involved, some will be more vocal than others and some stories and experiences will resultantly take precedence over others. To that end, providing dedicated time for all parties to speak and using multiple modalities to share information (written, online, etc.) may create a more equitable experience. Addressing financial barriers through payments and honorariums, covering parking and transportation costs also demonstrates value for participation while addressing a significant participation barrier.

### 5. Define What Quality Means

Improving the quality of care is high on the agenda of health care systems worldwide. There is concerted effort being put forward to measure quality to assess health system performance over time and inform improvements. At our meeting, a manager noted that there seems to be a difference in recognition and definition of what quality is, when looking at priorities across manager, provider and patient/caregiver groups. For instance, patients and caregivers may tend to prioritize the relational aspects of care<sup>23</sup> and overall care experience as crucial components of quality; whereas providers and managers (driven, in part by policy incentives) tend to prioritize reducing falls risks, infection control and decreasing hospital length of stay. Since many initiatives that call for a co-design approach are meant to improve quality, sharing and consensus of definitions is required.

### 6. Be Mindful of Whose Experience is Being Represented

*“The voice of few is not the voice for all”*

The notion of ‘representation’ and the avoidance of ‘tokenism’ was discussed by participants. A health care manager stated: *“I don’t have to ask 96,000 people; I just need to know when I reach saturation.”* In this instance, saturation was meant to refer to capturing a broad range of a particular experience. A proposed strategy was to capture ideas from a smaller group of stakeholders (i.e., caregivers involved in specific initiative) then member check with a broader stakeholder group afterward (e.g., in this case, caregivers, generally). A researcher concurred that it is important to be cognizant that a few select people/perspectives do not represent the whole. Moving beyond the inclusion of the

*“the usual suspects”* and reaching out to marginalized populations (who are more likely to be excluded from engagement activities) was recommended.

### 7. Address Language and Power

*“Health providers may take the pen and change the words”*

As different types of stakeholders come together (patients, caregivers, providers, managers, decision makers) the different language used to share ideas and experiences becomes more apparent. “Taking the pen and changing the words” speaks to the ease at which the words and stories of one stakeholder group (such as patients and caregivers) may be misunderstood, or mis/reinterpreted by another stakeholder group. Using the language of caregivers directly, for instance, may start to address this challenge.

A participant noted that *“we can’t help everyone and do everything but we need to be mindful of whose interests are being served.”* It’s important to recognize the power imbalances inherent in any group that combines different types of stakeholders. A willingness to take a step back (particularly those who are naturally in positions of power - such as researchers, providers or managers) is necessary to create a space for users to define their role and share their perspectives. A program lead participant noted: *“If we just shut up and stand to the side, the sharing can happen, we don’t always have to lead everything.”* Creating a comfortable space, where patients and caregivers feel safe sharing their point of view is incumbent upon paying attention to body language, emotional cues and implementing deliberate practices to support engagement. For example, dedicated time and space for users to take the lead or participate in activities such as chairing meetings, leading a discussion, participating in rounds and having dedicated time to share is required. Further, paying attention to the attitudes of provider and managerial staff (e.g., such as paying attention to ‘eye rollers’ as noted by a manager participant and calling out behaviors among people who threaten a comfortable environment, will support the redistribution of power). Equally important is recognizing staff that are making a genuine effort to engage caregivers, and providing the means to do so (dedicated time in their work day, ongoing recognitions, etc.)

### Procedures

### 8. Engage Early

Too commonly, patients and caregivers are brought into change initiatives and research activities *after* the problem has been identified or after the activity is underway or being implemented. Starting conversations early –during the agenda setting and question formation stage– was recommended and coincides with best practice in co-design in research<sup>24</sup>. Since the co-design process is not static, ongoing check-ins (“is this working?”), open mindedness, flexibility and re-visiting of roles is required.

Any engagement activity takes time, and mistakes and missteps should be expected and serve as important milestones and learning opportunities. In addition, as projects/initiatives come to an end it is important to close the loop and share why (or why not) certain recommendations are being taken up. As noted by a quality improvement specialist, there is *“No utility if you can’t get closure to what is happening.”* To that end, if caregivers are aware of the impact that their participation in engagement activities is they may be more likely to participate in the future.

### 9. Clarify Roles and Expectations

In engagement activities it is not always clear what the role of each stakeholder is (and what the role ought to be). Role expectation and preference needs to be continually revisited throughout any initiative. Importantly, awareness of individual constraints may help address expectations and increase sensitivities. For instance, managers and care providers may have the best of intentions to involve caregivers in activities but might be facing real barriers in terms of time from clinical practice and other organizational initiatives. Similarly, on the caregiver side, engagement may fluctuate based on competing priorities, level of burnout, and interest. Roles should be revisited and adaptable over time with ongoing communication to discuss barriers and strategies to overcome them.

### 10. Listen and Act on What you Hear

*“It’s a battle every day just to be heard”*—Caregiver participant  
Caregiver participants emphasized the importance of *“Listen(ing) with kindness”* and being *“mindful of the emotion and feeling behind what caregivers are saying.”* Active listening and presence enable a therapeutic relationship where important details of a caregiver experience can be better understood. A caregiver participant and co-author (CA), noted that all those involved in care and program design need to ask themselves *“where is the caregiver voice in what I do?”*

Simply asking, *“how are you doing?”* and repeating this question frequently provides an ongoing opportunity for the caregiver to open up. The notion of preparing providers to listen was emphasized. When caregivers are asked what they need, they may not know or may not be in the right mindset to articulate it. It’s incumbent on others, such as care providers, to help caregivers figure this out. This is particularly challenging for young caregivers (youth) who remain mostly under the radar when it comes to caregiver recognition and articulation of needs. A second critical piece is acting on what is heard. A participant asked, *“What do you do with the story you are hearing?”* Health systems are obsessively measured for performance, with some growing activity on capturing the needs and experiences of patients (and sometimes) family and friend caregivers<sup>25</sup>. The challenge is that after data are collected, it is unclear what (if anything) is done *in response* to the information captured. The challenge relates to

capacity – care providers may be reluctant to ask or probe into areas of need/unmet need if they feel they do not have the capacity or resources to respond. A participant suggested that someone on the care team can champion efforts to both engage with families and with other sectors to leverage capacity to respond to needs.

### 11. Measure

*“No numbers without stories and no stories without numbers”*  
Measuring engagement can happen at many levels, including at the level of the individual- *“Do engagement activities make a difference for caregivers?”* and the organisational level- *Are there processes in place to involve caregivers in decision making?* Participants noted that it’s important to know (but not always clear) if engagement activities make a difference. This leads to the question of what, exactly, should be measured? A researcher noted that patients and caregivers can identify the relevant outcomes, indicators and measures to include in a project or initiative.

Participants also discussed how information should be collected. There was consensus that we should *“not survey people to death, there are other ways to collect information.”* Establishing an emotional connection through storytelling and use of multimedia (caregivers sharing their ideas and stories over video) can be useful strategies that can give important context to statistical outputs. *Finally*, coinciding with the aforementioned recommendation of engaging caregivers, particularly in the early stages, we need to measure the impact of doing so. Most importantly, without a clear purpose or mechanism to respond and feed results back to caregivers, inertia will set in and stall efforts to sustain engagement activities. As noted by a caregiver participant, it is not enough to ‘tick the box’ on caregiver engagement. Simply listening to or collecting a story is not enough. Engagement work is an ongoing and iterative process which may lead to larger substantial changes over time. A way to measure progress is to assess the extent to which similar issues keep being raised.

### 12. Create a Community of Learning (Training, Education)

Participants noted that a set of learning competencies for all types of stakeholders involved in an engagement activity is required. For instance, learning how to be reflexive – in tune with how your presence, actions, behaviors and approaches influence others—is a critical skill that can be learned over time. Thinking critically and questioning assumptions will facilitate open mindedness to diverse perspectives. This of course, must be supported by active listening (being fully present and refraining from interrupting or problem solving).

Tools should be developed to support all parties to engage. For example, a more accessible environment can be created by knowing the types of questions to ask, learning how to effectively tell a story, how to advocate,

use lay terminology as well as use tangible tools like translators.

The participants liked the term *Community of Learning* which honored the learning needs of all parties and the importance of bi-directional learning. It was noted that the core principles outlined in this paper can serve as a template for engagement learning activities and core competency development to support a community of learning.

### **Implications on further practice and generalized recommendations**

Our paper outlines core principles to support engagement of caregivers in practice and research. These principles are borne from the perspectives of experienced stakeholders—caregivers, care providers, researchers, health managers and system leaders—who came together, from across Canada for a two-day meeting to share their perspectives on how to better support meaningful caregiver engagement in health care organizations and research.

Engaging caregivers in research and practice can serve several aims, including and not limited to: helping research and practice become more relevant to both the patient and caregiver experience; and designing and evaluating services so that they are better calibrated to both patient and caregiver needs. Most importantly, for caregivers, it provides an opportunity to shed light on a perspective that is often overlooked, particularly in healthcare where the focus is predominantly on the patient.

Participants emphasized the importance of creating a *community of learning* – a space where various stakeholders come together to learn from each other, acquire competencies and advance an agenda. Other principles in this paper are more procedural in nature (e.g., clarifying roles, increasing opportunities to engage, engaging early and measuring) as well as principles that require a cognitive shift and degree of situational awareness (e.g., recognizing caregivers, facing fears, addressing issues related to language and power and being mindful of whose experience is being represented). The remaining two principles, policy levers and blunt environmental changes, represent the role of context in enabling engagement activities. While our focus is on caregivers, these principles are relevant to patients as well; in fact, our findings align with previous research on patient engagement within health care.

Baker and colleagues<sup>26</sup>, coined the concept *engagement capable environment*, comprised of three core processes: enlisting and preparing patients, engaging staff to involve patients and ensuring leadership support and strategic focus. Our 12 principles provide additional fodder to operationalize the processes proposed by Baker and

colleagues<sup>26</sup>—for example, *how* to involve caregivers in engagement work as well as *the types* of competencies required for caregivers, staff and system leaders<sup>25</sup>. Similar to Baker and colleagues' engagement capable environment concept<sup>26</sup>, the principles presented in our paper—a combination of procedural, cognitive and policy/environmental factors need to operate in tandem to be successful. For instance, increasing opportunities for caregivers to engage will not be successful if issues of power dynamics are not addressed and if leadership buy-in does not occur. Previous work on factors that enable a person centred environment by Luxford et al<sup>20</sup> similarly outline a combination of factors that need to coincide in order for organizations to have a person centred ethos including committed senior leadership, active engagement of patients and caregivers, clear communication of vision, a focus on provider satisfaction, measurement and feedback reporting of patient experiences, adequate resources for re-design work, a culture supportive of change and learning as well as accountability and incentives. Similarly, a systematic review conducted in 2018 by Bombard et al<sup>18</sup> on the strategies and contexts that enable patient engagement in health care quality improvement activities, noted the importance of: role clarification, early engagement, training, sensitization to cultural issues within organizations, addressing provider skepticism, recruiting a diverse group, as well as strategies to equalize power, increase comfort and deliberate equally<sup>18</sup>.

The 12 principles from our study demonstrate an alignment with the patient engagement literature. One key factor, which may need special consideration for caregivers, is the taxing nature of their role, and how this will limit their time to engage in any activity, whether it is in research or practice. Thus, using creative and flexible approaches for engagement and reducing barriers, through the use of technology or paying for services (respite) so that caregivers can participate more fully will be required.

The examples and strategies that coincide with the 12 principles (see Table 1) provide insight into *how* they can be operationalized (e.g., working with caregivers to co-create a meaningful research question or providing opportunities for caregivers to lead discussions and chair meetings). Furthermore, while some principles may be easier to implement in the shorter term (e.g., blunt changes) others may require a longer term plan (e.g., addressing issues of power imbalances and organizational culture in support of engagement activities).

The culture shift required, is perhaps the key enabler to moving this agenda forward. Jim Conway, former Senior VP at the Institute for Health Improvement and former CEO of the Dana-Farber Cancer Institute, shares important insights in a recent book on Patient Engagement. He articulates the real struggles that



organizations have in doing this work, for fear that it will take away from other pressing issues such as patient safety and meeting financial goals. Through his own experience as a health leader, he personally witnesses a shift in culture and understanding when patients and caregivers are invited into the circle, noting that people need to witness it to see its value. Patients and caregivers can see things that we do not see, and can collectively, with providers, managers and researchers, find the answer<sup>25, 26</sup>.

### Suggestions for further exploration or research in this area

Our paper is a product of in-depth deliberation with various stakeholders from caregivers to executive directors who discussed their engagement experiences. The concrete examples provide other researchers and health care organizations substantive guidance on how to move forward with engagement activities with a population that is often overlooked. Caregivers, often described as the invisible workforce, have tremendous insight into the system and the patients in them, and without their perspectives any attempt to improve quality in health care systems may not be fully informed. The core principles identified in our analysis can be used as a framework for a variety of activities including curriculum development (including core competency training), program design and evaluation of engagement activities. Most importantly, these insights can be used to support the development of learning health systems<sup>27</sup>, systems that are equipped to engage with caregivers, capture their story and feed this into new quality improvement strategies and rapid cycle evaluations. This iterative and ongoing quality improvement cycle means that even if we don't get it right the first time, we create the mechanisms to feed the caregiver voice and perspective, as one of many data points, to guide system change.

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