

CAREGIVER PERSPECTIVES ON MEANINGFUL ENGAGEMENT

The [Rules of Engagement guidelines](#) were originally developed by Ontario patients and family caregivers. The guidelines consists of 15 recommended approaches for health care organizations to use when they were involving family caregivers.

Patient and caregiver engagement has become more commonplace in healthcare organizations in recent years. Furthermore, the Ontario government has released legislation and guidance that require meaningful engagement and involvement with patients and caregivers to inform healthcare improvement.

As a response to the changing landscape and caregiver engagement in Ontario Health Teams (OHTs), the Ontario Caregiver Organization (OCO) held two caregiver sessions - Preparing Caregivers for Meaningful Involvement with OHTs - in Spring 2021. Through these interactive discussions, over 60 caregivers started a discussion about what a caregiver experience would look like if the approach to these rules was implemented well within an Ontario Health Team. Through these two sessions, caregivers selected and discussed 7 of the 15 rules of engagement.

This document captures the original engagement principle (Rule of Engagement) and its definition, along with a summary of the input the OCO heard from caregivers at the sessions to define what the caregiver experience could feel like if these principles were implemented well.

We are grateful to the caregiver partners who co-developed these sessions and to the caregiver participants who shared their expertise and experience that helped shape this document.

OCO is committed to supporting caregivers in their work with OHTs and look forward to our continued work in this area.

Engagement Principle	Engagement Principles	The Desired Caregiver Experience
<p>Consider a range of engagement formats</p> 	<ul style="list-style-type: none"> • Offer a number of ways for caregivers to help improve the quality of health care and the health care experience. • Formats should be dependent on the objectives and stage you are at within your engagement work. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • participate in multiple ways and in the language of their choice (i.e. share healthcare experience in writing, share a video, provide written feedback, attend a meeting with interpretation). • be selected for the ‘right’ format for the ‘right’ goal. This could be achieved through a chart/tool for when to use different formats (i.e. courses for individual learning, Town Halls for broad community reach, etc.). • be encouraged to share their story (experience) because organizations recognize that storytelling is important. This shows the power of narrative and allows organizations to benefit from different experiences.
<p>Recruit wisely</p> 	<ul style="list-style-type: none"> • Recruit wisely. • Aim for a mix of people who are new to public engagement and those who are experienced or even seen as champions in the role. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • be valued for different skills/roles. (organizations will get something new and different from each engagement opportunity) • have their skills and interests aligned with the opportunity, topic, or engagement formats. • be approached by someone they already know. • see healthcare organizations partner with other organizations to develop recruitment strategies to reach specific communities. • have barrier-free opportunities to participate. • have a variety of different level and time commitments for participation to ensure there is flexibility and respect for each person’s time and availability. • have increased representation and ensure a diverse range of people from each community’s demographics are involved. • be paid for their time to contribute.

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<p>Be clear about your purpose, objectives and scope of influence</p> 	<ul style="list-style-type: none"> • Be clear about your purpose, objectives and scope of influence. • From the start, give your participants clear understanding of the engagement’s purpose, objectives, conditions for success, and level of involvement. • Tell the participants the level of influence or authority your organization has to implement changes and be clear about the of your organization’s power from the start. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • not feel rushed (i.e. having too many topics on the agenda) and attend meetings set up to get meaningful input. • know what topics are within scope. • know that all ideas are welcome to stimulate ideas on how to address or identify future projects, but there may need to be a ‘parking lot’ list for ideas that are not included/ possible in the current topic. • feel heard and know that there is enough time for conversation, and they will not be rushed. • understand the roles and responsibilities for other people involved before the meeting/engagement event starts. • know what they have shared accountability of and what they have individual accountability for.
<p>Give participants the tools they need</p> 	<ul style="list-style-type: none"> • Give participants the tools they need. • Provide participants with accessible, relevant, and balanced resources and support, so they can build their knowledge and skills. This will also increase their confidence and capacity to engage. 	<p>Caregivers want:</p> <ul style="list-style-type: none"> • a Glossary of terms (acronym list) often used in healthcare organizations • good storytelling examples & tips for “how to tell my story”. • a caregiver advocacy toolkit. • evaluations to provide feedback. (pre and post engagement opportunities) • a technology 101 overview – someone from the organization to check with them to be sure they have the technology knowledge and tools to be able to participate. • information provided ahead of any meetings or activities, to give them time to prepare. (this reflects that people learn/process/prepare differently) • a clear description of what ‘involvement’ means and what it looks like for the organization that they are involved with. • an overview of the Ontario health care system • an orientation to the project, topic and all the partners involved. • a list and summary of who’s involved in the project/ committee/engagement opportunity. • regular communication updates. • jargon to be avoided and not used at the meeting or in the materials. (i.e. language is not a barrier to their participation) • a buddy system (peer connection) for patients and caregivers.

Engagement Principle	Engagement Principles	The Desired Caregiver Experience
<p>Give participants the recognition they deserve</p> 	<ul style="list-style-type: none"> • Give participants the recognition they deserve. • Always acknowledge the contributions and impact of participants when reporting to the public and other audiences. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • be asked at the beginning of their involvement about how they want to be recognized. • be recognized in a way that is meaningful for them (different formats include honorariums, covering costs to participate, written or verbal thank yous). • A standardized approach (detailed in Terms of Reference or other guidance documents) to recognition to ensure everyone has the same understanding.
<p>Report back</p> 	<ul style="list-style-type: none"> • Commit to a feedback loop at the beginning and follow through. • Tell or show participants what you did, or didn't do, with their information or advice. • Reporting back is also linked to how you've acknowledged them in your activities or materials. 	<p>Caregivers want to:</p> <ul style="list-style-type: none"> • see what has changed or what progress has been made based on their involvement. • a feedback loop that they understand and can rely on. This can take many forms including meeting minutes, follow-up and thank you letters, and regular communications. • be told or shown how their feedback was used (or not used and why). Updates can be given at the next meeting or in a summary letter/email. They are interested in the long-term impact of their involvement as well - a letter, call or email outlining how the change has impacted the lives of patients/caregivers, or how it has been sustained for 6 or 12 months, is also important. • a report back as an important act of recognition or acknowledgement.