

Preparing for Patient-Oriented Research Meetings with Older Adults and Caregivers

**Trainee Workbook**



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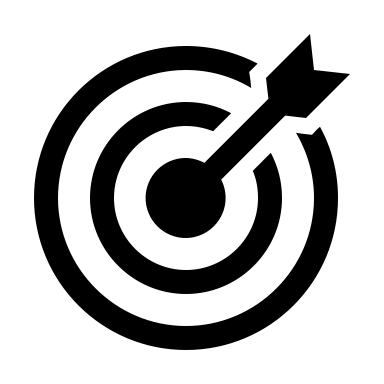
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PURPOSE OF THIS WORKBOOK



This workbook was created to support research trainees who are planning to hold virtual or in-person meetings with older adults and caregivers to inform research planning, implementation, and knowledge mobilization.

This workbook provides suggestions to consider when planning: decisions and activities to be completed before, during, and after a meeting with older adults. It can be used for planning virtual or in-person meetings, although some prompts may not apply for all settings. We provide space for trainees to document their decisions and actions to facilitate the reporting of their engagement activities and outcomes, as well as to plan future meetings, as part of their program of research.

**NOTE:** This workbook is not intended to be a comprehensive manual or how-to guide for community engaged or patient-oriented research. Systematic reviews, frameworks and guidance documents exist that can help research teams when designing their engagement strategy. Research teams are advised to consider if research ethics board review and approval is appropriate[[1]](#footnote-1) for their engagement plan and what institutional policies exist that may impact their plan (e.g., honorarium payments, confidentiality, collection, and storage of information). This workbook complements the McMaster Collaborative for Health and Aging’s “[Partnering principles and strategies: A guidance document](https://collaborative-aging.mcmaster.ca/resources/guidance-documents/),” which outlines key principles and best practices for engagement. This workbook is a practical tool, designed to be customizable, to support the intentional and ethical planning of meetings (virtual or in person) with older adults as part of an engagement plan.

## TARGET AUDIENCE

This workbook was designed for research trainees who are planning to engage older adults in a time-limited activity (e.g., one or two meetings) to inform or advise on their project as a starting point for community-engaged research. However, the questions to consider and encouragement for thoughtful reflection may be helpful for those interested in engaging individuals with relevant lived experience to inform research more broadly.

## WHO CREATED THIS WORKBOOK?

A team of researchers, older adult and caregiver partners, and trainees from the McMaster Collaborative for Health and Aging created this workbook through an iterative engagement process.

## Purpose of this workbook sectionHOW THIS WORKBOOK HAS BEEN ORGANIZED

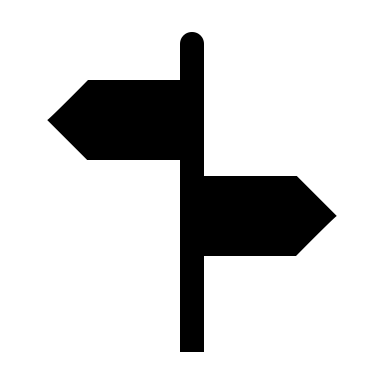
This workbook has been organized using questions and prompts for reflection alongside space for your own notes and resources, to facilitate the planning for, conduct of, and follow-up after a meeting with older adults. The workbook has been designed in a format that is easily modifiable (i.e., you do not need to complete every question!). You can remove sections that do not apply and add your own content. Trainees are encouraged to be creative and consider innovative ways they might use this workbook to develop and support meaningful engagement.

The workbook has been divided into the following sections:

1. [Guiding Principles](#_GUIDING_PRINCIPLES_1)
2. [Terms and Definitions](#_TERMS_AND_DEFINITIONS)
3. [Pre-Meeting: Considerations and decisions to inform pre-meeting activities](#_Pre-Meeting:_Considerations_&)
4. [Meeting: Considerations and decisions to inform the conduct of a meeting](#_Meeting:_Considerations_&)
5. [Post-Meeting: Considerations and decisions to inform post-meeting activities](#_Post-Meeting:_Considerations_&)

LET’S GET STARTED

# GUIDING PRINCIPLES



Patient-oriented research can help address health inequities. Research decisions and actions related to the meaningful engagement of people with lived experience are critical to a research project’s potential to support health equity.

The following six guiding principles, adapted from [Health Quality Ontario’s Patient Engagement Framework](https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf), are presented in the McMaster Collaborative for Health and Aging’s [Partnering principles and strategies: a guidance document for researchers, older adults and caregivers](https://collaborative-aging.mcmaster.ca/wp-content/uploads/2023/03/Partnering-Principles_MCHA_2023.pdf) as a foundation for approaching engagement with older adults and caregivers regardless of the forum or length of commitment.

Considerations of equity, diversity and inclusion should be a consistent thread throughout the engagement process and the interpretation and enactment of the principles below.

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|  | **CLEAR COMMUNICATION** – The purpose of the roles/opportunities for Older Adults, Caregivers, and Public Research Partners are clearly communicated |

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|  | **INFORMATION EXCHANGE** – Information is shared in a context of trust where Older Adult, Caregiver, and Public Research Partners feel comfortable sharing their views openly and honestly |

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|  | **EMPOWERMENT –** Older Adult, Caregiver, and Public Research Partners are empowered to openly express their opinions, perspectives, and concerns |

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|  | **TRANSPARENCY –** Researchers are honest about their apprehensions, resource limitations, and knowledge gaps when it comes to engaging with Older Adults, Caregivers, and Public Research Partners |

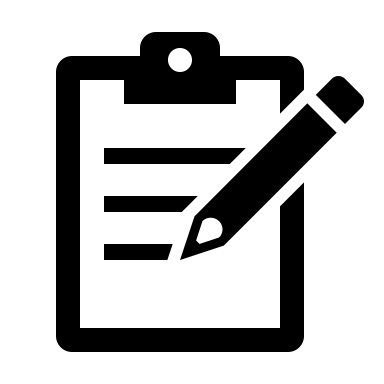
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|  | **MUTUAL RESPECT** – Researchers demonstrate respect for their Older Adult, Caregiver, and Public Research Partners by actively showing signs of appreciation for their time, ideas, lived experiences, various world views and cultural locations |

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| Icon  Description automatically generated | **RESPONSIVENESS** – Researchers act upon the voices of patients, caregivers, and the public in ways that demonstrate the positive impacts of this input |

Guiding principles sectionWhile not explicitly named above, **confidentiality** is a cornerstone of the principles of information exchange and mutual respect. Confidentiality should be considered and reinforced within the research structures and actions of the researchers and openly discussed with Older Adult, Caregiver and Public Research Partners.

As you work through this workbook and your journey of partnering with older adults in research, we encourage you to frequently reflect on these principles: what actions are you taking in support of these principles? What opportunities can you take to strengthen your commitment to them?

# **TERMS AND DEFINITIONS**



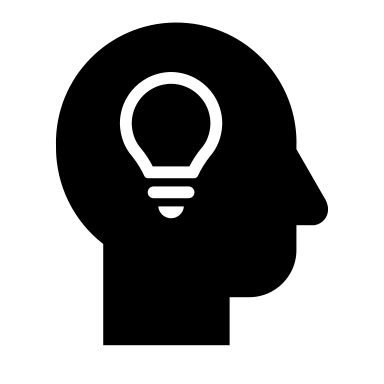
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| Icon  Description automatically generated | **PATIENT-ORIENTED RESEARCH**: The [Canadian Institutes of Health Research](https://cihr-irsc.gc.ca/e/41204.html) states that “Patient-oriented research is about engaging patients, their caregivers, and families as partners in the research process. This engagement helps to ensure that studies focus on patient-identified priorities, which ultimately leads to better patient outcomes.” However, there are many terms that may be used with the common philosophy of engaging and partnering with people with the lived experience most relevant to the research. The language used may depend on the discipline, country, or community of the research. |

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| Icon  Description automatically generated | **TRAINEE:** In this tool, we use the term trainee inclusively as any individual interested in enhancing their research skills through action. Regardless of an individual’s career or education standing, meaningful partnership and engagement with older adults may be a new skill and approach. |

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| Icon  Description automatically generated | **OLDER ADULT**: We use the term older adult in this tool to refer broadly to people with relevant lived experience who are older. As a Collaborative of researchers focused on aging, older adults and the caregivers of older adults have an important lived experience. However, for each specific project and engagement opportunity research teams must identify whose perspective is most important to include, potentially prioritizing individuals who face the greatest barriers. |

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| Icon  Description automatically generated | **ACCESSIBILITY**: Accessibility refers to the design of products, services and environments that is inclusive and accessible to a diverse population, including persons with disabilities[[2]](#footnote-2). Accessibility requires proactive identification and removal, or supported navigation, of barriers as an ongoing process[[3]](#footnote-3). For inclusive engagement of older adults, accessibility considerations include identifying and addressing barriers related to knowledge, technology, finances, physical spaces, and social norms. |

# Pre-Meeting: Considerations & Decisions to Inform Pre-Meeting Activities



**Understand & Consider:** Before you book a time to meet with older adults you may want to gather some information and consider the following questions. This pre-work will help ensure you have the ideal set-up (e.g., length of time, location, supports) for your meeting.

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| A: How do you plan to establish a relationship before you meet with older adults? |  | * Can you call individuals or attend a “pre-meeting” to introduce yourself? * Can you circulate a welcome note or brief bio about yourself to share with older adults? |

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| B: How will you prepare older adults to engage meaningfully? |  | * Can you include clear “asks” in your agenda or pre-meeting communication (e.g., please review the attached document and consider…)? * Consider including your discussion questions in your agenda so that the older adults can prepare for the conversation. * Invite the older adults to contact you in advance of the meeting if they have any questions. |

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| C: In what wayswill you planfor accessibility(e.g., location, food, technology, information)? |  | * Who can you ask to learn about individual preferences and accessibility requirements? * Consider visiting your venue for in-person meetings in advance to understand accessibility considerations (e.g., closest accessible bathroom, location of elevators, signage). * Consider offering printing (and mailing) for any written materials. |

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| D: How will you promote (physical and emotional) safety for the older adults? |  | * Are there infection control considerations or requirements? * Consider creating time in your agenda to discuss group norms or expectations to create a safe space at the start of your meeting. * Consider which questions or topics may be sensitive or potentially triggering. * Consider how you may redirect the conversation and address topics or actions that may be upsetting or triggering. |

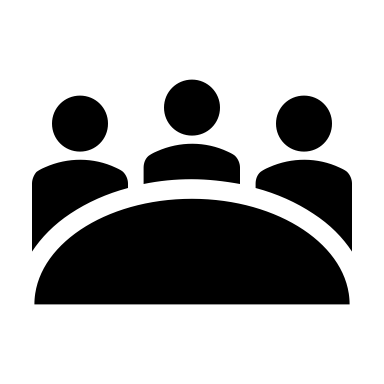
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| E: What tools or strategies will you use to engage partners in a meaningful way? |  | * Can you include an icebreaker? This may be directly linked to your content or other important contextual factors such as the date of the meeting. * Could an activity during the meeting be used to support the learning or experiential objectives of the meeting? * Can pre-meeting activities, integrated polls, break-out rooms, or peer facilitators support engagement? |

Pre-Meeting: Considerations & Decisions to Inform Pre-Meeting Activities section

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| F: How will you ensure that there is enough time for discussion on your meeting agenda? |  | * Would pre-meeting homework and/or review of materials be feasible and beneficial? * Consider prioritizing agenda items and putting lower priority items at the end. |

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| Notes: Type your own notes in here!  Resources: Track the resources you have used here! |

# Meeting: Considerations & Decisions to Inform Meeting Activities



**Understand & Consider:** As you prepare for your time with older adults, the following questions and considerations may help you identify activities and resources in the meeting that can support your engagement goals.

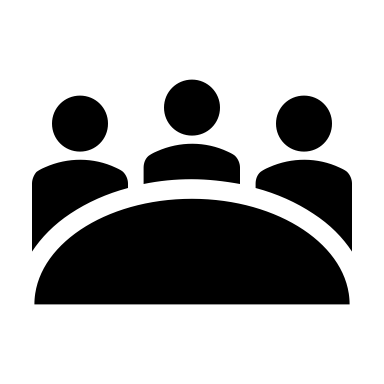
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| A: How will you introduce yourself in the meeting? |  | * How can you address power and perceived power relationships (e.g., acknowledge the expertise of everyone involved, share your own areas for growth such as your commitment to, but limited experience with, partnered research)? * Consider how you can continue to strengthen your relationship through activities and actions in the meeting. |

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| B: How might you ensure  those who attend the meeting feel comfortable?  *(e.g., snacks, breaks, activities, comfort items)?* |  | * Consider accessibility and individual preferences. |

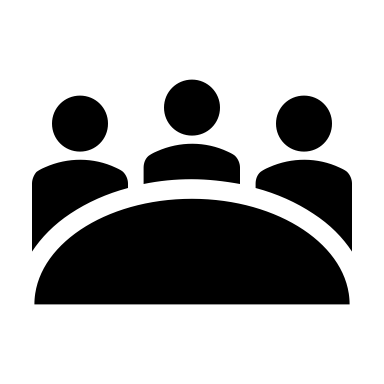
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| C: Consider potential what-ifs *(e.g., attendance changes, technological challenges, disruptive behavior, offensive comments)* |  | * Discuss potential roles and actions with any co-facilitators. * Consider reviewing a contingency plan with your mentor or team (e.g., who and how to address potential situations in the meeting, process for following up with participants after an upsetting incident). |

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| D: How will thoughts, ideas, questions, and concerns be captured? |  | * Consider having a note-taker separate from the role of facilitator. * Is it appropriate to audio-record all or part of the meeting? |

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| E: How will engagement  be captured? *(e.g., number of partners, themes)* |  | * Consider how you will describe and record who and how you engaged with older adults and ensure you are prepared to capture this information (e.g., gender, age). * Consider asking individuals how they would like to be described in future reports and project activities (e.g., what demographics and experiences are important to contextualize their experience). |



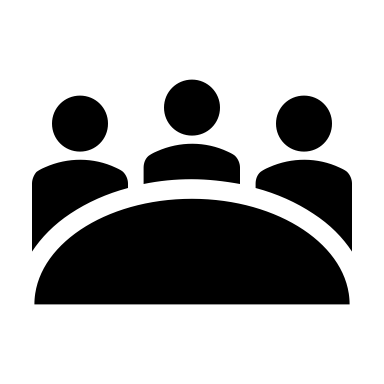
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**Provide:** In addition to information and resources provided to older adults to meet your meeting objectives, consider what information to provide in support of the guiding principles of engagement (i.e., clear communication, transparency, mutual respect, responsiveness).

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| F: Tell individuals when and how you will follow-up *(e.g., meeting summary, project next steps, process feedback)* |  | * How can you address power and perceived power relationships (e.g., acknowledge the expertise of everyone involved, share your own areas for growth such as your commitment to, but limited experience with, partnered research)? * Consider how you can continue to strengthen your relationship through activities and actions in the meeting. |

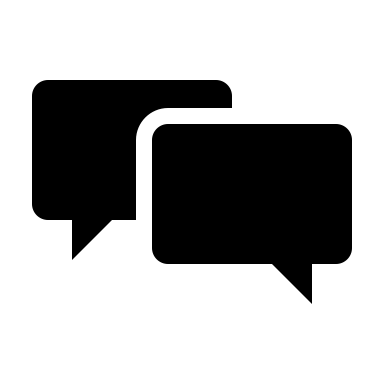
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| G: Inform individuals of when and how honorariums and reimbursements  (e.g., parking fees) will be provided |



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| H: Invite additional feedback |  | * If you are asking individuals for feedback on the engagement process, consider having details (e.g., link to an online survey) ready to share at the end of the meeting, in addition to sending information in a follow-up email. * Consider offering multiple ways for individuals to share additional thoughts (e.g., is there a peer who can help facilitate follow-up conversations? Provide an email address and phone number). |

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# Post-Meeting: Considerations & Decisions to Inform Post-Meeting Activities



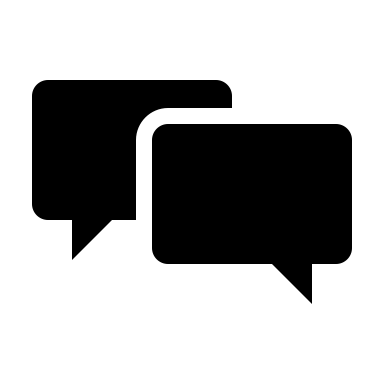
**Understand & Reflect:** Throughout your planning process and after your meeting, you may want to gather some information and consider the following questions to help you understand the value (and limitations) of your engagement and how you can build upon this work.

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| A: If sensitive topics were discussed, how will a debrief be provided? |  | * Debrief with a peer or mentor if you are uncomfortable with any behaviours, actions, or content of discussion during the meeting. * If you are worried that individuals may have been triggered or need support after the conversation, are there external resources you can refer them to as part of your follow-up plan (e.g., provincial hotlines, community-based resource materials)? * Consider sending a follow-up note to individuals to check-in and thank them for their participation. |

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| B: How will the information and perspectives discussed (e.g., feedback, outputs) be used? |  | * Consider reviewing the meeting notes immediately after the meeting (to add details and correct errors). * Is it appropriate to share your meeting notes or a high-level summary with other research team members? * Consider using a research log to facilitate and record resulting actions or decisions as they occur. |

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| C: Whose voice may not have been captured? |  | * Considering health equity, what experiences and perspectives may be important to this work that have not been represented in this engagement? * Consider if there are other strategies you can use to support the representation of perspectives from individuals with more diverse experiences and identities (e.g., is there existing literature? Are there organizations you can contact who advocate and represent individuals whose perspectives you were missing?). |

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| D: How will diverse perspectives be included? |  | * Consider how you can recognize feedback and perspectives that may have been in the minority or contrary to the majority (individual follow-up may help to understand and decide on appropriate next steps). |

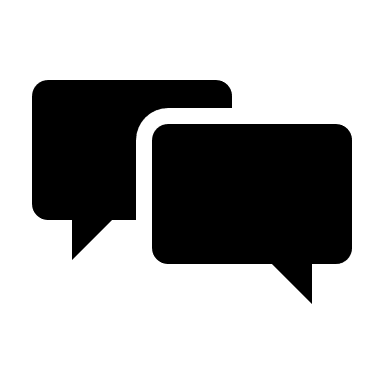


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| E: How will relationships be maintained and strengthened? |  | * Consider if there are other opportunities or related resources you can share that individuals may be interested in. |

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| F: How can this experience contribute to your future research and engagement plans? |  | * Consider writing reflective notes (in this workbook or in a separate log) about how the meeting went: what went well? What do you want to do differently next time? Are there ideas or skills you want to explore or develop? |

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| Notes:Type your own notes in here   Resources: Track the resources you have used here |

**Provide:** Consider the guiding principles as you contemplate what to provide to the older adults after the meeting, to continue to build trust, relationships, and the exchange of knowledge.



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| G: Identify and share a short, medium, and long-term plan for follow-up with individuals |  | * Consider sharing public events and knowledge products from your project, or that build on the conversation, immediately after the meeting and as they become available. * Share any materials which are created where this engagement strategy is mentioned (consider setting yourself a reminder aligned with project or output deadlines). |

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| H: In what ways can you solicit feedback specific to the process of engagement? |  | * Can you share a short survey for partners to share their experience? * Consider asking any staff or colleagues that facilitated the engagement for their feedback and to share any considerations that the older adults may discuss later (where appropriate). |

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| Notes:Type your own notes in here   Resources: Track the resources you have used here |

# RESOURCES

We encourage you to add, revise, and annotate this list of resources.

## General Patient-Oriented Research Resources

* [SPOR (Strategy for Patient-Oriented Research) Patient Engagement Framework,](https://cihr-irsc.gc.ca/e/48413.html) CIHR (Canadian Institutes of Health Research)
* [Ontario’s Patient Engagement Framework](https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf), Health Quality Ontario
* [Partnering principles and strategies: A guidance document for researchers, older adults, and caregivers,](https://collaborative-aging.mcmaster.ca/resources/guidance-documents/) McMaster Collaborative for Health and Aging

## Meeting Facilitation and Activity Ideas

* [Art-Based Evaluation Toolkit](https://www.artreach.org/artbasedevaluation), Artreach Toronto
* Switzer S, et al. [A seat at the table: designing an activity-based community advisory committee with people living with HIV who use drugs](https://d1wqtxts1xzle7.cloudfront.net/57920044/A_Seat_at_the_Table-with-cover-page-v2.pdf?Expires=1664831007&Signature=XyDbBMVgbgio7AovARfEaps6yULEPjR9IZuVlblM4qcskUxz0di0K-EmiDIQC5PhfdmfHiuJW9V0v2p~Fa3dZaGCNJyNpba3mSPXUNK5sBFKP90TOPOfDcwBTVinRgd3Pe1W9zf3b4q9iYnEi5ir3newKzknZYNQYgajlGF4w9rWHboXNmiYMG2HF0bGA1wZoy82Og-6VTPI37R0KAr3znDbsU~tqS-amRZFBgudoEs922odbcvFqAwd4jI7JGw~OI655LzEdtN6qSHJi1qJBva-4ezlWPjZFZWMGNSqWkHIWwIRRCn5KTW~tD0B6VhZcbqaeq1YpRoZByq~pPlF0w__&Key-Pair-Id=APKAJLOHF5GGSLRBV4ZA). 2019 Jun;29(7):1029-42
* [Facilitation tools for meetings and workshops](https://seedsforchange.org.uk/tools.pdf), Seeds for Change, UK

## Equity, Diversity & Inclusion

* [Fairness is Excellence: The Ontario SPOR SUPPORT Unit’s Equity Framework](https://ossu.ca/resources/equity-framework-and-curriculum/)
* [Methods for Supporting Diverse Patient Engagement in a Diverse World,](https://www.bcahsn.ca/initiatives/learning-tool-diverse-communities) BC SUPPORT Unit Tapestry Project

## Ethical Consideration when Engaging People with Lived Experience in Research

* [Ethical Considerations for Partnering in Patient-Oriented Research guide,](https://absporu.ca/wp-content/uploads/2020/11/AbSPORU-PE-Platform_Ethical-Considerations_Oct2020_23.pdf) Alberta SPOR SUPPORT Unit

## Compensation Related Resources

* [Considerations when paying patient partners in research,](https://cihr-irsc.gc.ca/e/51466.html) CIHR
* [The Research Compensation Series](https://amandagrenier.com/pubs/research-compensation-series/), output of AGE-WELL CC1 Crosscutting Theme on Knowledge Mobilization and Commercialization.

## Knowledge Translation

* Barwick M (2008, 2013, 2019). [*Knowledge Translation Planning Template*](https://www.sickkids.ca/contentassets/4ba06697e24946439d1d6187ddcb7def/79482-ktplanningtemplate.pdf)*.* ON: The Hospital for Sick Children.

This workbook was created by the McMaster Collaborative for Health and Aging to support trainees in their meaningful and ethical engagement with older adults and/or caregivers in their research.

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Rebecca Ganann

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1. See for example:

   <https://static1.squarespace.com/static/599c81bcccc5c54ab629580e/t/5a6a04640d92977af646f3ae/1516897381224/QI%2Bvs%2BResearch%2B-%2BDo%2BI%2BNeed%2BREB%2BApproval_V2.pdf>

   <https://uwaterloo.ca/research/office-research-ethics/research-human-participants/pre-submission-and-training/human-research-guidelines-and-policies-alphabetical-list/does-my-data-collection-activity-require-ethics-review#participant> [↑](#footnote-ref-1)
2. For more definitions see: <https://accessibilitycanada.ca/aoda/definitions/> [↑](#footnote-ref-2)
3. For more about the Accessibility for Ontarians with Disabilities Act:

   * <https://aoda.ca/>
   * <https://accessibility.mcmaster.ca/legislation/aoda/>

   [↑](#footnote-ref-3)