

# Partnering principles and strategies: A guidance document for researchers, patients, and caregivers

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The following guidance document is to be used to plan for and involve **Patient, Caregiver, and Public Research Partners** in the activities and projects by the McMaster Institute for Research on Aging (MIRA) Collaborative for Health & Aging. Below, we outline the core principles that should guide the involvement of Patients, Caregivers, and Public Research Partners in activities of the Collaborative and the best practices for carrying this out.



**The mandate of the McMaster Institute for Research on Aging Collaborative for Health & Aging** is to build capacity and advance Ontario's health care system by using an integrated, coordinated, and people-centered approach.

The MIRA Collaborative for Health & Aging seeks to strengthen Ontario's capacity in patient-oriented research and improve health system performance and patients' experiences by advancing the science of patient engagement and methods and tools in patient-oriented research on aging.

Researchers and Patient, Caregiver, and Public Research Partners from the MIRA Collaborative for Health & Aging have developed this step-by-step guide that includes core principles to involve Patient, Caregiver, and Public Research Partners and the best practices for carrying them out.

**Clear communication** – The purpose of the MIRA Collaborative for Health & Aging and roles/opportunities for Patients, Caregivers, and Public Research Partners are clearly communicated.

**Information exchange** – Information is shared in a context of trust where Patient, Caregiver, and Public Research Partners feel comfortable sharing their views openly and honestly.

**Empowerment** – Patient, Caregiver, and Public Research Partners are empowered to openly express their opinions, perspectives and concerns.

**Transparency** – MIRA Collaborative for Health & Aging researchers are honest about their apprehensions, resource limitations, and knowledge gaps when it comes to engaging with Patients, Caregivers, and Public Research Partners.

**Mutual Respect** – MIRA Collaborative for Health & Aging researchers demonstrate respect for their Patient, Caregiver, and Public Research Partners by actively showing signs of appreciation for their time, ideas, lived experiences, various world views and cultural locations.

**Responsiveness** – Members of the MIRA Collaborative for Health & Aging act upon the voices of patients, caregivers, and the general public in ways that demonstrate the positive impacts of this input.



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**Guiding Principles for Partnering** (adapted from Health Quality Ontario's Patient Engagement Framework)  
<https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>

## Best practices for involving Patient, Caregiver, and Public Research Partners in Research Initiatives

### Activities

#### 1. RECRUITMENT

- a. Identify a member of the Collaborative who will act as a primary liaison with **Patient, Caregiver, and Public Research Partners**
- b. Develop a draft role description for **Patient, Caregiver, and Public Research Partners** that will subsequently be refined with their input. Role description should include:
  - i. purpose of activities or project(s)
  - ii. potential opportunities to be involved – negotiated roles should align with **Patient, Caregiver, and Public Research Partner** interests and availability
  - iii. anticipated time commitment, meeting frequency
  - iv. reimbursement policy
- c. Consider representation – patient/caregiver/citizen perspectives, gender, health care/community sectors, equity, diversity, and inclusion

### Key considerations

- Give thoughtful selection to who will be contacting the Partner
- Liaison needs to identify who they are and the organization they are representing
- Provide adequate time for meeting/call
- Telephone manner is important
- Make the Partner feel at ease; don't rush the call/meeting
- Be prepared to:
  - take more time
  - listen
  - start to build a relationship
- Avoid jargon
- Avoid acronyms
- Use clear language



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### Activities

## 2. ORIENTATION

First meeting with the potential Partner to explore interest in becoming involved

- a. Review goals and objectives of MIRA Collaborative for Health & Aging
- b. Have Partner share their interest in becoming involved as a research partner (experiences as a patient/caregiver/citizen, previous experiences as a research partner, as relevant) and have MIRA Collaborative for Health & Aging member explain why they want them to be involved
- c. Explore what assets/strengths the Partner brings – seek to align with MIRA Collaborative for Health & Aging activities
- d. Share role description
- e. Mention opportunities to:
  - i. participate in other activities or projects
  - ii. contribute to presentations with diverse audiences
  - iii. contribute to grant development for future funding
- f. Review compensation
  - i. Honorarium – Not all Patient, Caregiver, and Public Research Partners will be interested in the same approach. Recognize some will have restrictions (e.g., social assistance). Type and amount should be mutually negotiated (review relevant compensation documents resources)
  - ii. travel and parking costs
- g. Confidentiality/ethics
- h. Photo/video release
- i. Review consent form for Patient, Caregiver, and Public Research Partners
- j. Individual discussions – accommodations to participate in MIRA Collaborative for Health & Aging
  - i. need for respite support
  - ii. need for transportation support
  - iii. comfort with and access to using technology for communication/document sharing
  - iv. preferred method to communicate (phone, email, mail)
  - v. dietary restrictions
- k. Any additional Partner needs to prepare for the first meeting

### Key considerations

- Encourage Partner to think about their experiences in the community, current/previous work lives/roles, the skill set they have developed over time
- Encourage Partner to consider how these experiences and skills can help to inform the work of the MIRA Collaborative for Health & Aging
- Potential role(s) will depend on activity or project
- Ensure that activity or project offers opportunities to provide input based on Partners' experiences
- Discuss what is meant by confidentiality. Explain ethics – approved and regulated by a research ethics board



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Activities	Key considerations
<p><b>3. MEETINGS</b></p> <p><b>a.</b> Agendas – ensure that opportunities for input for Patient, Caregiver, and Public Research Partners are built into each agenda</p> <p><b>b.</b> Materials – share in advance, ideally one-week in advance</p> <p><b>c.</b> Language – targeting non-expert audience; lay language</p> <p><b>d.</b> Written materials: Font type and size for accessibility</p> <p><b>e.</b> Meeting follow up – arrange a brief check in with Patient, Caregiver, and Public Research Partners following each meeting</p>	<ul style="list-style-type: none"><li>• Before meeting:<ul style="list-style-type: none"><li>• ensure Partner knows where to park, how to find room (e.g., designated person to meet individuals at elevators is helpful)</li></ul></li><li>• Review engagement principles</li><li>• Summarize action items and progress made since last meeting</li><li>• Close the loop on how research Partner contributions have been used/applied</li><li>• Recognize that Patient, Caregiver, and Public Research Partners will have different preferences for participating in meetings:<ul style="list-style-type: none"><li>• some will want an agenda item</li><li>• some would like pauses throughout the meeting to ask Patients/Caregivers/Public Partners for input (e.g., ask “would anything else be helpful”)</li></ul></li><li>• Always ensure that there is opportunity for contributions at the end (time built in for open discussion)</li><li>• Avoid rushing through meetings. This could convey a sense that work is already done, decisions already made</li><li>• Large groups discussions are challenging to involve people. Consider other ways of engaging for high-quality input</li><li>• Follow up after meetings (by email or phone) to thank the Partner and to see if there are other contributions. Follow up should be by main point of contact and should ask if the Partner has any additional thoughts on what was discussed</li><li>• All communication should include dates and target audience to support orientation to purpose</li><li>• Engage Partners early in development of materials or products to allow for greater contributions, rather than only having them respond to what is already developed</li><li>• Be open to suggestions and ideas</li><li>• Involve, inquire and ask questions</li><li>• Build in enough time to do this well</li></ul>



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COLLABORATIVE FOR HEALTH & AGING

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### HELPFUL RESOURCES:

- CIHR Strategy for Patient-Oriented Research - Patient Engagement Framework – <http://www.cihr-irsc.gc.ca/e/48413.html>
- ACHRU Patient and Public Engagement – <https://achru.mcmaster.ca/patient-public-engagement>
- Health Quality Ontario Patient Engagement Framework – <https://www.hqontario.ca/Portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>
- Compensation docs:
  - Richards DP, Jordan I, Strain K, Press Z. (2018). Patient partner compensation in research and health care: the patient perspective on why and how. *Patient Experience Journal*, 5(3): 6 - 12. DOI: 10.35680/2372-0247.1334 <https://pxjournal.org/journal/vol5/iss3/>
  - BC Centers for Disease Control Peer Payment Standards [http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer\\_payment-guide\\_2018.pdf](http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf)