

RECRUITMENT

Be creative in recruitment strategies. Consider using multiple platforms such as social media, newspapers, local TV, radio, and healthcare providers, to reach diverse audiences. Use lay language when recruiting. Be sure to avoid jargon and industry specific terms.

Build relationships outside research and academic centers to help facilitate recruitment. Consider community centers or industry organizations.

Clearly outline the research objectives to partners. Communicate expectations, roles and responsibilities, time commitments, and level of flexibility associated with involvement. Outline key information at the start: where, when, how-much time/energy/involvement.

Allow partners the ability to choose which aspects of the research process they wish to be involved with.

Recognize and communicate the value of peer-to-peer research partnerships - they help to build trusting relationships with partners engaging in research.

Respect the expertise that older adult and caregiver partners bring to the research and avoid tokenism. Recognize that one voice may not be enough to understand all patients' needs and wants. Multiple voices should be engaged as appropriate.

Researcher Resources:

1. Full CFN 2019 Conference Video (https://youtu.be/UI6YpYK_QN8)
2. Patients as Partners: CIHR Compensation Guidelines (<https://cihr-irsc.gc.ca/e/51466.html>)
3. Experience Cased Co-design Toolkit (<https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit>)
4. Patient and Community Engagement Research (<https://pacerinnovates.ca>)
5. Strategies for Patient Oriented Research (<https://cihr-irsc.gc.ca/e/48413.html>)
6. Alberta Innovates Patient Engagement Platform (<https://spor.albertainnovates.ca/the-alberta-spor-support-unit/patient-engagement-platform>)

Partner Resources:

7. Patient Advisors Network (<https://www.patientadvisors.ca>)
8. Patient Voices Network British Columbia (<https://patientvoicesbc.ca/patient-partners>)

Writing Resources:

9. CFN Guidelines for Writing a Lay Summary (<https://www.cfn-nce.ca/news/new-guidelines-for-writing-research-summaries>)

Engaging Older Adults Living with Frailty and Family Friend Caregivers in Research



Canadian
Frailty
Network

Réseau canadien
des soins aux
personnes fragilisées

Canadian Frailty Network
Citizen Engagement
Committee

<https://www.cfn-nce.ca/>

Engaging those living with frailty and their caregivers

Engaging older adults living with frailty and their caregivers in the research process, as partners, increases the relevance of conducted research and improves the quality of the research results¹. There are unique challenges to engaging older adults living with frailty and their caregivers and it can be hard to know how to start! We've created this quick reference guide to help.

COMMUNICATION IS CRITICAL

Marlyn Gill - Patient Partner

"Don't underestimate us! Give us a chance, that's all we need. If you invite [us] as experts, and we are experts... we will give you a marvelous amount of information"

Olive Bryanton - Research Scientist

"Everyone wants to learn, to share their knowledge, because they are experts in what they need and want"

RETENTION

Keep involvement accessible, hold meetings in a location that is comfortable and familiar for partners. Be flexible! Listen to the wants and needs of partners and try and accommodate these. Allow partners to work when and where they can and be aware of personal needs and routines. Consider integrating internet or phone platforms as engagement options.

Understand and respect the level of contribution partners wish to make and for which aspects of the research process. Respect other obligations, priorities, or activities that partners may have. Don't underestimate partners skills and abilities, or desired level of contributions and participation.

Check in before and after meetings to make sure partners are comfortable with tasks and understand the research process. Consider providing the opportunity for partners to review meeting agendas prior to meetings. Ensure partners have a way of speaking their mind by providing a safe space for everyone to contribute and engage quieter members during meetings. Follow-up after meetings to make sure partner contributions were not missed.

Engage partners in appropriate meetings to draw on their expertise as a resource where applicable. Give the same consideration to citizen partners as you would academic or industry partners during the research process, especially when scheduling meetings.

Follow-up with partners throughout the research process to make sure they are confident and comfortable in their roles. Let partners know the value of their contributions and impact of their work.

ETHICS AND COMPENSATION

Consult with research ethics boards to communicate the importance of collaboration and participation of older adults living with frailty and caregivers within the research process as both contributing researchers and partners.

Be aware of potential compensation policies for older adults/caregivers as partners, and older adults/caregivers as participants.

Ask how partners would like to be compensated for their time and expertise. This can take many forms: monetary, food and drink during meetings, respite care for loved ones, personal support for research partners, research resources, reimbursement for travel expenses, recognition of contribution in work. Write partner compensation into grants and budgets.

MEASUREMENT/FEEDBACK

Engage in ongoing feedback! Keep it simple: How's it going, how can we improve? How can we make this more enjoyable, supportive, or accessible for you?

Be conscious of who is conducting measurement/follow-up. Ensure that feedback remains true and honest to those who provided it, not censored or sanitized to pacify administrators/funding agencies etc.

Be proactive with feedback: communicate the impact and direction of future research that has stemmed from projects partners contributed to. Communicate the impact and effect of partners participation.

Thank partners for their time, effort, and commitment.

Reference:
1. Holroyd-Leduc, J., Resin, J., Ashley, L. et al. Giving voice to older adults living with frailty and their family caregivers. *Res Invol Engagem* 2, 23 (2016).