Older adults as research partners:

A systematic review of implementation and impact

Key Points

- We know more about what older adults do in their research partner roles than how they were engaged and with what impact.
- Older adults were more likely to be involved in carrying out and sharing results of research but were less often involved in designing it.
- The impacts that older adults have had as research partners include the creation of new and continuation of existing partnerships.
- Some older adult research partners reported feeling more socially connected and less lonely as a result of engagement in health research.
- ✓ More impact evaluation is needed to advance this field.

What is this research about?

Beyond traditional roles as research subjects, older adults are increasingly called upon as research partners to help design, carry out and share the knowledge produced from health research projects. Despite their active roles in research, little is known about the specifics of how they have been engaged and with what impacts.

The McMaster Collaborative for Health and Aging's Science of Engagement Working Group explored these questions through a systematic review.

How was this research carried out?

Researchers searched five databases of published literature from inception to September 2021 to find English articles where older adults were engaged as partners in health research in any care setting (e.g., community, acute care, long term care). Outcomes of interest included: process, implementation, impact, and experiences of older adults.

This review included studies with older adults (aged 50+) who were partners in health research and excluded studies that solely included older adults as research subjects.

Results

Most of the 62 included studies were carried out in the community setting. Most studies did not report information about the ethnicity of their research partners; 12 studies reported inclusion of older adult research partners from Black, Chinese, Hispanic and Indigenous and white communities. Older adult research partners had lived experience with cancer, frailty, dementia, mobility issues, self-harm, and caregiving.

Older adult partners were most likely to be engaged in the execution of research and least likely to be engaged in the preparatory stages of research. In more than one third of studies, older adult partners were engaged to translate research findings. In six studies, older adult research partners were engaged across all stages of research.

It was more common for studies to discuss how older adults were engaged; fewer discussed how the impact of engagement was measured.

Little is known about the impact of engagement using objective measures. The studies that quantitatively measured the impacts reported increased feelings of social cohesion and decreased feelings of loneliness, and improved abilities to self-manage their care. Others reported outcomes such as the creation of new research partnerships or continued collaborations between co-researchers on new projects.

More commonly, impacts were measured qualitatively. Some studies collected and reported older adult research partners' experiences or narratives. Others reported on researchers' perceptions of the impacts of patient engagement in research.





Research Phase	Involvement Activities*
Preparatory phase	 identifying topics identifying research questions input into engagement processes establishing Advisory Board/Council contributing to project design and management completing research training course
Study design	 providing feedback on study methods, measures, interview guides, questionnaires identifying community-relevant topics for focus groups, areas for action refining or co-designing models/processes (e.g., care pathways, lesson plans) testing interview guides refining consent forms ensuring culturally relevant data collection approaches shaping public-facing materials training student researchers
Recruitment	 assisting with recruitment and recruitment procedures recruiting other citizen partners, encouraging attendance explaining project purpose to community members
Data collection	 conducting key informant interviews participating in community workshops to identify preferences/priorities facilitating focus groups facilitating completion of surveys
Data analysis	 member checking/confirming accuracy of data interpretation prioritizing, co-analyzing, identifying key themes contributing to development of model reviewing results making sense of findings reflecting on actions taken
Knowledge translation	 providing feedback on knowledge translation materials (e.g., frameworks, reports, newsletters, leaflets, infographics, publications) orally presenting research findings at workshops, feedback events, and in the community advising on how to disseminate, promote, and advocate for the uptake of research finding

^{*} Summary of activities completed by older adult research partners reported in studies

Recommendations

- Equity, diversity, and inclusion of research partners is critical to advancing health equity through research; reporting socio-demographic characteristics of older adult research partners and how they were recruited and engaged is important to improve engagement practices.
- Rigorous evaluation and reporting of impacts of engaging older adult partners will advance the science. Tools such as Guidance for Reporting Involvement of Patient and the Public (GRIPP2) can help encourage better methods and impact (Staniszewska et al. BMJ 2017; 358:j3453).

Conclusions

This study helps to understand how, when, and with what impact older adult research partners contribute to health research. Older adult partners can contribute to research in impactful and meaningful ways, including mobilizing knowledge with key stakeholder audiences.

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