

RESEARCH BRIEF

Older people 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 about the impacts of their involvement.
- The impacts that older adults have had as research partners include the creation of new and continuation of existing partnerships.
- Impact evaluation is an emerging science.

What is this research about?

Older adults are frequently called on 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 impact.

The MIRA | Collaborative for Health & Aging's Patient Engagement Working Group by leadership of Drs. Rebecca Ganann and Julia Abelson set out to explore these questions through a systematic review of the literature.

How was this research carried out?

Researchers searched five databases of published literature from 2000-2019 to find English articles about engaging older adults as partners in health research in any care setting (e.g., acute care, long-term care, community). Outcomes of interest included: implementation, impact, effect, experience, process, development, monitoring, planning, and priority-setting.

This review focused on people aged 50 and older who were partners in health research. Studies focused solely on older adults as research subjects were excluded.

Results

Most of the 33 included studies were carried out in the community setting. Most studies did not report the socio-demographic characteristics of their research partners. Those that did, reported the inclusion of older adult research partners from Black, Chinese, Hispanic and Indigenous communities, as well as lived experiences with cancer,

disability, dementia, and self-harm, and experiences as caregivers.

Patient and public 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 about half of included studies, patient or public research partners were engaged to translate research findings. In four studies, older adult research partners were engaged across all stages of research (see table).

It was more common for studies to discuss how Patient and Public Involvement (PPI) was implemented; few discussed how PPI impacts were measured.

In studies where impact was measured, the following impacts were noted: the creation of new research partnerships and the continued collaborations between co-researchers on new projects. One study found that, by engaging in research, patient partners were influenced to better self-manage their care.

Recommendations from this study

This study helps us to understand how, when, and with what impact older adult research partners contribute to health research.

Rigorous evaluation of the impact of PPI approaches is infrequent. Tools such as Guidance for Reporting Involvement of Patient and the Public (GRIPP2) can help researchers to design studies that integrate impact measurement metrics and encourage better reporting of methods and impacts. Impact evaluation of engagement approaches is an emerging science.

Research phase	Involvement activities
Preparatory phase	<ul style="list-style-type: none"> Identifying topic Identifying research questions Input into engagement processes Establishing advisory board/council Contributing to project design and management
Study design	<ul style="list-style-type: none"> Providing feedback on study methods, interview guides, questionnaires Identifying community-relevant topics for focus groups, areas for action Co-designing or refining models Testing interview guides Refining consent forms Ensuring culturally relevant data collection approaches Shaping public facing materials
Recruitment	<ul style="list-style-type: none"> Assisting with recruitment and recruitment procedures Recruiting other citizen partners, encouraging attendance Explaining project purpose to community members
Data collection	<ul style="list-style-type: none"> Conducting key informant interviews Participating in community workshops to identify preferences/priorities Facilitating focus groups Facilitating completion of surveys
Data analysis	<ul style="list-style-type: none"> Member checking confirming accuracy of data interpretation Co-analyzing, identifying key themes Contributing to development of model Reviewing results Making sense of findings Reflecting on actions taken
Knowledge translation	<ul style="list-style-type: none"> Providing feedback on knowledge translation materials (e.g., frameworks, reports, newsletters, leaflets, 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 findings

Where do we go from here?

Our group continues to engage our patient partners in impactful and meaningful ways to translate these results (e.g. policy briefs, online learning modules, virtual presentations).

Study leads

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Co-Investigators

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Patient research partners

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