

Ethical aspects in scientific literature on participatory research approaches with older adults: a scoping review protocol

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ABSTRACT

Objective: This scoping review will systematically map and synthesize the ethical aspects addressed in the scientific literature on participatory research involving older adults. It will examine both procedural or principle-based research ethics and relational or situational ethics, exploring how these are shaped by contexts and considerations of diversity. The review will also identify conceptual frameworks and gaps to inform research and ethical practice.

Introduction: Participatory research with older adults is gaining momentum, with ethical considerations central to such approaches. Yet the ethical complexity of participatory processes is often underreported. This review will explore how ethical aspects are described in the literature.

Eligibility criteria: Studies will be included if they focus on individuals aged 60 and over who are involved in research through consultative, collaborative, or co-decisional roles. Eligible studies must explicitly address ethical aspects related to procedural or principle-based research ethics, relational or situational ethics, or both.

Methods: Given the growing emphasis on ethical considerations in participatory research involving older adults, a scoping review is appropriate for mapping the extent, range, and nature of the available evidence. The review will follow JBI methodology and established scoping review frameworks, incorporating both descriptive quantitative and qualitative analyses. Six databases will be searched: Web of Science, Scopus, PsycINFO, PubMed, CINAHL, and Sociological Abstracts. Two reviewers will independently screen titles and abstracts, and assess full texts for inclusion, with a third reviewer consulted as needed. Findings will be organized under conceptual and thematic headings and presented in tables, figures, and descriptive synthesis.

Review registration: OSF <https://osf.io/mr89x>

Keywords: ethical aspects; older adults; participatory approaches; research

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Introduction

Participatory approaches refer to collaborative processes where stakeholders actively contribute to the design and implementation of research, policies, and interventions that affect them.¹ Participatory approaches with older adults have been increasingly adopted in recent years, not only at the political and organizational levels but also in different fields of academic research, to address the emerging needs, opportunities, and challenges posed by an aging population.^{2,3} As suggested by existing evidence, the adoption of participatory approaches may increase the relevance and impact of the research by incorporating contributions from older adults to the design, implementation, and dissemination of the research.⁴ For example, directly involving older adults in relevant studies as *experts by experience* allows for adaptation to their personal experiences and real-life situations. Further, if rigorously applied, participatory research can empower older adults by increasing their control over the research process and its results, by facilitating mutual learning for both older adults and academic researchers.^{5,6}

Existing reviews have addressed participatory research either with older adults or from an ethical perspective, but rarely both simultaneously. Furthermore, reviews focusing on participatory research with older adults^{3,4,7,8} have primarily emphasized methodological considerations, specific health-related contexts, or particular subpopulations, with limited attention to ethical aspects as the primary focus. Conversely, reviews examining ethical challenges in participatory research⁹⁻¹³ have been conducted across general populations and, therefore, failed to explore how ethical issues manifest in participatory research involving older adults. Yet older adults may encounter distinct issues, such as ageism, social exclusion, or inequitable access to participation opportunities, that can significantly constrain their ability to engage meaningfully in research. By focusing explicitly on older adults, this scoping review is positioned to identify ethical considerations that are routinely overlooked or underexamined in broader reviews and to generate targeted recommendations on how to more effectively support the equitable and authentic inclusion of older co-researchers.

Defining participatory research approaches with older adults

Despite the benefits of participatory research approaches, there is no agreement on how they should be defined. Indeed, existing studies have highlighted the absence of a shared definition of participatory research approaches.^{14,15} As a result, studies that are considered *participatory* often deploy a variety of methods, and the degree to which older adults are involved in the research process varies greatly.¹⁶ In practice, older co-researchers may be involved in the entire research process or participate in a single or multiple research stages (eg, research design, data collection, analyses).¹⁴ This is dependent on the specific disciplines in which the study is grounded, its objectives, and the characteristics of the older co-researchers, such as their competence, levels of autonomy, and physical/cognitive impairment.

In this review, we address *participatory research approaches with older adults* as an umbrella concept encompassing diverse methodologies that actively involve older adults as co-creators of the research process rather than passive subjects.¹² These approaches include, but are not limited to, participatory action research, patient and public involvement, community-based participatory research, co-design, co-creation, citizen science, and inclusive research. While terminology varies across disciplines, the common principle is that research is conducted *with* or *by* older adults, not merely *about* them.⁶

Participatory approaches exist on a continuum, ranging from consultative roles, where older adults provide feedback on study materials or participate in advisory groups; collaborative involvement, which may see older adults co-analyze qualitative data, code interviews, or participate in workshops; and co-decisional roles, in which older adults share decision-making responsibilities, contribute to governance, or co-author outputs. In this scoping review, we aim to map this diversity of participatory research approaches and operationalize these levels of involvement to understand how the field conceptualizes and implements older adults' participation across different research contexts.

Ethical aspects of participatory research approaches with older adults

Ethical aspects in participatory research can be broadly understood through 2 complementary lenses:

Procedural or principle-based research ethics address principles such as informed consent, autonomy, confidentiality, and data management,⁸ whereas relational or situational ethics focus on epistemic justice,³ the negotiation of power and roles across different levels of involvement, and the situated, relational, and contextual practices often described as *everyday ethics*.⁴ Although previous reviews by Wilson and colleagues,⁹ Souleymanov and colleagues,¹⁰ and Mikesell and colleagues¹¹ have examined ethical issues in participatory research broadly, they have not addressed how these concerns manifest uniquely for older adults or how they may shift across different levels of involvement. As a result, important age-specific ethical dynamics remain insufficiently examined.

Within this conceptual distinction, previous studies of participatory research with older adults, although not primarily concerned with ethics, offer some relevant insights. Regarding procedural or principle-based research ethics, Schilling and Gherardus⁸ and Di Lorito *et al.*¹⁷ found that many participatory studies involving older adults did not report ethical approval procedures or informed consent processes. This omission is particularly concerning when researchers adopt ongoing or co-creative modes of engagement, where consent must be negotiated throughout the research relationship rather than secured at a single moment. Autonomy also emerges as a central issue. Older adults living with cognitive impairments may face challenges in making or expressing autonomous decisions about their involvement, and their communicative intentions may not be fully recognized.³ Ries *et al.*¹⁸ demonstrated that participation can still be ethically appropriate in such circumstances, provided that a representative consents based on the older adult's preferences and interests.

Confidentiality challenges in participatory research are another consideration. These challenges do not stem from age per se, but from the researcher roles assumed by lay participants when they move beyond the position of research subjects. As Bussu and colleagues¹⁹ observed, participatory roles may grant co-researchers access to sensitive or personal data that they would not encounter in non-participatory research designs, which they are charged with keeping confidential. This issue applies to participatory research generally, but becomes particularly salient in studies involving older adults, given that they frequently focus on health, care, and social vulnerability,²⁰ and given the close-knit community contexts

in which such research often takes place (eg, long-standing neighborhood ties, small local communities).²¹ Unlike traditional confidentiality concerns that apply primarily to participants, participatory approaches require explicit guidance on role-specific responsibilities, boundaries of access, and collective decision-making about data use. Such guidance is essential not only to safeguard participants but also to protect co-researchers, whose roles can expose them to unique ethical vulnerabilities (eg, facing accusations of privacy violations, risks of being perceived as responsible for data breaches).

In terms of relational or situational ethics, several studies highlight issues of epistemic injustice and power imbalance. James and Buffel³ showed that participatory research may inadvertently reproduce social inequalities by privileging older adults with greater social, territorial, or cultural resources over older adults with fewer such resources, thereby raising concerns about equitable inclusion. Corrado *et al.*⁴ similarly demonstrated persistent power imbalances in participatory projects, but this time between the main research team and the older adult co-researchers, with older adults often positioned as data sources rather than genuine partners in knowledge production. Beyond that, questions of recognition and ownership further complicate participatory relationships. As Carter and Beresford²² noted, older co-researchers often receive limited acknowledgment for their contributions, despite the centrality of credit allocation, co-authorship, and ownership of knowledge to participatory ethical principles. Moreover, the degree of participation assumed by older adults (eg, in consultative, collaborative, or co-decisional roles) may shape the nature of ethical challenges: while consultative involvement may raise questions about tokenism or limited influence, more sustained and multifaceted engagement increases the need for ongoing consent procedures, shared decision-making, and clarity regarding ownership of research outputs.¹⁴

Despite the relevance of both procedural or principle-based and relational or situational ethical concerns in research with older adults, a preliminary search of PubMed, Scopus, and Web of Science, complemented by searches of OSF, Figshare, Protocols.io, arXiv, and *JBI Evidence Synthesis*, revealed no existing or ongoing scoping reviews on this topic. This scoping review, therefore, aims to fill a critical gap by providing a comprehensive account of the ethical aspects discussed in the literature on participatory research involving

older adults, examining how these ethical issues are shaped by contextual factors and considerations of diversity, and identifying key areas requiring further investigation to inform future research and practice.

Review questions

What ethical aspects are addressed in the scientific literature on participatory research approaches involving older adults?

The primary research question is supported by 2 subquestions:

- i) How do contextual and diversity-related factors influence these ethical aspects?
- ii) What are the gaps in the current evidence base, which should be addressed by future research on the ethical aspects of participatory research approaches involving older adults?

Eligibility criteria

Participants

This review will consider studies focused on older adults, defined as people aged 60 and over, in line with the World Health Organization's² definition of older adults. Studies involving mixed-age populations will only be included if the results are disaggregated by age and can be extracted specifically for individuals aged 60 and over.

Concept

This review will include studies that examine ethical aspects in the scientific literature on participatory research approaches involving older adults. Ethical aspects are defined broadly to encompass both procedural or principle-based research ethics and relational or contextual ethics:

- *Procedural or principle-based research ethics* focus on individual rights and protections, including informed consent, autonomy, beneficence, non-maleficence, justice, integrity, confidentiality, anonymity, and the protection of vulnerable populations.
- *Relational or situational ethics* relate to the relational and collective dimensions of participatory research, such as negotiation of power, co-authorship, co-governance, ownership of research outputs, equitable involvement in decision-making, and recognition of participants' contributions.

For inclusion, studies must explicitly address ethical aspects, either in relation to procedural or principle-based research ethics, relational or contextual ethics, or both. Studies that only imply ethical considerations without explicitly labeling them as such will not be eligible. This operational criterion will ensure that all included studies contain ethical content sufficient to inform the review objectives.

Context

This scoping review will explore participatory research approaches involving older adults, in which they are actively engaged not merely as research participants, but as contributors through consultative, collaborative, or co-decisional roles.¹⁴ We will include studies based on their reported practices rather than solely on the presence of the term *participatory*. Studies will qualify if older adults are actively engaged in a single or multiple stages of the research process beyond being research subjects, such as through consultative, collaborative, or co-decisional roles. For each eligible study, the research team will review the study methodology and descriptions of participant involvement to assess whether they meet these criteria.

Types of sources

This scoping review will consider all types of scientific literature, consistent with JBI methodology. This includes primary research studies employing quantitative, qualitative, or mixed methods designs, as well as text and opinion papers. Gray literature, such as theses, dissertations, conference proceedings, and other relevant unpublished or non-peer-reviewed materials, will also be included when they provide information pertinent to the ethical aspects of participatory research approaches involving older adults. Editorials and letters to the editor that offer conceptual, ethical, or methodological insights will likewise be eligible. Literature reviews of any type (systematic, scoping, narrative, integrative) will be included but will be used solely to identify additional primary evidence sources.

Methods

Given the heterogeneity of approaches, definitions, and both ethical and participatory frameworks in the existing literature, a scoping review is more appropriate than a systematic review, which would require more narrowly defined criteria and focus. Methodological

guidance from Arksey and O'Malley,²³ Levac and colleagues,²⁴ and Peters *et al.*²⁵⁻²⁷ emphasizes the value of a scoping review for mapping key concepts, summarizing research findings, and pinpointing areas where further investigation is needed. Such a review is particularly valuable when addressing complex and underexplored subjects, such as the one under consideration.

The proposed scoping review will be conducted in accordance with the JBI methodology for scoping reviews,²⁵⁻²⁷ as well as previously established methodological frameworks.^{23,24} It will be reported in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)²⁸ and recent work by Peters *et al.*,²⁹ which were reviewed to ensure a comprehensive and robust approach in the development of the protocol and the review. This protocol has been registered in OSF (<https://osf.io/mr89x>).

Search strategy

The search strategy was developed in accordance with the guidance provided by Peters *et al.*,²⁹ in collaboration with a professional librarian. An initial limited search of Web of Science (Core Collection) and Scopus was undertaken to test the search terms and strategy, assess the yield of relevant articles, and identify missing keywords in titles, abstracts, and indexing terms, as well as problematic terms that generated large numbers of irrelevant results. The findings from this pilot search were used to develop a full search strategy for 6 databases: Web of Science (Core Collection), Scopus, PsycINFO (APA PsycNet), PubMed, CINAHL (EBSCOhost), and Sociological Abstracts (ProQuest). The search strategy, including all identified keywords and index terms, will be adapted for each included information source. Gray literature will be identified through the selected academic databases (eg, theses, dissertations, and conference proceedings indexed within these sources), rather than through separate targeted gray literature searches. The reference lists of all included studies will be screened for additional papers. All searches will be conducted by a professional librarian. A sample search strategy for Scopus is presented in Appendix I.

No language, publication type, or date filters will be applied during database searches. Because the search strategy uses English keywords, it may primarily retrieve studies with English titles and abstracts. At the full-text stage, only records available in English

will be included due to the language capacity of the review team. All records excluded for language reasons will be documented to enhance transparency and allow readers to assess any potential impact on the completeness of the dataset. No date restrictions will be applied in order to capture the full range and development of the literature on ethical aspects of participatory research involving older adults.

Study selection

Following the search, all identified records will be compiled and uploaded into Covidence (Veritas Health Innovation, Melbourne, Australia) and duplicates removed. A training session will be conducted alongside a pilot test of the selection process, in which a random sample of 25 titles and abstracts will be independently screened by all reviewers. This pilot aims to ensure consistency, clarify eligibility criteria, and familiarize the team with the screening procedures.

Following the pilot test, a multidisciplinary team including experts in psychology, sociology, ethics, communication, health and social work, nursing, medicine, gerontology, education, and related fields will conduct the screening and selection of studies for this scoping review using a structured and systematic approach. The aim is to ensure consistency and reproducibility throughout, following a clearly defined 3-step process.

In the first step, titles and abstracts will be screened by pairs of reviewers from a team of 13 for assessment against the eligibility criteria for the review. In the second step, potentially relevant papers will be retrieved in full and their citation details imported into Covidence. In the final step, the full text of selected citations will be assessed in detail against the eligibility criteria by 2 reviewers independently. Reasons for exclusion of full-text papers that do not meet the eligibility criteria will be recorded and reported in the final scoping review. Any disagreements that arise between the reviewers at each stage of the selection process will be resolved through discussion or with a third reviewer. The results of the search will be reported in full in the final scoping review and presented in a PRISMA flow diagram.³⁰

Data extraction

Data will be independently extracted from papers included in the scoping review by pairs of reviewers from a team of 13 using a data extraction tool developed by the reviewers. The data extracted will include

bibliographic details, research objectives, article types, ethical considerations that were addressed, and specific participatory research approaches that were used, among other relevant aspects. For empirical studies, details regarding the sample and methodological design will also be extracted. A draft extraction tool is provided (see Appendix II).

The draft data extraction tool will be pilot tested on 5 randomly selected studies to assess its clarity and consistency and to identify any relevant information that may have been overlooked in the initial version. Based on the results of this pilot test, the tool will be refined and adjusted. Once the final version of the data extraction tool has been established, it will be used to extract data from all included articles. Any disagreements that arise between the reviewers during data extraction will be resolved through discussion or with a third reviewer. Authors of papers will be contacted to request missing or additional data, where required, with up to 2 contact attempts made within a 15-day period. If no response is received and the missing information is essential for data extraction, the study will be excluded from the review.

Data analysis and presentation

A combination of descriptive quantitative and qualitative analyses will be conducted. Descriptive quantitative analysis will include frequency counts and distributions of key study characteristics, while descriptive qualitative analysis will involve content categorization and thematic coding of ethical considerations and participatory research approaches. The findings will be organized and presented in tables or, where appropriate, as figures. Alongside these visual representations, a descriptive synthesis of the extracted data will be provided to offer further context and interpretation. The results will be grouped under key conceptual and thematic headings, which will be developed inductively from the data. Each thematic category will be clearly defined and explained to enhance transparency and understanding.

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Author contributions

RS and DL drafted the manuscript. AU, BG, SI, TY, NY, OG, KP, AW, AO, MK, SH, and JP contributed to the conceptual development and iterative revision of the scoping review protocol. JP conducted the preliminary searches. All authors reviewed and approved the final manuscript.

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Appendix I: Search strategy

Scopus		
Search conducted: November 27, 2025		
Search	Query	Records retrieved
#1	"Old* adult*" OR "Old* people" OR "Old* individual*" OR "Old* person*" OR "Older adulthood" OR "Late adulthood" OR "Old age" OR Geriatric* OR Elder* OR Senior* OR Aging OR Ageing	2,616,714
#2	Ethic* OR Moral* OR Integrity OR Equalit* OR Inequalit* OR Equit* OR Power* OR Inclusiv* OR Justice OR Oppress* OR Autonom* OR Self-determination OR Beneficence OR Non-maleficence OR Fair* OR Privacy OR "Informed consent" OR Protect* OR Discriminat* OR Non-discriminat* OR Confidential* OR Dignity OR Anonym* OR Recogni* OR Transparen* OR Complexit* OR Right* OR Reciprocit* OR Agency	22,576,418
#3	"Participat* research*" OR "Participat* design*" OR "Participat* evaluation*" OR "Participat* science" OR "Inclusive research*" OR "User-led research*" OR "Community research*" OR "Community-engaged research*" OR "Community-based research*" OR "Community science" OR "Acti* research*" OR "Acti* inquir*" OR "Acti* anthropology" OR "Acti* learning" OR "Acti* science" OR "Collaborative research*" OR Co-research* OR "Citizen science" OR "Patient involv*" OR "Patient engag*" OR "Public involv*" OR "Public engag*" OR Co-creat* OR Co-product* OR Co-design* OR "Consult* research*" OR "Appreciative inquir*" OR "Asset-based community development" OR "Decoloniz* methodolog*" OR "Emancipat* research*" OR "Health impact assessment" OR "Patient-centered outcome* research*" OR "Popular educat*" OR "Popular epidemiolog*" OR "Practitioner inquir*" OR "Pragmatic action research*" OR "User-centered design* research*" OR "User involv*" OR "Living lab*" OR "Stakeholder* engag*" OR "Peer research*" OR "Peer-led research*" OR "Democratic research*" OR "Practice-based research*" OR "Transformative research*"	342,538
#4	#1 AND #2 AND #3	5047

Appendix II: Draft data extraction instrument

Reviewer details	Reviewer initials
	Data of extraction (date, month, year)
Bibliographic details	Author(s) (family name, initials)
	Year of publication
	Title
	Journal
	Issue
	Country of affiliation of the first author
Research aim/question	Main research aim/question addressed in the paper
Type of paper	Type of paper (empirical, review, text and opinion paper)
Ethical aspects addressed	Ethical aspects discussed (eg, procedural/relational/contextual ethics, autonomy/self-determination, beneficence, non-maleficence, justice/equity/fairness, privacy, informed consent, protection of vulnerable populations, non-discrimination, confidentiality, dignity, or other relevant aspects not listed)
	Ethics approval obtained (Y/N/unclear)
	Type of ethics review body
	Informed consent procedures described? (Y/N/unclear)
	Ethical framework or guidelines referenced
	How ethical challenges were addressed
	Outcomes related to ethical practice
Type of participatory research approach addressed	Characteristics of older adults' involvement in the research process (co-designing research, collaborative data collection, joint data analysis and validation, involvement throughout the entire research process, or other)
	Term used to describe participatory approach (participatory research, participatory design, inclusive research, user-led research, community-engaged research, action research, collaborative research, co-research, citizen science, patient and public involvement/engagement, co-creation, co-production, co-design, consultative research, or other)
	Duration and intensity of involvement
	Training/support for co-researchers
	Remuneration or recognition mechanisms
Contextual factors	Research setting (home, nursing home, community, etc)
	Language and accessibility adaptations
Attention to diversity	Consideration of diversity among older adults (older migrants, older adults from diverse ethno-cultural backgrounds, low-income older adults, LGBT older adults, institutionalized older adults, oldest old, older adults with disabilities, older adults with cognitive impairment or dementia, or other groups)
Characteristics of the methodology <i>(Empirical papers only)</i>	Type of methodology (quantitative, qualitative, mixed methods)
	Type of research design (cross-sectional, longitudinal, sequential; observational, experimental)
	Data collection technique used (questionnaire, interview, focus group, mixed, other)
Characteristics of the sample <i>(Empirical papers only)</i>	Number of participants
	Age range
	Mean age
	Sex distribution (%women, %men)
	Educational attainment (low: 0–9 years/primary or secondary school; medium: 10–15 years/high school or vocational training; high: 16+ years/at least bachelor's degree)
	Living arrangements (living at home, in residential aged care facilities of any kind, in hospital, or other)
	World region where the sample was collected (North America, Europe, Oceania, Asia, Latin America, Africa)
Main conclusions of the study	Key findings and conclusions of the study
Reviewers' notes	Additional notes from reviewers (any relevant information in light of the scoping review's objectives not covered previously)

Y, yes; N, no; LGBT, lesbian, gay, bisexual, and transgender.