

Inclusion (rather than exclusion) of older adults in research: ethical concerns and guidelines

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Background:

- Ageism: prejudice, stereotypical assumptions and discrimination based on age, are omnipresent in research.
- More so among older adults with cognitive impairment.
- Upper age limits are mostly unjustified by researchers. Justifications that are explicitly expressed state that participants need to be reliable, able to provide valuable information and be competent to give consent.
- Exclusion can have negative outcomes on research validity and may affect older adults health and well-being.

Objectives: ageism - an ethical dilemma?



EuroAgeism is a multidisciplinary and multinational innovative research network about Ageism.



As part of EuroAgeism, we aim to conduct ageist free research, identify guidelines for inclusion of all older adults and advocate for non-ageist research.

Methods:

A review of the literature focused on identifying considerations and guidelines in themes of inclusion, consent, autonomy, privacy with a specific focus on older adults with cognitive decline.

Results:

As a default, prefer inclusion

Do not use upper age limits in a study with inherent relevance to older adults.

Do not exclude based on numeric age

But if necessary by function criteria that can be measured and justified.

Increase ethics committees awareness

to request justification for exclusion.

Adapt research materials

e.g. questionnaires and informed consent.

Account for the setting

Timing and the location of consent and data collection procedures plays a significant role.

Consider qualitative methods

which are often more suitable for research involving older adults with cognitive decline.

Respect older adults autonomy

Do not make presumptions regarding what data they are willing to enclose and who they are willing to share it with.

Conclusion:

1

Inclusion rather than exclusion of all older adults in research may provide a better and accurate understanding of the studied subject.

2

Inclusion can reduce the stigma and exclusion older adults endure in research and in society, give a sound to their unique voice and improve their well-being.

3

Competency to participate should be assessed in a broader and more holistic way rather than age-based assumptions.



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