

Older Adults Priority Populations Toolkit



A guide for researchers starting to conduct research with older adults

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I. Historical and Current Issues Regarding Research Population

A. Unclear Definitions

One of the first challenges in considering research with older adults is exactly how the group is defined, both in the term(s) used and associated definitions. The term senior citizen refers to an “elderly person, especially one who has retired” and elderly is defined as, “rather old” or “of, relating to, or characteristic of later life or elderly persons.”^{1 2} Neither provides a clear definition as to when older age begins.

Healthy People 2020 uses the term Older Adults, giving this Toolkit its title. While Healthy People 2020 does not give a specific definition, it does refer to people aged 65 and older.³ However, some of the evidence-based practices listed on their website refer to people over 40 and over 50.⁴ Conversely, the full retirement age for receiving Social Security benefits is gradually rising from 65 to 67 because of improvements in health and longer life expectancy. Even so, retirees can start receive reduced benefits at age 62.⁵ Medicare benefits begin at 65, providing the clearest marker.⁶ Nevertheless, there is no single, universally-accepted definition of when someone becomes an older adult.

There is an important distinction to be made between chronological age, biological age, and mental age; their relationship varies significantly from person to person.⁷ Nevertheless, for the purposes of study and learning, some marker is needed, so we will use the age of 65. This should still be understood to be a general term and not a precise definition.

B. Theories & Understanding of Older Age

The American Medical Association defines geriatrics as, “the branch of medicine that focuses on health promotion, prevention, and diagnosis and treatment of disease and disability in older adults.” Geriatric specialists often have to deal with complexity in their cases: patients may be facing medical conditions (such as diabetes or heart disease) along with geriatric conditions (such as dementia or incontinence). They often work with a team that includes nurses, social workers, physical therapists, occupational therapists, pharmacists, nutritionists, and others to manage these conditions and promote the highest quality of life possible.⁸

Reflecting the vast improvements in public health and medicine, and the associated aging of the overall population, a new field of geroscience has emerged recently. Geroscience is defined as, “a cross-disciplinary field focused on understanding the relationships between the processes of aging and age-related chronic diseases.” One distinction between geroscience and most other biomedical research is the move away from focusing on single diseases. Aging causes not only a loss of function in itself, but also an increased susceptibility to disease, which in turn further diminishes function. Consequently, ways to promote healthy aging are central in addition to the prevention and management of chronic diseases.⁹

Despite the youth of the field of geroscience, important findings have been discovered. Current evidence suggests that the specificity of symptoms becomes reduced in older adults, making it harder to distinguish between different possible diagnoses. An additional complication comes from the fact that many people do in

fact have multiple conditions: over 60% of people receiving Medicare aged 65 or older have at least three chronic conditions. The increased likelihood of multiple conditions also complicates treatment plans.

That people become more frail as they age is not surprising. But frailty itself, once thought of as a confounding variable in the study of disease, is actually a key factor in whether and how conditions manifest themselves. Frailty can be thought of as a syndrome, one that has several signs or symptoms: weak muscles, reduced physical activity, slower walking, being exhausted easily, and losing weight for no reason connected to a specific disease. Having one or two of these characteristics increases the odds of developing further symptoms. Frailty both increases the likelihood that people will develop chronic diseases, and the presence of chronic diseases changes the way frailty subsequently develops. In other words, the presence of frailty and chronic disease influence and reinforce each other. Research that leads to a more thorough understanding of these processes, which can lead to better treatment and wellness promotion plans, will be a focus in the next several years.¹⁰

C. Older Adults' Shifting Composition and Role in Society

Advances in life expectancy, coupled with the aging Baby Boomer generation, mean that over the next few decades, the US will likely experience several demographic shifts in the older adult population. Firstly, there will be a larger number of people aged 65 and over, rising from an estimated 49.2 million in 2016 to a projected 78 million in 2035. Moreover, this group will make up an increased share of the total US population, from 15.24% in 2016 to 21.64% in 2035; at this point, older adults will outnumber children under the age of 18. Within the over-65 group, changes will also take place, with a greater share of people over the age of 85 (13.0% in 2016 to 15.1% in 2035). The number of centenarians will nearly double.¹¹ These shifts signal the “graying” of America.

Accompanying these shifts will likely be changes in the way older adults live. Previous research has focused on the needs of this group, but increasing attention has been given to their ability to be resources: to family members, community organizations, and other older adults. This resource mindset opens up the possibility to view the many roles that older adults can occupy. Some are obvious, such as parent of an adult, grandparent, volunteer, and member of a faith community. Others, however, may be just as important to them, including entrepreneur, learner, person who is dating, etc. Rather than being a period of life with an abundance of free time, the multiple roles older adults inhabit can be a source of strain. This is especially true of older women, who often have normative expectations of caring for others placed upon them. Recognizing the many roles older adults play and acknowledging the work they are already doing can help others avoid placing too many additional responsibilities on them while keeping options open to them.¹²

D. Instances of Mistreatment and Discrimination

Elder mistreatment is a significant problem for older adults. It is defined as, “(a) intentional actions that cause harm or create a serious risk of harm (whether or not harm is intended) to a vulnerable elder by a caregiver or other person who stands in a trust relationship to the elder or (b) failure by a caregiver to satisfy the elder’s basic needs or to protect the elder from harm.”¹³ This mistreatment can take several forms: physical abuse,

psychological abuse, sexual assault, material exploitation, and neglect.¹⁴ Estimates of the prevalence vary. What is particularly relevant for research is the prevalence of abuse by care workers: about 16% of care workers reported committing psychological abuse, while about 10% reported committing physical abuse. Additionally, while more than 80% of nursing home staff observed abuse, far fewer reported the abuse to the supervisors.¹⁵

Ageism refers to negative perceptions, attitudes, and treatment solely on the basis of advanced age. Ageism must be overcome among both individuals and systems in order to ensure effective services for and research with older adults.¹⁶

E. Health Inequities

That older adults face the highest rates of mortality and morbidity is natural given the life course. However, inequities exist. The different health outcomes found among the general population, such as reduced health for racial and ethnic minorities and lesbian, gay, and bisexual adults, continue into older age. This will be a worsening problem as more racial and ethnic minorities become older adults unless interventions across the lifespan can bring about equity.^{17,18}

F. Underrepresentation in Research

Despite the array of health conditions facing older adults, they are less likely to be enrolled in clinical trials and other research. Although they make up two-thirds of cancer patients, older adults represent just 25% of cancer clinical trial participants. Participation is even lower for older adults from racial and ethnic minority groups.¹⁹ Researchers place several barriers in the way of older adults' participation, including explicit exclusions based on age and limits on comorbidities. Participant barriers include problems with insurance, difficulty with communication, and physical disabilities. Recommendations for overcoming these barriers include developing best practices and standardizing protocols, establishing and reinforcing guidelines, employing age-friendly methods of communication, supporting geriatric education and training, improving federal monitoring and accountability, reducing clinical trial costs, and responding to the effects of race/ethnicity and age.²⁰ Also see Section V, Recruitment & Retention Best Practices.

G. Multiple Sources of Identity

An individual who is an older adult should be viewed in the context of multiple identities. In addition to their age, their race and ethnicity, sexual orientation, gender identity, citizenship status, class, and many other aspects influence how they view themselves and their risk and resilience factors for health outcomes. Recognizing these dynamics is a critical step to building relationships with research participants.

H. Engaging the Community in Research

Traditional research is when academic researchers control the design and execution of a research project with little to no input from the population being studied. Additionally, the purpose is the generation of knowledge for its own sake; fostering change can be a goal but is not a requirement. Increasing the involvement of the

community being studied is a key component of community-engaged research (CEnR), community-based participatory research (CBPR), and participatory action research (PAR). The population being studied participates in as many aspects of the research as possible, with the requirements for the former being less exhaustive than the latter two approaches. However, all share a desire to produce research that can make a positive impact on the lives of participant population as well.²¹ See Section V, Recruitment and Retention Best Practices, for further information.

¹ Senior Citizen. (2019). *Merriam-Webster*. Retrieved from <https://www.merriam-webster.com/dictionary/senior%20citizen>.

² Elderly. (2019). *Merriam-Webster*. Retrieved from <https://www.merriam-webster.com/dictionary/elderly>.

³ Older Adults, Overview. (2019). *Healthy People 2020. Office of Disease Prevention and Health Promotion, Department of Health and Human Services*. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/older-adults>.

⁴ Older Adults, Interventions & Resources. (2019). *Healthy People 2020. Office of Disease Prevention and Health Promotion, Department of Health and Human Services*. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/older-adults/ebrs>.

⁵ Retirement Age Calculator. (n.d.). *Social Security Administration*. Retrieved from <https://www.ssa.gov/planners/retire/ageincrease.html>.

⁶ Getting Started with Medicare. (n.d.). *Centers for Medicare & Medicaid Services*. Retrieved from <https://www.medicare.gov/sign-up-change-plans/getting-started-with-medicare>.

⁷ Fried, L.P. & Ferrucci, L. (2016). Etiological role of aging in chronic diseases: From epidemiological evidence to the new geroscience. In F. Sierra & R. Kohanski (eds.), *Advances in Geroscience* (37-51). New York, NY: Springer.

⁸ Geriatric Medicine. (2019). *American Medical Association*. Retrieved from <https://www.ama-assn.org/specialty/geriatric-medicine>.

⁹ John B. Burch, Alison Deckhut Augustine, Leslie A. Frieden, Evan Hadley, T. Kevin Howcroft, Ron Johnson, Partap S. Khalsa, Ronald A. Kohanski, Xiao Ling Li, Francesca Macchiarini, George Niederehe, Young S. Oh, Aaron C. Pawlyk, Henry Rodriguez, Julia H. Rowland, Grace L. Shen, Felipe Sierra, Bradley C. Wise, *Advances in Geroscience: Impact on Healthspan and Chronic Disease, The Journals of Gerontology: Series A, Volume 69, Issue Suppl_1, June 2014, Pages S1–S3*, <https://doi.org/10.1093/gerona/glu041>.

¹⁰ Fried, L.P. & Ferrucci, L. (2016). Etiological role of aging in chronic diseases: From epidemiological evidence to the new geroscience. In F. Sierra & R. Kohanski (eds.), *Advances in Geroscience* (37-51). New York, NY: Springer.

¹¹ Projected Age Groups and Sex Composition of the Population: Main Projections Series for the United States, 2017-2060. U.S. Census Bureau, Population Division: Washington, DC. <https://www.census.gov/data/tables/2017/demo/popproj/2017-summary-tables.html>, <https://www2.census.gov/programs-surveys/popproj/tables/2017/2017-summary-tables/np2017-t2.xlsx>

¹² Vidovicova, L. (2018 March). New roles for older people. *Journal of Population Ageing*, 11(1), 1-6. <https://doi.org/10.1007/s12062-017-9217-z>

¹³ National Research Council (US) Panel to Review Risk and Prevalence of Elder Abuse and Neglect: Bonnie, R.J., Wallace, R.B. (Eds.). (2003). *Elder Mistreatment: Abuse, Neglect, and Exploitation in an Aging America*. Washington, DC: National Academies Press. <https://www.ncbi.nlm.nih.gov/books/NBK98802/> doi: 10.17226/10406

¹⁴ Lachs, M.S., & Pillemer, K. (2004 October 2-8). Elder abuse. *The Lancet*, 364(9441), 1263-1272. [https://doi.org/10.1016/S0140-6736\(04\)17144-4](https://doi.org/10.1016/S0140-6736(04)17144-4)

¹⁵ Cooper, C., Selwood, A., & Livingston, G. (2008 March). The prevalence of elder abuse and neglect: a systematic review. *Age and Ageing*, 37(2), 151–160. <https://doi.org/10.1093/ageing/afm194>

¹⁶ Remnet, V.L. (1989). *Understanding Older Adults: An experiential approach to learning*. Lexington, MA: D.C. Heath and Company.

¹⁷ Moreno-John, G., Gachie, A., Fleming, C. M., Nápoles-Springer, A., Mutran, E., Manson, S. M., & Pérez-Stable, E. J. (2004). Ethnic Minority Older Adults Participating in Clinical Research. *Journal of Aging and Health*, 16(5_suppl), 93S-123S. <https://doi.org/10.1177/0898264304268151>

- ¹⁸ Fredriksen-Goldsen, K.I., Kim, H.-J., Barkan, S.E., Muraco, A., & Hoy-Ellis, C.P. (2013). Health Disparities Among Lesbian, Gay, and Bisexual Older Adults: Results From a Population-Based Study. *American Journal of Public Health*, 103, 1802-1809. <https://doi.org/10.2105/AJPH.2012.301110>
- ¹⁹ Moreno-John, G., Gachie, A., Fleming, C. M., Nápoles-Springer, A., Mutran, E., Manson, S. M., & Pérez-Stable, E. J. (2004). Ethnic Minority Older Adults Participating in Clinical Research. *Journal of Aging and Health*, 16(5_suppl), 93S-123S. <https://doi.org/10.1177/0898264304268151>
- ²⁰ Herrera, A. P., Snipes, S. A., King, D. W., Torres-Vigil, I., Goldberg, D. S., & Weinberg, A. D. (2010). Disparate inclusion of older adults in clinical trials: priorities and opportunities for policy and practice change. *American journal of public health*, 100 Suppl 1(Suppl 1), S105–S112. doi:10.2105/AJPH.2009.162982
- ²¹ Brown, S.C. (2001). Methodological Paradigms that Shape Disability Research. In G.L. Albrecht, K.D. Seelman, and M. Bury (Eds.), *The Handbook of Disability Studies*. Thousand Oaks, CA: Sage Publications.

II. Health and Research Practice

This section provides examples of evidence-based practice for health and research that have been adapted to the unique needs of older adults. At the end is a portal for searching for other evidence-based practices.

A. Best Practices and Interventions

Abdominal Aortic Aneurysm: Screening Guidelines

<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/abdominal-aortic-aneurysm-screening>

Cognitive Impairment: Screening in Older Adults

<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/cognitive-impairment-in-older-adults-screening?ds=1&s=cognitive%20impairment>

Falls Prevention in Community-Dwelling Older Adults: Interventions

<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/falls-prevention-in-older-adults-interventions1>

Hearing Loss: Screening in Adults Age 50 Years and Older

<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/hearing-loss-in-older-adults-screening?ds=1&s=hearing%20loss>

Interventions for Preventing Falls in Older People Living in the Community

<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD007146.pub3/full>

Intimate Partner Violence, Elder Abuse, and Abuse of Vulnerable Adults: Screening

<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/intimate-partner-violence-and-abuse-of-elderly-and-vulnerable-adults-screening1>

Physical Activity: Community-Wide Campaigns

<https://www.thecommunityguide.org/findings/physical-activity-community-wide-campaigns>

Physical Activity: Creating or Improving Places for Physical Activity

<https://www.thecommunityguide.org/findings/physical-activity-creating-or-improving-places-physical-activity>

Physical Activity: Social Support Interventions in Community Settings

<https://www.thecommunityguide.org/findings/physical-activity-social-support-interventions-community-settings>

Repositioning for Pressure Ulcer Prevention in Adults

<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD009958.pub2/full>

Screening for Colorectal Cancer: U.S. Preventive Services Task Force Recommendation

<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/colorectal-cancer-screening>

Statins to Prevent Cardiovascular Disease: Preventive Medication in Adults Ages 40 to 75 Years at Low Risk

<https://www.uspreventiveservicestaskforce.org/Page/Document/UpdateSummaryFinal/statin-use-in-adults-preventive-medication1?ds=1&s=statins>

B. Searchable Databases:

Healthy People 2020 Best Practice Research Search

<https://www.healthypeople.gov/2020/tools-resources/Evidence-Based-Resources>

National Institute on Aging Research Resources

<https://www.nia.nih.gov/research/resources>

III. National and Local Data

Information provided in this section includes links to various data sources on the population's health and demographic characteristics, both nationally and specific to Chicago and the greater metropolitan area.

A. General Data

Administration for Community Living: Profile of Older Americans

<https://acl.gov/aging-and-disability-in-america/data-and-research/profile-older-americans>

Federal Interagency Forum on Aging Related Statistics

Aging Stats

<https://agingstats.gov/>

Older Americans: Key Indicators of Well-Being

<https://agingstats.gov/docs/LatestReport/Older-Americans-2016-Key-Indicators-of-WellBeing.pdf>

National Institute on Aging: Publicly Available Databases for Aging-Related Secondary Analyses in the Behavioral and Social Sciences

<https://www.nia.nih.gov/research/dbsr/publicly-available-databases-aging-related-secondary-analyses-behavioral-and-social>

Pew Research Center

Family Support in Graying Societies

<https://www.pewsocialtrends.org/2015/05/21/family-support-in-graying-societies/>

At Grandmother's House We Stay: One-in-Ten Children Are Living with a Grandparent

<https://www.pewsocialtrends.org/2013/09/04/at-grandmothers-house-we-stay/>

Led by Baby Boomers, divorce rates climb for America's 50+ population

<https://www.pewresearch.org/fact-tank/2017/03/09/led-by-baby-boomers-divorce-rates-climb-for-americas-50-population/>

More older Americans are working, and working more, than they used to

<https://www.pewresearch.org/fact-tank/2016/06/20/more-older-americans-are-working-and-working-more-than-they-used-to/>

Number of U.S. adults cohabiting with a partner continues to rise, especially among those 50 and older

<https://www.pewresearch.org/fact-tank/2017/04/06/number-of-u-s-adults-cohabiting-with-a-partner-continues-to-rise-especially-among-those-50-and-older/>

On average, older adults spend over half their waking hours alone

<https://www.pewresearch.org/fact-tank/2019/07/03/on-average-older-adults-spend-over-half-their-waking-hours-alone/>

Population Reference Bureau: Fact Sheet – Aging in the United States

<https://www.prb.org/wp-content/uploads/2016/01/aging-us-population-bulletin-1.pdf>

US Census Bureau

Aging-Accessible Homes (Visualization)

<https://www.census.gov/library/visualizations/2017/comm/again-accessible-homes.html>

How Common Are Specific Disabilities by Age? (Visualization)

<https://www.census.gov/library/visualizations/2017/comm/cb17-ff11-disabilities.html>

Measuring America: Older People Living With Grandchildren: 2012-2016 (Visualization)

<https://www.census.gov/library/visualizations/2018/comm/children-grandchildren.html>

Percentage of Veterans Among the Adult Population (Visualization)

<https://www.census.gov/library/visualizations/2018/comm/percentage-veterans.html>

The Population 65 Years and Older: 2016 (Visualization)

<https://www.census.gov/library/visualizations/interactive/population-65-years.html>

The Population 65 Years and Older in the United States

<https://www.census.gov/content/dam/Census/library/publications/2018/acs/ACS-38.pdf>

Older Americans with a Disability: 2008–2012

<https://www.census.gov/library/publications/2014/acs/acs-29.html>

Older People Projected to Outnumber Children for First Time in U.S. History

<https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html>

Selected Tables on the Older Population in the U.S., by State, and by County

<https://www.census.gov/data/tables/time-series/demo/age-and-sex/aging-pop-acs.html>

CDC Wonder

<https://wonder.cdc.gov/>

B. State and Local Data

America's Health Rankings, 2018 Senior Report: Illinois

<https://www.americashealthrankings.org/learn/reports/2018-senior-report/state-summaries-illinois>

Illinois Department of Public Health: Fall Injuries among Older Adults

<http://dph.illinois.gov/sites/default/files/publications/publications-ohpm-older-adult-falls-100217.pdf>

Illinois Department on Aging: State Plan on Aging for FY2017-FY2019

<https://www2.illinois.gov/aging/Resources/Documents/StatePlanOnAging.pdf>

Substance Abuse and Mental Health Services Administration: Illinois Profile

<https://acl.gov/sites/default/files/programs/2016-11/Illinois%20Epi%20Profile%20Final.pdf>

US Census Bureau

Chicago Quick Facts

<https://www.census.gov/quickfacts/fact/table/chicagocityillinois/HSD410215>

Illinois Community Facts

https://factfinder.census.gov/faces/nav/jsf/pages/community_facts.xhtml?src=bkmk

Illinois Quick Facts

<https://www.census.gov/quickfacts/IL>

Voorhees Center for Neighborhood and Community Development at UIC

How Accessible is Chicago Transit to Persons with Disabilities?

<https://voorheescenter.wordpress.com/2015/11/20/how-accessible-is-chicago-transit-to-persons-with-disabilities/>

Planning Transportation to Meet the Needs of an Aging Illinois: An Assessment

https://utc.uic.edu/wp-content/uploads/Planning-Transportation-to-Meet-the-Needs-of-an-Aging-Illinois-2.26_reduced-1.pdf

IV. Ethical and Regulatory Issues

Working with priority populations often entails special ethical and regulatory considerations. This section describes those ethical challenges you may face when conducting research with older adults.

A. Applying the Belmont Report: Principle of Respect for Persons

One of the three key principles of the Belmont Report is respect for persons. This principle is made up of two components: “first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection.”²² Tension can occur in defining whether and to what extent people have diminished autonomy. Older adults may have diminished autonomy from a number of sources: a preexisting disability, dementia, or other cognitive impairment.²³

When someone has been determined to be in this situation, a family member, friend, or state entity typically makes the decision on whether they will participate in research or not. At UIC, assent from potential participants who have diminished capacity to give consent, along with the consent of their legally authorized representatives, must be given for them to participate in research. Guidance specific to the UIC IRB can be found at <https://research.uic.edu/human-subjects-irbs/policies/decisionally-impaired-and-cognitively-impaired-subjects/>

Tools are available to help determine a potential participant’s capacity to consent. One such tool, the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR), is available at http://www.prpress.com/MacArthur-Competence-Assessment-Tool-for-Clinical-Research-MacCAT-CR_p_167.html (fee required).

B. Other Considerations in Research with Older Adults

Comprehension of the study information is necessary if participants are able to give truly informed consent. Several characteristics are associated with lower comprehension: advanced age, lower verbal intelligence, negative mood, and having less formal education. However, including people with these characteristics is crucial so as not to bias one’s sample and therefore reduce generalizability. Methods for increasing comprehension that have been shown to be effective include presenting the information with a video or pictures, lowering the reading level of the content, using a larger font, testing for comprehension, and having multiple people provide information. These methods did not improve comprehension in all settings, serving as a reminder of the need to continually evaluate the effectiveness of these methods as they are implemented.²⁴

Though research participants across the lifespan can benefit from interactive techniques, these approaches can be particularly beneficial with older adults. Teach-Back is one such technique: after information is shared, participants are asked to teach the information back to the research staff in their own words. The research staff can then clarify as needed, repeating key points to ensure understanding.²⁵ Another is paraphrase testing. This is where research staff take drafts of documents (like survey questions) and asks people who could qualify for the

study to report back what they believe the document or questions are saying. If there is a discrepancy between what the researchers intended and participants' perceptions, that indicates the document needs to be rewritten.²⁶

A theme running through each of these points about the amount of information provided and the comprehension of study information is that each individual will have unique needs and preferences. Although certain procedures must be followed for all participants, to the extent possible, tailoring to each participant can improve the chances of taking informed consent correctly.²⁷

²² National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. (1978). *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Bethesda, MD: The Commission. Retrieved from https://www.hhs.gov/ohrp/sites/default/files/the-belmont-report-508c_FINAL.pdf.

²³ Kim, S.Y.H., Karlawish, J.H.T., & Caine, E.D. (2002 March-April). Current state of research on decision-making competence of cognitively impaired elderly persons. *The American Journal of Geriatric Psychiatry*, 10(2), 151-165. <https://doi.org/10.1097/00019442-200203000-00006>

²⁴ Sugarman, J., McCrory, D.C., & Hubal, R.C. (1998). Getting meaningful informed consent from older adults: A structured literature review of empirical research. *Journal of the American Geriatrics Society*, 46, 517-524. <https://doi.org/10.1111/j.1532-5415.1998.tb02477.x>

²⁵ Interactive Techniques. (2019). *Multi-Regional Clinical Trials: The MRCT Center of Brigham and Women's Hospital and Harvard*. Retrieved from <https://mrctcenter.org/health-literacy/tools/overview/interactive-techniques/>.

²⁶ Paraphrase Testing. (n.d.). *Plainlanguage.gov*. Retrieved from <https://www.plainlanguage.gov/guidelines/test/paraphrase-testing/>.

²⁷ Sugarman, J., McCrory, D.C., & Hubal, R.C. (1998). Getting meaningful informed consent from older adults: A structured literature review of empirical research. *Journal of the American Geriatrics Society*, 46, 517-524. <https://doi.org/10.1111/j.1532-5415.1998.tb02477.x>

V. Recruitment and Retention Best Practices

A. *Universal Design for Research*

A promising model for increasing participation of older adults in general research is Universal Design for Research, or UDR. Taking inspiration from Universal Design in architecture, where structures and environments are designed so that all people can use them without further adaptation, UDR provides four rules for making research more inclusive:

1. Plan your research to include all potential participants who meet the inclusion criteria, regardless of their current abilities or disabilities;
2. Do not create exclusion criteria unless there is a compelling scientific rationale;
3. Provide multisensory, flexible options for recruitment, research instruments (such as questionnaires), measurements, and responses from participants, with reasonable accommodations that invite and facilitate participation by persons with disabilities; and
4. When you do not know how to include someone with a disability, consult someone who does (the potential research participant, another person with that disability who is knowledgeable about the range of methods people use for living fully with it, or a professional who works with persons who have that disability).²⁸

Although originally created to foster inclusion of people with disabilities, they can easily be applied to older adults. Following these principles can allow older adults to participate in more types of research without significant modifications or added costs. This would be in keeping with the Belmont Report principle of justice, that populations should not be unduly excluded from participating in research.

B. *Community-Based Participatory Research Principles*

As mentioned in Section I, Community-Based Participatory Research (CBPR) and Participatory Action Research (PAR) are complimentary methods for addressing the hesitance some people with disabilities have for participating in research. A major tenet of CBPR is that community members (either on their own or through organizations) have a real voice in setting the research agenda, planning the project, implementing the plan, and realizing outcomes. Relatedly, the community should see real benefits from the process in addition to the generation of knowledge that benefits the researcher.²⁹ Similarly, PAR typically results in action steps that achieve or move towards a material improvement in the lives of the people who participated in the research. Four principles inform the approach: power sharing, mutual respect for experience and expertise, informed decision making, and maximum involvement [of participants in the research process].³⁰ These are approaches to research more than specific methodologies; though they naturally fit with qualitative research, they can be used in quantitative and mixed-methods research as well.

C. Community-Engaged Research: A Less Intensive Alternative to CBPR

Using the community-based participatory research (CBPR) approach involves significant investments of time and other resources. Moreover, it may be difficult if one's institutional setting is not designed to support CBPR. Community-engaged research (CEnR) is a less-intensive alternative that may be attractive to researchers who want to involve the community but may not be able to use the full CBPR model. Many of the principles remain the same.

The first step is to learn about the community. This may seem obvious, but it involves building relationships, getting to know the history, culture, and power structures, and understanding the norms and values. The second step is for researchers to share power and show respect. Researchers should listen carefully and be open to difficult conversations about power dynamics. Additionally, small steps like providing food for meetings can go a long way to helping community members participate. The third step is to include partners in all phases of research. While CEnR does not require completely equal decision-making power between researchers and community members, the views and goals of the latter should be incorporated into the study plan and execution whenever possible. The final step is for community partners to be compensated fairly. Researchers conduct studies for a living and get paid for their work; community partners should be afforded the same opportunity.³¹ Some research partners may not be interested in financial compensation; in these cases, consider if there are other benefits, such as access to campus resources or help in other areas you can provide.

Engaging the community using these principles can help your project be more responsive to the community's needs as well as more successful in achieving your goals.

C. Engaging Older Adults in Research

Once participants have been recruited into the research study, retaining them is essential to ensure adequate power for one's conclusions and so as to avoid non-participation bias. A wide variety of strategies exist to retain participants in studies: financial and nonfinancial incentives, reminders, community involvement, and many others. A meta-analysis suggested that while the effectiveness of the various methods is difficult to determine, what is clear is that using a variety of methods rather than relying on one or two is more likely to be effective.³²

Several studies have engaged older adults in research and provide guidance on what has worked. Community-engaged research (CEnR) tends to be more commonly used than community-based participatory research (CBPR), as research topics more often come from researchers than are developed jointly. A community advisory board (CAB), however, is a critical vehicle through which older adults give input and feedback. Several elements of engaged research have been demonstrated in these studies, including empowerment of older adults, co-learning between academic and community researchers, capacity building for older adults, and a balance between research and action. The success of studies in achieving these goals suggests this model can be used in other studies with older adults.

Despite these successes, challenges and opportunities remain. As with many priority populations, the balance of power between academic and community researchers continues to be an issue, particularly because of ageism.

Several strategies can be employed to ameliorate this situation. Honoring the knowledge and life experience of older adults can help them feel like their contributions are valued. Building bi-directional trust can take time but is an important foundation on which research can be built. Ensuring that older adults have appropriate training for the roles they will be undertaking gives them the tools to be successful. Finally, most participatory studies have been qualitative with small sample sizes. There is therefore an opportunity to enact studies using quantitative methods and/or larger sample sizes, to enhance generalizability of this body of research.³³

²⁸ Williams, A.S., & Moore, S.M. (2011). Universal Design of Research: Inclusion of Persons with Disabilities in Mainstream Biomedical Studies. *Science Translational Medicine*, 3(82), 82cm12. <http://doi.org/10.1126/scitranslmed.3002133>.

²⁹ Israel, B.A., Schulz, A.J., Parker, E.A., & Becker, A.B. (1998). Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. *Annual Review of Public Health*, 19, 173-202. Retrieved from <https://www.annualreviews.org/doi/pdf/10.1146/annurev.publhealth.19.1.173>.

³⁰ Brown, S.C. (2001). Methodological Paradigms that Shape Disability Research. In G.L. Albrecht, K.D. Seelman, and M. Bury (Eds.), *The Handbook of Disability Studies*. Thousand Oaks, CA: Sage Publications.

³¹ Michener, L., Cook, J., Ahmed, S.M., Yonas, M.A., Coyne-Beasley, T., & Aguilar-Gaxiola, S. (2012). Aligning the Goals of Community-Engaged Research: Why and How Academic Health Centers Can Successfully Engage with Communities to Improve Health. *Academic Medicine*, 87(3), 285–291. <http://doi.org/10.1097/ACM.0b013e3182441680>.

³² Robinson, K.A., Dinglas, V.D., Sukrithan, V., Yalamanchilli, R., Mendez-Tellez, P.A., Dennison-Himmelfarb, C., & Needham, D.M. (2015 December). Updated systematic review identifies substantial number of retention strategies: using more strategies retains more study participants. *Journal of Clinical Epidemiology*, 68(12), 1481-1487. <https://doi.org/10.1016/j.jclinepi.2015.04.013>.

³³ Blair, T., Minkler, M. (2009 October). Participatory Action Research With Older Adults: Key Principles in Practice. *The Gerontologist*, 49(5), 651–662. <https://doi.org/10.1093/geront/gnp049>

VI. Recruitment Templates & Resources

The following are links to flyers and other outreach material templates, as well as other resources that can help you develop your outreach materials.

General Outreach Templates, Best Practices, and Resources

<http://www.ccts.uic.edu/content/recruitment-templates>

FDA Research Volunteer Brochure

http://go.uic.edu/FDA_Research_Volunteer_Brochure

Flyer Templates Featuring Photos of People Aged 50+

African American Woman

http://ccts.uic.edu/sites/default/files/res_flyer_AFR_F_50.doc

Caucasian Woman

http://ccts.uic.edu/sites/default/files/res_flyer_CAUC_F_50.doc

Hispanic/Latina Woman

http://ccts.uic.edu/sites/default/files/res_flyer_HPC_F_50.doc

Asian American Couple

http://ccts.uic.edu/sites/default/files/res_flyer_ASIAN_50.doc

National Institute on Aging Brochure

Clinical Trials and Older Adults: How to decide if a trial is right for you

<https://order.nia.nih.gov/sites/default/files/2019-06/clinical-trials-and-older-adults-booklet-508.pdf>

NIH Flyers

“Feeling Better. Brought to You by Clinical Trials.” Flyer

<https://www.nih.gov/health-information/nih-clinical-research-trials-you/feeling-better-brought-you-clinical-trials-flyer>

Is Clinical Research Right for Me?

<https://www.nia.nih.gov/sites/default/files/clinical-research-infographic-508.pdf>

Simplified Recruitment Language

http://go.uic.edu/Simplified_Recruitment_Language

Supporting Enrollment & Engagement in Clinical Research

<http://www.ccts.uic.edu/sites/default/files/uploads/Example%202.pdf>

VII. Community Engagement Resources

The following is a list of community organizations who work with and on behalf of older adults. We are not endorsing them, nor have they agreed to be listed here. Instead, these listings are provided as an example of the kinds of organizations that are working with this population. This list is illustrative, not exhaustive.

A. Local Organizations

Access Living

<https://www.accessliving.org/>

Anixter Center

<http://www.anixter.org/>

The Catholic Charities – Archdiocese of Chicago – Senior Services

<https://www.catholiccharities.net/AboutUs/ServiceAreas/SeniorServices.aspx>

Centers for New Horizons – Adult and Protective Services

<http://cnh.org/aps.html>

The Chicago Lighthouse – Seniors Program

<https://chicagolighthouse.org/program/seniors-program/>

City of Chicago Department of Family & Support Services: Senior Services – Area Agency on Aging

<https://www.chicago.gov/city/en/depts/fss/provdrs/senior.html>

CJE SeniorLife

<https://www.cje.net/>

Coalition of Limited English Speaking Elderly

<http://clese.org/>

Community Care Programs (PDF Listing)

https://www2.illinois.gov/aging/CommunityServices/Documents/ADS_IHS_PSA.pdf

Housing Opportunities & Maintenance for the Elderly, H.O.M.E.

<https://www.homeseniors.org/>

Metropolitan Family Services – Senior Services

<https://www.metrofamily.org/programs-and-services/emotional-wellness/senior-services/>

Sinai Community Institute

<https://www.sinai.org/content/sinai-community-institute-0>

B. National Organizations

AARP

<https://www.aarp.org/>

The Administration for Community Living

<https://acl.gov/>

Alzheimer's Association

<https://www.alz.org/>

Catholic Charities USA

<https://www.catholiccharitiesusa.org/>

Gay and Lesbian Association of Retiring Persons, GLARP

<http://www.gaylesbianretiring.org/>

Medicare Rights Center

<https://www.medicarerights.org/>

National Caucus and Center on Black Aging

<https://ncba-aging.org/>

National Council on Aging (NCOA)

<https://www.ncoa.org/>

BenefitsCheckUp – website administered by NCOA

<https://www.benefitscheckup.org/>

National Senior Games Association

<https://nsga.com/>

The Red Hat Society

<https://www.redhatsociety.com/default.aspx>

Senior Corps – The Corporation for National and Community Service

<http://www.seniorcorps.org/>

VIII. Centers at UIC and C3 Working on the Issue

Please note: This list is intended to be illustrative rather than exhaustive. Resources to find individual researchers include <https://projectreporter.nih.gov/reporter.cfm>, <https://clinicaltrials.gov/>, <https://www.researchgate.net/>, and <https://scholar.google.com/>.

A. University of Illinois at Chicago

Center for Research on Health and Aging: The Center for Research on Health and Aging tests and builds evidence about how older adults can prevent disability and maintain health and examines how the health care system can address the health needs of older adults.

<https://www.ihrp.uic.edu/center/center-research-health-and-aging>

College of Medicine, Geriatric Medicine Fellowship: The UIC Geriatric fellowship provides comprehensive training in gerontology and geriatrics with opportunities for participation in gerontological research.

<https://chicago.medicine.uic.edu/departments/academic-departments/medicine/academic-internal-medicine-and-geriatrics/geriatric-fellowship-program/>

B. Northwestern University (Northwestern Medicine)

Healthy Aging Lab: Our healthy aging research programs focusing on older adults seek to document the physical and mental health of diverse aging populations, develop programs that promote well-being of older adults, and enhance resources for caregivers.

<https://labs.feinberg.northwestern.edu/simon/research/healthy-aging.html>

Geriatrics Research: Provides links to other researchers and labs focused on geriatric research.

<https://www.medicine.northwestern.edu/divisions/general-internal-medicine-and-geriatrics/research/geriatrics-research.html>

C. University of Chicago

National Opinion Research Center (NORC): Center on Demography and Economics of Aging: The Center has nourished an environment for research in the demography and economics of aging by providing research support services, encouraging the development of new research projects and research foci, and facilitating collaborative research and teaching among scientists working in the field of aging research.

<https://coa.norc.org/>

School of Social Service Administration: Older Adult Studies Program: The School of Social Service Administration designed the Older Adult Studies Program to meet the challenge of an aging society by preparing its graduates to become leaders in the field of aging. This program combines an understanding of the person-in-environment as well as an awareness of the web of institutional relationships linking the older adult to society and social policy.

<https://www.ssa.uchicago.edu/older-adult-studies>

UChicago Medicine, Geriatrics and Palliative Medicine: Research Programs: Within the Section of Geriatrics and Palliative Medicine, faculty and staff conducting research include experts in geriatric medicine, nursing, social work, sociology, psychology, education, gerontology, and ethics, frequently working together in interdisciplinary teams.

<https://medicine.uchicago.edu/sections/geriatrics-palliative-medicine/research-programs/>

IX. Measuring Instruments

The following are scales that have been tested with older adults (or their caregivers) and have shown good psychometric properties. This listing is illustrative rather than exhaustive.

A. Instruments for Use with Older Adults

Chemotherapy Risk Assessment Scale for High-Age Patients (CRASH) score
<https://doi.org/10.1002/cncr.26646>

Comprehensive Geriatric Assessment for Older Patients with Cancer
https://www.oncoconferences.ch/mm/Weiterfuehrende_Literatur_Joerg_Beyer_5.pdf

Disability Assessment for Dementia Scale
<https://www.ncbi.nlm.nih.gov/pubmed/11391090>

Disability Assessment Scale (post-stroke)
<https://doi.org/10.1053/apmr.2002.35474>

Groningen Activity Restriction Scale
[https://doi.org/10.1016/S0277-9536\(96\)00057-3](https://doi.org/10.1016/S0277-9536(96)00057-3)

Hamilton Scales in Assessment of Anxious Older Adults
<https://doi.org/10.1023/A:1010967725849>

Impact on Participation and Autonomy Questionnaire
<https://doi.org/10.1053/apmr.2001.18218>

Kinesthetic and Visual Imagery Questionnaire (KVIQ) for Assessing Motor Imagery in Persons with Physical Disabilities
<http://doi.org/10.1097/01.NPT.0000260567.24122.64>

Measuring Loneliness Among Middle-Aged and Older Adults: The UCLA and de Jong Gierveld Loneliness Scales
<https://doi.org/10.1007/s11205-013-0461-1>

Pain Disability Assessment Scale
<https://www.ncbi.nlm.nih.gov/pubmed/21178590>

Participation Survey/Mobility (PARTS/M)
<https://doi.org/10.1016/j.apmr.2005.09.014>

Short Form of the Center for Epidemiologic Studies Depression Scale (CES-D)
[https://doi.org/10.1016/S0749-3797\(18\)30622-6](https://doi.org/10.1016/S0749-3797(18)30622-6)

The Spielberger State-Trait Anxiety Inventory (STAI): the state scale in detecting mental disorders in geriatric patients

<https://doi.org/10.1002/gps.1330>

World Health Organization Disability Assessment Scale (WHODAS II)

<http://www.ingentaconnect.com/contentone/mjl/sreh/2012/00000044/00000009/art00007?crawler=true&mimetype=application/pdf>

B. Instruments for Use with Others (family members, health care providers, etc.)

The Burnout Measure, Short Version

<http://dx.doi.org/10.1037/1072-5245.12.1.78>

Kogan's Old People Scale (Attitudes towards Older Adults)

Original scale: <https://psycnet.apa.org/doi/10.1037/h0048053>

In a modern paper: <https://doi.org/10.1016/j.ijnurstu.2012.11.021>

Maslach Burnout Inventory – Human Services Survey (MBI-HSS) [Fee required]

<https://www.mindgarden.com/117-maslach-burnout-inventory>

Multidimensional Scale of Perceived Social Support

<https://doi.org/10.1080/13668250600561929>

X. Program Announcements for Grants

The grants programs below either expire no earlier than September 2020, or have ongoing postings about new grant opportunities.

Grants Listing on the Administration for Community Living's Website

<https://acl.gov/grants/open-opportunities>

National Institutes of Health (NIH)

Clinical Research to Improve the Oral Health of Older Adults (R01 Clinical Trial Not Allowed)

<https://grants.nih.gov/grants/guide/pa-files/PAR-19-239.html>

Diet and Physical Activity Assessment Methodology (R01 Clinical Trial Not Allowed)

<https://grants.nih.gov/grants/guide/pa-files/PA-18-856.html>

Early-Stage T1 Translational Aging Research (Bench to Bedside) for the Development of Novel Therapeutics (R33 Clinical Trial Optional)

<https://grants.nih.gov/grants/guide/pa-files/PAR-19-304.html>

Early Stage Testing of Pharmacologic or Device-based Interventions for the Treatment of Mental Disorders (R33- Clinical Trial Required)

<https://grants.nih.gov/grants/guide/rfa-files/RFA-MH-18-703.html>

Environmental Influences on Aging: Effects of Extreme Weather and Disaster Events on Aging Populations (R01 Clinical Trial Optional)

<https://grants.nih.gov/grants/guide/pa-files/PAR-19-250.html>

Pragmatic clinical trial on efficacy of managing reduced iron stores on risk of clinically important events in older adults with heart failure and anemia (U01 Clinical Trial Required)

<https://grants.nih.gov/grants/guide/pa-files/PA-19-230.html>

Sensory and motor system changes as predictors of preclinical Alzheimer's disease (R01 Clinical Trial Not Allowed)

<https://grants.nih.gov/grants/guide/pa-files/PAR-18-519.html>

Underactive Bladder and Detrusor Activity in Aging (R01 Clinical Trial Optional)

<https://grants.nih.gov/grants/guide/pa-files/PA-18-570.html>

XI. Community Stakeholder Involvement

This section presents information for individuals and organizations to help them understand research and the research process, along with resources showing how to get involved in clinical trials and other research

A. Resources on Older Adults at UIC

Center for Research on Health and Aging at the Institute for Health Research and Policy
<https://www.ihrp.uic.edu/center/center-research-health-and-aging>

College of Medicine, Geriatric Medicine Fellowship
<https://chicago.medicine.uic.edu/departments/academic-departments/medicine/academic-internal-medicine-and-geriatrics/geriatric-fellowship-program/>

B. General Resources for Individuals

Building Trust between Minorities and Researchers
<http://buildingtrustumd.org/unit/importance-of-research/understanding-health-disparities>

National Institutes of Health – Clinical Research Trials & You
<https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics>

Research Fundamentals for Activists
<http://www.treatmentactiongroup.org/sites/default/files/201305/RFA%20FINAL.pdf>

Research Match (search for clinical trials to join)
<https://www.researchmatch.org/>

C. General Resources for Organizations

Alliance for Research in Chicagoland Communities, Northwestern University
<http://arccresources.net/>

Center for Clinical and Translational Sciences
<http://www.ccts.uic.edu/>

Community Based Participatory Research 101: From a Community Partner Perspective
Harlem Community & Academic Partnership
<https://ccph.memberclicks.net/assets/Documents/CNREI/cbpr%20101%20presentation.pdf>

A Quick Start Guide to Conducting Community-Engaged Research
Southern California Clinical and Translational Science Institute, Office of Community Engagement
http://oprs.usc.edu/files/2013/01/Comm_Engaged_Research_Guide.pdf

UIC Office of Community Engaged Research and Implementation Science
<https://cancer.uillinois.edu/outreach-program>

UIC Office of Community Engagement and Neighborhood Health Partnerships
<https://oceanhp.uic.edu/>

XII. Team Readiness to Work with Special Populations

This section provides resources to help research teams conduct an initial assessment of their readiness to engage with older adults.

A. Cultural competency training

Cultural Competence Assessment Instrument (CCAI)

<http://cebmdr.ahslabs.uic.edu/wp-content/uploads/sites/5/2014/04/CCAI.pdf>

National Research and Training Center (NRTC) Training and Education: Toolkit and Training on Assessing Cultural Competency in Peer-Run Mental Health Programs

<http://www.cmhsrp.uic.edu/nrtc/starcenter.asp>

B. Team diversity representation

Making sure that the research team has some representation of the target special population group helps establish trust, understanding, and credibility. For example, when conducting research with seniors, having older adults as team members can help to build trust and understanding between the research team and community members. This step, however, is not sufficient by itself: other efforts described elsewhere in this toolkit should also be used to garner community support and involvement.

C. Implicit-association test (IAT) – Offers a way to probe unconscious biases

Implicit Association Test (IAT)

<http://projectimplicit.net/nosek/iat/>

Look Different's Implicit Association Tests

<http://www.lookdifferent.org/what-can-i-do/implicit-association-test>

Project Implicit

<https://implicit.harvard.edu/implicit/>

D. LH-STEP – Helps assess an individual's capabilities by measuring skills, abilities, and potential for success.

http://www.creativeorgdesign.com/tests_page.php?id=477

E. Resources to Evaluate & Foster Attitudes Necessary for Working with Older Adults

The Burnout Measure, Short Version

<http://dx.doi.org/10.1037/1072-5245.12.1.78>

Kogan's Old People Scale (Attitudes towards Older Adults)

Original scale: <https://psycnet.apa.org/doi/10.1037/h0048053>

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<https://www.mindgarden.com/117-maslach-burnout-inventory>

Multidimensional Scale of Perceived Social Support

<https://doi.org/10.1080/13668250600561929>

Citing the CCTS's Priority Population Toolkit

The Older Adults Priority Population Toolkit was developed by the UIC Center for Clinical and Translational Science's Recruitment, Retention and Community Engagement Program.

The National Institutes of Health requires that investigators cite the CTSA grant if they used any CCTS services or resources to support their research. The CCTS relies on these citations as a critical performance measure when reporting annual productivity to NIH.

To cite the CCTS, the following text is recommended:

“The University of Illinois at Chicago Center for Clinical and Translational Science is supported by the National Center for Advancing Translational Sciences, National Institutes of Health, through Grant UL1TR002003. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.”

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