NYU Langone Health
Office of Science and Research
Clinical and Translational Science Institute
Integrating Special Populations Core
Engaging Special Populations Best Practice Brief
Older Adult Population
12 April 2022



Integrating Special Populations

Overview

Demographic Profile

The US population is experiencing two major demographic shifts: an increase in life expectancy and an increase in diversity. The population of older adults (65+ years) is expected to increase from 15.2% in 2016 to 23.4% by 2060.¹ According to the US Census projections, almost 17% of the US population is 65 years of age and older in 2020.² Older adults over the age of 65 make up 13% of the NYC Population, accounting for 1.1 million people.³ The race and ethnicity of the NYC older adult population varies - 44% percent of older adults identify as White, 22% as Black, 21% as Latino and 12% as Asian/Pacific Islander.³ Half of the older adult population in NYC is foreign-born, only 66% is English proficient and 60% has a high school diploma or less.³ 32% of older adults in NYC live alone, whereas 33% live in multigenerational households.³ Only 3% of older adults in the NYC live in nursing homes.³ The older adult population makes up a large and significant demographic of the NYC population and is important for inclusion in population health research.

Older Adults in NYC

- 13% of the NYC population is over the age of 65.
- The majority of older adults in NYC reside in Brooklyn and Queens.
- Non-Hispanic Whites make up the largest group of older adults in NYC compared to other racial/ethnic groups.
- Hispanic- Latino/a/x have the longest lifespan compared to other racial/ethnic groups in NYC.
- Less than 40% of the older adult population is retired.

Figure 1. Demographic data on the older adult population in NYC provided by the NYC Office of Health and Mental Hygiene & the NYC Comptroller's Office. 3,4

NYC residents by age group (years)

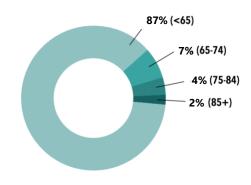


Figure 2. Residential data on the older adult population in NYC provided by the NYC Office of Health and Mental Hygiene.³

Health Profile

Older NYC adults have the third highest life expectancy in the US.⁵ The US average life expectancy is 78 years old, however, in NYC it is 81 years old.⁶ NYC older adults are living longer than most other states, yet many older adults live with multiple co-morbidities.³ 27% and 36% of the older adult population in NYC is considered obese or overweight, respectively.³ 28% of older adults suffer from diabetes, 65% have hypertension, 51% have joint pain (arthritis) or limited mobility, and 13% have memory loss.³ Older NYC adults are also at high risk for cancer and carcinogen exposure, with risk increasing with age. Latino/a/x and Black men and women have the highest rates of disease compared to non-Hispanic White NYC older adults.³







Older Adult Engagement in Research

Community engaged research is the process of addressing issues affecting the target populations of a study by collaborating and involving those directly impacted by studies in the research process⁷. The extent to which a research study requires community involvement will vary depending on the needs of the study. Thus, community engaged research exists on a spectrum (as seen in Figure 3). For a community-engaged study that moves further to the right on the spectrum, there is greater community involvement with a stronger bidirectional relationship and shared leadership between researchers and the community⁷. Community-based participatory research (CBPR) studies are research studies formatted to incorporate community members into the research process. The CBPR approach has shown much success in conducting research within disenfranchised communities since community engaged research facilitates trust and effective communication, which can later lead to community buy-in and future study sustainability.

Community Engagement Continuum

| Outreach | Consult | Involve | Collaborate | Shared Leadershi |
|---|--|---|---|---|
| Some Community Involvement Communication flows from one to the other, to inform Provides community with information. Entities coexist. Outcomes: Optimally, establishes communica- tion channels and chan- nels for outreach. | More Community Involvement Communication flows to the community and then back, answer seeking Gets information or feed- back from the community. Entities share information. Outcomes: Develops con- nections. | Better Community Involvement Communication flows both ways, participatory form of communication Involves more participa- tion with community on issues. Entities cooperate with each other. Outcomes: Visibility of partnership established with increased coopera- tion. | Community Involvement Communication flow is bidirectional Forms partnerships with community on each aspect of project from development to solution. Entities form bidirectional communication channels. Outcomes: Partnership building, trust building. | Strong Bidirectional Relationship Final decision making is at community level. Entities have formed strong partnership structures. Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built. |

Figure 3. As study moves further to the right on the spectrum, the greater bidirectional relationship and shared leadership between researchers and the community. Source: Principles of Community Engagement Report (2nd Ed.), Clinical and Translational Science Awards Consortium, Community Engagement Key Function Committee Task Force on the Principles of Community Engagement⁷

Best Practices in Engaging the Older Adult Community

When specifically addressing the older adult community, there are several specific considerations for an effective community engaged approach:

- Establish a strong relationship with community members by helping to address barriers to care that already exist for the aging community (e.g., lack of interaction with medical staff, perception of helplessness in care settings, understanding consent process)⁸
- Emphasize consistent consultation, asking participant perceptions on topics, and interpersonal relationships helps combat stigma and distrust of academic institutions⁸
- Understand the population's needs and motivations then provide resources and tools to aid the community⁹
- Consider physical, digital, and social barriers to giving consent and to overall participation and help to overcome feasibility challenges using institution or study resources⁹







Recruitment Best Practices

Outreach

- Establish a respectful partnership between investigators, participants, families and caregivers, funding agencies, regulators, institutions, providers, and study stakeholders¹⁰
- Determine strategies to reach the most vulnerable members of the aging population ¹⁰
- Broaden your study inclusion criteria to determine outreach population¹⁰
- Partner with communities by developing community advisory boards to promote and advertise the research study in a culturally applicable and linguistically appropriate way¹⁰
- Train researchers and staff on the cultural and social practices of the aging community by speaking with community members and families, participating in community events, hosting interactive gatherings, and attending groups for the aging 10
- Utilize research coordinators and/or other research staff members that can help ensure better communication with visually- or hearing-impaired community members¹⁰

Scheduling and Costs

- Incorporate flexible data collection schedules in your protocol¹⁰
- Involve participant's family in planning/logistic stages¹⁰
- Provide accessibility services or other support services¹⁰
- Conduct study in flexible locations (e.g., acute care or long-term care facilities, assisted living, public housing, retirement homes, hospitals, support groups, and nursing facilities)¹⁰
- Consider transportation needs and resources for your study participants¹⁰
- Consult advisory board to determine fair and culturally appropriate compensation for participation 10
- Allocate funds for extra resources to provide rigorous follow up and technical assistances for participants 10
- Measure time and cost of participation to provide to participants during the consent process¹⁰

Education and Language

- Create marketing materials using plain language and larger fonts (see plain language quidelines)^{11,12}
- Explain research objectives, protocols, PI contact information and follow up procedures with consideration for personal literacy and organizational health literacy (see health literacy guidelines)¹³
- Implement transcreation approach, the process of translating intervention material messaging using language that resonates with the community/target population¹⁴
- Provide options for participants to complete study measures independently or with the help of a research assistant or family member¹⁵
- Provide options for study measures to be administered verbally¹⁵

Cultural Sensitivity and Values

- Aim to maintain a familiar lifestyle for older adults instead of creating study environments that may inconvenience the participants¹⁵
- Consider cognitive activity and overall interests and motivations of study participants¹⁰
- Address participants with appropriate language to indicate mutual respect⁷
- Providing peer interaction and in-person assistance when introducing new topics or technology to older adults (e.g., using grandkids to help with facilitation)¹⁵
- Think of ways to utilize existing features to address and alleviate the needs of older adults instead of delivering new ideas or innovative features¹⁵







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Special Populations

Internal & External Resources:

| Research & Recruitment | NYULH Trainings & Resources* | Health Profiles | National Organizations |
|--|------------------------------------|----------------------------------|------------------------------------|
| Resources | | | |
| Challenges and practical | CDC Plain Language | NYC Department for the Aging | AARP |
| recommendations for recruiting | | (DFTA) Profile of Older New | |
| older adults study | | <u>Yorkers</u> | |
| Recruitment and Retention of Older | CDC Health Literacy | <u>Life Expectancy Report of</u> | American Society on Aging |
| People in Clinical Research study | | Older Adults in NYC | |
| | | | |
| Lessons on Recruitment and | CDC Select Terms for Populations | Healthy People 2020 – Older | National Council on the Aging |
| Retention from Elders Report | | <u>Adults Report</u> | |
| | | | |
| Evidence for strategies to improve | FOCUS Inclusive Mindset Training | <u> US Census Bureau – Older</u> | Administration for Community |
| recruitment and retention of older | | Population and Aging Report | <u>Living</u> |
| adults study | | | |
| 5 1 1 6 5 1 1 1 5 5 1 | | | |
| Evaluation of Recruitment of Older | FOCUS Design Thinking, Social | US Dept of Health and Human | |
| Adults of Color into Self- | Innovation, and Complex Systems | | prevention resources |
| Management Pathway Program | <u>Training</u> | Community Living Profile of | |
| study | | Older Americans Report | |
| Guidance for Recruiting Older | FOCUS Instructional Design: Adult | Population Reference Bureau - | FDA – Tips for Seniors |
| Adults in Clinical Research study | Learners Training | Aging in the US Factsheet | TIPS TOT SETTIONS |
| | <u>Learners framing</u> | Aging in the OS ractsheet | |
| Guidelines for Evaluating | FOCUS Strategies to Address | Social Isolation and Loneliness | National Institute on Aging at |
| Recruitment in Diverse Populations | Unconscious Bias Resource | in Older Immigrant Adults | NIH |
| Studies systemic review | | study | |
| | | | |
| Representation of | FOCUS Strategic Resources and | | The Senior Corps - network of |
| <u>Underrepresented Populations in</u> | Support Services for Investigators | | programs for older adults |
| Clinical Trials systemic review | <u>& Study Teams</u> | | |
| "Let him speak:" roles and behaviors | FOCUS Marketing to Diverse | | Consider Constitute Administration |
| of family companions in primary | _ | | Social Security Administration |
| care visits study | Audiences Training | | |
| care visits study | | | |
| | FOCUS Creating a Culture of | | |
| | Collaboration Training | | |
| | FOCUS Communicating Across | | |
| | Cultures Training | | |
| | FOCUS Best Practices for | | |
| | Managing Projects Across | | |
| | Cultures Training | | |
| | FOCUS Cultural Competency at | | |
| | NYULH Training | | |
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Special Populations

| Research and Recruitment Resources | NYULH Trainings & Resources* | Health Profiles | National Organizations |
|------------------------------------|--|-----------------|------------------------|
| | FOCUS Strategic Resources and Support Services for Investigators & Study Teams | | |
| | FOCUS Interpersonal Communication Training | | |
| | FOCUS Managing a Diverse Team Training | | |
| | FOCUS Diversity, Inclusion and Belonging Training | | |

^{*} FOCUS only accessible with Kerberos ID

