

Tips for Researchers: Engaging LGBTQ+ Elders and Elders Living with HIV

SAGE is committed to supporting LGBTQ+ elder visibility by increasing participation in all mainstream research. An empowered community leads to the greatest increase in authentic research and intervention participation. Considering the history of harm against the LGBTQ+ community and those living with HIV by medical and scientific communities, building back trust is vital to increasing research participation among those who are impacted by these harms or have experienced them directly.

Understanding the research experiences of LGBTQ+ elders and those living with HIV can help researchers and health interventionists take steps toward transforming research practices so that no one is invisible.

METHODS

SAGE held two discussion groups with LGBTQ+ older people interested in discussing their experiences as participating in clinical research. Participants included folks of various racial backgrounds, gender identities and sexual orientations, and health statuses. Participants discussed their positive and negative experiences participating in research, how research about LGBTQ+ people has changed, and what influences their trust and motivation surrounding research participation. Themes from participant discussion were used to compile a list of best practices for researchers.

RECOMMENDATIONS FOR RESEARCHERS

Intentional Inclusion and Fostering Community: Going beyond typical outreach efforts such as community advisory boards and study recruitment, and fostering community and connection is advised for researchers hoping to enhance their relationships with LGBTQ+ elders and increase study participation. LGBTQ+ elders in the discussion groups,

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continually referenced their interest in staying up to date on research efforts, better understanding research processes, and getting to know researchers that are studying their community. By getting involved in local community centers, attending events, and inviting elders to learn more about research and study results, researchers can create a sense of belonging and mutual respect for LGBTQ+ elders, and can increase a sense of community ownership of research efforts.

Cultural relevance and responsiveness:

Researchers should ensure that the studies they conduct are relevant and responsive to community needs. One participant said that as a Black man, it was clear when researchers did not take the time to verify questions made sense to the population they intended to research. Taking the time to get community feedback throughout the research process on the questions, topics, and aims of the study, as well as the results, can be instrumental in ensuring that the unique communities represented in the study are able to participate to the fullest and view the study as a productive and valuable contribution.

Accessibility: Providing flexibility and considering accessibility for visual, auditory, motor, or cognitive disabilities

can ensure that you receive the highest level of participation in your research. LGBTQ+ elders indicated that lack of accessibility was a primary reason they were unable to participate in research studies. Recommendations include offering a number of times for participation, virtual options with accessibility considerations, and opportunities for elders to request additional accommodations.

Research team visibility: When conducting research with LGBTQ+ older adults, it is important for researchers themselves to be open about their LGBTQ+ identity or allyship. One participant shared a positive experience participating in a study conducted by a researcher who openly shared their LGBTQ+ identity. This participant shared how knowing the researcher was part of the LGBTQ+ community made them much more comfortable participating as their whole self. Knowing that LGBTQ+ researchers are involved in the design of the study can increase participant confidence that the research and study results will be inclusive, affirming, and supportive of their needs and identities.

Trust: It is critical for LGBTQ+ elders to have confidence that the research they are engaging in is sponsored by organizations that have a history of supporting the LGBTQ+ community and

using research to make a positive impact. Many LGBTQ+ elders may have encountered situations that led to their distrust of researchers. One participant recalled a study they participated in that used the results to perpetuate harmful stereotypes about transgender women living with HIV/AIDS, damaging an already at-risk community. Organizations conducting research with LGBTQ+ elders are encouraged to share their history with the LGBTQ+ community, current aims with their study, desired outcomes, and their funding source to promote a sense of authenticity, good-will and transparency to increase participant trust.

Provide Opportunities for Impact:

LGBTQ+ elders indicated in the discussion that they are motivated to participate in research because they are interested in improving the understanding of their identities, the illnesses that affect them, and supporting research that has a positive impact. Survivor's guilt was named by one elder who described his feeling of obligation to continue participating in HIV research to honor those who have died from the disease and support research to prevent such deaths in the future. Participants also conveyed their strong desire to participate in research that makes up for past disinformation about LGBTQ+ individuals and those living with HIV and support research that seeks to improve

conditions for their communities. Furthermore, participants indicated that they appreciated being treated like an expert rather than a subject, with opportunities to provide feedback throughout the research process and participate in interview-based studies. Researchers involving LGBTQ+ elders should consider this feedback by providing opportunities beyond participation and investing in disseminating the study results beyond academic audiences. Additionally, giving LGBTQ+ elders the opportunity to be a part of interpreting, disseminating, and developing research agendas can fulfill the strong interest expressed by LGBTQ+ elders in being a part of contributing to research with impact.

KEY TAKE-AWAYS

Inclusion of LGBTQ+ elders in research is critical for better understanding the impact of lifetime stressors and social determinants of health that disproportionately impact them. Adopting culturally relevant and responsive practices demonstrates researcher investment and care for all participants. Researchers interested in engaging this population can better the experiences and treatment of LGBTQ+ elders in research and improve the body of knowledge in medical and scientific communities on LGBTQ+ elders by incorporating these best practices.