Trust and Willingness to Participate in Research Among Sexual And Gender Minorities: Results from the RISE Registry

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Background

- An estimated 2.7 million LGBTQIA+ individuals are currently over 50 and this group faces a combination of health disparities and social stressors which increase the risk of developing ADRD as they age.
- Data objectively measuring trust among minoritized groups participating in ADRD Clinical Research is limited and virtually no data exist regarding sexual and gender minority (SGM) populations.
- Research related to improving ADRD clinical research participation in other minoritized groups show understanding the unique needs of the population and tailoring outreach, recruitment, and study requirements can engage these participants.

Purpose

This study objectively investigates potential barriers to participation in ADRD clinical research, including trust and research procedures, among the SGM community.

Demographics

Characteristic	Mean ± SD N (%) N=56
Age	**49 ± 17**
Self-reported Gender Identity	
Male	23 (41%)
Female	19 (34%)
Non-Cis	14 (25%)
Self-reported Race	
White	40 (71%)
Non-White	16 (29%)

Methods

- The RISE Registry (N=1059) was an online research registry collected via REDCap of SGM caregivers of persons with ADRD or SGM persons with ADRD.
- A subset of eligible participants (N=56) completed pilot surveys to assess interest and barriers to participation in ADRD research.
- Questionnaires:
  - Trust in Research Questionnaire (Figure 1); Willingness to Participate in Research (Figure 2)
- Analysis:
  - Results were collapsed into agree/disagree categories
  - T-test and chi square analysis to ascertain potential response differences by sexual orientation, gender identity or race

Results

Table 1. Trust in Research Survey Results

Statement	Male N=23[1]	Female N=19[1]	Non-cis N=14[1]	p-value[2]
My attitude towards research is positive				0.5
No/Disagree	2 (8.7%)	0 (0%)	1 (7.1%)	
Yes/Agree	21 (91%)	19 (100%)	13 (93%)	
Researchers would not involve me in harmful research				0.4
No/Disagree	5 (22%)	3 (16%)	5 (36%)	
Yes/Agree	18 (78%)	16 (84%)	9 (64%)	
It is safe to be in a medical research study				0.3
No/Disagree	3 (13%)	0 (0%)	1 (7.1%)	
Yes/Agree	20 (87%)	19 (100%)	13 (93%)	
Researchers sometimes involve patients without consent.				0.7
No/Disagree	18 (78%)	15 (79%)	9 (64%)	
Yes/Agree	5 (22%)	4 (21%)	5 (36%)	
Researchers tell patients everything they need to know.				0.2
No/Disagree	8 (35%)	3 (16%)	6 (43%)	
Yes/Agree	15 (65%)	16 (84%)	8 (57%)	
Participants are like human guinea pigs.				0.3
No/Disagree	21 (91%)	16 (84%)	10 (71%)	
Yes/Agree	2 (8.7%)	3 (16%)	4 (29%)	
Researchers only care about what is best for the patient.				0.9
No/Disagree	13 (57%)	12 (63%)	9 (64%)	
Yes/Agree	10 (43%)	7 (37%)	5 (36%)	
Researchers unfairly select minorities for dangerous research.				0.3
No/Disagree	20 (87%)	15 (79%)	9 (64%)	
Yes/Agree	3 (13%)	4 (21%)	5 (36%)	
Comfortable with racially similar researcher				0.7
No/Disagree	18 (78%)	13 (68%)	10 (71%)	
Yes/Agree	5 (22%)	6 (32%)	4 (29%)	
Comfortable with SOGI similar researcher				0.2
No/Disagree	9 (39%)	11 (58%)	4 (29%)	
Yes/Agree	14 (61%)	8 (42%)	10 (71%)	

[1] N (%), [2] Fisher's exact test; Pearson's Chi squared test

No differences in responses were found by gender identity, sexual orientation, or race. Most participants reported a positive view of research (94%), reported feeling safe (92%), no intentional harm by researchers (77%), and disagreeing that researchers unfairly selected minorities for research (78%) (Table 1.). Willingness to participate in research procedures (Figure 3.) was over 50% of the respondents for 80% of the procedures.

Figure 3. Willingness to Participate in Research Survey Results

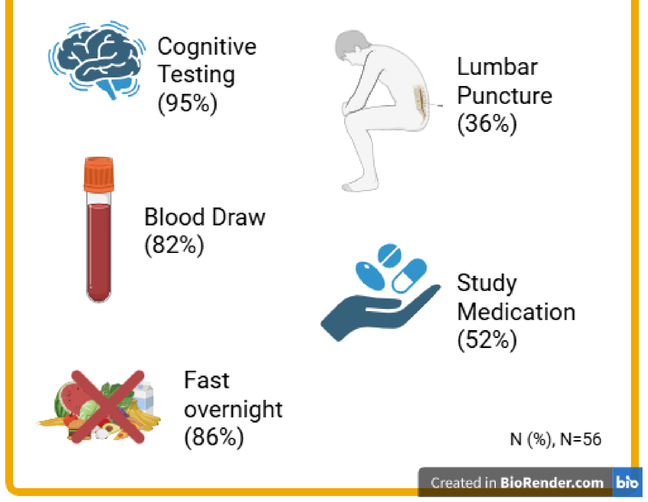

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Figure 1: Trust in Research Questionnaire

Strongly Disagree (1)	Disagree (2)	Agree (3)	Strongly Agree (4)

1. My attitude towards research is positive.
2. Researchers would not involve me in research that might be harmful.
3. It's safe to be in a medical research study.
4. Researchers sometimes involve patients in research without their knowlege or consent.
5. Researchers tell their patients everything they need to know about being in a reseach study.
6. People who participate in research are like human guinea pigs.
7. Researchers only care about what is best for each patient.
8. Researchers unfairly select minorities for their most dangerous research.
9. I would be more comfortable having research explained to me by a researcher with a racial or ethnic background similar to mine.
10. I would be more comfortable having research explained to me by a researcher with a sexual orientation or gender identity.

Figure 2: Willingness to Participate in Research

Would you be open to potentially participating in a research study involving any of the following after the study specifics and procedures are explained to you? (Check all that apply):

Blood Draw
Memory and thinking tests
Taking a medication
Lumbar puncture
Fasting overnight

Discussion

We found most SGM individuals surveyed were willing to participate in clinical research, including studies with invasive procedures. In this sample, we did not find a difference between gender identity (i.e., biological male, biological female, non-cis) in responses to the 10 question Trust in Research Questionnaire. The responses to these questionnaires were solicited from community populations who are not currently enrolled in ADRD research and did not receive the tailored education about study procedures that can increase willingness to participate.

While we recognize and acknowledge past atrocities to minoritized groups in healthcare and research, excluding minoritized groups like the SGM community, from ADRD research without understanding their interest and barriers to participation further marginalizes this group. Further research and larger samples investigating barriers to participation among SGM and underserved groups should be delineated.