



Research Inclusion
Supports Equity

RISE Registry Research Study Information Sheet

Thank you for your interest in using the RISE Registry as a recruitment tool to engage and include LGBTQIA+ adults and caregivers in your study! Funded by the National Institute on Aging, the RISE (Research Inclusion Supports Equity) Registry is a national, collaborative effort to increase inclusion of LGBTQIA+ adults in aging research. The project is led by Drs. Whitney Wharton from Emory University, Jason Flatt from the University of Nevada-Las Vegas, and Joel Anderson from the University of Tennessee-Knoxville.

A major aim of RISE is to establish a research registry of 1,000+ LGBTQIA+ people living with memory loss and LGBTQIA+ caregivers of people living with memory loss to engage and include them in research throughout the U.S. Part of this aim is to offer the RISE Registry as a recruitment tool for researchers. Information about how to use the RISE Registry in your study is outlined below.

Study Requirements

All studies using the RISE Registry must include questions collecting sexual orientation and gender identity (SOGI) from all participants or must specifically target LGBTQIA+ individuals in the inclusion criteria. The minimum SOGI data elements include sexual orientation, gender identity, and sex assigned at birth. If you do not already have questions collecting these data, sample questions are provided below.

In addition to these minimum data elements, study investigators are strongly encouraged to review existing resources to ensure they and their team will engage with the LGBTQIA+ community in culturally competent ways. Recommended cultural competency resources can be accessed using the links below:

- [Advocacy and Services for LGBTQ+ Elders \(SAGE\)](#)
- [GLMA: Health Professionals Advancing LGBTQ Equality](#)
- [LGBTQIA+ Aging Project at Fenway Health](#)

Approved studies will be promoted to potential participants via the RISE website and targeted emails and newsletters. If your study/program is not focused on LGBTQIA+, but you would like to be highlighted, please note this on the study request form.

Research Study Request Form

The first step in having your study promoted via the RISE Registry is to submit the study request form attached below. This form is **required** for review by the RISE Team.

The study request form includes fields for the following information: study title, investigator(s), institution(s), funding status, IRB status, study description, target sample size, inclusion/exclusion criteria, and timeline.

Review by RISE Team

Once received, the RISE Team will review your request. We may request a Zoom meeting if more information is needed to clarify or understand your request. You also may specifically request a consultation with the RISE Team using the study request form.

The RISE Team will review requests in the order in which these are received and will communicate a decision to the principal investigator within 30 days of receipt.

Participant Referral

All approved studies will be promoted via the RISE Registry through a listing on our website, as well as targeted promotion emailed to registry participants fitting the study inclusion criteria.

We will **not** share the contact information of RISE Registry participants directly with any researchers outside of the RISE Team.

Investigator Responsibilities

Investigators of approved studies must agree to the following responsibilities:

- Confirmation of IRB approval is required before studies are promoted via the RISE Registry. The IRB approval letter must indicate the RISE Registry as a source of recruitment. IRB-approved email script(s) must be submitted, if applicable.
- Notify the RISE Team of the outcome for all registrants identified within 30 days of study promotion and quarterly thereafter. These data include all potential participants screened for eligibility, enrolled and/or withdrawn, and those who complete the study. The RISE Team will provide you with a spreadsheet for tracking registrant contact data.
- All publications or presentations associated with or using the RISE Registry must adhere to the following guidelines:
 - The RISE grant must be cited using the following language: “The project described was supported by the National Institute on Aging of the National Institutes of Health under Award Number 1R24AG066599-01A1. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.”
 - Compliance with the NIH Public Access Policy (<https://publicaccess.nih.gov>) must be ensured by submitting final peer-reviewed journal manuscripts that arise from NIH funds to PubMed Central immediately upon acceptance for publication.
 - Investigators must notify and provide the RISE Team with a copy of publications or presentations. These will be included on the RISE website and quarterly newsletter.

If you have questions about the RISE Registry or would like more information, please contact Dr. Whitney Wharton (PI) at w.wharton@emory.edu.

Sample SOGI questions

What is your current gender identity? (Check all that apply)

- Female
- Male
- Gender non-conforming/Non-binary
- Trans female/Trans woman (Male-to-Female)
- Trans male/Trans man (Female-to-Male)
- Two Spirit
- Genderqueer
- I use a different term.

Please indicate the term(s) you use to describe your current gender identity? _____

What sex were you assigned at birth, on your original birth certificate?

- Female
- Male
- Intersex
- Prefer not to answer

How would you describe your current sexual orientation? (Check all that apply)

- Asexual
- Bisexual
- Gay
- Lesbian
- Queer
- Questioning
- Straight / Heterosexual
- Two Spirit
- I use a different term.

Please indicate the term(s) you use to describe your current sexual orientation? _____



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RISE Registry Study Request Form

Study Contact Information:

Principal Investigator: _____

PI Email: _____

Note: Students wishing to use the RISE Registry need to list a supervising faculty mentor.

Faculty mentor (if applicable): _____

Faculty mentor Email: _____

Study Contact: _____

Study Contact Email: _____

Study Consultation:

Would you like to schedule a study consultation meeting with a member of the RISE Team?
Consultations will be provided only in the context of the RISE Registry.

Yes No

If yes, what topics would you like to discuss during the consultation? Please select all that apply.

- Study design Eligibility criteria Sample size
 Letter of support Templates for data collection Templates for study recruitment
 Not listed; please specify: _____

Collaboration:

The RISE Registry investigators encourage collaboration among clinical investigator, particularly if an investigator is new to registry-based research. Investigators from our team interested in a similar topic may be recommended to collaborate on a project.

Would you be interested in a collaboration with a member(s) of the RISE Team?

Yes No

Study Information

Study Title: _____

Provide a brief statement describing the background and significance of the proposed study:

Provide a brief statement describing the project's main objectives and aims. Please be as specific as possible. Limit to no more than two objectives or aims.

SOGI Data Collection:

Which type(s) of SOGI data will you be collecting:

Sexual minority Gender minority Both sexual and gender minority

Are you using the SOGI questions suggested by RISE?

Yes No, I am using different questions.

If no, please describe the questions you will be asking:

Recruitment Status:

Ongoing

ClinicalTrials.gov ID (if applicable): _____

Study website (if applicable): _____

Other public access/study registration (if applicable): _____

Preparing for recruitment

Sexual and Gender Minority Groups of Interest:

All LGBTQIA+ All sexual minority All gender minority
 Lesbian Gay Bisexual Queer Transgender
 Intersex Asexual Not listed; please specify: _____

Study Design (select all that apply):

Observational study Interventional study Prevention study
 Online study Caregiver study
 Study for people with memory loss Study for people without memory loss
 Not listed; please specify: _____

RISE Referral Information

Target recruitment sample size from RISE Registry:

- <50 50–100 >100
 Not listed; please specify: _____

Referral start date: _____

Referral end date: _____

Characteristics to identify potentially eligible participants from the RISE Registry:

- Age Race Ethnicity Sexual orientation Gender identity
 Living with memory loss Caregiver

Inclusion criteria:

Exclusion criteria:

Can RISE Registry participants be enrolled in any other studies while they enroll in the requesting study?*

- Yes No

**If there is a request to block enrollment in other studies, this may affect the prioritization of promotion of your study.*

IRB Status*:

- Received IRB approval with the RISE Registry as recruitment source.
If approval has been received, please attach your IRB approval notice.
 Pending, IRB protocol is under review with the RISE Registry as recruitment source
 IRB protocol in preparation

**Example language to include the RISE Registry as a recruitment source: "This study will recruit from the Research Inclusion Supports Equity (RISE) Registry (Emory IRB No. 3337)."*

Funding Status:

- Funded If funded, please provide funding source: _____
 Under review
 Preparing proposal/funding application
 Other; please specify: _____

If no funds are currently available, is there a plan to submit an application for funding support?

- Yes Targeted funding source: _____ No

How did you learn about RISE?

- Community organization; please specify: _____
- Conference, community forum, workshop, webinar
- Email or listserv
- Social media such as Facebook, Twitter, or Instagram
- Word of mouth
- Other; please specify: _____

Investigator Responsibilities

Investigators of approved studies must agree to the following responsibilities:

- Confirmation that SOGI data will be collected as part of the study as described above.
- Confirmation of IRB approval is required before studies are promoted via the RISE Registry. The IRB approval letter must indicate the RISE Registry as a source of recruitment. IRB-approved email script(s) must be submitted, if applicable.
- Notify the RISE Team of the outcome for all registrants identified within 30 days of study promotion and quarterly thereafter. These data include all potential participants screened for eligibility, enrolled and/or withdrawn, and those who complete the study. The RISE Team will provide you with a spreadsheet for tracking registrant contact data.
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 - Investigators must notify and provide the RISE Team with a copy of publications or presentations. These will be included on the RISE website and quarterly newsletter.

Additional information or comments:

I, _____, (PI name), having read this form, hereby agree to act in accordance with the investigator’s responsibilities listed herein.

Once complete, please submit your request form to Dr. Whitney Wharton at w.wharton@emory.edu. The RISE Team will review the information you provided, and we will get back to you with any follow up.