



Exhale, The Family Caregiver Initiative Participant Informed Consent

Summary: As part of *Exhale, The Family Caregiver Initiative*, you are being asked to participate in an evaluation. The evaluation involves completing a survey now and completing follow-up surveys in 3 and 6 months. The purpose of the evaluation is to examine how well the program works. Evaluation results may be used to improve the program and for reports describing the findings. The evaluation is being done by The New York Academy of Medicine (NYAM). Funding has been provided by the Ralph C. Wilson Jr. Foundation and the Health Foundation for Central and Western New York.

Study Methods: If you participate in this evaluation, information collected through the *Exhale* will be shared with evaluators at NYAM. The information shared is listed here. It does not include your name or any information that can be used to identify you.

1. **Baseline survey:** The survey includes background questions on you and the person or people you care for, including questions on health, health care, respite, and caregiving. Caregiving questions ask about your responsibilities as a caregiver and how those responsibilities make you feel.
2. **Follow-up surveys:** Follow-up surveys will be conducted in 3 and 6 months. Questions will be similar to those included in the baseline. The follow-up survey will also include questions about *Exhale*, including what services you received and if they were helpful to you.
3. **Caregiver Intensity Index (CII):** If you complete the CII, responses will be linked to responses from the surveys using a unique ID number. The CII assesses the intensity of the caregiving experience.
4. **Interview or focus group:** You may be asked to participate in an interview or a focus group to discuss program services and activities, including strengths and weaknesses.

Your participation in the evaluation of the *Exhale* is completely voluntary: You may refuse to participate in the evaluation. If you decide to participate, you may still skip particular survey questions, and you may withdraw at any time. You may participate in the *Exhale*, even if you do not participate in this evaluation.

NYAM IRB

Approved Consent Form
Protocol # 111919-NYAM
Approval date: September 11, 2023
for use thru: September 10, 2024

Risks and benefits: Taking part in this evaluation may not benefit you personally, but we may learn new things that will help improve respite services for people caring for older adults.

We will keep any information you share with us confidential. Results will be reported without names or identifying information. We will not report personal information to any hospital, insurance company, or government agency.

If you have any questions, please ask. If you have questions later or feel that you have been treated unfairly or have been harmed by the evaluation, please contact:

Linda Weiss, PhD, Senior Researcher
Center for Evaluation & Applied Research
New York Academy of Medicine
1216 Fifth Avenue, New York, NY 10029
(v) 212-822-7298
lweiss@nyam.org

Elaine Larson, RN, PhD, FAAN, CI
Chair, Institutional Review Board
New York Academy of Medicine
1216 Fifth Avenue, New York, NY 10029
(v) 212-822-7287
ell23@cumc.columbia.edu

Consent Statement

I have read this form or it has been read to me. I have had a chance to ask questions about this evaluation and my questions have been answered. I agree to be part of this study. I will receive a copy of this form.