

Appendix 9.1. Information Letter to NIH Staff Introducing Survey, Stamped Approved by IRB

DEPARTMENT OF PUBLIC HEALTH SCIENCES

Division of Health Policy and Outcomes Research
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MEDICINE of THE HIGHEST ORDER

INFORMATION SHEET

Principal Investigator: Helena Temkin-Greener, PhD

Co-Investigators: Drs. Dana Mukamel, Timothy Quill, Sally Norton, Thomas Caprio, and Tobie Olsan

This form describes a research study that is being conducted by Dr. Helena Temkin-Greener from the University of Rochester's Department of Public Health Sciences. The purpose of this study is to assess and improve teamwork and palliative care in nursing homes and to examine their impact on resident outcomes. We are very pleased that your nursing home has agreed to participate in this study, and we expect the findings from this project will improve palliative and end-of-life care for residents and the quality of the working environment for staff.

If you decide to take part in this study, you will be asked to complete 1 survey that will take about 15 minutes or less to complete. The enclosed questionnaire asks about your experience working in your facility. We estimate that approximately 900 staff members in 30 nursing homes in New York State will take part in this study.

Some of the survey questions may be upsetting or make you feel uncomfortable. You can skip any of the questions you do not want to answer. All of the information we collect will be stored in a secure manner and only study team members will have access to it. There are no other expected risks to filling out the questions. There are also no expected benefits to you.

The University of Rochester is receiving payment from the Patient-Centered Outcomes Research Institute (PCORI) for conducting this research study. You will not be paid for participating in this study, but as a way of thanking you for your participation, we will enter you in a raffle with prizes of up to \$500 when we receive your completed survey. Please be sure to fill out the enclosed raffle ticket and send it back to us together with a completed questionnaire to enter this raffle.

The University of Rochester makes every effort to keep the information collected from you private. Sometimes, however, researchers need to share information that may identify you with people that work for your nursing home, regulators or the study sponsor. If this does happen we will take precautions to protect the information you have provided. Results of the research may be presented at meetings or in publications, but your name will not be used.

Your participation in this study is completely voluntary. Taking part in this research is not a part of your job duties, and refusing will not affect your job. You will not be offered or receive any special job-related consideration if you take part in this research. No one at your facility will know if you did or did not complete the survey, unless you tell them.

If you would like further information about this study, or have questions about the survey, please contact the Study Coordinator, Susan Ladwig MPH at: (585)276-3683 (telephone)
or by email: Susan.Ladwig@urmc.rochester.edu.

Please contact the University of Rochester Research Subjects Review Board at 265 Crittenden Blvd., CU 420315, Rochester, NY 14642, Telephone (585) 276-0005 or (877) 449-4441 for the following reasons:

- You wish to talk to someone other than the research staff about your rights as a research subject;
- To voice concerns about the survey;
- To provide input concerning the research process;
- In the event the study staff could not be reached.

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RSRB-University of Rochester-Approval
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