UNIVERSITY OF NEW ENGLAND

Center for Excellence in Aging and Health

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Legacy Scholars Program (LSP) Data Procedures

The LSP is a longitudinal research registry and data clearinghouse organized and managed through the Center for Excellence in Health & Aging (CEAH). Volunteers complete an annual self-report survey on health, wellness, life attitudes and daily function.[1]

Investigators affiliated with UNE may request to utilize de-identified LSP data (e.g., for exploratory analyses, hypothesis generation, student projects) and/or to recruit human subjects for IRB-approved studies. Contact Dr. Tom Meuser, CEAH Director, for all data access and participant recruitment needs (tmeuser@une.edu; 207-221-4140).

All LSP data functions are managed through REDCap (http://redcap.une.edu/) by staff affiliated with the CEAH.[2]

Adults, aged 55+ years, interested in joining the Legacy Scholars Program complete an initial registration survey that collects name, address, other contact information and basic demographics.[3] This survey resides in a stand-alone "project" in REDCap so that personal identifiers and research data are maintained separately.

This initial registration survey assigns a unique *LSP ID Number* to each participant. The LSP ID serves as a link to the annual survey that is accessible only by approved CEAH staff.

The LSP consent form and annual survey are housed in a separate project within REDCap. New volunteers receive an email with a survey link to complete online or an envelope in the mail for this purpose. Tracking of consent and annual survey returns occurs in REDCap. Specific procedures are defined below.

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[1] The REDCap data codebook is attached. Early items are stand-alone measures, whereas later items are from standardized inventories which may be scored. These include the AD8, GDS-15, Penn State Worry Questionnaire – SF, and the IPIP 5 Factor Personality Inventory.

[2] Tom Meuser, Principle Investigator; Regi Robnett, Co-Investigator; Katy Rudolph, Co-Investigator; CEAH Administrative Assistant.

[3] Initial Registration Survey: https://redcap.une.edu/redcap/surveys/?s=9HRLKDE9CP. The demographics collected here are not for research, but rather to know something about the volunteer and for cross-checking with the annual survey (e.g., to ensure that the same person who registered is completing the annual surveys).

Data Procedures:

1. Initial Recruitment. Potential volunteers learn about the LSP from a flyer, email, word of mouth, community event, etc.

2. Registration. The volunteer sends in the paper registration form or completes the initial registration survey online.

3. Paper Surveys. Paper surveys are received by the Administrative Assistant, who scans them as PDFs, saves them to a password-protected folder, and then hand enters the information directly to the initial registration survey online. When entered, these paper forms are placed in a locked drawer as backup documentation; and eventually shredded.

4. Survey Reminders. The Administrative Assistant distributes annual survey requests via email (or paper mail in certain instances) to LSP volunteers. This is accomplished by logging into the annual survey project and utilizing the "Manage Survey Participants" function.

   a. Volunteers receive emailed reminders (automated) every 3 days until the survey is completed. The Administrative Assistant monitors returns and coordinates with Dr. Meuser to contact non-responders by telephone as needed.

   b. Non-responders to the first annual survey are removed from the system after three months, as their participation as Legacy Scholars was never confirmed.

5. Data Downloads. Once per month, the Director transfers all data from each annual survey (T1, T2, T3…) to its own SPSS master data file. This file includes calculated fields for standardized inventories.

6. Data Usage. Investigators wishing to access data for exploratory or student projects must contact Dr. Meuser by email (tmeuser@une.edu). The email should include a basic description of the project and types of data that are needed. Dr. Meuser will communicate with the investigator about what's available and next steps, including IRB review.

7. New Study Recruitment. Investigators wishing to utilize LSP volunteers as human subjects should speak with Dr. Meuser before submitting an IRB application. Only IRB approved studies may access LSP volunteers. As the LSP pool grows, it is possible that most (all) participants for a given study may be recruited from this resource.

   a. Once IRB approval has been obtained, the investigator should send the stamped flyer to Dr. Meuser in PDF format. Any inclusion/exclusion criteria should be defined clearly. Dr. Meuser sends out recruitment requests. The investigator does not contact Legacy Scholars directly.

8. Scholars Volunteer for New Studies. Legacy Scholars are required to participate in one IRB-approved study in a rolling 3-year period. This is a minimal requirement, and one that most volunteers exceed. Once an IRB-approved flyer is distributed, it is up to individual

Legacy Scholars to contact the relevant investigator and volunteer to participate in their study.

9. New Study Enrollment & LSP Data Linkage. The Legacy Scholars Program is organized as a data clearinghouse. LSP annual survey data can be made available to investigators of approved studies to supplement the data they are collecting. Conversely, data from individual studies may be uploaded for inclusion with the annual survey to support future research projects. Scholars consent to this data exchange, but it is good practice to confirm this understanding and allow for choice with respect to individual studies. Investigators are encouraged to include the following questions in their registration process:

   a. Are you a member of the UNE Legacy Scholars Program (LSP)? Yes* / No / Unsure

      i. * The Legacy Scholars Program supports approved research studies at UNE. Are you comfortable with your data from this study being shared with the LSP database to support future research? Yes* / No

      ii. * Please provide your full name and year of birth to facilitate this linkage. Dr. Meuser (or an approved member of his team) will utilize this information to identify your LSP ID number and create a one-time "Dummy ID" to allow data to be transferred confidentially (i.e., without your name being used).

10. LSP Acknowledgement in Publication of Findings. Investigators publishing findings from studies which utilized Legacy Scholars are asked to note this in the acknowledgement and subject sections of their publication.