

Managing Remote Data Capture in a Longitudinal Epidemiological Study

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INTRODUCTION

There are known challenges related to retaining research participants and collecting complete data in prospective studies with multiple follow-up timepoints. The **Noise Outcomes in Service members Epidemiology (NOISE) Study** is an ongoing longitudinal study which has enrolled over 1,200 study participants since 2014 across three sites.¹

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Development

Exposure data collected by the NOISE Study can vary over time (Figure 1) This requires repeated data collection at time intervals which reasonably allow participant recall of exposures since the previous timepoint. As such, the NOISE Study was designed to include, following an in-person exam, annual surveys to update exposures and ascertain incident hearing loss and/or tinnitus.

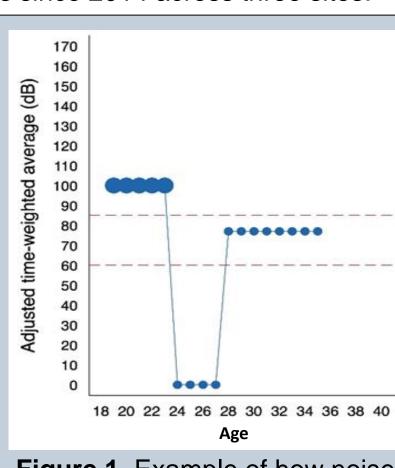


Figure 1. Example of how noise exposure varies over time necessitating repeat surveys.

METHODS

Study Sample:

 Veterans (within 2.5 years of separation) and active-duty Service members.²

<u>Sites:</u>

- NCRAR: National Center for Rehabilitative Auditory Research, Portland, OR
- HCE: Hearing Center of Excellence, San Antonio, TX
- SoCA: Naval Medical Center San Diego and Camp Pendleton, San Diego, CA

Tracking Database:

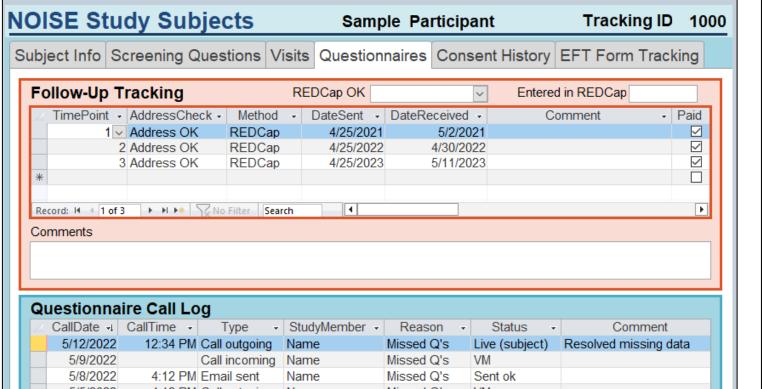


Figure 2. A Microsoft Access database tracks participant enrollment, follow-up target dates, data collection efforts and communication with participants. All study team members may access the database to ensure timelines are met.

PROCESSES



Figure 3. This diagram contrasts the processes involved in mailing paper questionnaires vs. utilizing the Research Electronic Data Capture³ (REDCap) system to collect survey data electronically. The REDCap method reduces time spent by participants and the study team, and improves response rate. *Calculated as of 11/30/2022

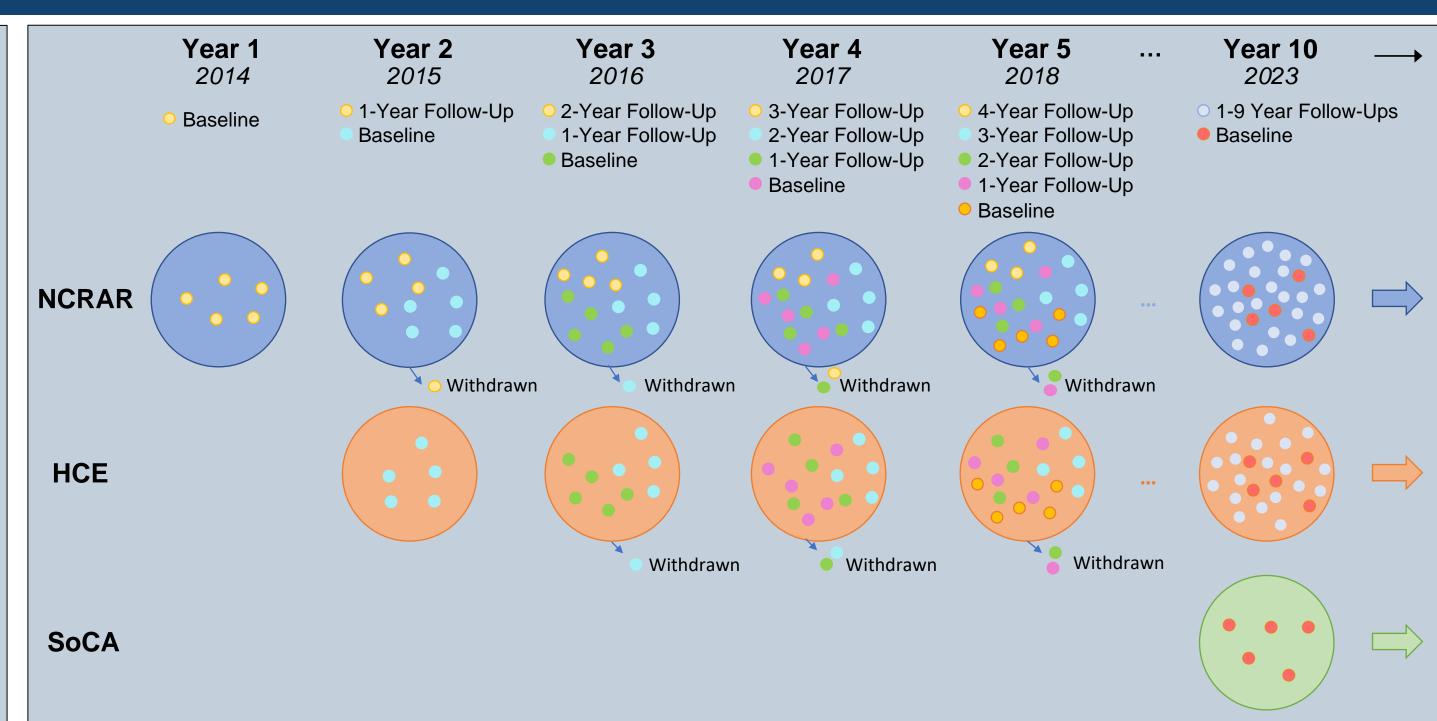


Figure 4. This diagram illustrates the growing cohort of enrolled participants over time, increasing complexity of participant groups reaching new timepoints each year, and expansion of the NOISE Study to additional sites.

DISCUSSION

- The goal of the NOISE Study is to capture changes in hearing loss, tinnitus and other health concerns over the careers and lifetimes of Service members and Veterans.
 Exposures and outcomes can vary over time, necessitating annual survey collection.
- Longitudinal studies are laborious and require a robust remote data collection system to ensure smooth data management.
- An Access database was leveraged to create a tracking system for meticulous record-keeping.
- Longitudinal studies require **flexibility for growth** of the study cohort and expansion to additional study sites.
- Multi-site studies require frequent communication across sites to maintain consistency in data collection processes.

- Data collection transitioned from paper packets to electronic data capture to reduce workload and improve:
 - Efficiency: reduced time preparing and entering data
 - Follow-up: increased response rate
 - Accessibility: participants appreciated ease of online surveys

Conclusion: As the NOISE Study nears 10 years of data collection, the significance of meticulous record-keeping, seamless communication among team members, and proactive anticipation of future needs are recognized as essential to the success of this project.

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