

U.S. Department of Veterans Affairs

/eterans Health Administration Office of Research & Development

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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Figure 1. Example of how noise

18 20 22 24 26

exposure varies over time

necessitating repeat surveys.

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.

METHODS

Study Sample:

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

Sites:

- 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:

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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

	Mail Questio Proced
Preliminary to Data Collection	 4-6 weeks date, call p address, ir coming so try calling
Survey Administration	 Send 64-p by mail 1-2 up target of
Data Collection Follow-Up	 1-2 weeks returned), packet, ren Weekly ren month foll Less frequ months fo resend quaneeded.
Data Verification and Cleaning	 Missing Data Once rece questionna items and As needed missed res flagged res Data Entry ar Double-en into two se databases minutes pe Periodicall comparing databases Periodicall comparing databases Clean Datase Clean (ver analysis databases
Overall Return	

the Research Electronic Data Cap REDCap method reduces time spe rate. *Calculated as of 11/30/2022

Emily J. Thielman, MS¹, Hannah Famili^{2,3}, Samrita Thapa^{1,4}, Leah Barger^{2,5}, Kelly M. Reavis, PhD^{1,4}

iled onnaire dures	REDCap Questionnaire Procedures	Year 1Ye201420• Baseline• 1-Yea• Baseline• Baseline
as prior to follow-up target participant to verify inform that surveys will be oon. If first attempt fails, g another time.		
page questionnaire packet -2 weeks ahead of follow- date.	 REDCap survey invitation is automatically sent (NCRAR) or sent by study team (HCE, SoCA) on follow-up target date. 	HCE
as after target date (if not), call to verify receipt of emind to fill out and return. eminder calls up to 1 ollowing target date. uent reminders up to 6 following target date. May uestionnaire packet if	 Survey reminder emails sent automatically (NCRAR) or by study team (HCE, SoCA) every 3 days, up to 3 reminders, or as needed. 1-2 weeks after target date (if not returned), call/text to verify receipt of email, remind to complete surveys. Less frequent reminders up to 6 months following target date. Resend survey link if needed. 	SoCA Figure 4. This diagram illustrate participant groups reaching net DISCUSSION
a Check eived, check over naire packet, flag missed d data quality issues. ed, call participant to obtain esponse(s) and clarify other esponses and Verification enter data by scanning twice separate destination es, requiring about 30 per packet. Illy verify data entry by ng the two scanned es, and fixing any ncies et erified) data may be used in	 Missing Data Check Once completed, check over questionnaires in REDCap, flag missed items and data quality issues. As needed, call participant to obtain missed response(s) and clarify other flagged responses Clean Dataset Data downloaded from REDCap are considered clean and may be used 	 The goal of the NOISE Study hearing loss, tinnitus and oth careers and lifetimes of Serv Exposures and outcomes of necessitating annual surver. Longitudinal studies are labor remote data collection system for meticulous records an agement. An Access database was level system for meticulous record. Longitudinal studies require for study cohort and expansion to Multi-site studies require for across sites to maintain conservations.
datasets.	in analysis datasets.	REFERENCES
57%	63%	 Henry JA, Griest S, Reavis KM, e Servicemembers Epidemiology (I Methods, and Baseline Results. J 885, 2021. Smith BD, Grush LD, Reavis KM,
ture ³ (REDCap) system to	mailing paper questionnaires vs. utilizing collect survey data electronically. The study team, and improves response	 Hearing Health: The NOISE Stud 22, 2021. 3. Harris PA, Taylor R, Minor BL, et Building an international commun Biomed Inform 2019 Jul;95:1032





tes the growing cohort of enrolled participants over time, increasing complexity of w timepoints each year, and expansion of the NOISE Study to additional sites.

y is to capture changes in ner health concerns over the vice members and Veterans.

- can vary over time, ey collection.
- prious and require a **robust tem** to ensure smooth data
- veraged to create a tracking ord-keeping.
- flexibility for growth of the to additional study sites.
- equent communication sistency in data collection

- 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 recordkeeping, seamless communication among team members, and proactive anticipation of future needs are recognized as essential to the success of this project.

ACKNOWLEDGEMENTS

This work was supported by a Department of Defense (DoD) Congressionally Directed Medical Research Program Investigator-Initiated Research Award (Grant #PR121146), a DoD Joint Warfighter Medical Research Program Award (JWMRP; Grant #JW160036 and #JW210396), a U.S. Department of Veterans Affairs (VA) Rehabilitation Research and Development (RR&D) Service Merit Award (C3701R/I01-RX003701). The US Army Medical Research Acquisition Activity, 820 Chandler Street, Fort Detrick MD 21702-5014 is the awarding and administering acquisition office for the DoD awards. This work was supported by the Office of the Assistant Secretary of Defense for Health Affairs, through the JWMRP under Award No. W81XWH-17-1-0020. This work was also supported with resources and the use of facilities at the Defense Health Agency Hearing Center of Excellence, Lackland Air Force Base, San Antonio, Texas, and the VA RR&D National Center for Rehabilitative Auditory Research (Center Award #C2361C/I50 RX002361) at the VA Portland Health Care System, Portland, Oregon. The views expressed are those of the authors and do not represent the views of the U.S. Department of Veterans Affairs, or the United States Government. Poster presented at the National Center for Rehabilitative Auditory Research, Portland, OR, September 2023.

et al. Noise Outcomes in (NOISE) Study: Design, Ear and Hearing 42(4):870-

l, et al. Military Service and dy. Audiology Today 33(4):12-

t al. The REDCap consortium nity of software partners. J