



NCS Vanguard Study Study Logistics

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Expanding the Objectives of the NCS Vanguard Study



- The NCS Vanguard Study to serve as a platform for design, development, and evaluation of state-of-the-art research methods to inform the elements of the Main Study, with a focus on
 - multi-disciplinary approaches
 - meeting/exceeding all ethical and scientific standards for research with human subjects
 - evidence based assessments for possible inclusion in the Main Study
 - early scientific contributions to research literature
 - serving as a mechanism for training new researchers

Overview of Presentation



- Three Discussion Topics/Tasks for the NCS Program Office
 - Optimize NCS Methodologies
 - Enhance Data Collection Models
 - Manage Resources

Topic 1: Optimize NCS Methodologies



Identify methodological approaches that may be used to optimize and evaluate NCS Study implementation logistics

- develop innovative methods and process
- leverage state-of-the-art information technologies

Innovative Methods & Process



Feasible

- Easy to collect
- Scalable
- Valid
- Reliable

Acceptable

- Low burden
- Low nonresponse

Cost effective

- Labor costs
- Materials/supplies/equipment
- Storage/shipping
- Analytic costs

What are the key priorities? What are the trade-offs?

- Use of a professional or alternative data collection staff?
- Use of various settings?
- Variances in data quality and data processing?
- Unforeseen considerations?

State-of-the-Art Informatics



- Design Requirements
 - Flexible
 - Scalable
 - Modular
 - Secure/FISMA compliant
 - Non-proprietary
 - Meets national/international data standards
 - Linkable to secondary data
 - Accessible and consistent with data sharing and data access policies

Possibilities...



- New open-source methodologies/instruments as alternative to proprietary options
- Subsampling for select measures
- **Technologies to better measure, for example...**
 - nutrition/food intake
 - sleep patterns
 - neurodevelopment assessments (e.g. self-collected via web)
 - biological samples (e.g. assays from blood spots)
 - environmental samples (e.g. self-collection)

Topic 2: Enhance Data Collection Models



Potential study visit locations and models that may be plausible in addition to home, clinic, or tertiary care centers

- How, where, and by whom data acquisition occurs
 - Need innovative methods to collect data in broad range of locations
 - Multi-modal data collection options
 - Data collection activities and possible staffing models

Possible Locations for Data Collection



Anywhere the participant agrees to...

- Clinic/hospital/health care provider
- Participant's home/yard/porch
- Schools
- Daycare settings
- Public space where privacy is possible (for example, library, community center, coffee shop)

Multi-Modal Data Collection Options



- Computer Assisted Interviewing (CAI)
 - Interviewer administered
 - In-person/face-to-face (CAPI)
 - Telephone (CATI)
 - Self-administered (CASI and AudioCASI)
 - Data collection tablet
 - Web-based
 - Mobile device
- Paper-and-Pencil Instrument (PAPI)

Range of NCS Data Collection Activities



- Field Training
- Household Listing
- Household Enumeration
- Recruitment
- Field Data Collection
- Observational Research

Possible Data Collection Models



- Data may be collected by:
 - Primary contractors (such as NCS Study Center staff)
 - Subcontractors (such as research organizations with experience in population based field work)
 - Health care providers
 - Participants through self-administered instruments
 - Teams traveling to participants homes
 - Transporting participants to central locations, such as a clinic, hospital or other health care provider facility

Topic 3: Managing Resources



- Organizational Challenges
- Participant Retention

Organizational Challenges



- Managing competing interests
 - Federal government
 - Local investigators
 - Universities
 - Health care providers
 - Hospitals
- Managing limited resources

Participant Retention



- Maximizing enrollment
- Minimizing attrition by optimizing participant experiences
 - Burden
 - Incentives
 - Family/community buy-in
 - Tangible impact
- Minimizing non-response and opt out
 - Individual visits
 - Specific data collection elements

Opportunities for Training and Career Development



- Platform for training new scientists/graduate students & NCS Scholars Program
 - Medical/clinical research
 - Epidemiology
 - Environmental sciences
 - Toxicology
 - Social sciences
 - Biostatistics
 - Health services research
 - Health informatics
 - Others...

Summary



- Upcoming challenges and opportunities
 - Develop, evaluate and validate methodologies that are cost effective, feasible, and scalable
 - maintain a broad range of data collection domains
 - develop and sustain innovative and collaborative partnerships
 - keep participants (and those who influence them) engaged
 - continue to evaluate logistics, methods and operations