



HIV NEUROBEHAVIORAL RESEARCH PROGRAMS DATA MANAGEMENT

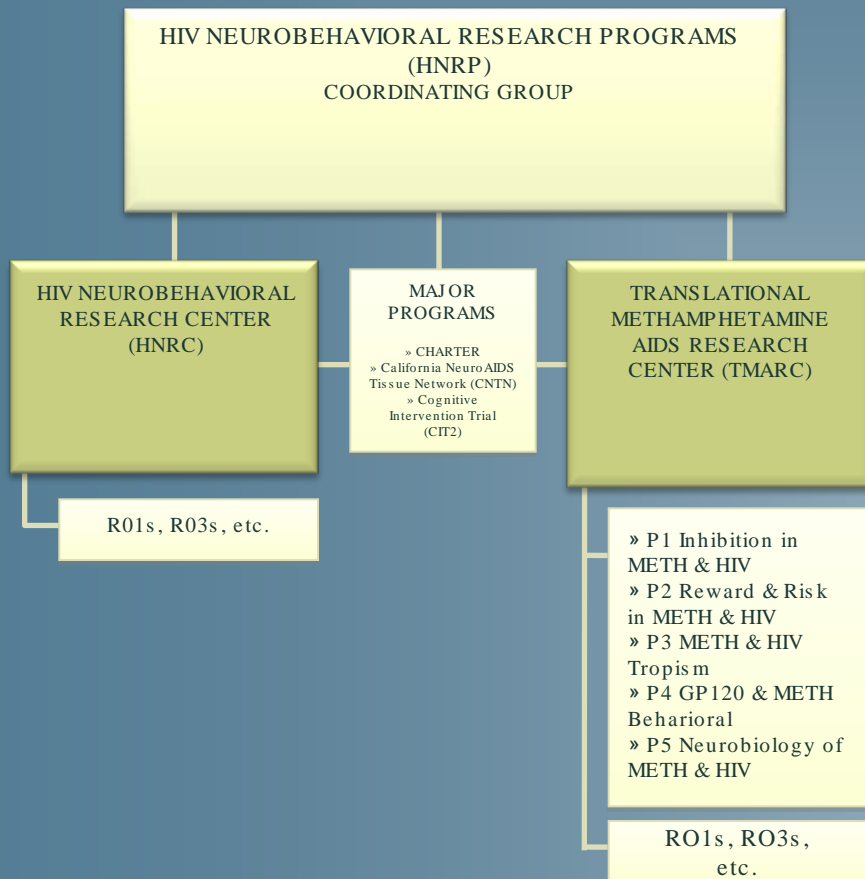
HIV NEUROBEHAVIORAL RESEARCH PROGRAM

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Data Management/Information Systems

HIV NEUROBEHAVIORAL RESEARCH PROGRAMS RESOURCES/DATA



- Support of over 80 studies across 29 sites in 12 countries
- Studies primarily longitudinal with 1000+ datapoints collected at individual visits
 - Substance Use
 - Treatment/Medical History
 - Labs/Specimens
 - Neuropsychological Testing
- Support for two national tissue/data resources:
 - www.nntc.org
 - www.charterresource.ucsd.edu

EXTERNAL DATA SOURCES

- Multi-site/lab data collection
 - » Web-based remote/on-site data entry
 - » High Speed Scanners incorporated for QA
- Secure Web-based data upload utility for external investigators
 - » Investigator Driven
 - » Data Quarantined/Reviewed
 - » EAV Storage Mechanism

RELATING ANALYSES TO FIELD

- Use validated instruments standard to the field whenever possible
- Expert annotation
- Use Self-Defining system
 - » Every datapoint carries with it meta information
 - » Data Dictionary provides methods to link versions etc.
- Storing raw data at the highest possible resolution
 - » Generate reports/support data point on demand
 - ARV Data Collection
 - Laboratory Data
 - Individual, Domain, and Global Scores
 - » Recalculate as necessary to meet research goals

HNRP DATA ACCESSIBILITY

- Public Web Sites for defined resources
 - » charterresource.ucsd.edu
 - » hnrc.hivresearch.ucsd.edu
- Scientific Incubation
 - » HNRC Developmental Core (hnrc.hivresearch.ucsd.edu)
 - » TMARC Pilot Projects (tmarc.hivresearch.ucsd.edu)
- Online Request Utilities (CHARTER)
 - » 1599 participants (674 longitudinal), 6000+ visits (2003-Present)
 - » 80,000+ specimens (plasma, CSF etc.) and linked data available

TECHNICAL COMMUNITY OBSTACLES

- Avoiding 'lowest common denominator' data consolidation
 - » Store data at highest possible resolution in most pristine state
 - » Provide investigators with options for selecting output
- Finding the 'sweet spot' between accessibility and security
 - » Stratify systems to meet needs
 - » Standardization of tools

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R01MH58076