

# FETAL ALCOHOL SPECTRUM DISORDERS IN ADULTS: HEALTH AND NEUROBEHAVIOR

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## The problem:

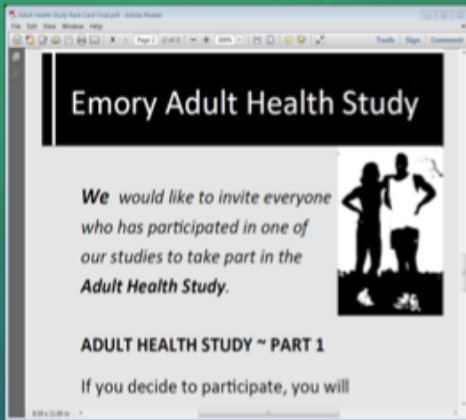
- Despite the prevalence of FASD and its life-long course, there is no empirical research about adult health, physical characteristics, neurobehavior or adaptive functioning in Middle Adulthood.
- The Developmental Origins of Health and Disease (DOHoD) hypothesis suggests that fetal programming by PAE should result in vulnerable organisms with increased sensitivity to stress, adverse health and functional outcomes.

## THE STUDY

- Multisite Collaborative Study (part of the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD))
- Sites include Atlanta, GA and Seattle, WA, with a parallel study in Vancouver, BC.
- Two “Tier” Assessment
  - Tier 1. Demographic and Health Survey
  - Tier 2. In-Depth Assessment of medical records, physical characteristics, immune function, mental health, cognitive functioning, social/adaptive functioning



- Tier 1



Example of the recruitment materials.

Adult Health Survey (N=500) of access to health care, chronic medical problems in midlife, ages 25-45.

*(Another 120 will be tested in Vancouver using the same form.)*

Health Issues to be assessed:

- Access to health care
- Sleep
- Vision/Health/Dental
- Allergies and Asthma
- Cardiovascular
- GI
- Diabetes
- Autoimmune disorders
- Arthritis
- Seizures
- Depression/Anxiety
- Other Medical problems

## TIER 2 ASSESSMENT

- This is intended to be an in-depth assessment of the Adults' current status. There will be several areas assessed:
  - Physical Characteristics
  - Psychological factors
  - Environmental
  - Substance Use
  - Health, including Immune Function
    - Medical records
- *120 individuals at each site (240 total) will be invited to complete this comprehensive assessment. They will be invited to the study site and will spend about 4 hours being evaluated and completing questionnaires.*
- *We will draw blood and take urine samples to confirm substance use reports and to allow assessment of metabolic status (A1C), liver function (GGT) and immune status.*

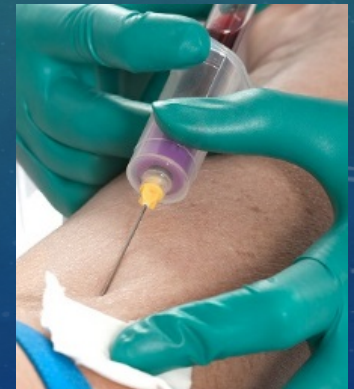
## TIER 2 ASSESSMENT-PSYCHOLOGICAL MEASURES

- Cognitive Functioning- “fluid intelligence” → • NIH Tool Box
- Adaptive Functioning → • Adaptive Behavior Assessment System, 3<sup>rd</sup> Ed
- Psychiatric Problems → • Psychiatric Diagnostic Screening Questionnaire (PDSQ)
- Substance Use → • AUDIT, Drug Grid, Lab tests
- Life Stressors and Resources (Moos) → • LISRES-2



## TIER 2- PHYSICAL ASSESSMENT

- Dysmorphology assessment → • Evaluation by Ken Jones
- 2-D Photography taken on site → • In collaboration with Peter Hammond
- Urine Toxicology for 7 drugs → • Sampled in Lab
- GGT → • Sampled in Lab
- A1C → • Sampled in Lab
- Immune Measures → • Samples sent to Joanne Weinberg, PhD
- Health History → • Abstracted from current medical records



# PROGRESS

- All the Administrative hassles
  - Co-ordination among three sites to develop materials.
  - Materials Transfer Agreements
  - IRB
  - Review assessment protocol and purchase materials
  - Develop Assessment tools and database in REDCap
  - Search databases for previous participants



# DEVELOPED HEALTH QUESTIONNAIRE

Based on the Centers For Disease Control's Behavioral Risk Factor Surveillance System (BRFSS) Questionnaires

Modified to include modules on vision, hearing, dental problems, seizures, immune disorders, etc.

Developed by three sites.

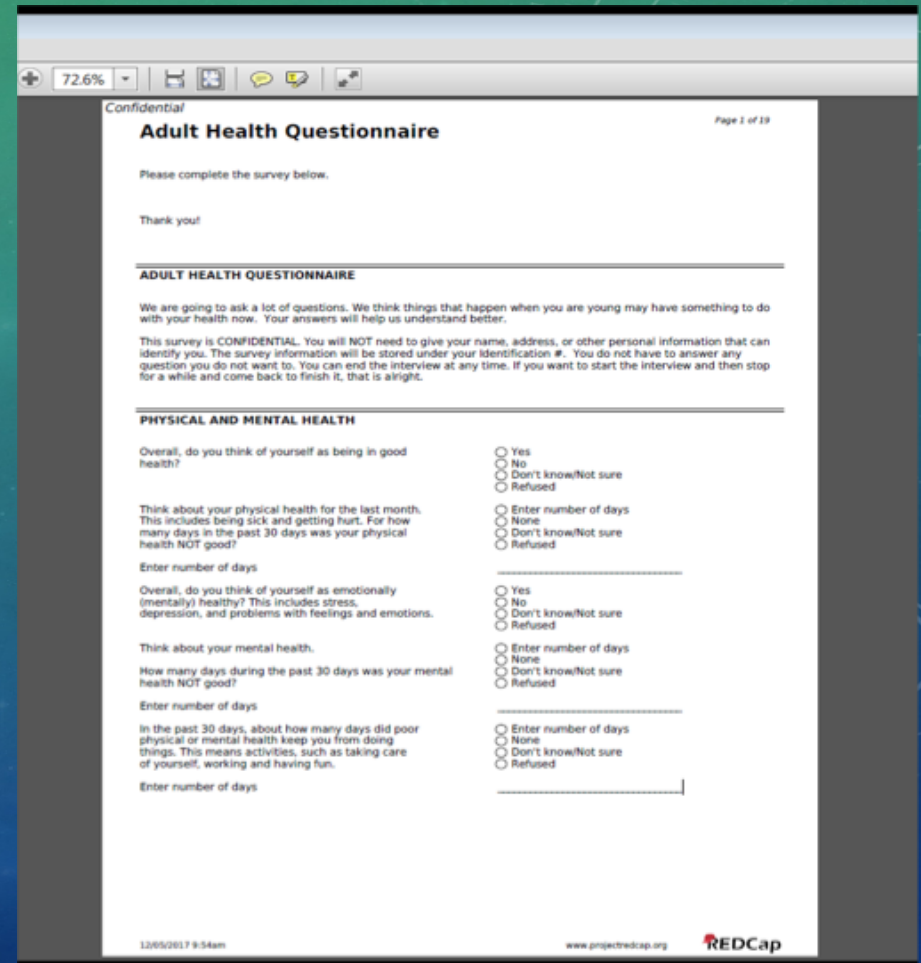
Using REDCap system, created data entry forms that can be accessed on computer or smart phone. Can be completed by participant directly or through interview.

System is confidential and HIPAA-compliant.

Converts directly to interactive database. Can be exported in Excel or SPSS.

Multisite access.

Piloted in Atlanta (N=10)



The image shows a screenshot of a web browser displaying a confidential adult health questionnaire. The browser's address bar shows a zoom level of 72.6%. The page is titled "Confidential" and "Adult Health Questionnaire" (Page 1 of 19). The form includes instructions to complete the survey, a "Thank you!" message, and a section titled "ADULT HEALTH QUESTIONNAIRE". It contains several questions about physical and mental health, each with radio button options for "Yes", "No", "Don't know/Not sure", and "Refused", and a field for "Enter number of days". The form is hosted on a REDCap system, as indicated by the URL "www.projectredcap.org" and the REDCap logo in the footer.



# IDENTIFICATION OF POTENTIAL PARTICIPANTS

Goal: Tier 1-500  
Tier 2-240

- Atlanta
- (Tier 1= 250, Tier 2=120)
  - Accessed databases from previous study waves and accumulated names, addresses, SS #; names of collaterals, Total potential subjects identified =
  - Contracted with Accurinet to allow computerized search for participants' current address, phone numbers.
  - Currently have located 60 previous participants who will be contacted when IRB completes review of recruitment materials.

*Potential problems for recruitment process:*

*Participant mobility. May have moved out of area.*

*No longer in "phone book". Cell phones don't have white pages.*

*Privacy concerns. People are much more worried about privacy than they were previously and may not answer phones.*

*Not interested in participating*

Seattle

- (Tier 1= 250, Tier 2=120)
  - Accessed databases from previous study waves and accumulated names, addresses, SS #; names of collaterals, Total potential subjects identified = 433
  - Contracted with TransUnion (TLO) to allow computerized search for participants' current address, phone numbers.
  - Currently have located 125 previous participants; so far 65 are interested in being in this new study. All will be contacted after IRB completes review of recruitment materials.

## TIME LINE

- Tier 1- Years 1-4
  - December 2017: Complete Administrative Requirements/ Develop Forms and Questionnaires/Recruitment Materials
  - January 2018: Initiate recruitment, Health Surveys, Registry
- Tier 2- Year 2-5
  - January - May, 2018: Obtain all materials, permissions, identify initial sample
  - July 2018: Begin Tier 2 Assessments