National Institute on Alcohol Abuse and Alcoholism
NIH...Turning Discovery Into Health®

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CIFASD Y2 Progress Update

Michael Suttie

CIFASD | Collaborative Initiative on Fetal Alcohol Spectrum Disorders

1

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Image Data Collection

PI	2D Images	3D Images
Wozniak	14	14
Mattson		47
Suttie	10	10
TOTAL	**24**	**71**

CR Upload – 3D Data: 62

2

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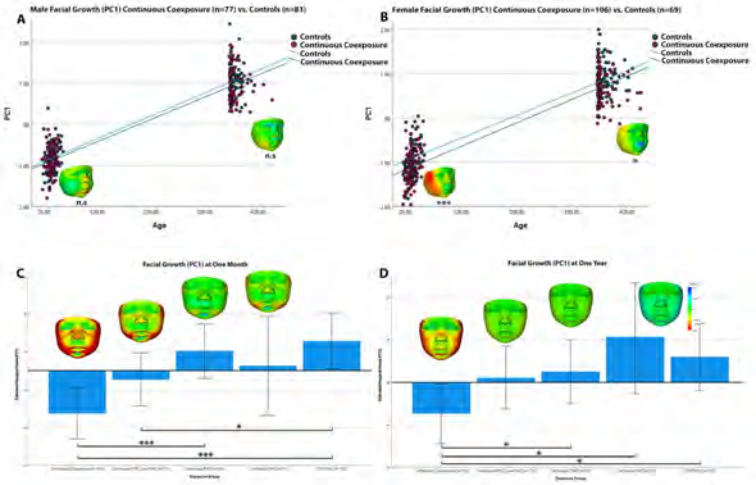
Alcohol-Smoking Paper Results



3

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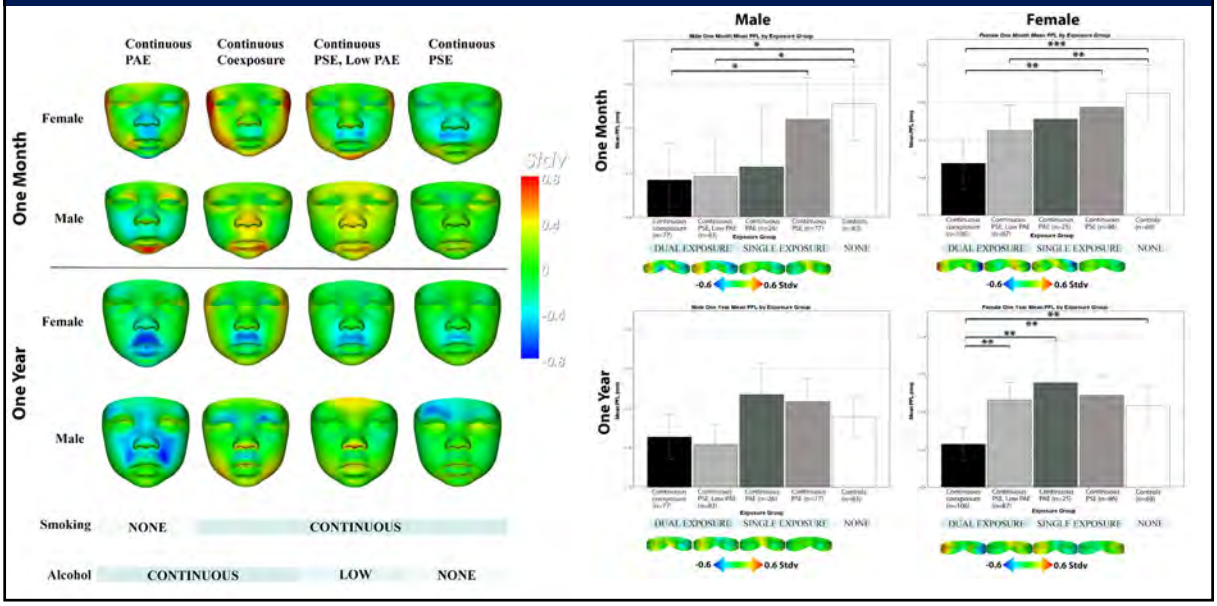

4

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New Results: Polysubstance Exposure

ALC (n=51)	ALC+MARIJUANA (n=53)	ALC+METHAMPHETAMINE (n=21)	COMBINATION (n=23)

5

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OxAdult 3D Recruitment

- **10 participants scanned since IRB approval in November**
  - **3D Canfield**
  - **3D FitsYou iPhone**
  - **2D Standard photos**
- **Images serve as data for camera validation, adult controls and 2D->3D methods**

FitsYou VS Canfield H2

EXAMPLE SCAN

6

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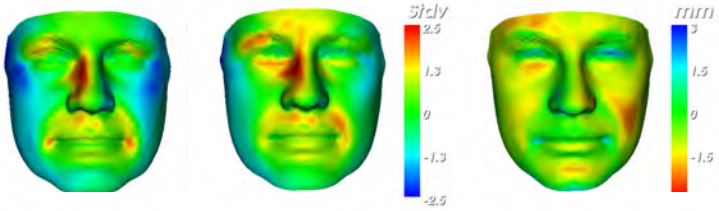
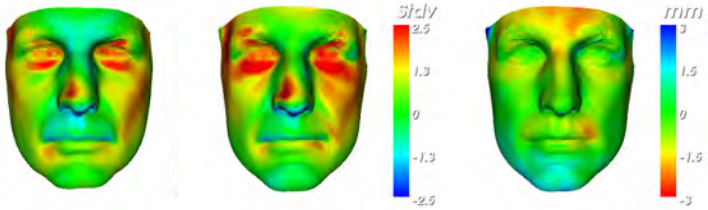
Differen

Canfield H2 FitsYou

38, Male



38 or something, Male



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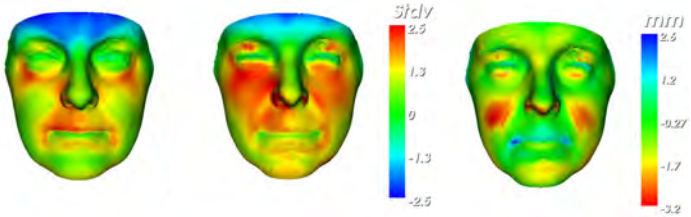
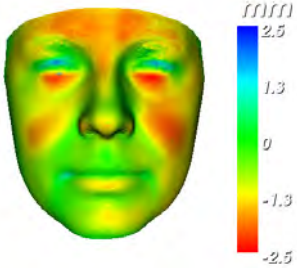
46, Female

Canfield H2 FitsYou

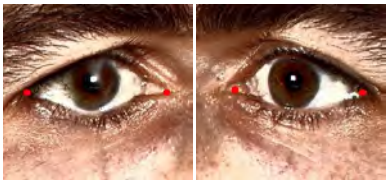


Mean Difference (n=10)



8

CanfieldH2

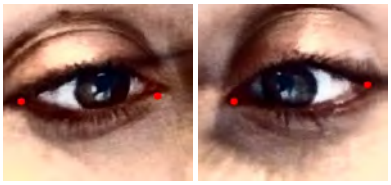

PFL=29.71mm

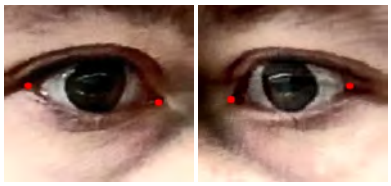
PFL=25.71mm

PFL=28.07mm

FitsYou

PFL=30.49mm


PFL=26.62mm


PFL=27.05mm

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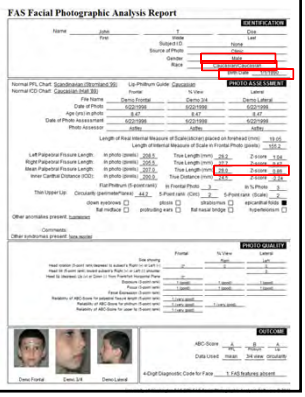
Technical Outputs/Ongoing Work

- MeshMonk – Improving FaceScreen
  - New collaboration with Dr Susan Walsh (IU) to convert available tools into Python for deployment/integration into FaceScreen.


FAS Facial Photographic Analysis Report

- 4-Digit OCR Report Scanner

  Simple OCR tool, specifically developed after receiving data from FAS Photograpic Analysis tool pdf reports. Available if anyone needs it!

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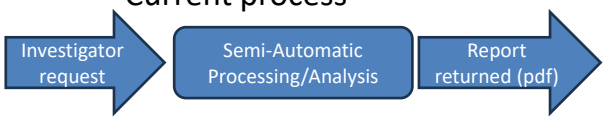
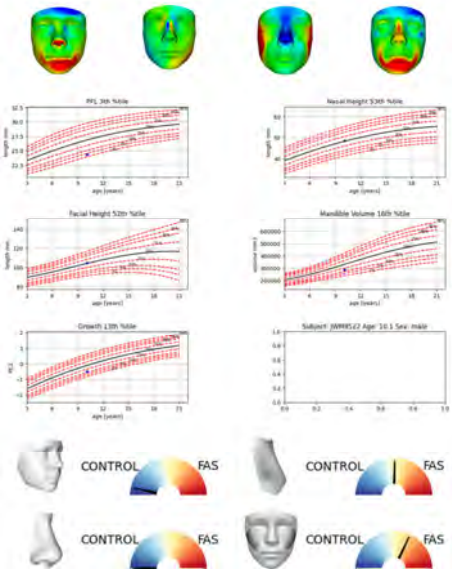
- Streamlined reporting
  - Current process



  - Goal



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Plan for Remaining Y2

- 2x new starters for January
  - 1 postdoc (machine learning)
  - 1 lead developer
- Face+Neuro improve and build (Dr Mattson)
- Face measures validation study (Dr del Campo)
- 3D camera shipment to adult site (Dr Stoner)
- Begin adult 3D analysis
- Drug coexposures paper (ACER)

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TIMELINE FOR PROJECT ACTIVITIES

		YEAR 1	YEAR 2	YEAR 3	YEAR 4	YEAR 5
Aim 1	Analysis of facial morphology and co-exposures					
	Sexual dimorphism in FASD analysis					
Aim 2	~~Intervention Study/Infant Analysis~~					
	Adult FASD facial analysis					
	Neonatal identification study (Transfontanelle US)					
Aim 3	FaceScreen Server: HIPAA Setup, Dev & Testing					
	Mobile 3D acquisition comparison analysis					
	Face-Neurocognition Analysis/Integration					
	Clinical tool deployment, validation and testing					

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Publications Y2

Machine learning approaches in the identification of children affected by prenatal alcohol exposure- a narrative review
Michael Suttie, Julie Kable, Amanda H. Mahnke, Gretchen Bandoli
ACER, Resubmitted to address reviewer comments

Mutations in the Bone Morphogenetic Protein signaling pathway sensitize zebrafish and humans to ethanol-induced jaw malformations
John R. Klem, Tae-Hwi Schwantes-An, Marco Abreu, Michael Suttie, Raeden Gray, Hieu Vo, Grace Conley, Tatiana M. Foroud, Leah Wetherill , CIFASD, and C. Ben Lovely
Science Advances, Under Review

Facial Dysmorphism Associated with Concurrent Prenatal Alcohol and Smoke Exposure
Michael Suttie[1,2], Leah Wetherill[3], Scott Parnell[4], Hein Oddendaal[5], Lut Geerts[5], Rosemary Meyer[5], Heidi Nolan[5], Lucy Brink[5], Tatiana Foroud[3], Peter Hammond[1,2] and the CIFASD
JAMA Pediatrics, Awaiting final edits from co-authors

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Abstract submissions

- RSA2024 Symposium Proposal
  - Title: ASSESSING THE HARMS OF PRENATAL ALCOHOL AND DRUG COEXPOSURE ON THE DEVELOPING FETUS
    - GENETIC FACTORS UNDERLYING SUSCEPTIBILITY TO PRENATAL ALCOHOL AND CANNABINOID EXPOSURE, SCOTT PARNELL
    - PRENATAL ALCOHOL AND DRUG CO-EXPOSURES IN A NATIONAL SAMPLE OF PREGNANT WOMEN, ANNA ZILVERSTAND
    - **THE IMPACT OF PRENATAL ALCOHOL AND POLYSUBSTANCE ON INFANT FACIAL DYSMORPHISM, MICHAEL SUTTIE**
    - MENTAL HEALTH AND LONG-TERM IMPLICATIONS ASSOCIATED WITH PRENATAL ALCOHOL AND MULTIPLE SUBSTANCE EXPOSURE, MONIQUE REBOE-BENJAMIN

ASSESSING THE HARMS OF PRENATAL ALCOHOL AND DRUG COEXPOSURE ON THE DEVELOPING FETUS

J.R. Klem[1], T. Schwantes-An[2], M. Abreu[2], M. Suttie[3], R. Gray[1], H. Vo[1], G. Conley[1], T.M. Foroud[2], L. Wetherill[2] , CIFASD, and C.B. Lovely[1]

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Assessment of Fetal Alcohol Spectrum Disorders (FASD) Using Novel Web-Based Tools

U01 AA014834
Sarah Mattson
San Diego State University

Summary of Progress by Study Aim

AIM 1

To assess the utility of the FASD-Tree/BRAIN-online system of evaluation in multiple clinical settings.

- Ongoing data collection from multiple sources

AIM 2

To compare FASD-Tree and BRAIN-online results to those from traditional and advanced physical measurements.

- Physical measurement training (Del Campo)
- MQ reliability (Riley/ Chockalingam
- Alaska Project (Del Campo)
- BRAIN-online/3D paper planning (Suttie)
- Met with Canadian FASD clinics

AIM 3

Extend assessment resources to other CIFASD5 projects.

- Provided link to BRAIN-online to CIFASD PIs
- Set up BRAIN-online to accept CIFASD participants from other projects

Recruitment & Data Collection

Neurobehavioral Assessment Flow Chart

Steps for participating in the CBT neurobehavioral assessment research project

Please reach out to cbt@sdsu.edu for any questions along the way. We are happy to help!

Complete pre-screen to ensure eligibility

FASD-Tree

MQ/3D

1

CBT Parent and Child Questionnaire

Time: 1-2 hours
Compensation: $25 amazon gift-card for parent

2

Behavior Assessment system for children 3rd Ed

Time: 15-30 minutes

3

Vineland-3 Comprehensive Parent/Caregiver Form

Time: 15-30 minutes

Compensation: $25 amazon gift-card for parent

4

Child Behavior Checklist

Time: 15-30 minutes

5

BRAIN-online

Time: 30-45 min.
Compensation: $25 amazon gift-card for parent

6

In-person Neuropsychological Testing for local families

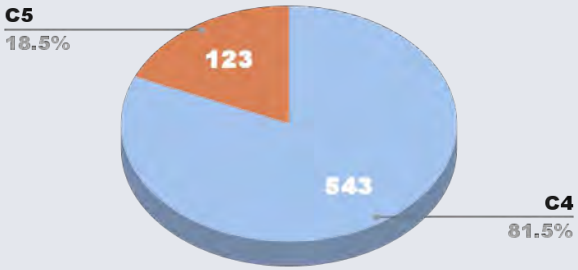
Time: 3-4 hours total
-1 session for ages 10+
-2 sessions for ages 5-9
Compensation: $25 amazon gift card for parent and $10-$15 per hr for child depending on age

7

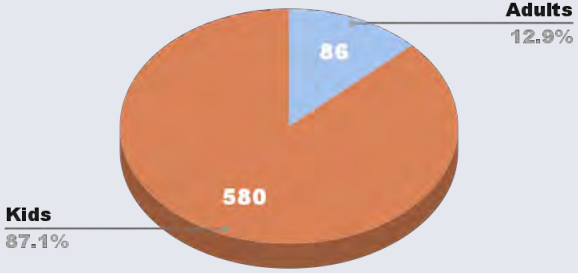
Results

Received 2-3 weeks after testing appointment

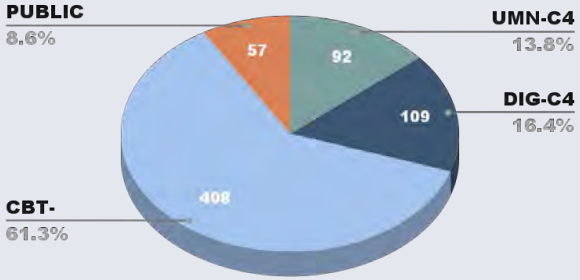
Overall Recruitment Stats



Total Recruitment For C4 and C5

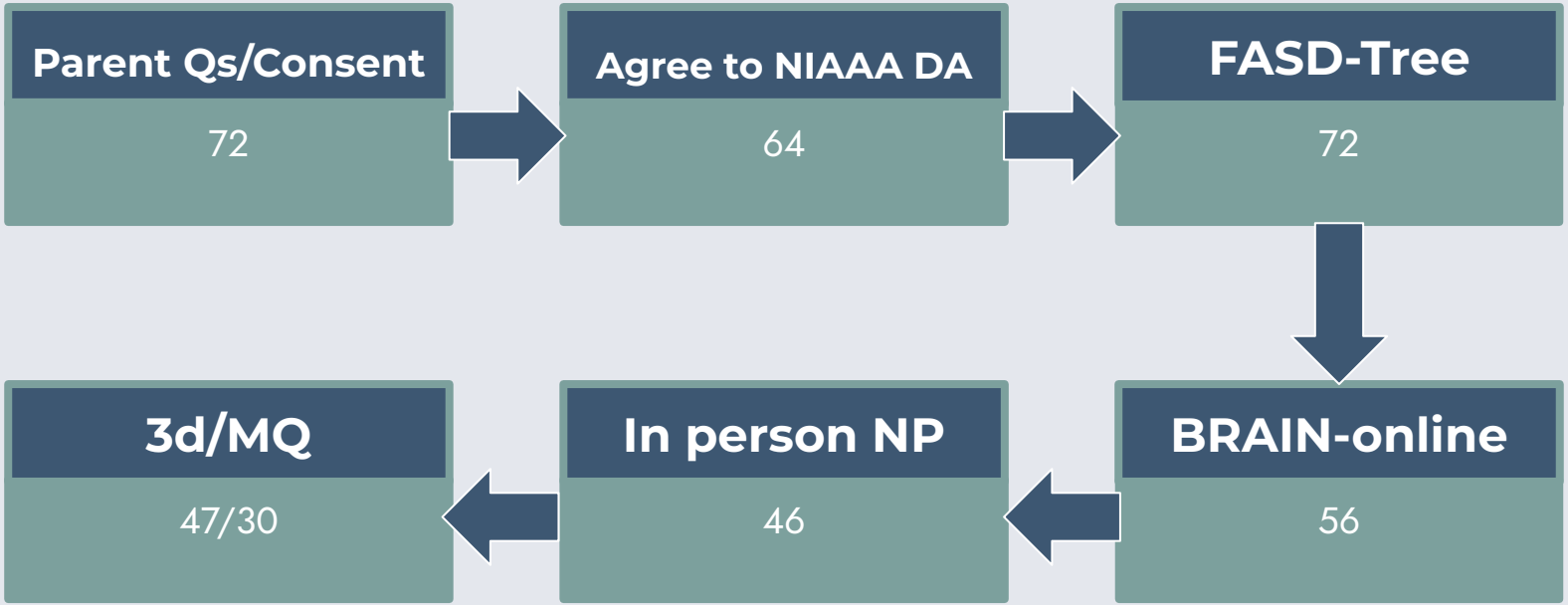


Age Group Distribution



All Current Recruitment Routes

C5 Local Enrollment Progress



Progress Toward Proposed Sample Size

Source	Aim	Total N	Completed to Date
UCSD Specialty Clinics	1,2	250	72 (29%)
Canadian FASD Clinics	1	250	1
Alaska FASD	1,2	150	0
Other FASD-National	1,2,3	250	57 (23%)
Community Controls	1,2	150	16 (11%)

Additional Recruitment Info

Physical Exams (+ MQ and 3D imaging)

- Children are referred from UCSD or Rady Children's with physical exam data or are self referred

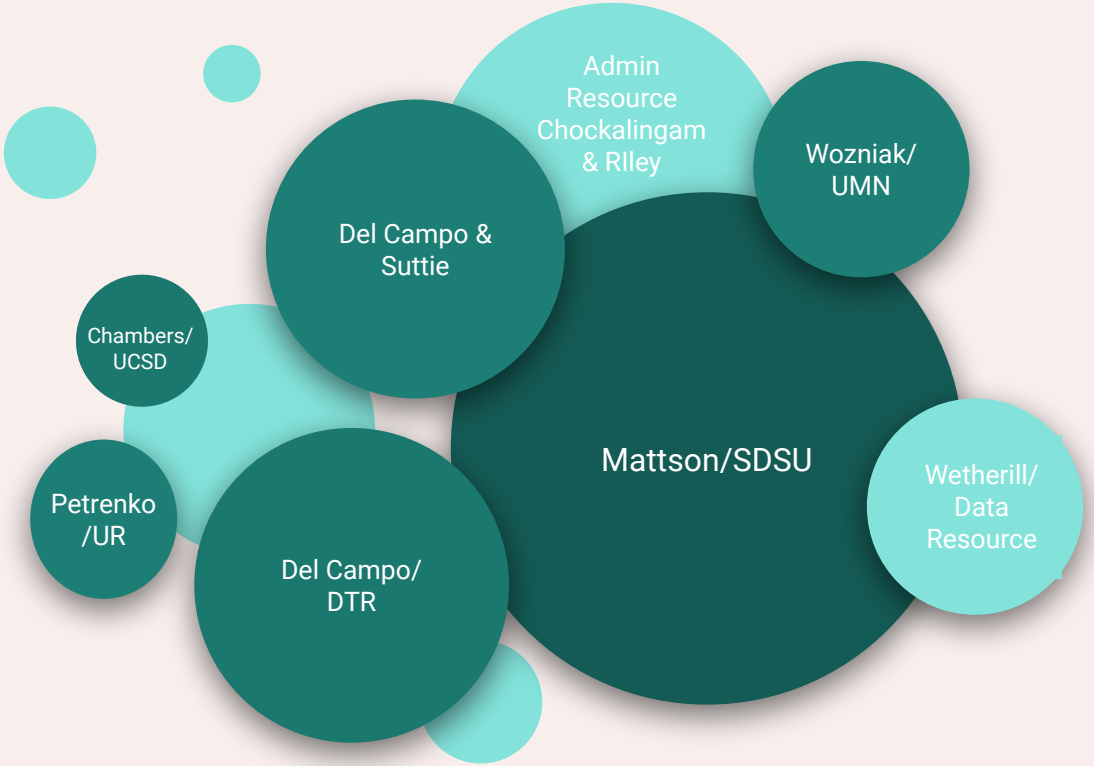
The Parent & Child Questionnaire

- Parent/Guardian completes Parent & Child Questionnaire (PQ)
- The consent has an opt-in for NIAAA$_{DA}$ Opting-in prompts additional questions on the PQ.

GUIDs

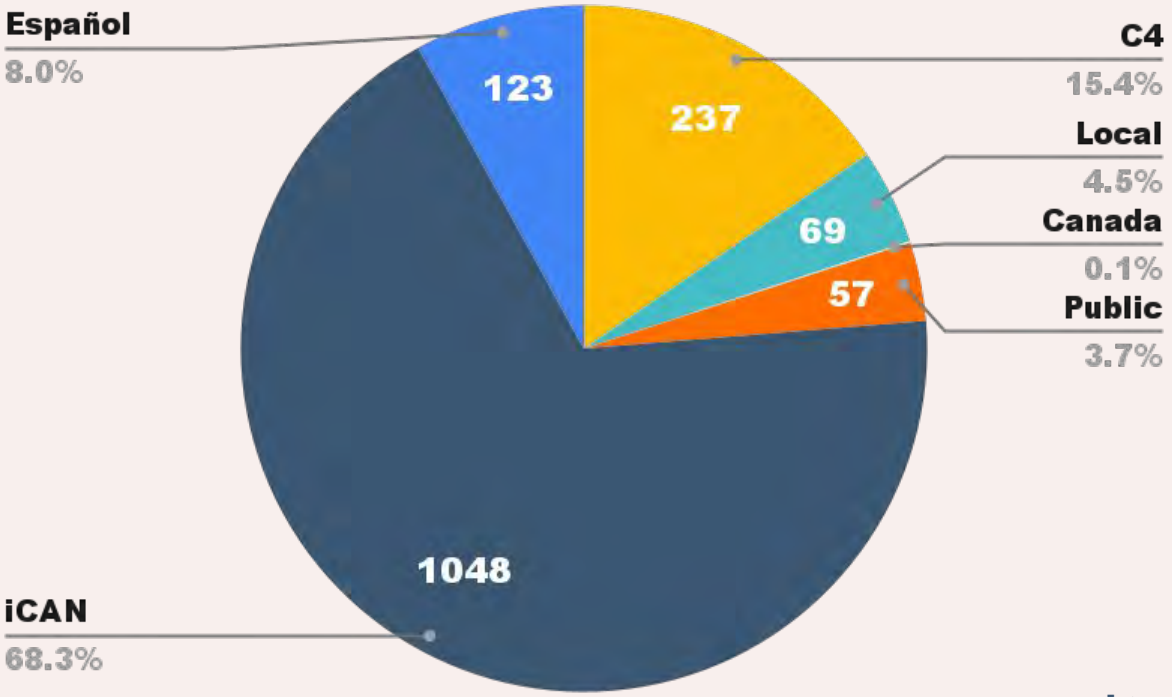
- Those additional questions on the PQ are used to create a GUID
- GUID Training was provided by Abigail Erickson and Indiana University
- Of 72 people asked, 64 (89%) said yes, 3 (4%) said no, 5 (7%) did not reply

Interactions with other CIFASD Projects/PIs



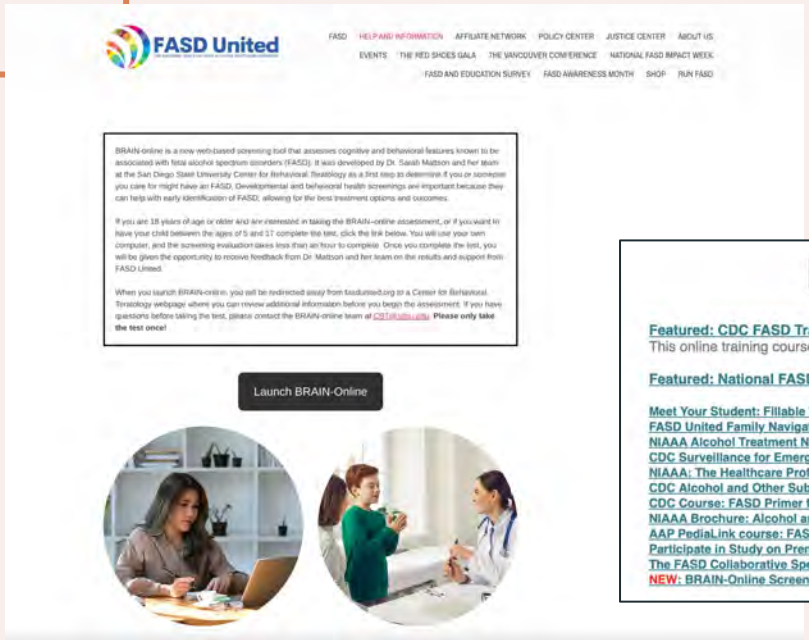
BRAIN-online

BRAIN-online Data Collected (Cleaned)



Total N = 1535

Online Presence for BRAIN-Online



RESOURCES

Featured: CDC FASD Training Website
This online training course is from the CDC's Collaborative for Alcohol-Free Pregnancy

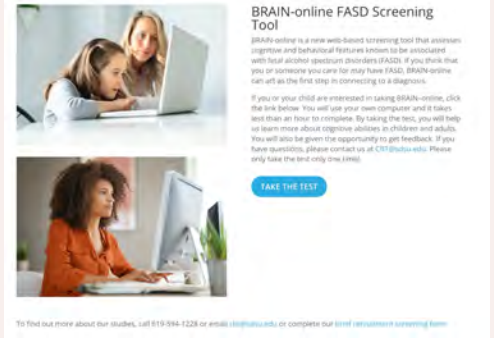
Featured: National FASD and Education Survey

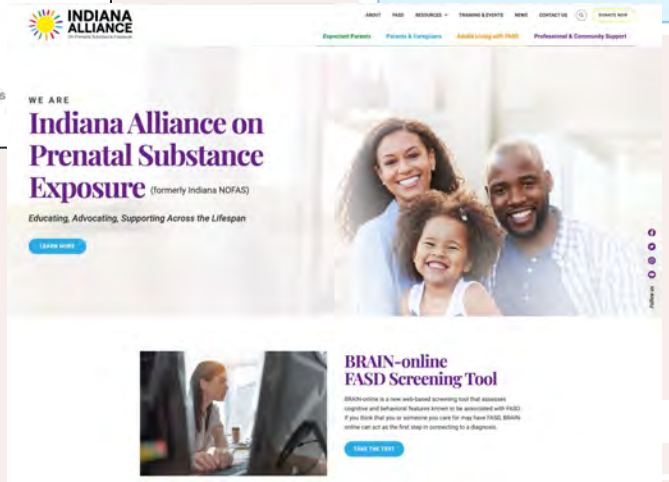
Meet Your Student: Fillable Tool for Educators
FASD United Family Navigator
NIAAA Alcohol Treatment Navigator
CDC Surveillance for Emerging Threats to Mothers and Babies Network (SET-NET)
NIAAA: The Healthcare Professional's Core Resource on Alcohol
CDC Alcohol and Other Substance Use Fact Sheet
CDC Course: FASD Primer for Healthcare Professionals
NIAAA Brochure: Alcohol and Your Pregnancy
AAP PediaLink course: FASD: Recognition and Management
Participate in Study on Prenatal Alcohol and Neuroimmunity (For Canadian participants
The FASD Collaborative Special Interest Groups (SIGs)
NEW: BRAIN-Online Screening Tool

BRAIN-online FASD Screening Tool

BRAIN-online is a new web-based screening tool that assesses cognitive and behavioral features known to be associated with fetal alcohol spectrum disorders (FASD). If you think that you or someone you care for may have FASD, BRAIN-online can act as the first step in connecting to a diagnosis.

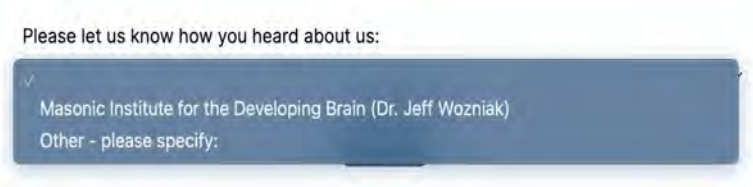
TAKE THE TEST



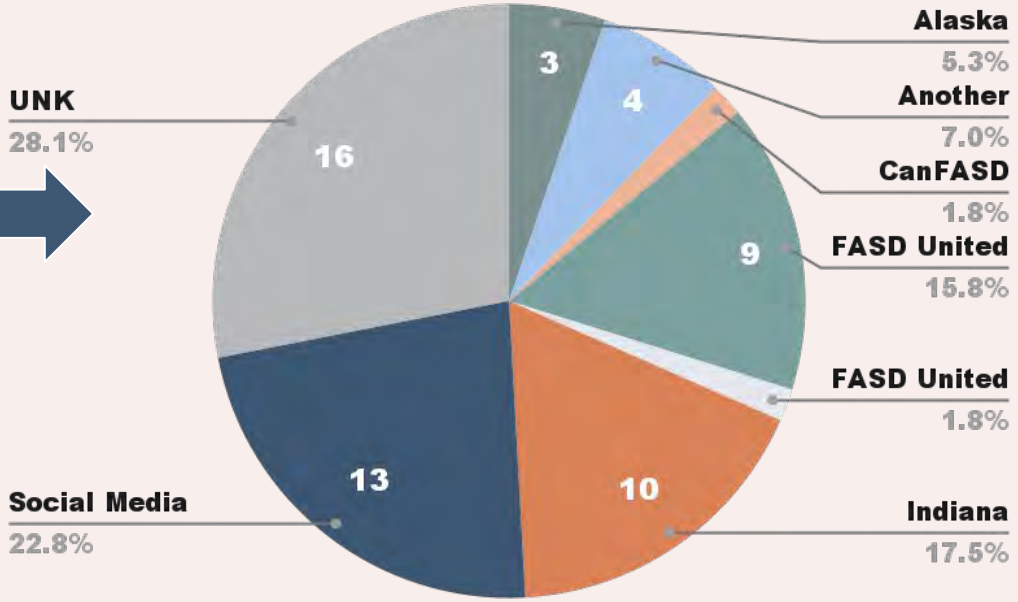


Non-CBT BRAIN-online Recruitment Options

Options given for our regular Public BRAIN-online study



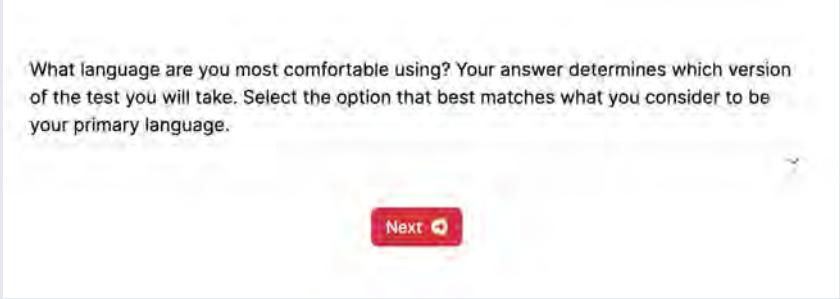
Options (so far) given for the CIFASD site version



Other BRAIN-online Data Sets

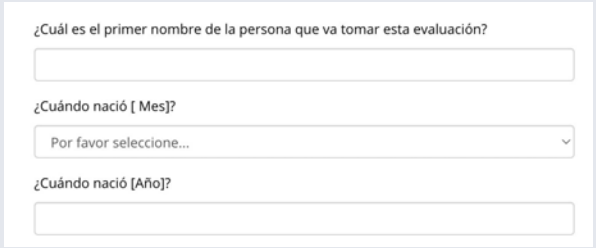
College-Age YA*

N = 1048



English vs. Spanish Speaking YA**

English N = 99
Spanish N = 24
Goal = 200



* Additional support from a seed grant from SDSU

** Additional support from an NIAAA diversity supplement

Average Completion Time for BRAIN-online

Age Group	N	Mean	SD
5-7 yrs	31	59.7 minutes	19.09
8-13 yrs	80	46.9 minutes	11.01
14-17 yrs	34	45.1 minutes	15.3
All ages	145	49.2 minutes	15.01

Total Child N: 145
Minimum Completion Time: 22 minutes
Maximum Completion Time: 132 minutes
N with Completion Time >60: 21

Results from BRAIN-online

Data from local participants

Behavior Screen

Below is a list of items that describe children and youth. For each item select the answer that best describes your child NOW OR WITHIN THE PAST 6 MONTHS. Answer all items as well as you can, even if some do not seem to apply to your child.

Acts too young
- Yes
- No

Clingy or dependent
- Yes
- No

Very talkative
- Yes

Tapping

You will be asked to place your wrist on the surface and tap the spacebar as quickly as you can with your index finger for 10 seconds. Do not move your hand or arm, only your finger. Begin Tapping when you see "GO."

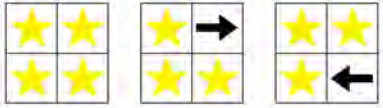
Let's try a practice trial for the right hand first!

Reacting

In this task, you will see a star ( ) appear on the screen. Whenever you see the star ( ) , tap the spacebar as quickly as possible using your dominant hand.

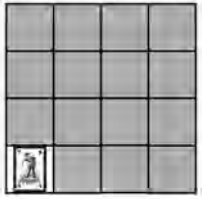
Inhibiting

In this task, you will see a series of arrows that appear in a grid. When you see arrows that are facing the right ( ), tap the spacebar. If you see an arrow facing the left ( ), do not respond.



Remembering

You are about to see some playing cards in a grid. Try to remember where each card is located.



Fishing

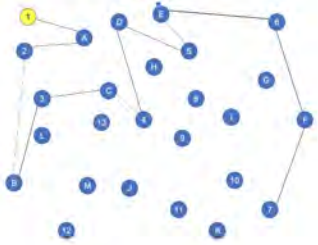
In this task you will see a line of fish swimming with each other. Only pay attention to the middle fish. If the fish is swimming to the left ( ), tap the left shift key. If the Fish is swimming to the right ( ), tap the right shift key.

Stepping Stones

In this task you will see 10 blocks on the screen. These blocks will light up in a certain sequence. When you see "GO" click the blocks in the same order you saw them light up. You will only see them once, so pay attention.

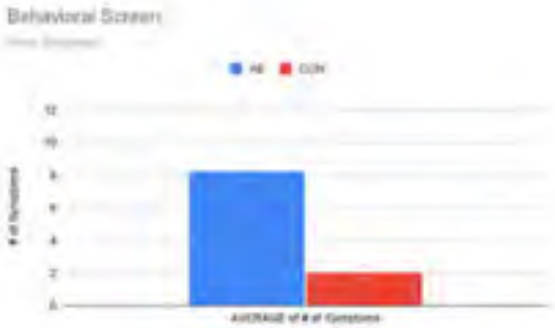
Connecting

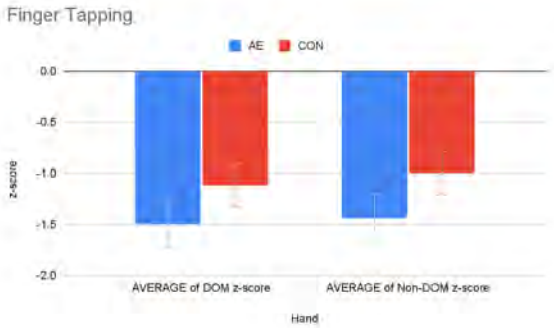
On the next screen, you will see numbers and letters in circles. Your job is to **click on the numbers as quickly as you can in order** (1,2,3, and so on) until you get to the end. Only connect the circles with numbers.

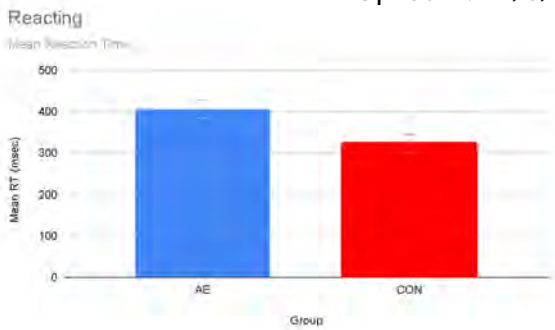


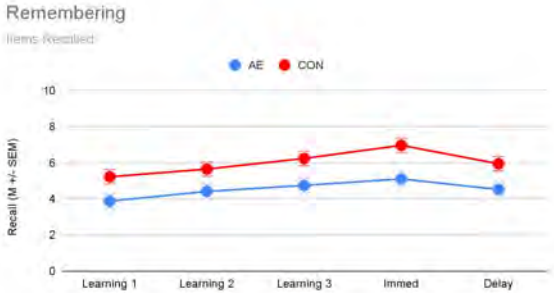
BRAIN-online consists of a 14-item behavioral screen and 7 subtests that measure fine-motor speed, reaction time, response inhibition/impulsivity, attention, problem-solving, processing speed, memory, spatial working memory, and set-shifting and requires 30-45 minutes to complete. It is completed online independently by each subject and reaction time and accuracy measures are available.

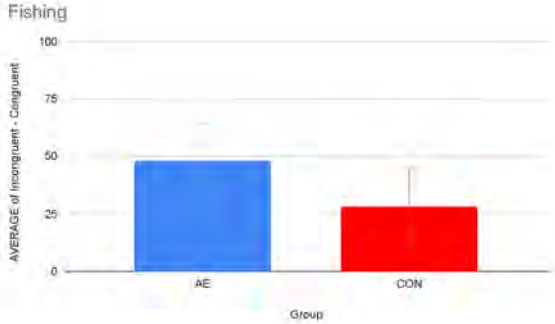
Updated: 12/6/23

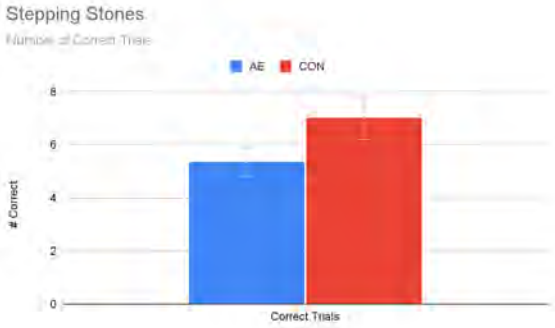


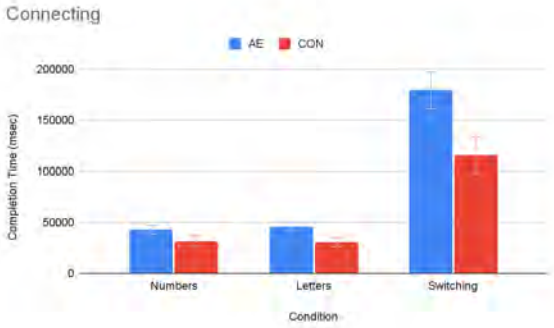








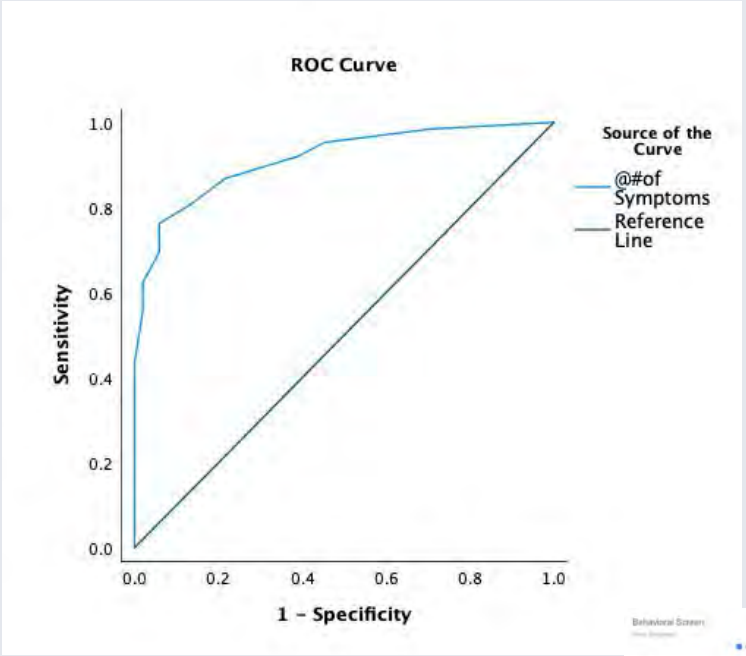




BRAIN-online results indicate that in comparison to controls, children with histories of prenatal alcohol exposure have: (1) higher scores on the behavioral screen), (2) lower scores (fewer taps) per 10 sec on Tapping, (3) longer and more variable reacting times on Reacting, (4) fewer items learned and recalled on Remembering, (5) more difficulty inhibiting on Fishing, (6) fewer correct on Stepping Stones, and (7) longer completion times on Connecting.

BRAIN-online Behavioral Questionnaire (BBQ)

- Data from 242 child (Mn=10y) participants were analyzed
  - 191 PAE/51 CON
- PAE group had higher scores (Mn=8.3) on BBQ than the CON group (Mn=2.1)
- ROC analysis indicated **outstanding discriminability** between groups (AUC=.914)
  - Optimal cut-off score of 4 or more endorsed items
  - Sensitivity=87%, specificity=78%, PPV=94%, NPV=62% for separation of PAE from controls. Overall classification accuracy was 85%



Major Research Accomplishments of C5: Summary

- ★ Data collection
- ★ Tool improvement
- ★ Training on dysmorphology and MQ
- ★ Finalized C4 Data with IU
- ★ C5 Data processing
- ★ Collaborated with or supported other C5 investigators
- ★ Received diversity supplement to support Celeste Estrada
- ★ Publications and presentations

Major Research Accomplishments of C5: Publications

1. Hyland, M.T., Courchesne-Krak, N.S., Bernes, G.A., Wozniak, J.R., Jones, K.L., Del Campo, M., Riley, E.P., Mattson, S.N., and the CIFASD (2023). Results of a screening tool for fetal alcohol spectrum disorders are associated with neuropsychological and behavioral measures. Alcohol: Clinical and Experimental Research, 47(8):1560-1569. Available online 16 June 2023.
2. Glass, L., Moore, E.M., and Mattson, S.N., (2023). Current considerations for fetal alcohol spectrum disorders: Identification to intervention. Current Opinion in Psychiatry, 36 (3): 249-256. Available online 2023 Mar 3.
3. Mattson, S.N., Jones, K.L., Chockalingam, G., Wozniak, J.R., Hyland, M.T., Courchesne, N.S., Del Campo, M., Riley, E.P., & the CIFASD. (2023). Validation of the FASD-Tree as a screening tool for fetal alcohol spectrum disorders. Alcoholism: Clinical and Experimental Research, 46 (1): 52-65. Available online 2023 Feb 20. **Highlighted as Article of Public Interest and subject of commentary.**
4. Poth, L.D., Love, T., Mattson, S.N. (2023). Profiles of language and communication abilities in adolescents with fetal alcohol spectrum disorders. Journal of the International Neuropsychological Society, 29: 724-733. Available online 3 November 2022.
5. Smith, et al. (2023). Polymorphisms in the choline transporter SLC44A1 are associated with reduced cognitive performance in both normotypic and prenatal alcohol-exposed children. American Journal of Clinical Nutrition, in press. Available online 27 November 2023
6. Gimbel, et al (2023). Delayed cortical thinning in children and adolescents with prenatal alcohol exposure. Alcohol: Clinical and Experimental Research, 47 (7): 1312-1326. Available online 02 May 2023
7. Gimbel, et al. (2023). Atypical developmental trajectories of white matter microstructure in prenatal alcohol exposure: Preliminary evidence from neurite orientation dispersion and density imaging (NODDI). Frontiers in Neuroscience-Neurodevelopment, 17, 1172010.

Major Research Accomplishments of C5: Book Chapters

1. Felichicchia, R.J., Veziris, C.R., and Mattson, S.N. Fetal alcohol spectrum disorders. In Ellenbroek, B.A., Olivier, J (eds.), Current Topics in Behavioral Neurosciences: Effects of Drug Exposure on Brain Development. Springer, in press.
2. Hyland, M.T., Courchesne, N.S., Sobolewski, C.M., Zambrano, C., and Mattson, S.N. Fetal Alcohol Spectrum Disorders: Neuropsychological outcomes across the lifespan. In O. Rahman, C. Petrenko (Eds.), Fetal Alcohol Spectrum Disorders: A Multidisciplinary Approach. Springer, in press.
3. Max, J.E., Mattson, S.N., Vaucher, Y.E., Nichols, S., and Nespeca, M.P. Psychiatric aspects of child neurology. In B.J. Sadock, V.A. Sadock, P. Ruiz (Eds.), Kaplan & Sadock's Comprehensive Textbook of Psychiatry, 11th Edition. Lippincott Williams & Wilkins, in press.

Major Research Accomplishments of C5: Abstracts

1. Veziris, C. R., Hyland, M.T., Kable, J.A,. Wozniak, J.R., Coles, C.D., May, P.A., Kalberg, W.O., Sowell, E.R., Riley, E.P., Mattson, S.N., & the CIFASD. Validation of the ND-PAE diagnosis in children with heavy prenatal alcohol exposure. Presented at the Research Society on Alcoholism meeting, Bellevue, June 2023. https://onlinelibrary.wiley.com/doi/full/10.1111/acer.15069
2. Estrada, C.S., Veziris, C.R. Hyland, M.T., Brucks, B. Mattson, S.N., & the CIFASD. Is there a relationship between COVID-19 related stress and alcohol use in college students? Presented at the Research Society on Alcoholism meeting, Bellevue, June 2023. https://onlinelibrary.wiley.com/doi/full/10.1111/acer.15069
3. Felicicchia, R.J., Hyland, M.T.,Roesch, S.C. & Mattson, S.N. Differences in the family environment in children with and without prenatal alcohol exposure. Presented at the Research Society on Alcoholism meeting, Bellevue, June 2023. https://onlinelibrary.wiley.com/doi/full/10.1111/acer.15069

RSA 2024 (Submitted as part of symposium)

Mattson, S.N., Hyland, M.T., Chockalingam, G., Wetherill, L., Wozniak, J.R., Riley, E.P., and the CIFASD. Development of an online cognitive test for fetal alcohol spectrum disorders.

Major Research Accomplishments of C5: Papers submitted or in preparation

1. **Sobolewski, C. M., Courchesne-Krak, N. S., Hyland, M. T., Bernes, G. A., Veziris,** C. R., Wozniak, J. R., Mattson, S. N., & CIFASD. Adaptive, externalizing, and internalizing behavior of children with prenatal alcohol exposure: A comparison of three parent-report questionnaires. Submitted to Developmental Neuropsychology.
2. **Veziris, C. R., Hyland, M. T.,** Kable, J. A., Wozniak, J. R., Coles, C. D., May, P.A., Kalberg, W.O., Sowell, E. R., Riley, E. P., Mattson, S. N., & the CIFASD. Validation of the ND- PAE diagnosis in children with heavy prenatal alcohol exposure.
3. **Veziris, C. R., Felicicchia, R.,** Villodas, M. T., & Mattson, S. N. A review of the effect of prenatal alcohol exposure and childhood adversity on externalizing disorders in childhood.
4. **Felicicchia, R., Courchesne-Krak, N., Hyland, M.,** Coles, C., Kable, J., Sowell, E., Wozniak, J., & Mattson, S. The impact of individual and family risk factors on the relationship between prenatal alcohol exposure and cognitive and behavioral functioning.
5. **Felicicchia, R., Hyland, M.,** Roesch, S., & Mattson, S. Exploring family environment characteristics in children with prenatal alcohol exposure.

Teaching/Outreach
Spreading the Word

Addiction Psychiatry Fellowship, UCSD School of Medicine (annual)

Substance Use Disorder Seminar, VASDHS/UCSD (annual)

Addiction Psychiatry Fellowship, UCSD School of Medicine (annual)

Child and Adolescent Neuropsychiatry, UCSD School of Medicine (biennial)

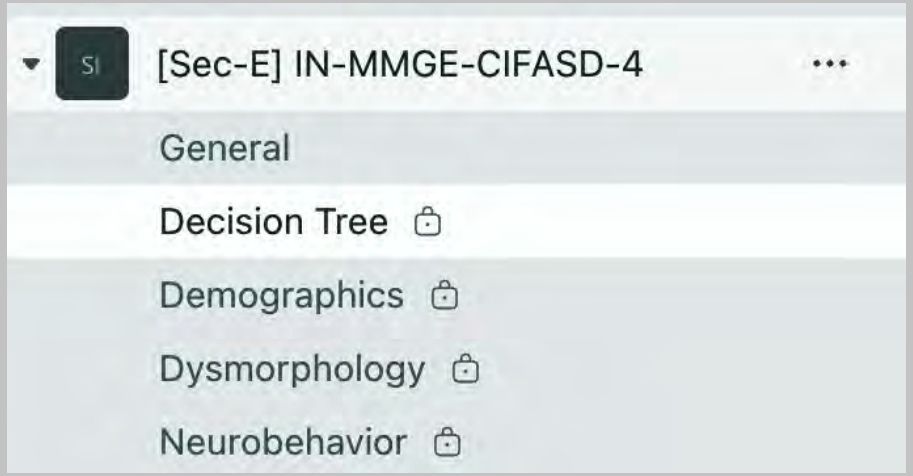
Major Goals to Complete in Year 2

- Submit papers for publication
  - BRAIN-online
  - Face/Neurobehavior (Suttie)
- Focus on recruitment of control participants, both local and national
- Continue recruitment development in Canadian FASD clinics
- Continue to provide support to Alaska project (Del Campo)
- Continue to provide assessment support for C5 projects as needed
- Provide support for Chambers San Diego Pilot project
- Continue discussions with FDNA
- Pursue options for public use of FASD-Tree and BRAIN-online

Data Processing Steps

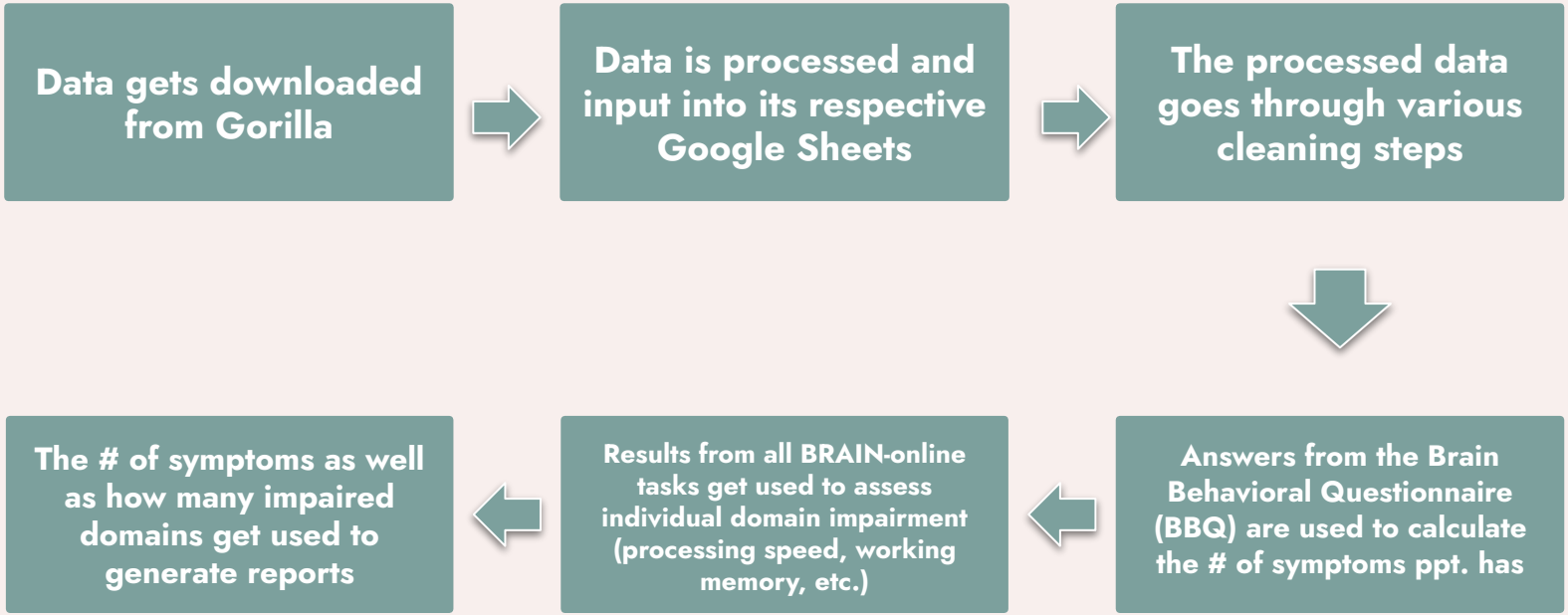
How raw data is prepared for reports and Central Repository upload

Finalizing all C4 Data



- Data from FASD-tree, our Parent Child Questionnaire, and Neuropsych Testing is downloaded from REDCap Cloud
- We run Macros and process all the data to match it up to the format of our data dictionaries
- After the data is ready to go, we upload it into Indiana University's Microsoft Teams
- The final step was to notify Dr. Leah Wetherill that everything was submitted and then submit a total count of participants as well as how many we had in each instrument

Where does BRAIN-online data go after test completion?



Finalization of Neuropsych Scores

Scoring NP Tests

Using Q-Interactive testers score each individual assessment administered to participant

Q-interactive

Score Reports

All scores are inputted into a report template as well as percentile ranks and descriptors

REDCap Cloud

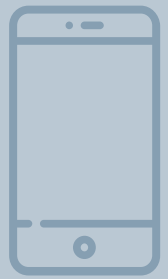
Data is finalized and entered into REDCap Cloud

Results Report Generated

Reports with all results is created and then sent off to families

➔ **Each step of this process requires everything to be rechecked at least twice before moving forward**

What Happens with Morpheus Q and 3D Imaging Data?



- Morpheus Q exams are done on our in-lab iPhone
- Data is automatically saved in the FASD-tree exams database
- After testing we enter their 'Morpheus Classic' data which is their Vermillion Border, Lateral Philtrum, Philtrum Lipometer and PFL data received from the referring Dysmorphologist

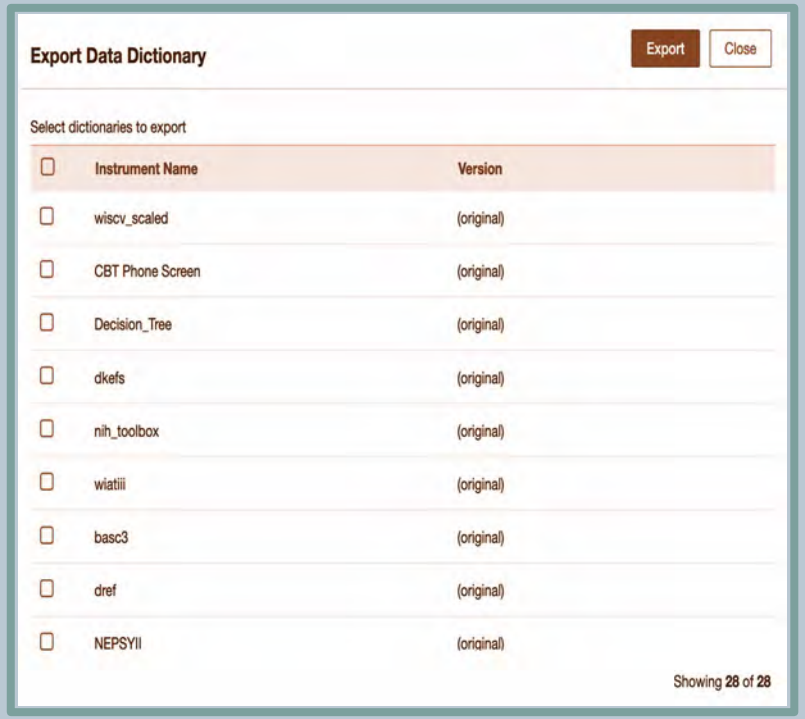
- 3D imaging is done the same time we do Morpheus Q
- Before taking photos all hair must be out of the child's face, any glasses have to be off, and they must be looking straight
- After all images are taken of the child we make sure they get stitched together properly
- A folder on our secure internal hard drive is create for each participant

- The only images we upload to the Indiana University Teams folder are those of kids who consented to have them shared, otherwise they stay on a secure internal hard drive
- Images are used by Dr. Michael Suttie in conjunction with participant's demographic info.

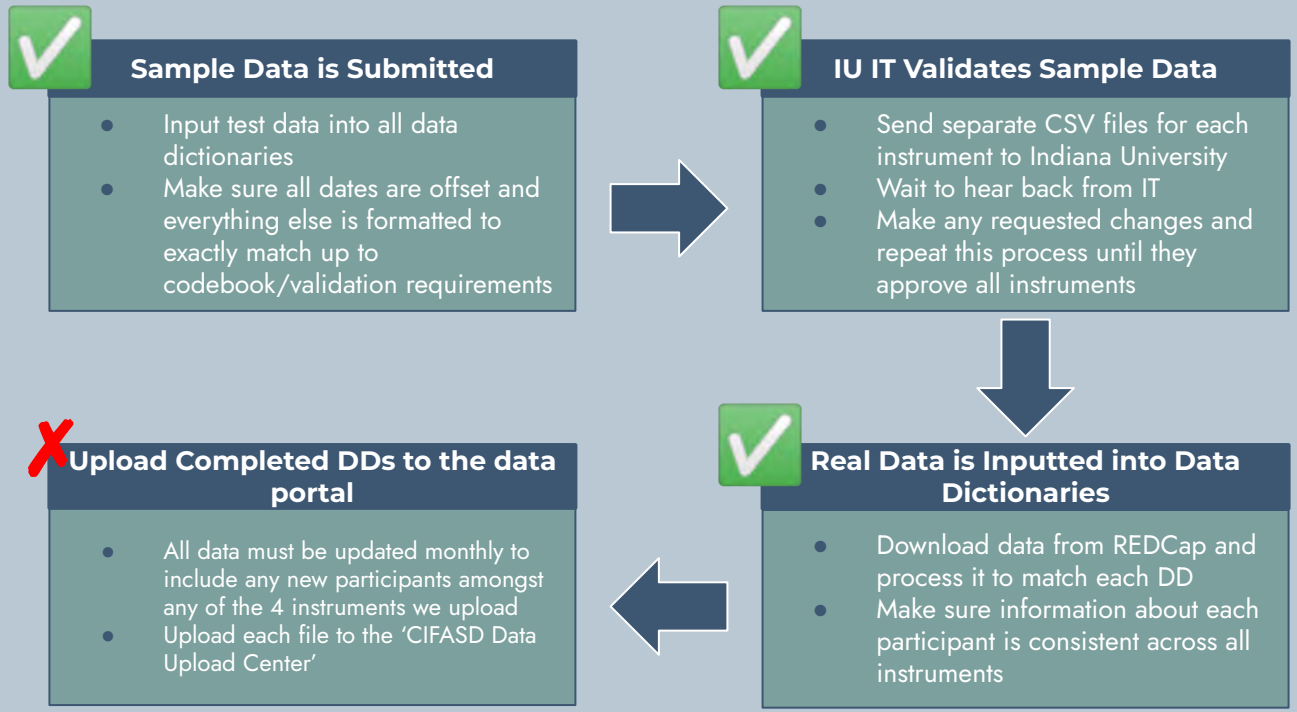
! MQ and imaging are only done if the parents and child consent **!**

Creating the Data Dictionaries

- Data dictionaries are generated for each instrument through REDCap Cloud
- All variables in our DDs must have explanations including the type of data; element name and description; whether it's required or not; and any validation requirements
- We generated a finalized DD, codebook, and upload template for all 4 of our upload structures and received approval from IU



Data Processing Effort



THANKS!

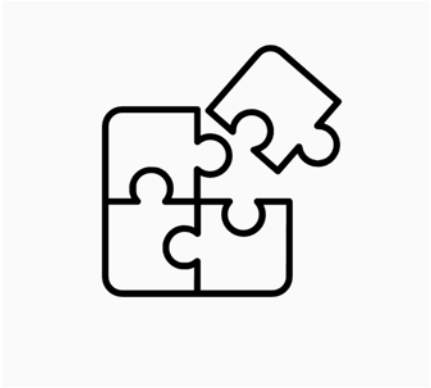
QUESTIONS?

CREDITS: This presentation template was created by **Slidesgo**, and includes icons by **Flaticon**, and infographics & images by **Freepik**

E-Health Applications

Ganz Chockalingam, Ed Riley, Sarah Mattson

E-Tree
(Sarah Mattson)

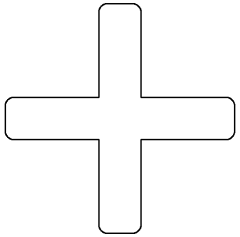


BRAIN
(Sarah Mattson)

MORPHEUSQ

Merge Two Applications

E-Tree



BRAIN

GORILLA Experiment Builder

We help ambitious behavioural scientists create and host online experiments easily

- ✔ Easy-to-use graphical interface — no coding necessary.
- ✔ Collect behavioural data with accurate reaction times.
- ✔ Build for free. Pay per respondent.

Sign Up OR See our Tools

BRAIN Online - Raw Data

R1C1 | ¿Event Index

¿Event Index	UTC Timestamp	UTC Date	Local Timestamp	Local	Local Date	Experiment	Experiment Version	Tree Node Key	Schedule ID	Participant Public ID	Participant Private ID	Participant Status	Participant Device Type	Participant Device	Participant OS	Participant Browser	Participant Monitor	Participant Viewport	Task Name	Spreadsheet Name
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29	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1
30	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1
31	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1
32	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1
33	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1
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37	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1
38	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1
39	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1
40	1.5995E+12	7/9/20 20:52	1.5995E+12	-7	7/9/20 13:52	11053	62	task-kzwl	6725420	CBT0002	1907027	complete	computer	Desktop or L	Mac OS 10.1	Chrome 85.0	1440x900	1440x719	Speed Tappi	Spreadsheet1

BRAIN Online

Tapping

You will be asked to place your wrist on the surface and tap the spacebar as quickly as you can with your index finger for 10 seconds. Do not move your hand or arm, only your finger. Begin Tapping when you see "GO."

Let's try a practice trial for the right hand first!

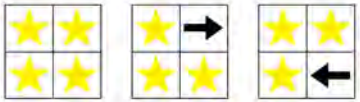
Click NEXT to continue

Reacting

In this task, you will see a star ( ) appear on the screen. Whenever you see the star ( ), tap the spacebar as quickly as possible using your dominant hand.

Inhibiting

In this task, you will see a series of arrows that appear in a grid. When you see arrows that are facing the right ( ), tap the spacebar. If you see an arrow facing the left ( ), do not respond.



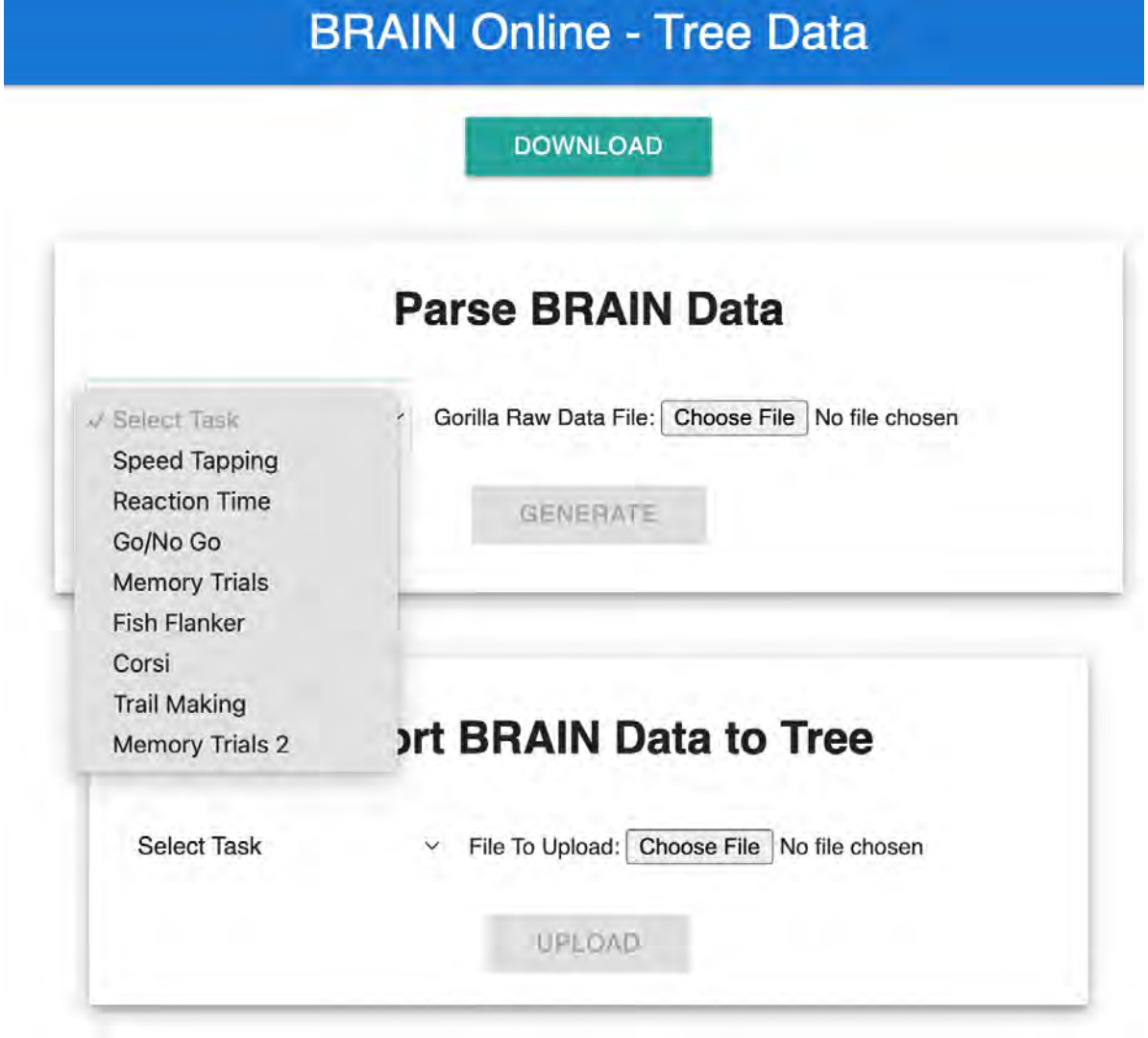
Remembering

You are about to see some playing cards in a grid. Try to remember where each card is located.

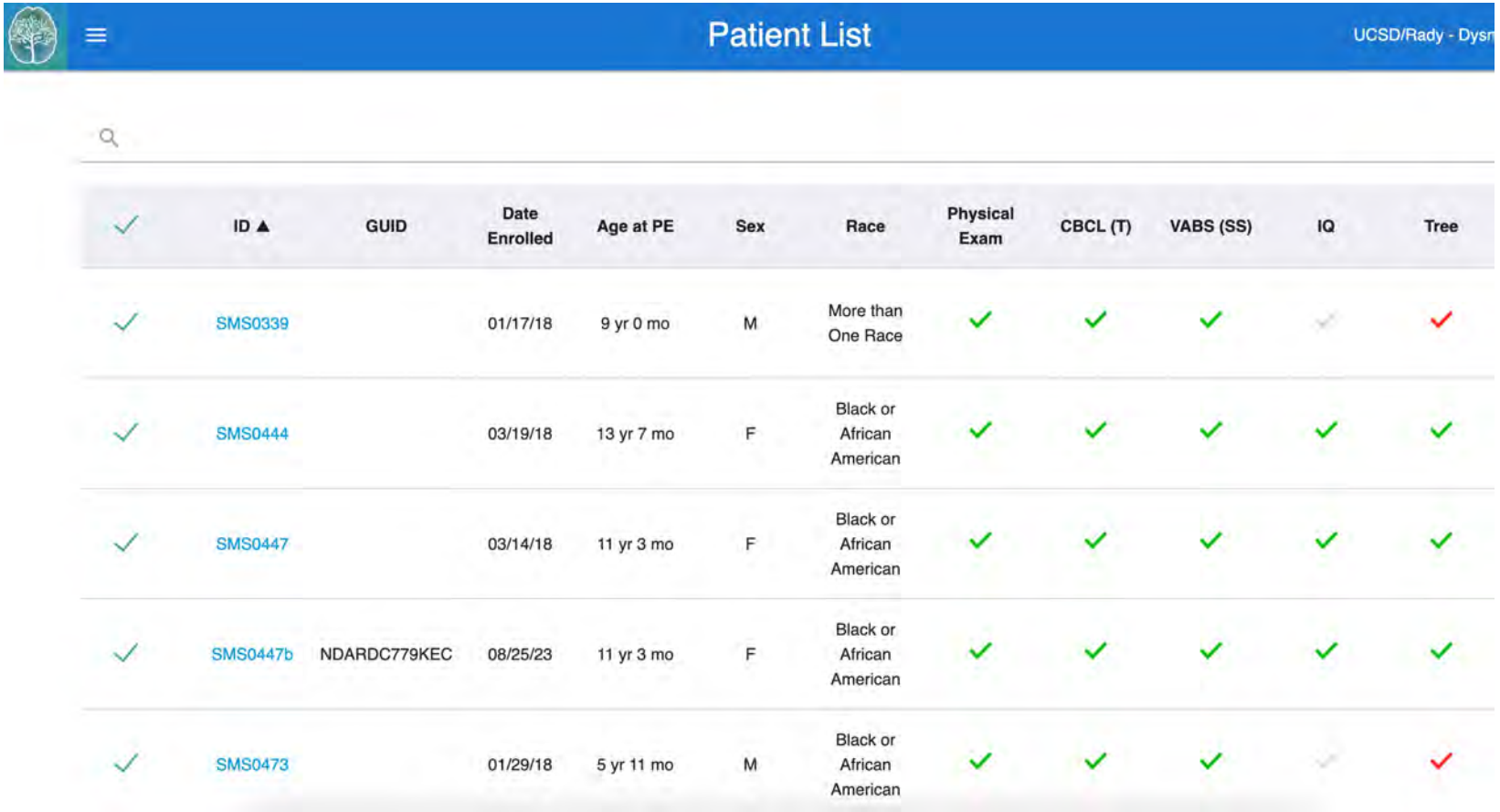
BRAIN Online

Data Processing

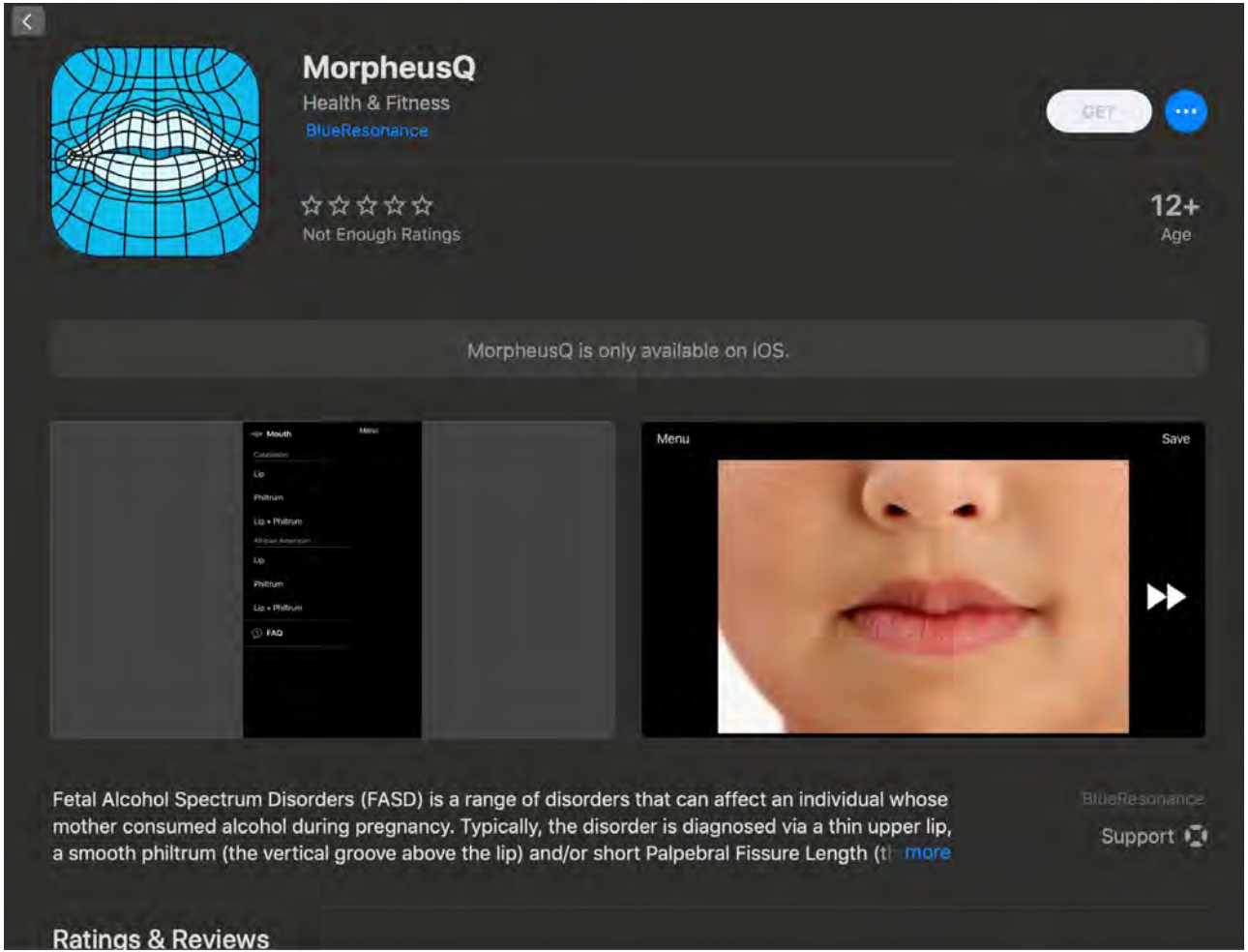
E-Tree

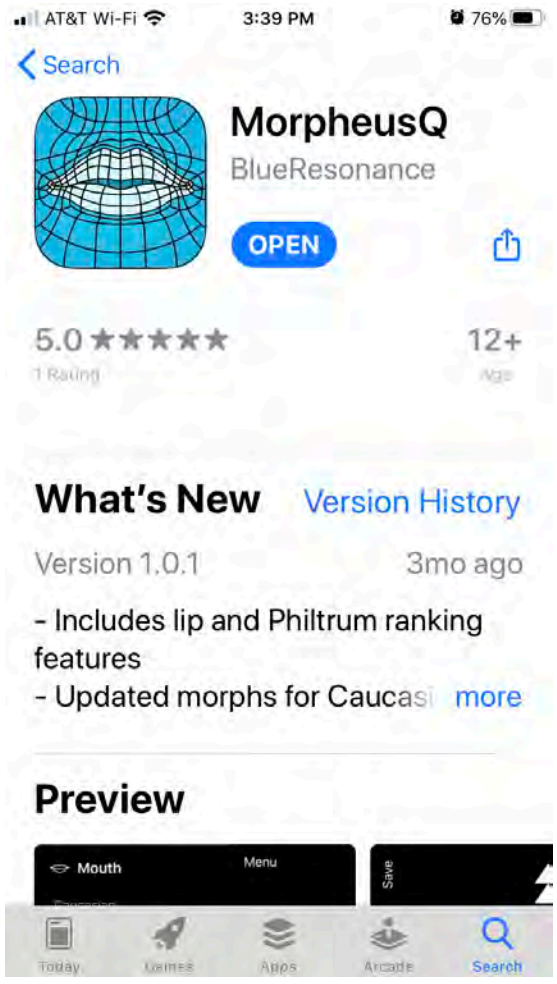


Combined Data Download



✓	ID ▲	GUID	Date Enrolled	Age at PE	Sex	Race	Physical Exam	CBCL (T)	VABS (SS)	IQ	Tree
✓	SMS0339		01/17/18	9 yr 0 mo	M	More than One Race	✓	✓	✓	✓	✓
✓	SMS0444		03/19/18	13 yr 7 mo	F	Black or African American	✓	✓	✓	✓	✓
✓	SMS0447		03/14/18	11 yr 3 mo	F	Black or African American	✓	✓	✓	✓	✓
✓	SMS0447b	NDARDC779KEC	08/25/23	11 yr 3 mo	F	Black or African American	✓	✓	✓	✓	✓
✓	SMS0473		01/29/18	5 yr 11 mo	M	Black or African American	✓	✓	✓	✓	✓


MorpheusQ
Health & Fitness
BlueResonance
GET
Not Enough Ratings
12+
Age
MorpheusQ is only available on iOS.
Mouth
Menu
Lip
Philtrum
Lip + Philtrum
FAQ
Menu
Save
Fetal Alcohol Spectrum Disorders (FASD) is a range of disorders that can affect an individual whose mother consumed alcohol during pregnancy. Typically, the disorder is diagnosed via a thin upper lip, a smooth philtrum (the vertical groove above the lip) and/or short Palpebral Fissure Length (t more
BlueResonance
Support
Ratings & Reviews


AT&T Wi-Fi
3:39 PM
76%
Search
MorpheusQ
BlueResonance
OPEN
5.0
1 Rating
12+
Age
What's New
Version History
Version 1.0.1
3mo ago
- Includes lip and Philtrum ranking features
- Updated morphs for Caucasi more
Preview
Mouth
Menu
Save
Today
Games
Apps
Arcade
Search

Cutoffs Established for Age/Race/Sex

1. **Support for Age groups**
   3-7 Yrs
   7-14 Yrs
   14-21 Yrs

2. **Race:**
   Caucasian
   African American
   Hispanic
   Asian

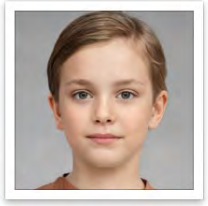
3. **Male/Female**

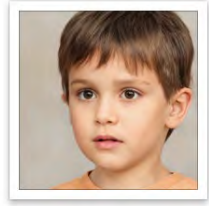
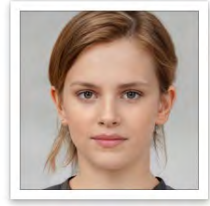
4x3x2 = 24 Subjects

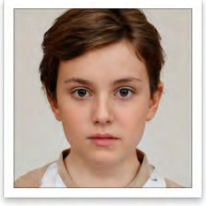
Front & Lateral View = 48

6 cutoffs per subject

6x48 = 288 cutoffs in total





Menu
Clear
Enroll Subject
Subject ID
FA6391
Sex
Male
Female
Age in Years (Ex. 7)
13
Ethnicity
African American
Hispanic
Asian
Submit

Response Statistics

Sort By

Difference, high to low

Step #	Resp Count	Average	Difference	View	Rank	Response #1	Response #2
11	2	2440	285	Side Philtrum	3-4	2297	2582
19	2	2400	283	Front Lips	3-4	2258	2541
133	2	3028	278	Front Lips	3-4	2889	3167
30	2	3755	274	Side Philtrum	4-5	3618	3892
9	2	2473	264	Front Philtrum	3-4	2605	2341
88	2	3613	262	Front Philtrum	4-5	3744	3482
33	2	2558	256	Front Philtrum	3-4	2430	2686
38	2	3287	252	Front Lips	4-5	3161	3413
36	2	3479	249	Side Philtrum	4-5	3603	3354
113	2	2461	246	Side Philtrum	3-4	2338	2584
103	2	2488	244	Front Lips	3-4	2366	2610
101	2	2827	238	Side Philtrum	3-4	2946	2708
23	2	2957	231	Side Philtrum	3-4	2841	3072
47	2	3051	221	Side Philtrum	3-4	2940	3161
141	2	2888	216	Front Philtrum	3-4	2780	2996
90	2	3893	215	Side Philtrum	4-5	4000	3785
99	2	3047	214	Front Philtrum	3-4	2940	3154
5	2	2801	214	Side Philtrum	3-4	2694	2908
3	2	2156	212	Front Philtrum	3-4	2050	2262

Leveraging Technology to Increase Quality of Life for FASD Across the Lifespan

Christie L. M. Petrenko, Ph.D. & Cristiano Tapparello, Ph.D.

Mt. HOPE family center

1850 MELIORA

UNIVERSITY of ROCHESTER

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Aims

Families Moving Forward CONNECT PRO

Aim 1: Mental Health Providers - Child

- Formative: design FMF Connect Pro and implementation packages (Year 1)
- 3-parallel arm RCT with 250 mental health providers (Years 2-5)

My Health Coach

Aim 2: Adults with FASD

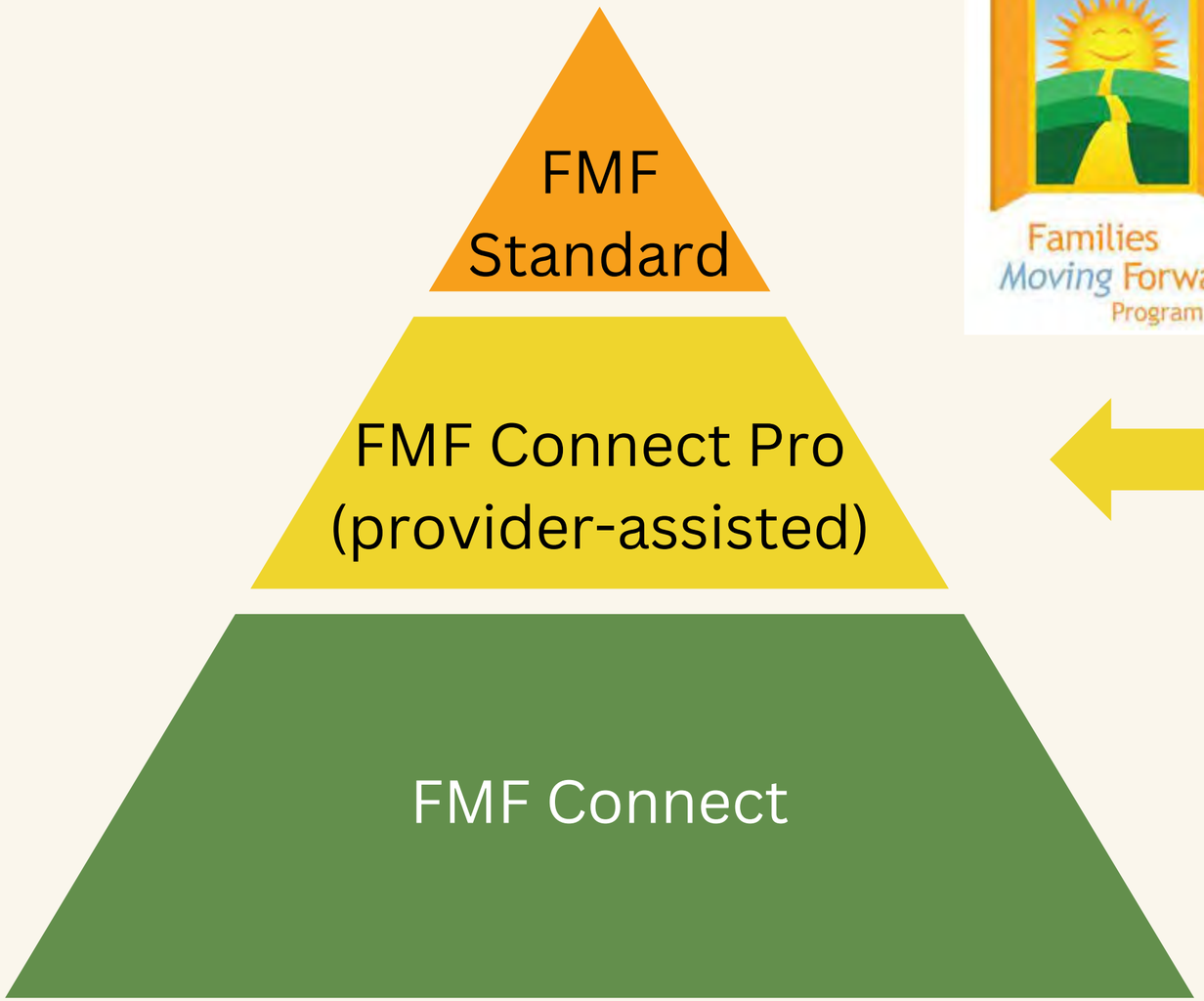
- 2 parallel arm RCT with 120 adults with FASD (Years 2-3)

Determined

Aim 3: Adolescents with FASD and their Caregivers

- Formative: design Determined app system (Years 3-4)
- Usability testing with 10 teens and caregivers (Year 5)

WHY: Building a Continuum of Care



Families Moving Forward Program

1:1 Program with therapist
In home, clinic, or telehealth
7-9 months
Therapists - 40+ hours training

This Project

Families Moving Forward CONNECT PRO

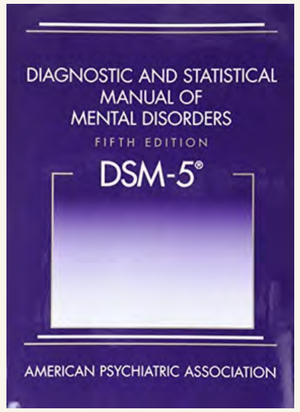
Families Moving Forward CONNECT

Self-directed app to be used by caregivers

WHAT: 3 Accessible Steps

1

Routine screening of prenatal alcohol exposure



2

Diagnose DSM-5 "Neurobehavioral Disorder Associated with Prenatal Alcohol Exposure" (ND-PAE)

3

Support caregivers using the FMF Connect app

HOW: Training Providers to do FASD-Informed Care

Introductory Webinar

1 Hour

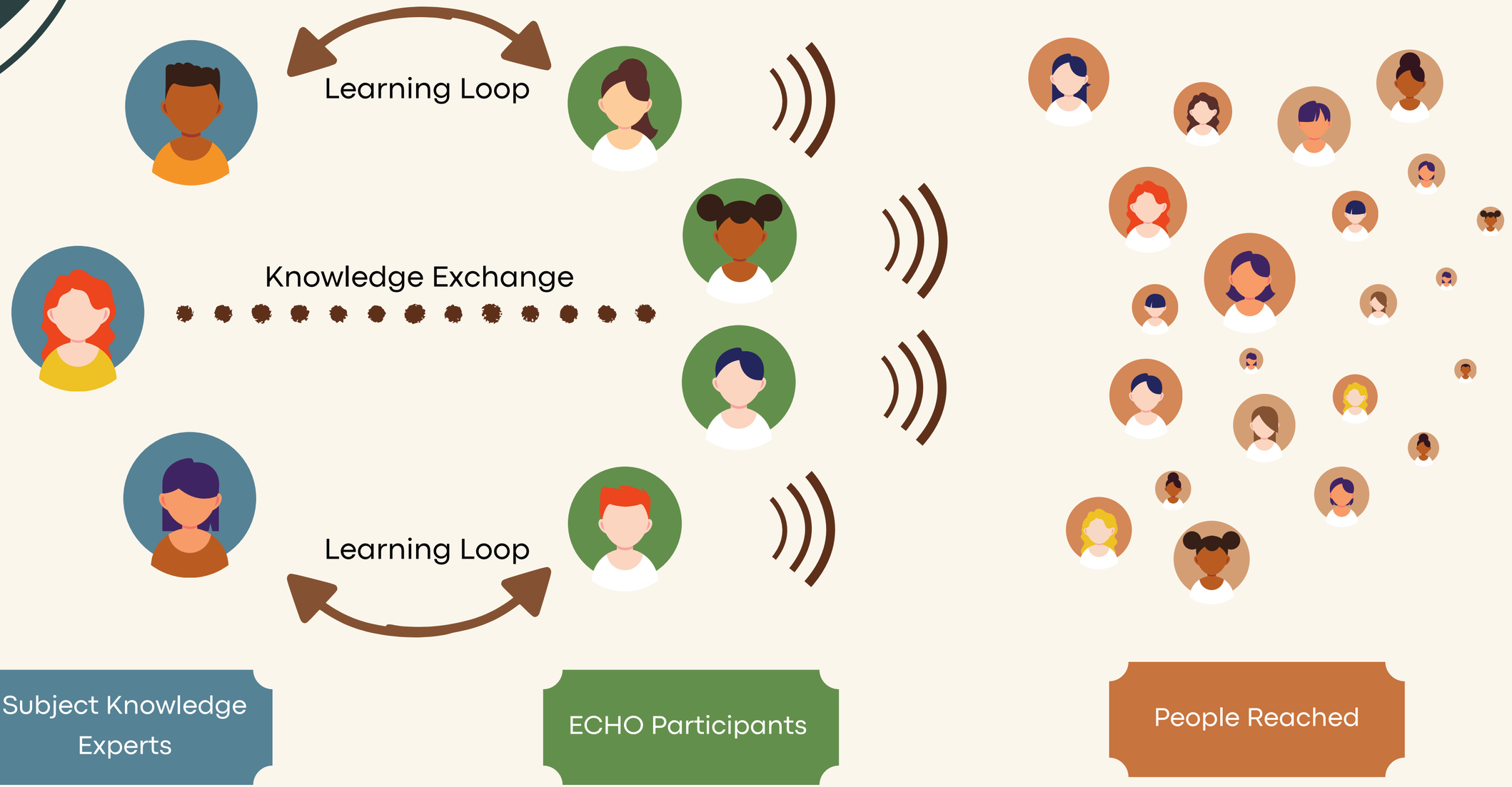
No-cost

Introduces FASD and FASD-informed care

Explains study and further training

1hr CEU credit

What is Project ECHO?



My Learning

Course Curriculum

4. Understanding Strengths and Differences

- Video #4: Understanding Strengths and Differences (12:04min)
- Activity #4: Creating the Child Profile Graph

5. Reframing

- Video #5: Reframing (13:51 min)
- Activity #5: Practice applying reframing
- Resources

6. Accommodations

© 2023 - FMF Connect

Both Training Methods Cover the Same Topics

1. Introduction to Training and FASD	8. Caregiver needs and supports
2. Screening for FASD and stigma	9. Trauma-responsive care
3. Applying DSM-5 criteria for ND-PAE	10. Brainstorming - Part 1
4. Understanding child strengths and differences	11. Brainstorming - Part 2
5. Reframing	12. Supporting success in school
6. Accommodations	13. Looking forward
7. Self-regulation and adapting child interventions	

Families Moving Forward CONNECT PRO

Accomplishments

Intervention & Training Development

- ✓ Website interface and functionalities determined
- ✓ Introductory webinar slides developed and piloted
- ✓ Training content and slides developed - 13 sessions
- ✓ ECHO training completed by team members
- ✓ Self-paced video series filmed and produced
- ✓ Core supporting materials developed (supplemental in progress)

Development Informed by:

2 Rounds of Focus Groups

- Round 1: 4 focus groups, 9 real participants
- Round 2: 4 focus groups, 18 real participants

All focus groups transcribed; thematic coding in progress

Community Hub Team meetings

- 10 held

Families Moving Forward

CONNECT PRO

Provider Dashboard Demonstration

Families Moving Forward CONNECT PRO

Accomplishments

Randomized Controlled Trial Preparation

- ✓ IRB - Rochester site approved 10/20/2023
- IN PROGRESS SCRI and Emory - sIRB in progress
- ✓ CEU accreditation approval - Introductory Webinar & ECHO
- IN PROGRESS CEU accreditation - in process for self-directed
- ✓ Measurement battery revised and finalized
- IN PROGRESS Study database being built by University IT

Families Moving Forward CONNECT PRO

Accomplishments

Randomized Controlled Trial Preparation

Clinical Trials registered 07/16/2023

IN PROGRESS

Working on data expected with DRC

IN PROGRESS

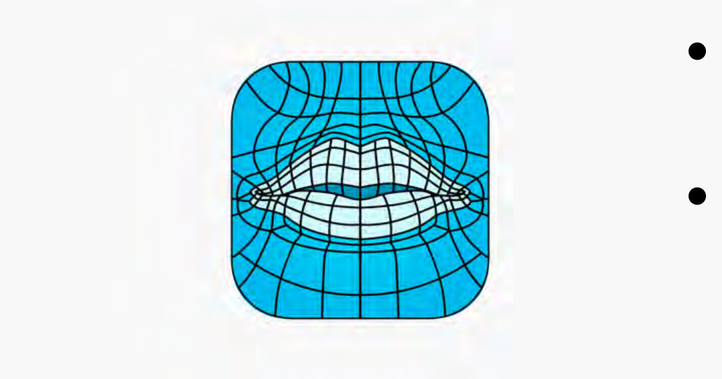
Recruitment spreadsheet with over 450 mental health providers in NY - gathering contact information

Aiming to launch recruitment January 2024

Interactions

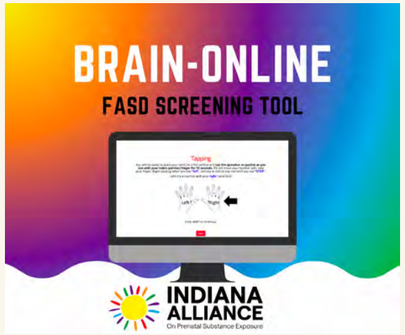
Families Moving Forward CONNECT PRO

- Other projects helped with recruitment for focus groups
- RCT recruitment support planned



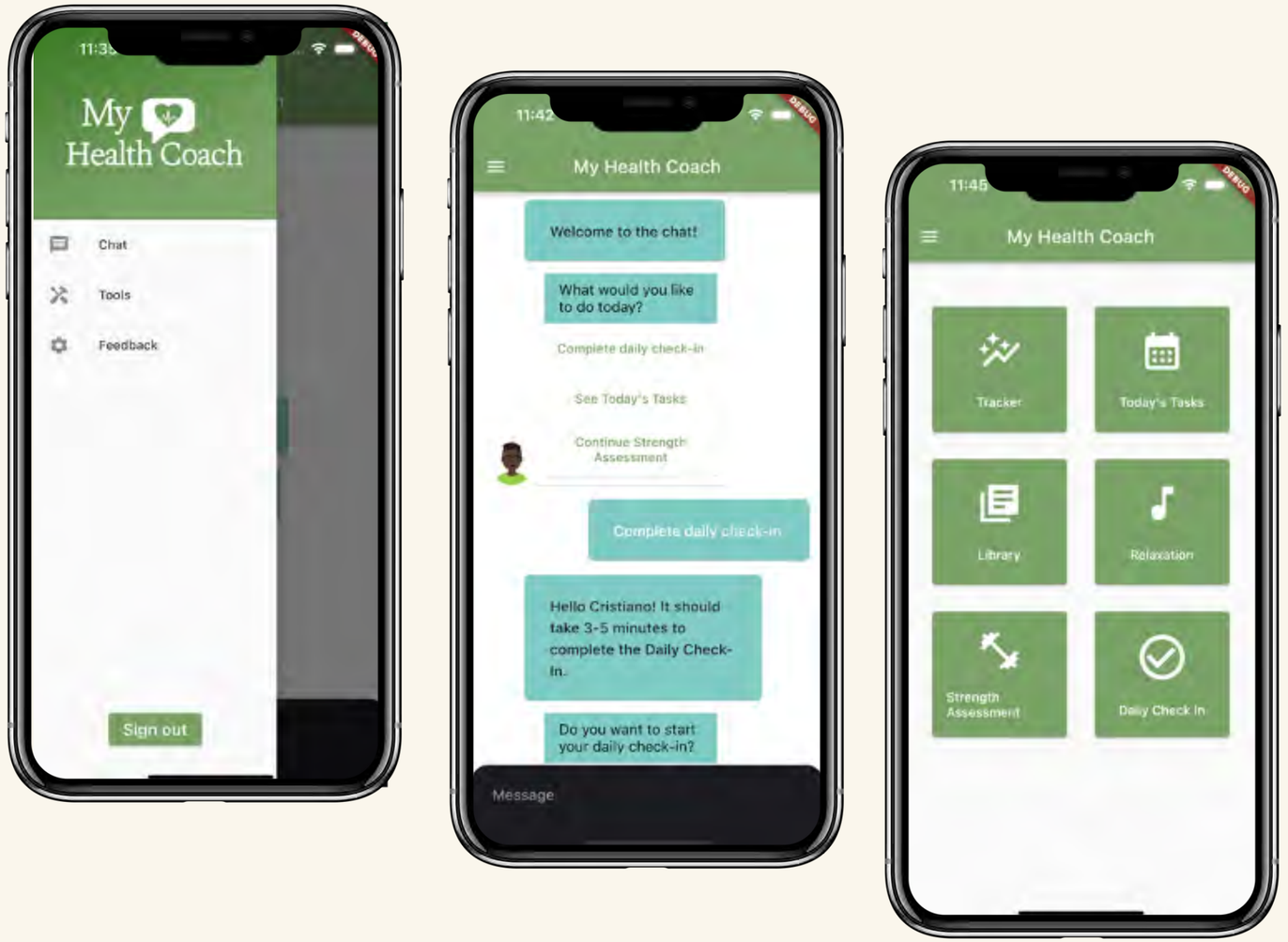
- Been implementing in clinic for several years
- Working with Miguel to get IRB approval to do larger protocol in our clinic

- Obtained IRB approval to share cardiac data
- Working on Data Sharing Agreement with Olivia and Boston Children's

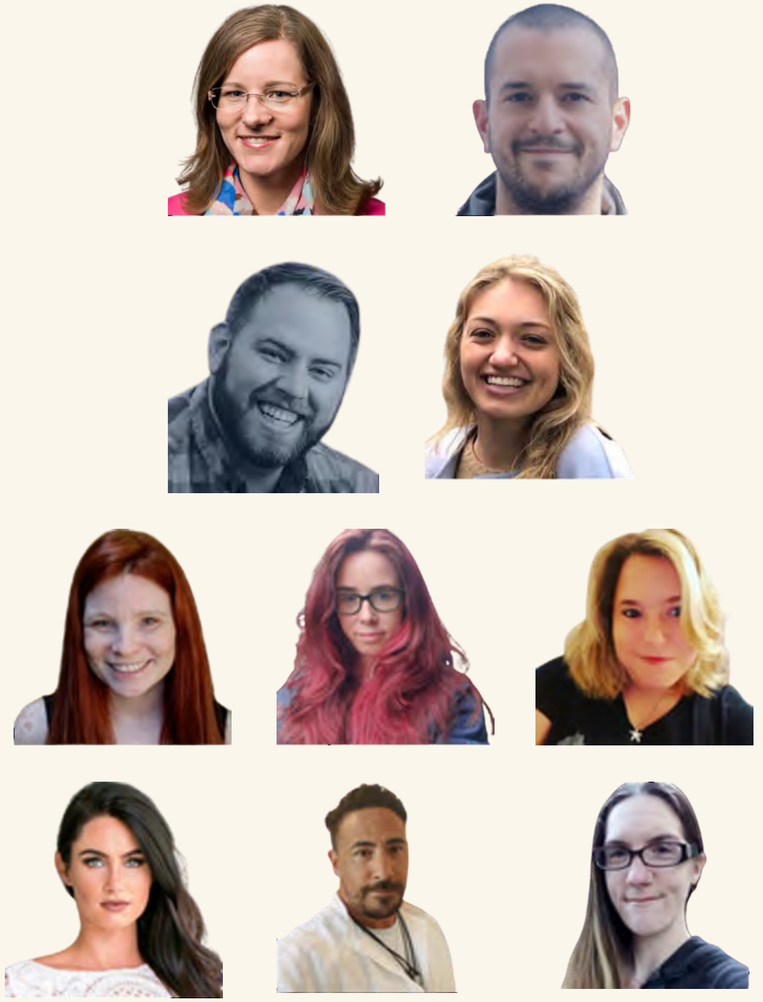


- Sent out recruitment information
- Highlighted in community presentations

My Health Coach



University of Rochester



Adult Leadership Collaborative of FASD Changemakers

Feasibility Trial Objectives

Trial Feasibility

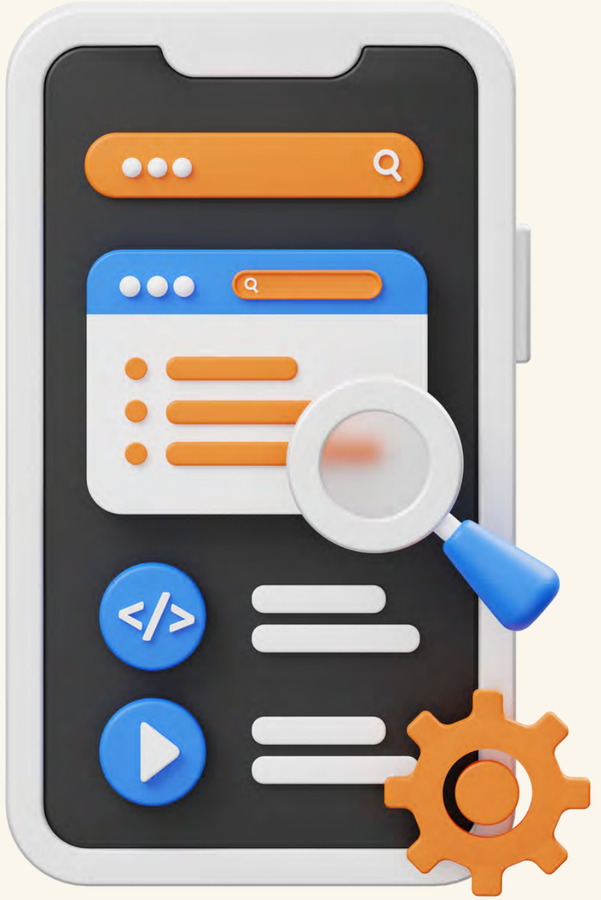
- Is recruitment sufficient to support a larger trial
- How much attrition occurs
- Are measure acceptable and sensitive to change

Intervention Feasibility

- Does the app work from technology perspective?
- Do users find it acceptable?

User Implementation

- What are usage patterns in the app?



Trial Feasibility - Recruitment

Recruitment

- Trial launched 3/20/2023
- Target n=40

- 75% of recruitment in first two weeks
- 100% of recruitment by week six

Eligibility

- 43 eligible

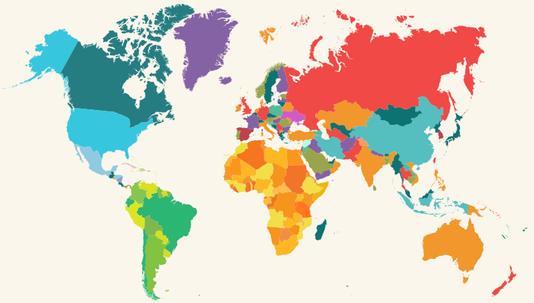
- 52 ineligible
  - 37 fraudulent
  - 2 ineligible
  - 1 withdrawal
  - 7 duplicates
  - 5 incomplete

Who Did We Reach?

- Gender
  - 21% male
  - 67% female
  - 12% transgender, non-binary, other

- Mean age
  - 28 years; range: 18-59

- Operating system
  - 42% iOS
  - 58% Android



- Country
  - United States - 24
  - Canada - 7
  - Netherlands - 4
  - United Kingdom - 4
  - Ireland - 1
  - Italy - 1
  - South Africa - 1
  - New Zealand - 1

Trial Feasibility - Attrition

	Eligible	T1 Complete	Received App	Installed App	T2 Complete	Interview Complete
My Health Coach	43	39	39	33	28	19
% of total		**91%**		**85%**	**72%**	**49%**

Higher T1 rate than expected
App install rate similar to our other app studies

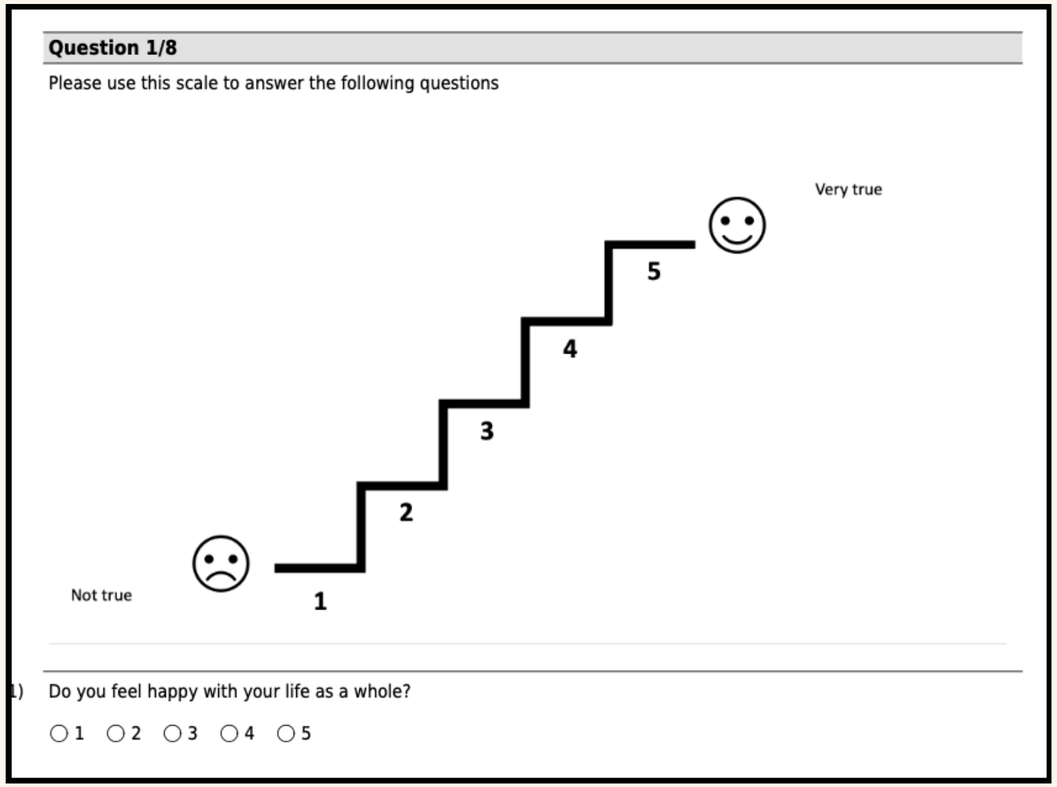
Attrition did not differ by demographics

Trial Feasibility Measurement

Survey completion better than expected

Participants able to complete online with minimal issues or questions

Good variability



Trial Feasibility - Measurement

Correlations

Baseline	Quality of Life
Autonomy	0.57
Relatedness	0.67
Competence	0.69

Follow-up	Quality of Life
Autonomy	0.27
Relatedness	0.38
Competence	0.30

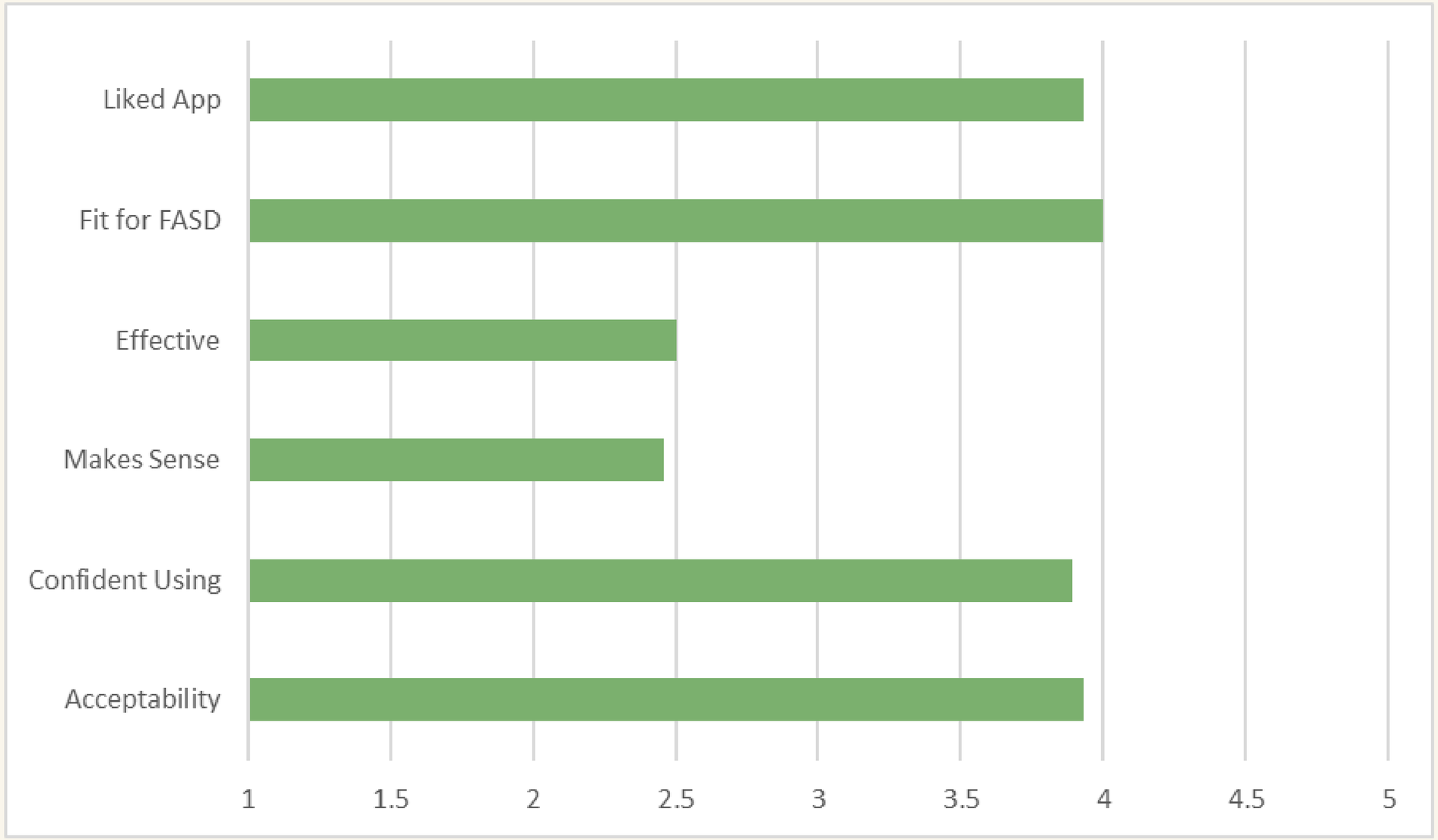
No significant change in means over time (*not designed to test efficacy)

Intervention Feasibility

- Most users able to install app without help or problems
- 2 major updates released that addressed minor bugs

- 34 submissions in Feedback section of app
  - Problems
  - Recommendations for future development
  - Positive feedback

Intervention Acceptability



User Implementation

Component	Mean	Range
App opened	37.39 times	1 - 202
Chatbot interactions	98.48 times	1 - 378
Daily Check-ins	10.00 times	0 - 38
Strengths assessment	32.52 items completed	0 - 37
PDFs opened in Library	7.97 times pdfs opened	0 - 40
Number of Trackers created	4.18 trackers	0 - 36
Trackers completed	70.85	0 - 590

Publication / Presentations

Publications

- Findings from focus group / survey study (Aim 1) submitted to *Digital Health* - under review
- CAB paper and feasibility trial manuscripts in progress

Presentations

- 3 co-presented with ALC; 13 additional presentations
- 2 accepted co-presented presentations for Seattle Conference in April

Questions

Data Coordination Resource (DCR)

Leah Wetherill, Ph.D.

Abigail Erickson, BS, CCRP

SCHOOL OF MEDICINE

Help Projects Prepare for Data Upload

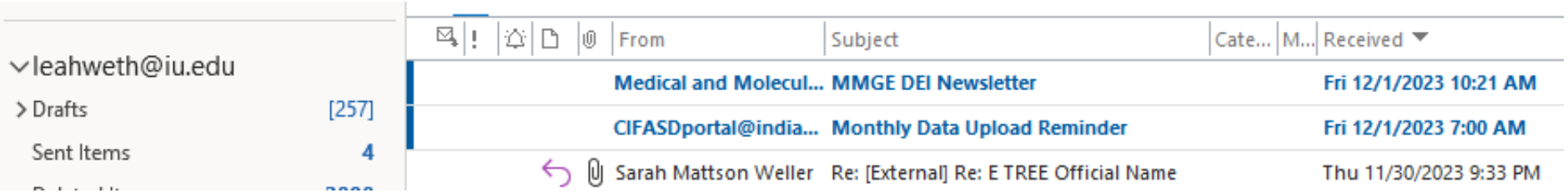
- IRBs – data sharing language approved for everyone
- GUID training and access
  - Training video and documents available in Teams
  - 6/7 projects have GUID tool from NIH
- All 10 projects provided data dictionaries
  - 1 project data dictionary to be modified (on hold)
  - Sample data received from 9 projects
  - Converted 7/10 data dictionaries to DCR/NDA format
- Those 7 projects can upload data to portal +2 almost…

Real-time Data Validation

- Automated data validation completed for 7/10 projects
- Automated reformat of data for NDA upload
  - Merge data from non-consenting projects with “parent” project assigning GUID
  - Merge data from projects collecting data for same structure
  - Assign consortium-wide “phenotype” of PAE (yes/no)

Automated Monthly Reminder to Upload Data

- Sent to all appropriate personnel
  - Provides links to portal, Teams folders, emails
  - Provides date portal will close



Hello,

This is your monthly reminder to submit your cumulative CIFASD5 data file(s) to the DCR Data Upload Center (DUC): https://cifasd.medgen.iupui.edu/. The portal will close on the 15th at 11:00 PM EST. Please note that the data you upload should be a cumulative file, containing all data collected to date. Please do not submit data for participants who have not consented to share their data with CIFASD, or who have rescinded their consent. If for some reason you are unable to submit data this month, please log into the DUC and choose an exemption.

Starting on the 16th, your ability to upload data or submit an exemption will be locked, and you will be marked as noncompliant in the administrative overview report.

Answers to FAQs, as well as instructions detailing how to submit data and manage your account can be found here: Teams Data Portal SOPs.
If you have any questions, please reach out to Leah Wetherill (leaweth@iu.edu) and/or Abby Erickson (agericks@iu.edu).

Thank you,
The DCR Team

CIFASD Data Portal

- 5/10 projects ready to upload monthly (+1 chart review – closed)
- Monthly status reset on 1st of each month
- Denominator = number of data structures project will upload
- Projects can choose an exemption if necessary

- https://cifasd.medgen.iupui.edu/adminoverview

CIFASD Data Portal

CIFASD Data Upload Center

Project Name	Project PI	Current Monthly Status
Whole Body Effects of PAE Across the Life Span: Early Markers of and Clinical Interventions for Children and Adolescents in Ukraine	Chambers	2/2 Successful Uploads ✓
A Multisite Study of PAE: Effects of Inflammation and Endocrine Dysfunction in Adulthood_Coles	Coles	Project Pending
Diagnostic-Telemedicine Resource	del Campo	1/3 Successful Uploads
Designing a Hybrid Intervention Strategy to Reduce Alcohol Exposed Pregnancies	DiClemente	Project Pending
Lifelong Impact of PAE on Stem Cell Dynamics and Cellular Aging	Mahnke	Exemption Submitted
Assessment of FASD Using Novel Web-Based Tools	Mattson	0/4 Successful Uploads
Development of Biomarkers in Deciduous Teeth of Children with FASD that Predict Neurobehavioral Performance	Montag	Project Pending
Leveraging Technology to Increase Quality of Life for FASD Across the Lifespan	Petrenko/Tapparello_U01	Project Pending
Mobile Health Tools to Promote Health in Adults With FASD	Petrenko/Tapparello_UH2	Project Pending
Defining Translational Approaches for the Image-based Detection of PAE	Suttie	1/1 Successful Uploads ✓
Cardiovascular Disease in FASD	Weeks	Project Closed
A Multisite Study of PAE: Effects of Inflammation and Endocrine Dysfunction in Adulthood_Weinberg	Weinberg	Exemption Submitted
Transcranial direct current stimulation (tDCS) and Cognitive Training in FASD	Wozniak	1/1 Successful Uploads ✓

CIFASD Data Portal

CIFASD Data Upload Center

	Chambers	Coles	del Campo	DiClemente	Mahnke	Mattson	Suttie	Weeks	Weinberg	Wozniak
2023-12-01	2/2	Pending	1/3	Pending	Exemption	0/4	1/1	0/1	Exemption	1/1
2023-11-01	Exemption	Pending	Exemption	Pending	0/1	Exemption	1/1	1/1	0/1	1/1
2023-10-01	0/2	Pending	0/3	Pending	0/1	0/4	1/1	0/1	0/1	1/1
2023-09-01	0/2	Pending	0/3	Pending	0/1	0/4	1/1	1/1	0/1	0/1
2023-08-01	0/2	Pending	0/3	Pending	0/1	0/4	0/1	0/1	0/1	0/1

Next: will work with Dr. Montag

- Upload data to portal
- Can include her data into Leaf ®

Data Upload to NIAAA Data Archive (NDA)

- https://nda.nih.gov/edit_collection.html?id=4512
- Uploaded data for two cycles

Dataset Name	ID	Status	Date	Submission Loading Status	Date of QA	QA Status	QA Errors
Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) Data Coordination Resource	57091	Private	03/31/2023	Upload Completed	05/08/2023	QA Passed	None
Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD) Data Coordination Resource	60721	Private	09/27/2023	Upload Completed	11/03/2023	QA Passed	None

Data Structures	#
Approved by NDA	24
Requested (to be approved or changed)	20
Total data structures	44

On Hold: Expand Functionality of Database

- Aims:
  - Implement Leaf ® and user-friendly interface to query data base (cohorts)
  - Create dashboard for Administrative Resource to track consortium progress
- Four projects have provided data (largest N = 14)
  - Need more data to define and test Leaf concepts
  - Concepts become building blocks to create cohorts in Leaf®

Data Access Committee

Leah Wetherill – chair

Tina Chambers

Sarah Mattson

Elizabeth Powell

Jennifer Thomas

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Updated Data Use Agreement

- Previously data access granted for one year from data of approval
  - Renewal with one-year report
- Access to data expires/renews February 15
  - Can be renewed through one-year report
- Removed out-of-date text

- Added suggested language to respect mothers and individuals affected by PAE

Updated Data Use Agreement

- Added required language for publications, posters, etc
  - **Acknowledgement:** *Data used in the preparation of this article were obtained from CIFASD consortium (https://cifasd.org/data-sharing/; **DOI/**), supported by the National Institute of Alcohol Abuse and Alcoholism (NIAAA). This manuscript reflects the views of the authors and may not reflect the opinions or views of NIAAA or CIFASD consortium investigators.*

  - **Metadata DOI:** *This is a multisite study supported by the National Institute of Alcohol Abuse and Alcoholism **under award numbers**…. CIFASD investigators designed and implemented the study and/or provided data but did not necessarily participate in the analysis or writing of this report. A list of CIFASD investigators can be found at https://cifasd.org/research-projects/phase2/, (phase 3 and 4). For up-to-date information on the study, visit https://cifasd.org.*

In Progress: Updates to Data Sharing Page

- Downloadable PDF of data request form
- Include links to CIFASD Projects for phases 1-4
  - For example: https://cifasd.org/research-projects/phase3/
  - Link includes a description of each project, PI name, etc.
- Finalize CIFASD 4 data (in progress)
  - All CIFASD 4 projects provided description of PAE & diagnosis
  - Most projects have final data files their Teams folders
- Downloadable excel file with detailed information for cross-project CIFASD 4 data

https://cifasd.org/data-sharing/

CIFASD 4 Data (Example)

PI	Description	Type	Genetic data	Cytokine data	3D	Dysmo	# unique IDs	Mult visits
Blanchard, Mooney	Effects of PAE on gut microbiome	Mice						
Chambers	Early predictors of FASD	Human	✓	✓	✓	✓	74-165	✓
Coles	Effect of PAE on health of adults	Human	✓	✓	✓	✓	382	✓
Jones	Dysmorphology	Human				✓	476	
Mattson	FASD-Tree	Human					129	
Petrenko, Tapparello	Feasibility, FMF Connect	Human	✓		✓		105, 129	✓
Weinberg	Effect of PAE on immune in adults	Human	✓	✓	✓	✓	71	
Wozniak	Neuroimaging	Human	✓		✓	✓	96	✓

In Progress: Updates to Data Sharing Page

	Phase 1	Phase 2	Phase 3	Phase 4
Dysmorphology	X	X	X	X
Neurobehavior		X	X	X
FASD-Tree				X
MRI		X	X	X
3D Imaging	X	X	X	X
Adult				X
Infant		X	X	X
Genetics		X	X	X
Cytokine			X	X
Mouse			X	X
Zebrafish			X	X

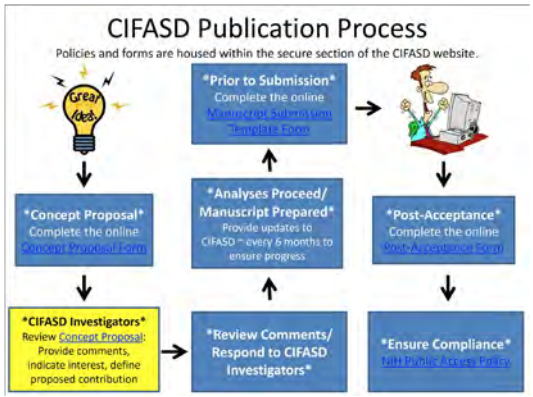
Will finalize updates before RSA – PLEASE include the link in your talks, posters, student posters, etc!!!
https://cifasd.org/data-sharing/

CIFASD 4 Data Availability

- Final data files due November 1, 2024
- Embargo on CIFASD 4 data ends December 2, 2024
- Embargo on cytokine data ends December 2, 2024
- CIFASD 4 available data will include all clinical, basic science, and UH2 data (or results, as appropriate)
- CIFASD 4 data will be separate from CIFASD 5 data

CIFASD Publications Policy Committee

- ★Sarah Mattson, PI (Chair)
- ★Joanne Weinberg, PI
- ★John Hannigan, SAB
- ★Elizabeth Powell, NIAAA
- ★Jennifer Thomas (ex officio, AdminR representative)



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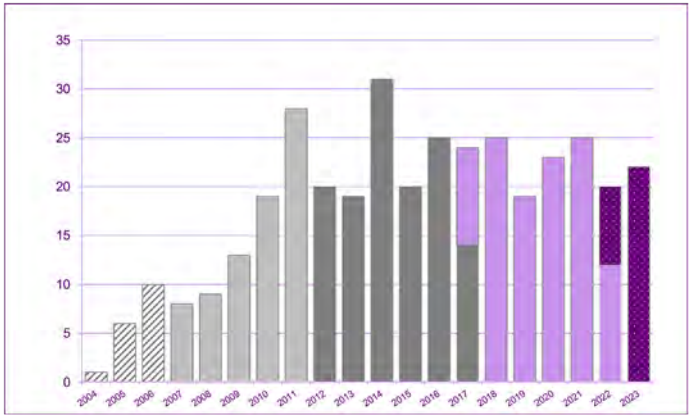
Publications by Year per PubMed

★Total Publications Citing CIFASD Grants = **367**



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Steps / Links

- Take action to ensure all of your CIFASD publications are in the proper stage of the **CIFASD Publication Policy protocol**:

You have an idea for a paper, complete the Concept Proposal Form.

You want to view/comment on concept proposals, go to the Concept Proposals (Viewing) document.

Google login is required to view and comment on concept proposals.

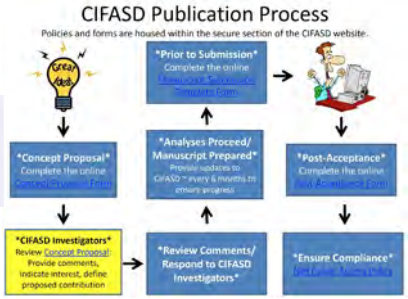
You are submitting a paper, complete the Manuscript Submission Template Form.

Your paper has been accepted, complete the Post-Acceptance Form.

vanderv@sdsu.edu Switch account

A copy of your responses will be emailed to the address you provided.

Submit



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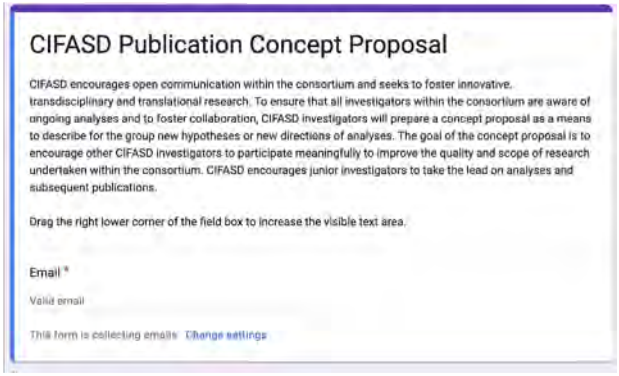
Drive

CIFASD Publication Concept Proposal



- ★ Used to help promote collaborative CIFASD research manuscripts
- ★ The submitter completes the form fields and enters updates as the concept moves into manuscript preparation modes and beyond
- ★ Total # Completed = 126 (CIFASD5 = 15)

4

Title of this concept proposal. *
Short answer text
CIFASD Publication Concept Proposal
Brief summary of this concept proposal's hypothesis/concept. *
Recommended 2-3 sentences.
Long answer text
Prior to submitting the outcome of this concept proposal in manuscript form to a journal, a CIFASD investigator must complete the online Manuscript Submission Form in order to receive CIFASD approval.
Please enter your initials here to indicate you are aware of this requirement.
Scope of analysis/data. *
Recommended < 1 paragraph.
Long answer text
Timeline for completion. *
Long answer text

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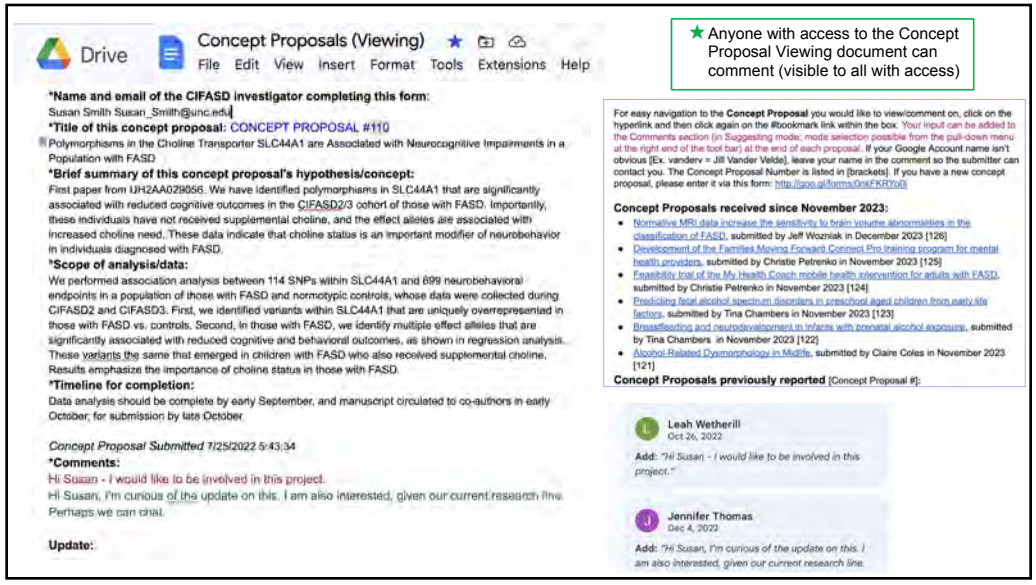
Drive
Concept Proposals (Viewing)
File Edit View Insert Format Tools Extensions Help
★Anyone with access to the Concept Proposal Viewing document can comment (visible to all with access)
*Name and email of the CIFASD investigator completing this form:
Susan Smith Susan_Smith@unc.edu
*Title of this concept proposal: CONCEPT PROPOSAL #110
Polymorphisms in the Choline Transporter SLC44A1 are Associated with Neurocognitive Impairments in a Population with FASD
*Brief summary of this concept proposal's hypothesis/concept:
First paper from UH2AA029056. We have identified polymorphisms in SLC44A1 that are significantly associated with reduced cognitive outcomes in the CIFASD2/3 cohort of those with FASD. Importantly, these individuals have not received supplemental choline, and the effect alleles are associated with increased choline need. These data indicate that choline status is an important modifier of neurobehavior in individuals diagnosed with FASD.
*Scope of analysis/data:
We performed association analysis between 114 SNPs within SLC44A1 and 699 neurobehavioral endpoints in a population of those with FASD and normotypic controls, whose data were collected during CIFASD2 and CIFASD3. First, we identified variants within SLC44A1 that are uniquely overrepresented in those with FASD vs. controls. Second, in those with FASD, we identify multiple effect alleles that are significantly associated with reduced cognitive and behavioral outcomes, as shown in regression analysis. These variants the same that emerged in children with FASD who also received supplemental choline. Results emphasize the importance of choline status in those with FASD.
*Timeline for completion:
Data analysis should be complete by early September, and manuscript circulated to co-authors in early October, for submission by late October
Concept Proposal Submitted 7/25/2022 5:43:34
*Comments:
Hi Susan - I would like to be involved in this project.
Hi Susan, I'm curious of the update on this. I am also interested, given our current research line. Perhaps we can chat.
Update:
For easy navigation to the Concept Proposal you would like to view/comment on, click on the hyperlink and then click again on the #bookmark link within the box. Your input can be added to the Comments section (in Suggesting mode; mode selection possible from the pull-down menu at the right end of the tool bar) at the end of each proposal. If your Google Account name isn't obvious [Ex. vanderv = Jill Vander Velde], leave your name in the comment so the submitter can contact you. The Concept Proposal Number is listed in [brackets]. If you have a new concept proposal, please enter it via this form: http://goo.gl/forms/OnkFKRYo0l
Concept Proposals received since November 2023:
Normative MRI data increase the sensitivity to brain volume abnormalities in the classification of FASD, submitted by Jeff Wozniak in December 2023 [126]
Development of the Families Moving Forward Connect Pro training program for mental health providers, submitted by Christie Petrenko in November 2023 [125]
Feasibility trial of the My Health Coach mobile health intervention for adults with FASD, submitted by Christie Petrenko in November 2023 [124]
Predicting fetal alcohol spectrum disorders in preschool aged children from early life factors, submitted by Tina Chambers in November 2023 [123]
Breastfeeding and neurodevelopment in infants with prenatal alcohol exposure, submitted by Tina Chambers in November 2023 [122]
Alcohol-Related Dysmorphology in Midlife, submitted by Claire Coles in November 2023 [121]
Concept Proposals previously reported [Concept Proposal #]:
Leah Wetherill
Oct 26, 2022
Add: "Hi Susan - I would like to be involved in this project."
Jennifer Thomas
Dec 4, 2022
Add: "Hi Susan, I'm curious of the update on this. I am also interested, given our current research line."

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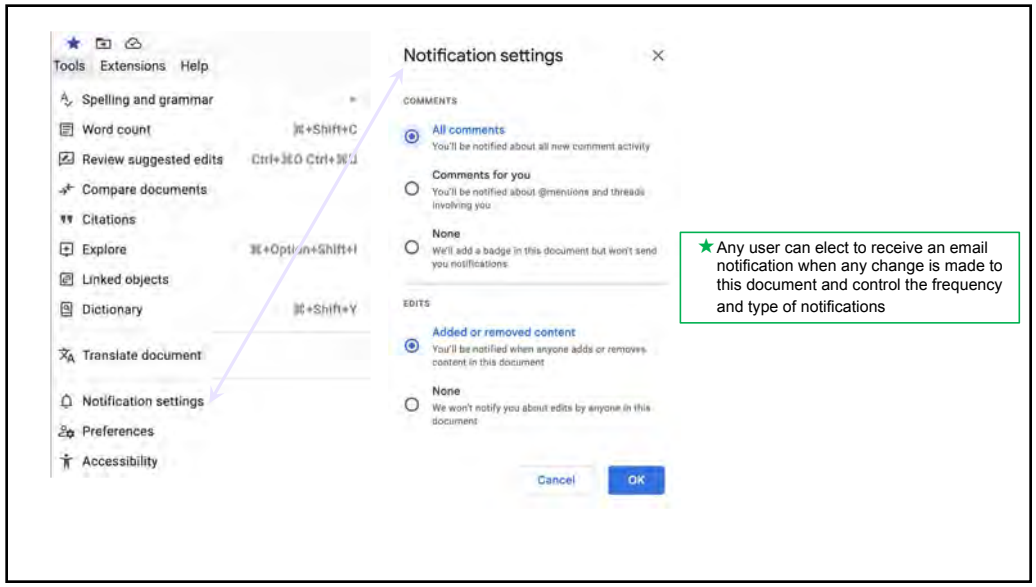

★ Any user can elect to receive an email notification when any change is made to this document and control the frequency and type of notifications

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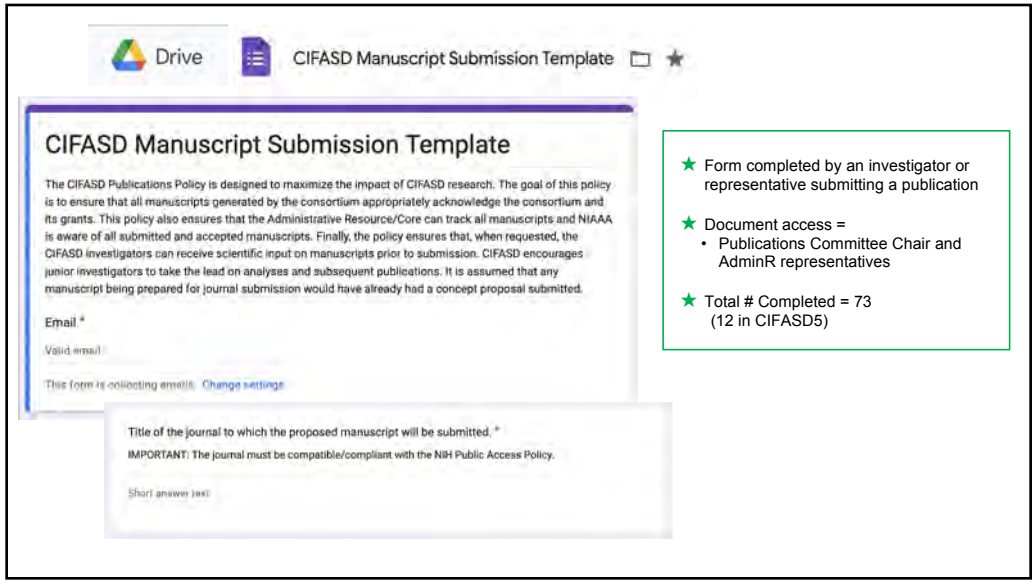

★ Form completed by an investigator or representative submitting a publication

★ Document access =
- Publications Committee Chair and AdminR representatives

★ Total # Completed = 73
(12 in CIFASD5)

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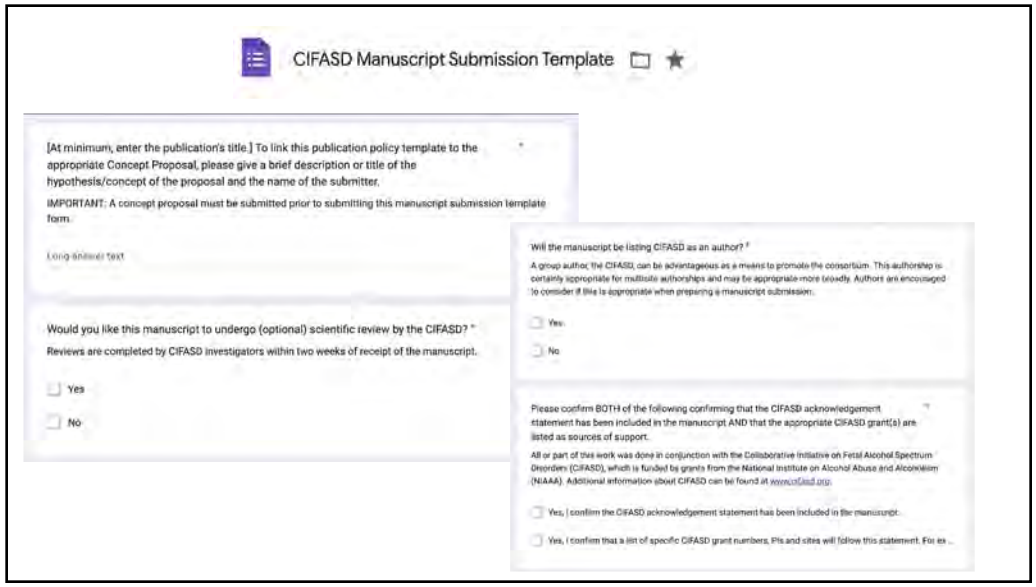

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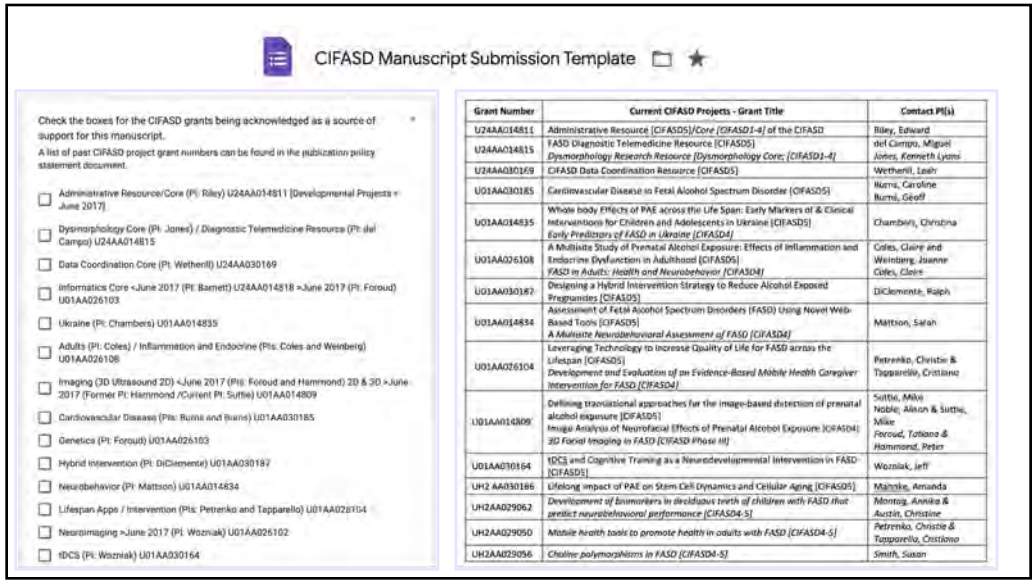

Grant Number	Current CIFASD Projects - Grant Title	Contact PI(s)
U24AA014811	Administrative Resource [CIFASDS]/*Core [CIFASD1-4]* of the CIFASD	Riley, Edward
U24AA014815	FASD Diagnostic Telemedicine Resource [CIFASDS] *Dysmorphology Research Resource [Dysmorphology Core; [CIFASD1-4]*	del Campo, Miguel *Jones, Kenneth Lyons*
U24AA030169	CIFASD Data Coordination Resource [CIFASDS]	Wetherill, Leah
U01AA030185	Cardiovascular Disease in Fetal Alcohol Spectrum Disorder [CIFASDS]	Burns, Caroline Burns, Geoff
U01AA014835	Whole body Effects of PAE across the Life Span: Early Markers of & Clinical Interventions for Children and Adolescents in Ukraine [CIFASDS] *Early Predictors of FASD in Ukraine [CIFASD4]*	Chambers, Christina
U01AA026108	A Multisite Study of Prenatal Alcohol Exposure: Effects of Inflammation and Endocrine Dysfunction in Adulthood [CIFASDS] *FASD in Adults: Health and Neurobehavior [CIFASD4]*	Coles, Claire and Weinberg, Joanne *Coles, Claire*
U01AA030187	Designing a Hybrid Intervention Strategy to Reduce Alcohol Exposed Pregnancies [CIFASDS]	DiClemente, Ralph
U01AA014834	Assessment of Fetal Alcohol Spectrum Disorders (FASD) Using Novel Web-Based Tools [CIFASDS] *A Multisite Neurobehavioral Assessment of FASD [CIFASD4]*	Mattson, Sarah
U01AA026104	Leveraging Technology to Increase Quality of Life for FASD across the Lifespan [CIFASDS] *Development and Evaluation of an Evidence-Based Mobile Health Caregiver Intervention for FASD [CIFASD4]*	Petrenko, Christie & Tapparello, Cristiano
U01AA014809	Defining translational approaches for the image-based detection of prenatal alcohol exposure [CIFASDS] Image Analysis of Neurofacial Effects of Prenatal Alcohol Exposure [CIFASD4] *3D Facial Imaging in FASD [CIFASD Phase III]*	Suttie, Mike Noble, Alison & Suttie, Mike *Foroud, Tatiana & Hammond, Peter*
U01AA030164	tDCS and Cognitive Training as a Neurodevelopmental Intervention in FASD [CIFASDS]	Wozniak, Jeff
UH2 AA030186	Lifelong impact of PAE on Stem Cell Dynamics and Cellular Aging [CIFASDS]	Mahnke, Amanda
UH2AA029062	*Development of biomarkers in deciduous teeth of children with FASD that predict neurobehavioral performance [CIFASD4-5]*	Montag, Annika & Austin, Christine
UH2AA029050	*Mobile health tools to promote health in adults with FASD [CIFASD4-5]*	*Petrenko, Christie & Tapparello, Cristiano*
UH2AA029056	*Choline polymorphisms in FASD [CIFASD4-5]*	*Smith, Susan*

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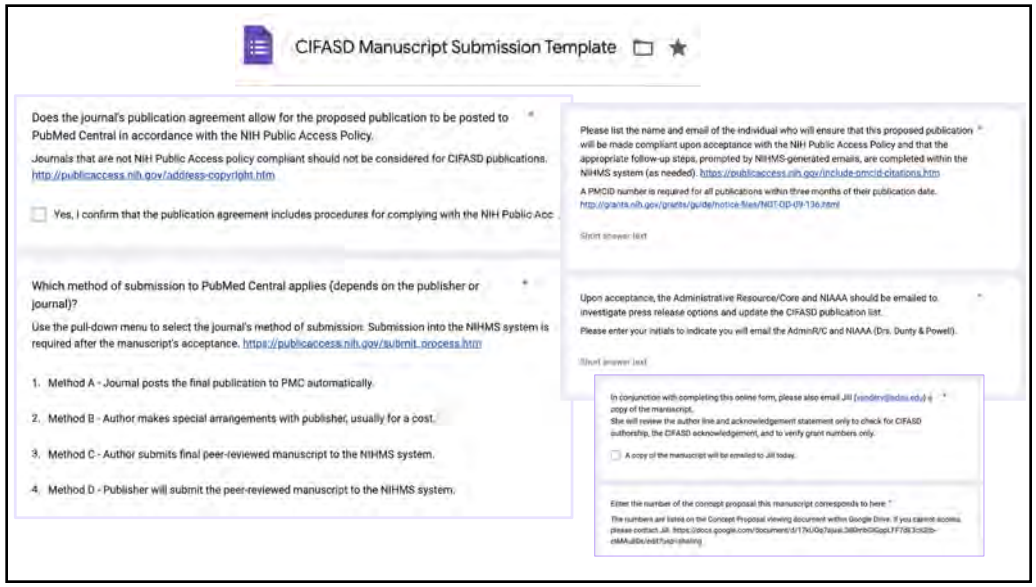
CIFASD Manuscript Submission Template
Does the journal's publication agreement allow for the proposed publication to be posted to PubMed Central in accordance with the NIH Public Access Policy.
Journals that are not NIH Public Access policy compliant should not be considered for CIFASD publications.
http://publicaccess.nih.gov/address-copyright.htm
Yes, I confirm that the publication agreement includes procedures for complying with the NIH Public Acc
Which method of submission to PubMed Central applies (depends on the publisher or journal)?
Use the pull-down menu to select the journal's method of submission. Submission into the NIHMS system is required after the manuscript's acceptance. https://publicaccess.nih.gov/submit_process.htm
1. Method A - Journal posts the final publication to PMC automatically.
2. Method B - Author makes special arrangements with publisher, usually for a cost.
3. Method C - Author submits final peer-reviewed manuscript to the NIHMS system.
4. Method D - Publisher will submit the peer-reviewed manuscript to the NIHMS system.
Please list the name and email of the individual who will ensure that this proposed publication will be made compliant upon acceptance with the NIH Public Access Policy and that the appropriate follow-up steps, prompted by NIHMS-generated emails, are completed within the NIHMS system (as needed). https://publicaccess.nih.gov/include-pmcid-citations.htm
A PMCID number is required for all publications within three months of their publication date.
http://grants.nih.gov/grants/guide/notice-files/NOT-OD-09-136.html
Short answer text
Upon acceptance, the Administrative Resource/Core and NIAAA should be emailed to investigate press release options and update the CIFASD publication list.
Please enter your initials to indicate you will email the AdminR/C and NIAAA (Drs. Dunty & Powell).
Short answer text
In conjunction with completing this online form, please also email Jill
copy of the manuscript.
She will review the author line and acknowledgement statement only to check for CIFASD authorship, the CIFASD acknowledgement, and to verify grant numbers only.
A copy of the manuscript will be emailed to Jill today.
Enter the number of the concept proposal this manuscript corresponds to here:
The numbers are listed on the Concept Proposal viewing document within Google Drive. If you cannot access, please contact Jill.

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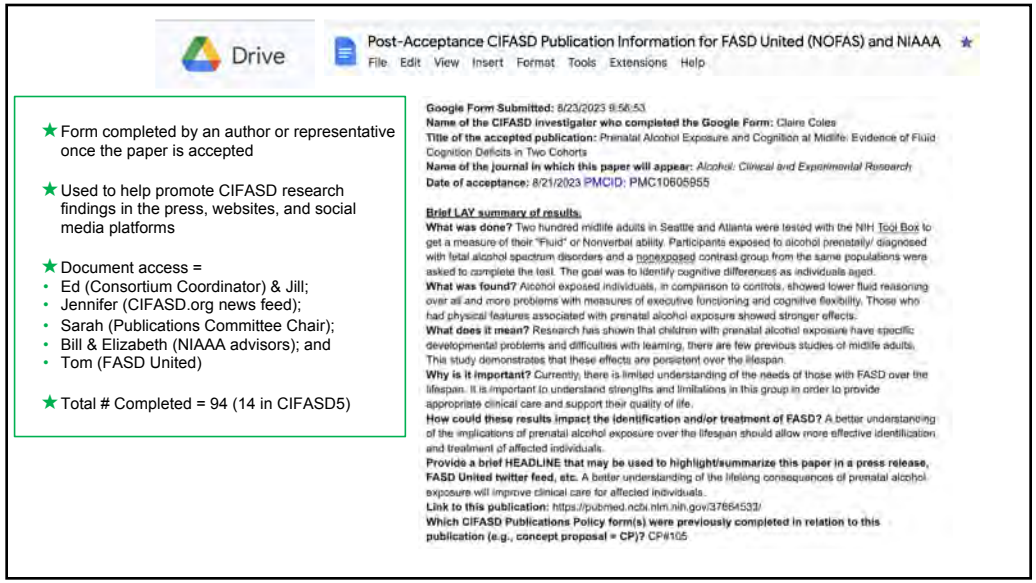
Drive
Post-Acceptance CIFASD Publication Information for FASD United (NOFAS) and NIAAA
File Edit View Insert Format Tools Extensions Help
★ Form completed by an author or representative once the paper is accepted
★ Used to help promote CIFASD research findings in the press, websites, and social media platforms
★ Document access =
• Ed (Consortium Coordinator) & Jill;
• Jennifer (CIFASD.org news feed);
• Sarah (Publications Committee Chair);
• Bill & Elizabeth (NIAAA advisors); and
• Tom (FASD United)
★ Total # Completed = 94 (14 in CIFASD5)
Google Form Submitted: 8/23/2023 9:56:53
Name of the CIFASD investigator who completed the Google Form: Claire Coles
Title of the accepted publication: Prenatal Alcohol Exposure and Cognition at Midlife: Evidence of Fluid Cognition Deficits in Two Cohorts
Name of the journal in which this paper will appear: Alcohol: Clinical and Experimental Research
Date of acceptance: 8/21/2023 PMCID: PMC10605955
Brief LAY summary of results:
What was done? Two hundred midlife adults in Seattle and Atlanta were tested with the NIH Toolbox to get a measure of their "Fluid" or Nonverbal ability. Participants exposed to alcohol prenatally/ diagnosed with fetal alcohol spectrum disorders and a nonexposed contrast group from the same populations were asked to complete the test. The goal was to identify cognitive differences as individuals aged.
What was found? Alcohol exposed individuals, in comparison to controls, showed lower fluid reasoning over all and more problems with measures of executive functioning and cognitive flexibility. Those who had physical features associated with prenatal alcohol exposure showed stronger effects.
What does it mean? Research has shown that children with prenatal alcohol exposure have specific developmental problems and difficulties with learning, there are few previous studies of midlife adults. This study demonstrates that these effects are persistent over the lifespan.
Why is it important? Currently, there is limited understanding of the needs of those with FASD over the lifespan. It is important to understand strengths and limitations in this group in order to provide appropriate clinical care and support their quality of life.
How could these results impact the identification and/or treatment of FASD? A better understanding of the implications of prenatal alcohol exposure over the lifespan should allow more effective identification and treatment of affected individuals.
Provide a brief HEADLINE that may be used to highlight/summarize this paper in a press release, FASD United twitter feed, etc. A better understanding of the lifelong consequences of prenatal alcohol exposure will improve clinical care for affected individuals.
Link to this publication: https://pubmed.ncbi.nlm.nih.gov/37664533/
Which CIFASD Publications Policy form(s) were previously completed in relation to this publication (e.g., concept proposal = CP)? CP#105

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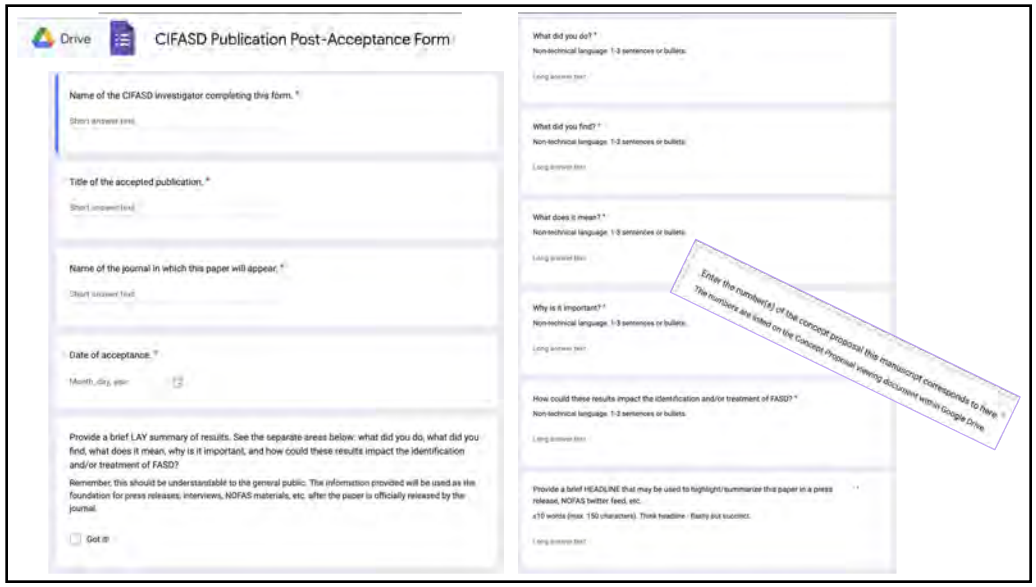

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CIFASD Publication Acknowledgement

- ★ Each publication should include the following statement:
  - ★ All or part of this work was done in conjunction with the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD), which is funded by grants from the National Institute on Alcohol Abuse and Alcoholism (NIAAA). Additional information about CIFASD, including information about data sharing, can be found at www.cifasd.org.
  - ★ New exact wording will be emailed out in the revised Publication Policy PDF.

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CIFASD as an Author

Per the CIFASD Publications Policy:

★**CIFASD Author**: A group author, the CIFASD, can be advantageous as a means to promote the consortium. This authorship is certainly appropriate for multisite authorships and may be appropriate more broadly. Authors are encouraged to consider if this is appropriate when preparing a manuscript submission.

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Recent **Qs** & Discussion

★ If a CIFASD PI or team member is working on a publication that is not reporting on CIFASD data, should they acknowledge the CIFASD grant they receive effort from as a source of support?

★ If a trainee was working on a U01 with CIFASD data and then later publishes on it while supported by an F31, it is appropriate to cite both grants, correct?

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CIFASD Publications Policy Committee

Objective and General Guidelines

The CIFASD Publications Policy is designed to maximize the impact of CIFASD research. The goal of this policy is to ensure that all manuscripts generated by the consortium appropriately acknowledge the consortium and its grants. This policy also ensures that the Administrative Core can track all manuscripts and NIAAA is aware of all submitted and accepted manuscripts. Finally, the policy ensures that, when requested, the CIFASD investigators can receive scientific input on manuscripts prior to submission.

CIFASD encourages junior investigators to take the lead on analyses and subsequent publications.

It is assumed that any manuscript being prepared for journal submission would have already had a concept proposal submitted and posted in the password protected area of the CIFASD website. It is also assumed that CIFASD investigators would have reviewed the concept proposal and contacted the individual who submitted the concept proposal to indicate their interest in participating in the analyses (and indicating how they would contribute). Lastly, it is assumed that individuals indicating their interest to participate in analyses will be contacted by the individual who commented on the concept proposal to discuss potential collaborative analyses.

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CIFASD Publications Policy Committee

Publication Policy

1) **Manuscript Submission Template**: CIFASD investigators will complete the online manuscript submission template for review by Administrative Core personnel prior to the submission of any manuscript. Submissions will be reviewed within 1 week of receipt and the submitter will be notified via email. The following information will be collected within the template along with a copy of the manuscript:
    - Title of the specific journal to which the manuscript will be submitted.
    - Confirmation that the appropriate acknowledgement is included in the manuscript.
    - Confirmation that the appropriate grants are listed in the manuscript.
    - Confirmation that the journal's publication agreement allows for the paper to be posted to PubMed Central in accordance with the NIH Public Access Policy. Identification of which submission method will be used and the individual who will ensure compliance.
2) **Scientific Review:** As requested, the publication policy will allow the CIFASD Administrative Core to coordinate a scientific review of the manuscript. This will be provided within 2 weeks of the receipt of the manuscript.
3) **CIFASD Author**: A group author, the CIFASD, can be advantageous as a means to promote the consortium. This authorship is certainly appropriate for multisite authorships and may be appropriate more broadly. Authors are encouraged to consider if this is appropriate when preparing a manuscript submission.
4) **CIFASD Acknowledgement Text**: Each publication should include the following statement.

All or part of this work was done in conjunction with the Collaborative Initiative on Fetal Alcohol Spectrum Disorders (CIFASD), which is funded by grants from the National Institute on Alcohol Abuse and Alcoholism (NIAAA). Additional information about CIFASD can be found at www.cifasd.org. [A list of specific CIFASD grant numbers, PIs and sites should follow this statement.]

The following page includes reference tables displaying all CIFASD grant numbers, titles and contact PIs.

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