**Cross-cultural consortium on irritability: Steering Committee Meeting Notes**

**10/6/2022**

**Purpose of this meeting**: Discuss results of the [interest survey](https://redcap.research.yale.edu/surveys/?s=Y9FHRL8RFKPF7LC3)

* Review results of the survey
* Discuss future directions

**Survey Results**

* 67 responders
* Data available
  + 34 samples to contribute, 12 with international data to contribute
  + Of the 22 US samples, there are diverse racial demographics and means collecting of community data
* Conference
  + Most interest in hybrid 2023 conference
* Research question interests
  + Symptom presentation/threshold
  + Measurement
  + Normative
  + Parent-child relation
  + Longitudinal outcomes
  + Risk/protective factors
  + Comorbidities
  + Pathophysiology
  + Genetics
  + Treatment
  + Phenotypes in childhood
  + Data sharing
  + Differences across developmental stages
  + Cultural/racial/ethnic influences on perception of irritability

**Survey Discussion**

**Response rate**

* Everyone echoed excitement about the very high response rate!

**Vermont Irritability Conference**

* There was an inquiry about the Vermont Irritability Conference (in response to a survey comment left by Gabrielle Carlson)
* Ellen and Argyris are on the steering committee for the Vermont Irritability Conference, and it is more domestic-focused
* The large amount of data that already exists is a positive, but harmonizing this data and organizing it to move forward may be difficult.

**Qualitative data conversation**

* It’s interesting there’s relatively less interest in qualitative data (37%), and this is where community engagement can come in.
* This may be due to the population that completed this survey, as it may have been mostly quantitative researchers. Both said this may be a reason to pursue it then.
* Could target qualitative researchers and bring them in to do this work and use their expertise. Can do engagement and quantitative research. Don’t want to rush the engagement work.
* Wan-Ling has reached out to a few qualitative researchers and not had any success; Argyris’s connections would be helpful, Jennifer also has some new connections to try. Potentially bringing in a qualitative researcher to speak at the conference could be useful

**Timeline**

* December 2022 is feeling soon for a potential conference.
* Mentioning of garnering some early energy toward a manuscript soon with currently available data, and then planning a conference for later, followed by engagement and collection- motivation might be stronger if we get an early win, so to speak
* Next steps then: how do we want to retrieve this data from everyone who is willing to share it?

**Data Consolidation**

* Could potentially collect summary statistics rather than individual level data
* Could collect research questions first and then contributors can decide if their data will be valuable in answering the questions
* Have 34 PIs – could be more datasets (if each PI has more than one), or fewer (if multiple PIs collaborated in collection)
* Some regulatory steps to take around getting permission to share data
* Would we want a meeting with these 34 responders, or a secondary survey more specific to data-sharing?
* Could first generate questions as this steering committee and send those to the 34 researchers, so they can specify which questions they are interested in and hoping to address with their data
* Massi has worked with [this website](https://www.maelstrom-research.org/) to consolidate data

**Action Items**

* Wan-Ling to send around a data-table with 34 researchers, their type of data, their interests, their regulatory barriers
* Wan-Ling to pull data from the 34 datasets this week
* Volunteers (Ellen, Jennifer, Manish, Massi) and Wan-Ling to form a sub-group to spearhead the creation of the manuscript. They’ll meet a few times in October and keep the larger committee updated with these efforts