

Team meeting

Date: 3/14/19

Present: Tiffany Hutchins, Laura Lewis, Liliane Savard, Hope Morris, Emily Coderre, Claudia Abbiati. Patricia Prelock absent.

Roles

Minutes = Claudia

Equalizer = None

Time keeper = Emily Coderre

Updates

Liliane has been looking for a parent advocate. Vermont Family Network has asked 2 families who have declined and she is currently pursuing a third.

Liliane provided updates on new information/ notes on Dropbox. Tiffany, Hope, and Laura to have invitations sent to their med.uvm.edu email accounts.

Re: EMR update. Liliane has learned about consent for re-contact or how to do a full-questionnaire process for potential participant recruitment. Per Liliane, Patty has verbalized interest in a secure fax number to receive this information from ASD Clinic.

Advocate advisors, stipend, funding

Haven't secured a self-advocate for ASD. Liliane plans to go through Green Mountain Self-Advocate.

Additional Team Members

Liliane has become aware of more members for this group, such as Shelley Velleman and Deborah Hertz.

Review the questionnaire

Liliane has updated this and included a table per the recommendation of Tiffany. Will be tricky to input into REDCap (task for Claudia).

Tiffany worried about diagnosis of ASD. Parents could be worried about siblings having ASD diagnosis, but don't know (suspected). This was changed to add a third box "suspected" (Now: yes, no, suspected).

Tiffany wants a language item, but feels there is a better way to ask it. Maybe we have something about language (e.g., non-verbal, limited use of language such as 2-3 word utterances, uses language flexibility and appropriately).

Liliane: Keep the first table, but add a column about expressive language.

Emily: Can it be setup so more than 1 item can be selected. Can we have a language comprehension piece in addition to expressive language?

Add “language” item (nonverbal, limited verbalization, fluent?) and “Age of diagnosis” item.

Laura wants information on age, but doesn’t need a whole column on this.

Discuss quality improvement initiatives

Liliane had a choice of quality improvement initiatives. QI = when you collect data for the purpose of improving training/ practice, not published. In this case, you don’t need IRB approval because it is for internal practices.

All the pediatricians at UVMHC are mandated to do QI training and initiatives as part of their work. If we put QI and research in our project aims section, we can become interesting as a group (to school districts trying to improve retention of children with ASD, pediatricians who work with families/ children with ASD, CDCI who provides training to providers). We could do QI research in collaboration with pediatricians/ specialists, such as Jeremiah Dickerson.

Hope: Sounds like VCHIP grants would be helpful. Lots of QI grants through college of medicine.

For VCHIP, you can include an IRB approved study if appropriate.

We need to be clear on expectations and how we connect with others.

Hope: The way to go is to access the grant funding. This will remove some of these concerns around expectations. Funding supports your project, so you don’t have to worry about doing QI for someone else.

Laura: This collaborative should be more owned by QI and clinicians, and the researchers are another component on it.

Vermont Autism Collaborative = as the new name. All in attendance agree on the new name.

Hope is on the Autism Working Group and there are several people from all around the state. This would be a great group to bring in, but they may not have the time and ability to take action.

Discuss IRB sections

How are we going to access the data?

- Committee? Any three individuals who are available (parent advocate, self-advocate), except data manager.
- Per Liliane, we need to mention studies that have been approved previously (already have IRB approval).
- We have a limit of number of contacts.
- Contacting participants from multiple studies. This should be based on the exclusion criteria of researchers. Participants should be not excluded from other studies if they are currently enrolled in one unless this meets a study's exclusion criteria. Maximum times per month?
- Emily: We could send out a monthly email about studies that are currently being conducted and participants can indicate which studies are they interested in. These emails will be individualized based on which ones they meet inclusion criteria for. Then they can follow a direct link to the study or PI.

What do we agree to put in? Good faith agreement?

Next Meeting: Late April.

Topics: Data manager, number of times contact (how many times and who does).

Liliane to email team members with an action list so we know what to bring and to come prepared with for the next meeting.