

COST ESSEA

Work Group 1 and Work Group 2 Meeting in LONDON, September 9th – 10th 2013

Day 1 – September 9th

Attendees:

Terje Falck-Ytter, Bonnie Auyeung, Tony Charman, Anneli Kyllainen, Isabel Gammer, Przemek Tomalski, Teea Gliga, Gian Candrian, Andreas Muller, Luke Mason, Eric Zander, Petra Warreyn, Sarah Lloyd-Fox, Herbert Roeyers, Mark Johnson, Sven Bolte, Greg Pasco, Lizzie Shephard, Anna Blasi, Kim Davies, Ricardo Canal Bedia, Marie Gomot, Erica Salomone.

Welcome and introduction

Recap of Bilbao meeting (Terje Falck-Ytter; TFY)

Update on progress of key projects (either verbal or with slides), with group discussion of next steps:

- standardization of data handling (Emily Jones; EJ)
 - o meeting held at Birkbeck, with development of cross-site data handling guidelines
 - o series of mini-projects generated on EEG analysis (e.g. re-referencing, interpolation, artifact detection methods) and ET data collection (e.g. coding methods for fixation durations). Work ongoing.
 - o Development of newborn and 3m protocols. 3m protocol is designed to be low-cost, and could potentially be used at sites without developed sib programs.
 - Could develop similar protocols to 3m protocol for older age groups. Designed as a distance protocol, so that families can participate from a wide geographical area.
 - TC noted strengths of such a low cost protocol.
 - EJ/TG will work on developing set of standardized videos for 3m protocol with other partners (Maria-Luisa Scattoni, Vasu Reddy), and will then work on website to host and allow parents to upload clips.
 - o Clinical mapping – will be next step, discussed in current meeting. Przemek leading. Goal is to know availability of core measures in COST countries, so can begin to create broader research collaborations within early autism.
 - TC noted WHO drive to explore less expensive measures in order to increase research capacity. Good to map similar things within Europe.
- methodological trends in autism research (Sven Bölte, SB)
 - o group identified to run search strings.
 - o Search strings made (EEG, genetics, autism, ASD etc)
 - o Limited to children under 5 years.
 - o Examining affiliation, impact, developmental trends, technologies.
 - TC noted that iAAC has a global map of autism research, good to use as model.
- engaging community in research (Sue Fletcher Watson; SFW)

- goal is to gather information from autism community about work with at-risk infants. Will be useful for internal guidelines, forming consent forms, understanding what procedures families may be more or less supportive of, guiding use of language etc.
- initial calls held; draft procedure generated (focus groups, then parent questionnaire).
 - Focus groups will be in 4 countries (pragmatic), but then survey will expand to multiple COST countries (ideally all).
 - Possibility to use expertise or contacts developed from the Group 4 survey.
 - Suggestion for sites interested in translating to recruit Masters students.
- guiding young children with autism through experimental procedures (Anneli Kylliäinen; AK)
 - first draft has been prepared; further work will occur during meeting.
- technology mapping (Marie Gomot; MG)
 - We discussed the aim of this activity. It was noted that the value of detailed info on equipment is rather short lasting, and the consensus seemed to be that mapping of expertise is of more value. Potential output is internal or public 'database' for expertise info.
 - When an expertise network has been identified, could apply for a training grant to form a training network.
 - EJ suggested that EEG/ET conversations in EU AIMS could be migrated to expert groups in something like Linked In. Will talk with LM about this.
- internet assessment of child behavior (TFY)
 - Separate funding needed, thus not likely to be a regular COST activity.

1pm to 2pm Optional Talk

Professor April Benasich: 'Early plasticity in language development'.

2pm

Lunch

2.30 - 5 Individual project planning

Three groups were formed for parallel meetings:

- i) mapping availability and standardization of clinical measures across sites (Sven, Przemek)
- ii) engaging community in research (Sue FW)
- iii) guiding young children with autism through experimental procedures (Anelli)

5-6 Group discussion

- update from each mini group on plans for final year:

- i) mapping availability and standardization of clinical measures across sites (Sven, Przemek)
 - a. Primary strategy is to define key measures and ask representatives from all ESSEA countries to report on issues including availability, translations, standardization, copyright.
 - b. Timeline: Sept/October – prep spreadsheet; November – EU AIMS sites; by end of year, other sites. Paper April 2014.

- ii) engaging community in research (Sue FW)
 - a. Plan is to first create focus groups (in more than one country) with parents, practitioners, and people with ASD. Based on these discussions, a survey will be created and distributed via network. Timeline for this project is <12 months, and desired output is both communication guidelines and an scientific article.
 - iii) guiding young children with autism through experimental procedures (Anelli)
 - a. work is progressing and submission should be possible later this year. Autism Research possible outlet.
- discussion of future funding possibilities and conferences submissions.
- - possibility of forming an expertise training network raised.
 - Need for individual groups to form ideas for future funding was raised.
 - Key areas may include home protocols for testing infant sibs; innovative methods of working with low-functioning children.

Suggestion to consider a scientific panel at IMFAR, or alternatively a Special Interest Group (SIG) submission. Decision to continue these discussions in the near future. Mark Johnson informed about a likely invited symposium for high risk sibling studies at the 2013 ICIS to be organized by TFY.

Tony Charman informed about next years ESSEA activities:

MC meeting in April (Utrecht) NOT CONFIRMED

ESSEA conference, in September (Toulouse) NOT CONFIRMED

More information about these events will come during the next months.

6.30 Dinner.

Day 2 – September 10th

Parallel sessions:

- i) COST-EU-AIMS meeting
- ii) Continued mini group work