

COST ESSEA Meeting in Utrecht, April 7-8, 2014

Minutes: WG 1 and 2 Workgroup Meeting

1. Discussion of mini-projects:

- Anneli Kylliäinen provided feedback on manuscript that is being prepared on practical guidelines for experimental studies of children with ASD. Manuscript submitted to ECAP. Herbert suggested that future manuscripts should be forwarded to an alternative journal as there are a number that have been submitted to date to ECAP. Agreed to determine appropriate journals on an article by article basis. Sven Bölte discussed infancy screening instrument-mapping project (EU AIMS VS REST OF EUROPE). Some data are awaited and several groups expressed an interest in submitting information. The implications of using translated instruments that are under copyright was discussed. Smaller countries bear substantial costs with translating instruments and a source of funding should be identified to support this (Mark Johnson suggested that the Gates Foundation might be a potential source). This could be a recommendation from the paper.
- Systematic review of publications in field of early ASD research conducted in Europe relative to rest of world. Economic indicators and influence on ASD research.
- Survey on ethical procedures. This is being organized by ethical considerations of ASD research – surveying experts. There was no update
- Engaging in autism research and ethical considerations (Astrid Vicente + Sue Fletcher Watson). Focus groups (parents, professionals, adult self-advocates) to develop a questionnaire to ask target groups about their experiences of participating in autism research. Questionnaire is being translated prior to being sent out to groups. Astrid will circulate the questionnaire to those who are interested in translating the questionnaire into their own language for implementation. Groups still have time to participate in this project if they are willing to circulate the questionnaire by the deadline (May xx)
- Standardization and harmonization of EEG and eye tracking data collection and analysis. Nothing new to report.

Looking back – evaluating WG1/2 activities:

- Evaluation of the WG activities will inform the feedback to COST at the end of the project.
- Establishment of a network and making connections across the different countries.
- Possibly write a position paper on subject of Early Autism Research in Europe to influence social policy and future research (that synchronizes with point 3 (looking to the future))

Looking Forward – continuing the actions efforts into the future:

- Future conference submissions – e.g. Symposia at IMFAR, Society for Research in Child Development. Symposia should be discussed and finalized at the meeting in Toulouse. (This is relevant to all work groups)
- Future funding – look at next year's calls, ask COST office and NCPs for advice.
- Erasmus + - Funding for education and training. Collaboration, knowledge alliances, joint masters programs – could be useful for the development of a fellowship scheme growing out of the COST action.
- Przemek Tomalski agreed to develop a complete mailing list for WG1/2

WG 1 & 2 Breakout session 07/04/14 and 08/04/14

Review of the objectives of WG1 and WG2 in Memorandum of Understanding

What metrics best reflect the activities?

- Projects (Circulate to group for feedback)(Peter):
 - o What new projects were developed as a result of the participation in COST
 - o Were research projects established between groups sharing the same protocols/ objectives or analytical methods?
 - o Development of collaborations with other disciplines (E.g. infant experimental scientists not previously involved in autism research)
 - o Did projects involve ESRs?
- Literature based reviews on state of the art to identify gaps and needs for further development (Sven/ Terje)
- Questionnaire based surveys on state of the art and to identify gaps and needs for further development (Sven/ Terje)
- Outputs of STSMs (Astrid) between labs for training. Training School (Terje). Method sharing (Emily).

Outputs (Peter):

- Publications (Papers/ Conference proceedings (posters/ oral presentations) (Circulate to group for feedback)*
- Grants (in prep/ submitted/ approved) (Circulate to group for feedback)*
*These should highlight the involvement of ESRs
- General dissemination (e.g. Lay public, other professionals, general media)
- Training of other non-expert professionals

AOB:

Future Directions (WG1/2):

- Distribution list for WGs, will facilitate circulation of funding opportunities (Przemyslaw)
- Dissemination project - Dissemination of literature on early signs and symptoms of ASD to all countries
- Post COST networking activities – satellite meeting at European conference establishing a network, inter lab exchange – MOA – hosting of students, Erasmus + (students/ other academic work, masters programs)(potential funding), Marie Curie, ASSIST-ID
- New collaborations? Strengthening of existing collaborations – Growth of collaborations within the consortium – funding opportunities - identification
- Relationship with EU AIMS??
- Position paper (Screening. evaluation, intervention)– Consortium as a whole – current expertise, where gaps are, future directions. Possible journals - European Journal of Paediatrics/ ECAP/ Specialists.
 - o Screening – 1/ screening methods in Europe/ which countries have existing screening programs 2/ Ethics surveys 3/ EAR study
 - o Evaluation – 1/ Lit review of novel methods in at risk/ ASD infants 2/ Projects with common evaluation protocols
 - o Interventions – 1/ TAU 2/ Mapping of interventions...? Others

- Future funding – lobbying through NCPs for H2020, discussions with NCPs for feedback at the Toulouse meeting. Identification of funding opportunities and subgroups to work together to pursue these.