

BM1004 Enhancing the Scientific Study of Early Autism (ESSEA)

Minutes of WG1+WG2 joint meeting and WG1 separate meeting in

Tours (France), 2012, Tuesday May 29th

JOINT WG1 & WG2 meeting

Participants: Sven Bölte (lead WG1), Terje Falck-Ytter (lead WG2), Herbert Roeyers (co-lead COST ESSEA), Catherine Barthelemy, Astrid Vicente, Silvana Markovska-Simska, David Mankuta, Marie Gomot (co-lead WG2), Chantal Kemner (co-lead WG1), Mayada Elsabbagh, Peter Marschik, Anneli Kyliäinen, Eva Dudova, Michal Hrdlicka

- STSMs were discussed, to get a sense of who would like to apply. Peter M was interested in sending a collaborator for eye tracking.
- Discussion on BASIS/ESSEA joint meeting on the September (18th to 20th) in London: Terje clarified the connection between WG1/WG2 and the BASIS group, and the participation of these WGs was discussed. Suggestion that relevant work from each WG should be presented at the Annual BASIS meeting in September. Chantal K is interested in presenting work plans from the Dutch group, and Peter M would like to present data on early signs of autism in Rett's syndrome. David Mankuta would like to present on maternal/neonatal blood biomarkers and intra-uterine environment in ASD singletons/multiplex families. An overview on the WG1 and 2 mapping exercises by Terje FY or Sven B are optional.
- Sven B will not be able to attend the September meeting, and Chantal K will take on his role.
- The level of participation of COST members in WG activities was discussed: are conference calls the best forum for discussion, set up online forum in the works.
- Discussion on what are the goals for WG1. Feeling that after the initial mapping exercise there is some vagueness regarding the concrete objectives and what we want to achieve. Suggested concrete activities are the ethical mapping and new actions on the results of the barriers mapping exercise. Synchronization of protocols would also be an achievement, with team work on behavioral measures that can be shared by all sites.
- Deeper scientific presentations on WG1 & 2 member's work is desirable so that everyone understands what each group is doing. This partly can be achieved at the next WG1 & 2 meeting in London. The training school will also be a good event for this, but not everyone will be there.
- Catherine B suggested sharing PhD students – co-supervision and building a bank of topics for PhD students.
- Another joint project could be an application for a European project in the next FP7 call, although it is not yet known if there will be an adequate call.

Separate WG1 meeting

Participants: Sven Bölte (lead WG1), Herbert Roeyers (co-lead COST ESSEA), Astrid Vicente, Silvana Markovska-Simska, David Mankuta, Chantal Kemner (co-lead WG1), Mayada Elsabbagh, Peter Marschik, Eva Dudova, Michal Hrdlicka

- Sven B presented the mapping barriers/opportunities results, and Mayada E presented items to be included in the planned mapping of ethical principles. These were discussed in the WG. The mapping will include COST members and other international projects. There was a discussion on what high risk group means. Chantal K referred a Dutch study in preparation looking at high risk children from parents with psychopathology. Specificity of age group, population high risk; questionnaire was shown and some points were referred/discussed, e.g. embedding into clinical services, focus on longitudinal studies, prenatal recruitment. Peter M referred study in preterm infants and Fragile X.
- David M, Astrid V, Peter M, Herbert R are interested in participating in the ethical mapping study.
- Peter M and Sven B will write the barriers and opportunities paper for ECP during the summer. Jan Buitelaar (Editor) has given positive signals to publish such as submission.
- Authorship strategies were discussed, no general rule but possibility is that writing group is author, others acknowledged as part of the group, which still grants reference in PubMed. To look at BASIS document on the subject.
- Repository of ethical and research protocols requested by members.
- Also discussed availability of tools in low/middle income countries. Activities to improve availability as possible WG output in the future. For instance, an initiative to see which behavioral measures can be translated and validated was discussed, but agreed to postpone until the group defines a protocol. Agreed that we should move forward with cross borders research without trying to force any particular instrument. Mayada E cited an upcoming paper showing this was a major setback for research.
- Barriers mapping showed that 40-60% of WG countries struggle with traditions hampering research, lack of awareness of autism, autism stigmatization, and lacking cooperation with authorities. Fine mapping of these challenges and deliverables to improve situation as optional future WG activities. WG leads/co-leads (and other members) to suggest new actions based on the barriers results to be discussed at the London meeting.

Astrid Vicente & Sven Bölte