

COST Action BM1004: Enhancing the Scientific Study of Early Autism (ESSEA)

30th April, 1st May 2013, Bilbao, Spain

WG3 meeting

13.30 to 15.00; 15.30 to 17.00; 8.30 to 10.30

MINUTES

Participants: Ricardo Canal Bedia, Evald Saemundsen, Filippo Muratori, Irma Moilanen, Nada Pop-Jordanova, Tatjana Zorcec, Patricia Garcia-Primo, Rafal Kawa, Synnve Schölberg, Annika Hellendoorn, Sigridur Loa Jonsdottir, Arlette Zermeño Proal, M^a Victoria Martín and Herbert Roeyers.

1. Overview of current situation of ASD Screening Programs in Europe:

The purpose is to provide an overview of the different screening studies/programs across Europe, and to discuss the influence of several variables on the outcomes of the screening. This review might facilitate the choice for a screening method that fits a specific context.

The current situation of that paper was discussed. It was agreed to add data provided by France, incorporating Bernadette Roge as author

Responsible: Patricia Garcia-Primo and Annika Hellendoorn. **Reviewers:** Ricardo Canal, Herbert Roeyers, and Tony Charman

Next step: Close the paper and circulate it among authors. Finish it before the summer. Submit it in September

2. Survey on “Developmental surveillance across European countries”

The purpose is to compare the current situation of early developmental surveillance across different European countries, to identify the keys to widespread screening programs in the EU, to search out the main barriers in implementing screening programs for ASD and to highlight the best practices to overcome them.

Current situation: The questionnaire has been distributed to members of the COST project representatives from each country. Ricardo Canal and Arlette Zermeño gave a summary of the survey results (see slides). Twenty two countries responded and the total number of respondents to date is 33. Two countries that have not yet responded (The Netherlands and Portugal) will be approached through personal contacts of COST network.

Three countries answered “no” to question no. 5 (If your answer was Health services, is there any well-child surveillance protocol in your country?). There was a discussion about how a protocol is understood. How is the surveillance early childhood development in these countries will be verified. The only misunderstanding reflected in some of the answers, was about a screening study and a screening program (offered to the general population). Definitions that discriminate between those two approaches were not clear.

We have information about start dates of the studies/protocols or programmes more precisely, and whether there are screening projects of temporary duration, a screening program for special needs groups, or for the general population? Synnve suggests that we have data on all three types. Contact persons in relevant countries will be asked to clarify this if their answers are not clear.

Discussion about the difference between the time compulsory education starts and the time children really start school. In many countries for example, most children start kindergarten or preschool before 3 years of age, but compulsory education starts at 6 years of age. It was agreed the need to get information about this issue.

Also we need to clarify the questions that have differences in between the same country, such as, National or International guidelines for screening, and differences between regions in the same country such as whether there are national or regional parents organizations, hospitals or to which doctors or institutions the children with developmental difficulties are referred.

More precise questions need to be asked during our next round, such as if a screening programme is running within the educational section, but not only the health system (Rafal). Also, to define some questions better (Irma). Discuss the above mentioned issues in the paper in relation to strength and limitations.

Herbert suggests that we send each country (contact person) a summary of their data when it has been analyzed and ask them to verify it. Inform them that this procedure is for reliability purposes, and also that the study will be published.

Evald reminded us that we need to document the data collection process.

Responsible: Ricardo Canal Bedia, Sigridur Jonsdottir, Nada Pop- Jordanova, Rafal Kawa, Irma Moilanen, Patricia Garcia-Primo, Arlette Zermeño and Vioqui Martin, Evald Saemundsen, Synnve Schjolberg

Next step: Send questionnaires that have been filled out to a ESSEA-COST contact person in each country (22 countries, or 26 when all have responded), and answers to questions that need clarification. Arlette is going to contact each country for further definitions, inconsistencies or lack of information.

It was decided to send e-mails to representatives of each country in May and give one week for responses. A telephone conference will be held in the middle of June (after 11 and before 17). Before the conference call, Ricardo and Arlette will send an excel document to the WG members with the main results. We also need to get answers from two more countries; to analyze the data; and aim to have an outline for a paper ready for the fall meeting.

3. Paper on " Challenges and opportunities in screening for ASD – Setting characteristics and organization of services" (COP)

The purpose is to write a paper about challenges in conducting screening studies based on input from experienced researchers.

Current situation: Evald gave an overview of the history of the COP paper (see slides), and discussed how it overlaps with or touches upon issues in Patricia's and Annika's paper, the Bölte et al's (2012) paper as well as the survey.

There was also a discussion about an overlap with the survey (2.) : It is difficult to continue with the paper unless constantly needing to refer to the situation in Europe with reference to the survey data. Evald showed some text examples from Sigridur Loa where this became apparent when she was writing about "how to embed screening into the existing services". Decision: To finish the developmental survey first and put the COP paper aside until we know how much the survey will overlap with the COP.

Irma suggested that if there are participants in WG3 who are working on a Ph.D. that they will be given an opportunity to work on intended publications from the WG. Nada supported this suggestion.

Responsible: Synnve Scholberg, Evald Saemundsen, Ricardo Canal, Sanne Lemcke, Rafal Kawa.

4. Cultural differences in delay in ASD diagnosis among immigrants

This issue was discussed on Tuesday April 30 and Wednesday May 1. Rafal gave an introduction about a project that relates to cross cultural differences. When visiting Iceland last fall, he met a group of Polish parents, and had the opportunity to discuss cultural differences with his Icelandic colleagues, regarding parental perception of the diagnosis of ASD.

It was discussed if a study on cross cultural differences in Europe regarding identification and diagnosis of ASD would fit into the COST-ESSEA action, or if we should aim for an application for a European grant when the action is over. No decision was taken at the meeting, but there was a lively exchange of ideas.

A possible methodological approach could be both quantitative and qualitative (parents perception of the severity of the diagnosis, stigma, etc.). Possible aims could be: How professionals in the different cultures attend to the diagnosis of ASD, and how parents make use of available services (Ricardo). Also, if age of parental concerns is independent of cultural differences – available ADI-R protocols could be used for this purpose (Sigridur Loa). It could also be made a proposition of a model for studying cultural differences (Rafal). Evald suggested that we could start to investigate if there is a delay in diagnosis among immigrants and minorities in certain countries compared to the native population. In some countries, databases are available that will be able to give an answer on this issue. As background information, it would be interesting to look at the distribution of immigrants in some countries. This is available through the National statistics, and is readily accessible in most countries. Synnve mentioned the Horizon 20 could possibly provide an opportunity to apply for a grant to study what causes a delay in diagnosis and ways to improve access to health services.

The main topics of this WG was the discussion about possible research concerning differences in early diagnosis and treatment of children in immigrant families in different countries (time from the first concerns, how cultural differences affect the reliability of the diagnosis, differences between native and immigrant families in perceiving severity of the symptoms, level of stress and expectations

in native and immigrant families, reasons for delay in the diagnostics -language, attitude, cultural differences-)

The conclusion of the discussion was to check the differences among countries in immigrant families in terms of the time from the first concerns of the families until they are diagnosed. Available databases will be analyzed.

Responsible: Rafal Kawa, Evald Saemundsen, Ricardo Canal (Other group members could join).

5. WG3 &WG4 – a joint meeting

There was a short joint meeting of WG3 and WG4 where it was decided to focus on a possible collaboration on the influence of cultural differences on diagnosis and treatment. Bernadette Roge from WG4 presented a questionnaire about parental perception of control - a religious belief questionnaire-. Rafal introduced ideas from WG3 about a possible project with the aim of studying the influence of cultural differences on a possible delay in diagnosis. WG4: Do cultural differences affect the choice of treatment or access to services/treatment? Iris suggested that we could take samples from different institutions/countries to begin with (a possible STSM).

Iris Osterling: ADI-R toddler study - over 900 participants. Sensitivity was lower with the new ADI-R for toddlers than the US samples but specificity was similar.

6. Joint STSM WG3 proposal (2013-2014)

Patricia introduced an idea that could be considered for a Joint STSM in the near future. It would involve pooling data and statistically analysis of ASD screening items being used or that have been used (e.g.UK) at European level considering the final ASD diagnosis after screening. Based on the idea that a careful characterization of samples are of key importance interpreting psychometric properties of the screening instruments under investigation, she proposes statistical analysis (discriminant, logistic regression,...) and comparable estimates by ages, case ascertainment,... in the biggest sample that could be achieved in Europe so far. Likelihood ratio per item will be calculated. Bias of items selection and comparison among tools needs to be considered carefully

The main objective would be identification of the most operational “behaviors surveyed” across screening tools.

- Logistical issues are still pending but it was agreed in the MC Meeting that Belgium, Netherlands, UK, Italy, France, Spain could be the sites to provide this data
- Sites to provide these data
- The sites inclusion criteria should be sites with :

Screening tool items data + diagnosis with standardized tools

- Selection of behaviours/items surveyed across tools (despite wording)

Minutes by Sigridur Loa, Arlette, and Ricardo