

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

7th April and 8th April 2014 Utrecht, Netherlands

WG3 meeting

13.30 to 15.00; 16.00 to 17.30; 9.00 to 10.30

MINUTES

Participants: Ricardo Canal Bedia, Evald Saemundsen, Irma Moilanen, Tatjana Zorcec, Rafal Kawa, Annika Hellendoorn, Sigridur Loa Jonsdottir, Sanne Lemcke , Fabio Apicella, 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.

Annika informs everyone that the paper 'Screening for Autism Spectrum Disorders: State of the art in Europe', written by Patricia, Annika and several other authors, has been revised one time and was accepted for publication in European Child and Adolescent Psychiatry.

All attendees praised the work done by Patricia and Annika, and value of the paper for future screening programs were discussed.

2. Survey on "Developmental surveillance across European countries"

The purpose of this action 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.

Ricardo informs that Portugal joins the survey, and a respondent from Germany is incorporated. Now we only need to get one informant from Hungary and one from Austria. Tatjana notes that we could use Balkan network to spread the survey. Bulgaria & Greece could be added.

Data gathered so far suggest great homogeneity in general aspects of the public health system, such as the existence of developmental surveillance services, primarily through health services, and similar procedures among countries for accessing to diagnostic services when developmental problems are detected. In 90% of countries the path is the pediatrician. Similarly, 90% of the countries have a well-child surveillance protocol. It was found that the greatest number of matches between countries in the well-child surveillance protocol is 1, 12 and 24 months of age. And that 100% of the countries include at least one visit between 18 and 24 months. See Table.

	1 month	6 months	12 months	18 months	24 months	30 months	36 months
Belgium	YES	YES	YES	NO	YES	YES	NO
Czech Republic	YES	YES	YES	YES	NO	NO	YES
Denmark	YES	YES	YES	NO	YES	NO	YES
England	YES	NO	YES	NO	YES	NO	NO
Finland	YES	YES	YES	YES	YES	YES	YES
France	YES	YES	YES	NO	YES	NO	YES
Germany	YES	YES	YES	NO	YES	NO	YES
Iceland	YES	YES	YES	YES	NO	YES	NO
Ireland	YES	YES	YES	YES	YES	YES	NO
Italy	YES	YES	YES	YES	YES	YES	YES
Macedonia	YES	YES	YES	YES	NO	NO	YES
Netherlands	YES	YES	YES	YES	YES	NO	YES
Norway	YES	YES	YES	YES	YES	NO	YES
Poland	YES	YES	YES	YES	YES	NO	YES
Romania	YES	YES	YES	YES	YES	YES	YES
Spain	YES	YES	YES	YES	YES	NO	YES
Sweden	YES	YES	YES	YES	YES	NO	YES
YES	100%	94%	100%	71%	82%	35%	76%
	100%		100%	100%			

Although screening through health services at 18-24 months seems the best way to screen, it should be noted that additional screening through the educational system and at older ages may also be beneficial, for instance to follow-up children. Other relevant data are that all countries have national parents' support groups and/or patients' Organizations for ASD, which, although usually not provide diagnostic services, many have resources for early treatment. In relation to national/international guidelines, rules, laws and resources for early detection, it was found that very few European countries have developed specific guidelines and standards for the early detection of ASD, and is also infrequent the use of international guidelines. Only 18% of responding countries indicated that there is some program/study on early detection of ASD, and more than 50% of the countries participating in the survey have never been developed experiences or studies on early detection of ASD.

Rafal and Evald will work with Ricardo on the introduction for this paper.

It was agreed to circulate a first draft of the report in the first week of June.

3. Cultural differences in delay in ASD diagnosis among immigrants

Rafal presents an update on the immigrant project, which is designed as a review. The purpose of this review is to provide a systematic analysis of studies concerning prevalence of ASDs among immigrants, trying to get specific conclusions for the European context. Results from studies conducted in North America indicate large racial/ethnic disparities in the diagnosis of ASDs. Black, Hispanic, Asian and children from other ethnic groups were significantly less likely to be diagnosed with ASDs than were Caucasian children. Other data show, that immigrant children have similar prevalence rates of ASDs as native children, although they are diagnosed later. The relationship between immigrant status and ASD diagnosis is not fully understood.

A comprehensive literature search for original articles reporting ASD prevalence was undertaken. Data across studies were compared with a particular focus on variables of immigrant status and ethnicity. Following databases were searched: Academic Search Complete, ERIC, Health Source: Nursing/Academic Edition, MasterFILE Premier, MEDLINE, PsycARTICLES, PsycINFO, SocINDEX, Teacher Reference Center and Google Scholar. Keywords: autism or ASD and immigrant or emigrant or immigration or ethnic minority or emigration or ethnicity or ethnic. 924 articles were browsed, 146 matched the criteria, 17 from Europe

The review indicates, so far, that most of the European studies consisted of registry analyses and focused on African immigrants. Also, the review shows that children who are born to immigrant mothers with an immigrant partner, have an increased risk of autism and intellectual disability and lowered risk of Asperger's syndrome. No reports on lower prevalence of autism in European studies, and lack of data concerning prevalence rates of ASDs in immigrants from European countries.

After a discussion on the results obtained up to now, it is considered that the review should still continue and it is agreed that those responsible for the action to continue with the review of articles. Other aspects considered necessary are: a) collecting quantitative information regarding delay in diagnosis and prevalence of ASD among immigrants (information from pilot study in Iceland and possibly from data files/registers in other countries); an b) identifying factors that contribute to delay in diagnosis and prevalence among immigrants (may also be qualitative information that can be collected through, for instance, questionnaires/interviews).

4. Multi-site/country data pooling of different ASD screening instruments: A joint effort towards early detection in Europe

The purpose of this study is to answer the following questions: Are all the ASD screening tools, which are used in Europe, measuring early signs and symptoms of autism? What kind of constructs are the different screening tests measuring?

Autism screening data-sets from seven European countries (Belgium (CESDD, ESAT, SCQ & M-CHAT), Finland (CHAT & autism items from the BISTEA), France (M-CHAT & CHAT), Italy (M-CHAT), The Netherlands (ESAT, SCQ & CSBS-DP), Spain (M-CHAT) and United Kingdom (CHAT)) will be analysed in order to address these questions.

To do this, firstly the items will be matched by face validity. Afterwards, with the objective of demonstrating that the face validity is equivalent to the construct validity in each and every one of the tests; a series of factor analyses on two levels will be conducted. The first level will analyse the tests independently, allowing to confirm that the items formulation may be different, but the meaning is the same in all tests. The second stage will be to analyse more than one instrument at a time, giving results to confirm if the selected tools are measuring the construct that we want to measure, how they differ from each other, or if all are measuring the same entity.

The final part of the study will be focused on analysing what are the factors from the previous analyses which best identify ASD in early years. Having reached this point, we believe it would be interesting to create a new test with the items from the most discriminative factors, and analyse its psychometric properties and assess what results it could offer. Moreover, it is considered interesting to analyze the advantages and disadvantages of using a test of these features, and propose new ideas to improve the screening of ASD in Europe.

Expected date of manuscript submission: December 2014.

5. Evaluation report WG3.

We discussed the attainment of the goals that were stated in the memorandum of understanding. We concluded that we have achieved or are still working on the objectives that were stated in the memorandum of understanding. Regarding the goal of designing European guidelines on screening it should be concluded that it is impossible to identify the screening method that will be most effective across Europe. It is not a 'one size fits all' story. It is however possible to identify some general factors that should be considered when designing a screening study. These factors will interact with context-specific factors. The paper "Screening for Autism Spectrum Disorders: State of the art in Europe" presents the main issues to be considered in a screening program/study for ASD.

The WG has also been working to see whether the different screening programs work differently in different communities. The "Developmental surveillance across European countries" survey will provide us with information that characterizes the structural differences between countries, and the study of pooling data sets of different ASD screening instruments help us to identify the differences between instruments used in European countries. In addition to specific publications for each project, useful findings for future studies of early detection of autism in the European context will be obtained.

After a discussion on the activities carried out and those that are still running, the conclusion is that the WG3 has established the methodological basis for an interdisciplinary scientific network in which a very fruitful and enriching discussion has developed about what are the most appropriate methods and contexts for early detection of ASD.

Minutes by Ricardo and Annika