

## WG3

# Testing how well screening instruments work in prospectively identifying cases

## MC meeting Ghent, Belgium (5<sup>th</sup> November 2012)

### Minutes of the meeting

8.30 am to 16.00 pm

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#### List of attendees:

Ricardo Canal Bedia - Spain (Co-lead), Irma Moilanen - Finland, Sigridur Jonsdottir - Iceland, Rafal Kawa - Poland, Sanne Lemcke - Denmark, Synnve Scholberg-Norway, Nada Pop-Jordanova - Macedonia, Tatjana Zorcec-Macedonia, Evald Saemundsen- Iceland, Annika Hellendoorn- Netherlands, Mieke Dereu- Belgium, Patricia Garcia-Primo - Spain.

#### Welcome and Introduction

Tony Charman welcomed everyone and announced that Emma van Daalen has decided to step down from leading WG3. The Core Group will discuss candidates for replacement after the Ghent meeting. From then, onwards the chair of the group was taken by Ricardo Canal. Patricia Garcia and Rafal Kawa agreed to take minutes.

#### 1. Activities of WG3:

##### a) Survey on “Developmental surveillance across European countries”

The primary goal is to compare the current situation of early developmental surveillance across different European countries. Ricardo presented the questionnaire developed by the members of the group involved. The feasibility and accuracy of the questions included were extensively discussed. It was finally decided to re-edit the questionnaire considering only these 3 main aspects: a) Situation of general Surveillance and early detection of Neurodevelopmental Disorders in each country, b) whether there are National Guidelines or not, c) whether there are specific screening procedures for ASD or not. The group will also prepare a database with contacts from European countries. Moreover an intense evaluation of the different “screening national guidelines” when available in Europe was agreed to be done. Again, the discussion about whether we should attain European guidelines or recommendations was raised and still needs further discussion.

**Responsible:** Ricardo Canal, Rafal Kawa, Sigridur Jonsdottir, Nada Pop- Jordanova, Patricia García (Also Irma Moilanen- contact list: European Psychiatrists )

**Workplan:** New questionnaire (26<sup>th</sup> Nov) /Feedback from WG3 (3<sup>rd</sup> Dec.) /Last version of questionnaire (21<sup>st</sup> of Dec) /Telephone conference: Doodle Pool just after Christmas

**b) "Challenges concerning screening studies "**

Output will be the submission of a paper about challenges in conducting screening studies based on input from experienced researchers (after several email exchanges and conference calls the group have decided that interviews and qualitative analysis is not the best methodology to use for this manuscript).

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

**Workplan:** Synnve and Evald to read manuscript from Patricia García and Annika Hellendoorn . Circulation of first draft among WG3 (3<sup>rd</sup> Dec.-Synnve to send it-)/Feedback from WG3 before mid January /Final Structure of the manuscript and work division (17<sup>th</sup> of Jan)/ Compilation of the big document by Mid February.

**c) "Overview of current situation of ASD Screening Programs in Europe" (Patricia & Anika)**

The goal of the study was to provide an up-to-date overview of different population-based ASD screening procedures across Europe and to compare different screening methods. Patricia quickly went through the oral communication presented in Tours (most WG3 members were not present in Tours). Positive comments were made to this work and also Synnve and Evald commented the utility of it for the manuscript that they are planning on challenges. It was then decided that Patricia will send them the "draft paper "to check the extension of the discussion on some of the factors included in the results section that may overlap with their reflection on challenges.

Now the paper is under revision by Tony Charman and Herbert Roeyers

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

## **2. Planning for pendent activities and STSM**

**a) Updating COST website.**

Ricardo to ask Tony about the process to update WG3 section on the ESSEA website.

**b) Macedonia presentation: "Autism in Macedonia-current conditions and future plans"**

Tatjana Zordec presented the work they do at University Children's Hospital in Skopje, Macedonia. Their main concern is that they do not have access to standardized tools for ASD diagnosis.

**c) STSMs**

Ricardo Canal encouraged WG members to think of possible STSM projects for Phd students who could visit their countries as well of thinking of possible STSM candidates of their countries to go abroad. He also insisted on the idea that each STSM application needs to include a concrete output (publication, abstract,...) expected to achieve after the STSM.

### **3. Joint meeting WG4 (ethical survey)**

There is a suggestion, in analogy with WG1/2, to do a mapping exercise of ethical procedures and issues in relation to screening and intervention studies. Mayada kindly offered to help with that, if we decide that we want to do this exercise. We concluded that, as the most likely source for funding for any multi-site intervention study would be EU funds, then such a study would be bound by EU regulations and practice. Therefore WG3 and WG4 have decided not to go ahead with surveying people to find out about differences between countries.