

## **WG1: At-risk groups**

MC meeting Padua (19<sup>th</sup>-20<sup>th</sup> September 2011)  
**Summary of the presentations and discussion**

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### **Agenda**

1. Membership of WG1 & currently/ pilot/ planned studies (initial mapping exercise)
2. Proposed workplan
3. Prioritized WG issues
4. Planned activities for 2012

#### **1. Membership & currently/pilot/planned studies (initial mapping exercise)**

A mapping exercise has been conducted to identify existing activities of members of the work-group. A list of ongoing full scale, pilot, and planned studies has been compiled. This will be made available on the COST website (WG1). Short presentations on full scale and pilot studies were given on BASIS (Elsabbagh, UK), Ghent University Siblings Study (Warreyn, Belgium), EXPRESS and EASE (Bölte, Sweden), studies in between pre-term birth and ASDs (Mankuta, Israel), identifying earliest signs of autism (Vicente, Portugal), Predictors at birth and in premature babies (Farroni, Italy).

#### **2. Proposed workplan**

A draft workplan was presented (WG leader, co-leader) and discussed. This will be made available on the COST website (WG1). Key Objectives of the proposed plan are:

- ✓ Facilitate interactions and learning among EU sites conducting research in the relevant areas.
- ✓ Identify barriers to conducting research and how to overcome these (Identification of potential limitations in conducting research, learning from existing examples of overcoming difficulties and developing pragmatic approaches to overcoming difficulties).
- ✓ Improve synergy in research assessment protocol among EU research sites.
- ✓ Compare ethical and clinical management approach among ongoing EU studies.
- ✓ Facilitate training of junior scientists and sharing of technical expertise through lab exchanges (STMs).
- ✓ Improve evidence-based community practice and support responsible communication of scientific findings.
- ✓ Evaluate possibilities for collaboration with industry.

#### **3. Prioritized WG issues**

(a) To map and find solutions for research barriers (among other things problems of funding and recruitment were discussed), (b) map and discuss clinical and ethical

management of research activities from a European perspective (largely varying ethical demands between countries, and (c) the need for researchers to be more proactive on these issues were discussed), and the will of WG members to participate in data sharing repositories were identified as next core interests of WG1.

#### **4. Planned activities for 2012**

It was decided to target on these three issues in 2012 by:

For (a): conducting a mapping exercise on experienced research barriers and solutions within the WG.

For (b): conducting a mapping exercise on ethical management in high-risk research in relation to clinical services

For (c): to initiate STSM to map the possibilities for data sharing between WG members with regards to data and technical demands. The repository by the BASIS project (UK) will serve as a model for these activities.

The WG chair and co-chair of WG1 are preparing these activities during fall 2011.