



(Enhancing the Scientific Study of Early Autism)

COST Action BM1004

COST WG4 Meeting Minutes 9 October 2013

9 am to 4 pm Research Beehive, Newcastle University.

Present:

Helen McConachie, Anett Kaale, Frédérique Bonnet-Brilhault, Bernadette Rogé, Jonathan Green, Antonio Narzisi, Erica Salomone, Iris Oosterling, Petra Warreyn, Sue Fletcher-Watson, Mikael Heimann, Selda Ozdemir

Work on outcome measures:

Presentations on harmonizing or recommending outcome measures.

Helen McConachie: Evaluation of outcome tools for young children with autism.

MeASURe project conceptual framework for what to measure, and initial conclusions on strong tools.

WHAT and HOW, in children up to 6 years of age.

WHAT: depending on theoretical frameworks (ICF, DSM5, ...). Method: Q-sort of 62 concepts by parent groups, sorted in importance for them.

HOW: searched published studies 1994-2012, 129 tools. Categorized within conceptual framework + reviewed measurement properties (COSMIN). → 52 tools.

In progress. Reports will be:

- tool name, authors, content, age range, cost, training, ...
- COSMIN ratings
- Use of the tool, potential for blinding (!), limitations, ... (e.g., ESCS ceiling effect)

Discussion: Mismatch between 'what' and 'how', e.g. parents value child happiness highly. But are our interventions aiming to increase happiness? Should they, or should they focus on improving communication and social skills, with happiness as a longer term aim?

Anett Kaale: Outcome measures in European early autism treatment studies 2002-2013

Tools used in published studies (2002-2013) in Europe, and apparent sensitivity.

For now: 17 studies (from table). Listed all outcomes.

Excel file with tab per category (IQ, play, social-communicative behaviour, language, ...)

Table: number of studies measuring this domain, number of measures used, names of measures

83 different outcomes in 17 studies, used 50 different instruments. Not enough info on how the instruments were used (established way or not, subscales, ...).

Per domain: sensitivity to treatment change & sensitivity to change over time.

Summary: instruments found to have sensitivity in controlled or RCT (underlined). Social Communication measures are more likely to be sensitive as they are proximal to the intervention. Discussion of how to address the clinical relevance of the change: eg through asking parents about whether the degree of change was worthwhile; rating the Clinical Global Impressions-Improvement; calculating which individuals made clinical and reliable change, etc

Iris Oosterling: Tools used to measure parent-child interaction.

Global measures + frequency counts PCI measures. Based on early intervention summary table and master's thesis Chloè (student Petra). Whether or not used in intervention studies, whether or not change was measured.

Discussion: how to proceed with this? Helen & Petra agreed to write conceptual paper on this in 2014.

Question: how do we transfer these skills from one lab to another? Very difficult for other labs to establish reliability. Culture of certain concepts in certain labs.

Need to synchronize use of measures over labs. Cannot do that for all measures, so again we need to decide on which ones. But that depends on the type of intervention. → to pick up in conceptual paper Helen & Petra.

Antonio Narzisi: Toward an EU shared outcome protocol... A question emerged from the Padova meeting.

Described a protocol for measurement in naturalistic study in early autism in Italy.

First study about TAU in Italy, several centres involved throughout the country. 70 toddlers, 2-5 years (see Muratori et al, nr 17 in table)

Protocol chosen based on Eikeseth 2008 paper (ranking in 4 levels, best level includes diagnosis according to ICD or DSM, based on established measures: VABS, MCDI, PSI, CBCL)

Discussion: is there variability in individual trajectories of change, or does the average account for all?

Can measures be combined in a kind of 'change' measure, i.e. does improvement in one measure mean improvement in the other? correlations between change scores?

Perhaps we should look more into treatment as usual: what is happening in practice, which aspects seem to be beneficial (e.g., involvement of parents), rather than add a 'branded' intervention as common project?

→ again need of set of simple outcome measures to be able to do that across countries.

(Note: not only ask about number of hours but also number of people providing that.)

Bernadette Rogé: Early intervention in autism. Parents' perceptions: burden, satisfaction and perceived social support.

Burden: objective and subjective aspects. Linked to practical aspects (e.g., service availability) and perception of the situation (e.g., concern for the future).

Pilot study in 75 parents. Burden Inventory Questionnaire; measure of processes of care (MPOC20); satisfaction with services scale, social support questionnaire. Internet survey + several semi-structured interviews (to illustrate the results). 53% feels a severe burden, 41% moderate, 6% no or light. → early

intervention programs should include solutions to reduce the burden. Outcome evaluations should take into account the burden of the parents.

Questions are also asked in a positive way (e.g., do you have opportunities to be happy together with your child?). → this is important! (cf. PSI, negative phrasing)

Related: informal care cost (amount of time you spend parenting above what you would normally do), in PACT follow-up people are asked to keep a diary of two days (week day and weekend day).

→Bernadette also has a list of 'burden' measures from other populations, can send it around.

These 5 presentations were followed by a more general discussion of outcome measures, and future work on harmonizing measures across European early intervention studies. Discussion points were:

- Difference between aiming to produce 'internal guidelines' or journal publication with recommendations.
- Need to discuss overall and more specific goals for the outcome measure work / what questions do we want to answer? What do we need to take into account other than possibility to blind and sensitivity to change?
 - o We also need to take into account clinical significance of measures and change
 - o Importance of knowing test-retest reliability of the instrument in order to judge the reliability of change
 - o Often parents report change but formal instruments not: is this because parents are not blinded or because the measure is not capturing it?

→ Possible paper, would be valuable: to give overview of European intervention research, lay out problems, try to suggest solutions. Possibly specific questions to be asked (e.g., correlation between parent report and direct assessment). Anett will take the lead on this paper, WG members will comment and contribute.

Mapping of published and ongoing studies:

Petra Warreyn

(Nb. Agreed in telephone conference: Include controlled group early intervention studies, completed in Europe. Children with ASD; also siblings and at risk samples. Exclude: medication and biomedical interventions; very short experimental interventions (e.g. 2 lots of 3 minutes).)

→ see ppt and tables in attach

Papers in preparation:

Erica Salomone: TAU Survey Sent round a first version of the paper, focusing on treatment, not educational system. Discussion on what information to be included and what not. Possibly in supplementary material. WG members to send additional comments within two weeks from now (Oct 23th)

Helen McConachie, Sue Fletcher-Watson: Parent adherence summary, embedded in editorial. Group discussion: not entirely clear what the aim is: presenting COST ESSEA or presenting adherence data. Adherence data may be presented as a case example of what the WG is doing. There may need to give

more firm conclusions; specific advice. Do we need an introduction on adherence (what, why is it important, ...)? Adding other examples of national guidelines. Adapting title including adherence. Sue and Helen will produce second draft for circulation.

Iris Oosterling, Helen McConachie: data sharing. Issue with PACT data. Reformulate goals and apply to PACT consortium before proceeding.

- ➔ This points to the general need of a formal method for data sharing. Applies to all workgroups. Agreed to take this back to Tony and Herbert. There is also no collaborators' agreement.

Discussion of draft authorship guidelines.

We discussed several possibilities, including a group authorship. Actions: Helen and Petra will rewrite the guidelines. Make a plan consulting people taking the lead up till now suggesting a list. Circulating this to WG4. Petra and Helen to take the guideline to ESSEA core group in February. The plan should also include details for who is circulated in a paper and when in the process (for being able to comment early enough).

IMFAR 2014:

At this time, not enough people are planning to go to submit a scientific panel.

STSMs:

Herbert and Petra have a new PhD student who will work on parent-child interaction and child-child interaction coding. She would like suggestions on a joint piece of work that could be the focus for a STSM.

Frederique has a child psychiatrist doing an MD, who would like training in coding parent-child interaction. (Frederique: professional caregiver – child interaction)

Iris and Anett also think of a student who may want to joint this STSM.

Sue has about 50 T1 T2 tapes with agreement from parents for sharing for coding.

Action points: Petra will ask Astrid about calls for 2014; and will organise a call with Helen, Sue, Anett, Frédérique, and Iris.

Other agenda items

Next meetings:

- April 7 & 8, 2014: MC+ WG meetings in Utrecht
- September 11 & 12, 2014: Conference in Toulouse. Maximum 150 people. MC members + ESR's involved in the meeting. Followed by Arapi meeting on Sept 13th (where perhaps some COST members will be invited to speak)

Selda suggests the possibility to write a book about autism practices in Europe; early intervention practices in different countries. In different COST projects people write books on the main issue of the project. Target audience is usual professionals and researchers. Possible chapter: why do countries choose what they choose? e.g., PRT in Netherlands, ESDM in France, Or guidelines for different kinds of early autism research. Or theoretical background of several programs developed in Europe (descriptive). Discussion: why book instead of journal paper, e.g., in European Journal of Child Psychiatry? or even a special issue?

Selda will share information about the books published by other actions.

If anyone else is interested in comparing national guidelines, Erica would be willing to join that. → this will be an agenda point for the next conference call. People already interested in doing that can let Erica, Helen & Petra know.

News from WG1 & 2:

Sue Fletcher-Watson: With colleagues in WG1&2, I am helping to conduct a small evaluation of the ethics around the study of so-called "at-risk" infant groups. We will carry out focus group discussions with stakeholders including parents, clinicians / practitioners and adults with autism. Then possibly follow-up on these with an online questionnaire for wider distribution. Questions are likely to probe how people feel about the whole ESSEA research strand, and specifically things like the use of "at-risk" language or how to manage the vulnerability of families enrolling in ASD-sib research projects. I thought this might be of interest to members of WG4. I think the intention is to produce a short bit of internal guidance for COST ESSEA members on dealing with these specific ethical issues, based on stakeholder perspectives, and hopefully a journal article too a bit further down the line.

- Petra/Helen will forward the email sent on this subject by Emily Jones (to WG's 1 and 2) to the WG4 members (and ask Ricardo to do the same for WG3).