

# ANNEX III: ALL PARTNER MEETING



Regional Meeting of Partners – Maastricht, 2-5 August 2006

Crowne Plaze Hotel, Maastricht

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**coinciding with**  
**IASSID Europe Conference 2-5 August 2006**

**Attendees:**

Austria:	Barbara Brehmer representing Professor Germain Weber
Belgium:	Professor Geert Van Hove
Finland:	Dr. Tuomo Maatta
France:	Professor Charles Aussilloux representing Dr. Bernard Azema
Germany:	Professor Meindert Haveman
Italy:	Dr. Serafino Buono
Ireland:	Professor Patricia Noonan Walsh/Christine Linehan/Marie O'Connor
Lithuania:	Dr. Arunas Germanavicius
Netherlands:	Marja Veenstra/Astrid Meis
Norway:	Dr. Jan Tossebro
Romania:	Dr. Alexandra Carmen Cara
Slovenia:	Dr. Dasa Moravec Berger
Spain:	Professor Luis Salvador
Wales, UK:	Professor Mike Kerr/Dr Jon Perry

**Wednesday 2<sup>nd</sup> August**

11.00 IASSID Europe Conference Registration

14.00 IASSID Europe Opening Ceremony

16.00-19.00 POMONA Meeting

**Agenda**

**1. Welcome**

Introductions by Professor Patricia Noonan Walsh.

**2. Review of Minutes of Regional Meetings in Barcelona, Graz & Ljubljana –**

Accepted without change.

**3. Interim Report to European Commission:**

Technical report submitted and approved.  
 Financial report submitted and currently under review.

#### 4. Work Packages – Progress Reports

**Work Package 1:** Coordination – progress to first Interim Report outlined briefly by Patricia Noonan Walsh.

**Work Package 2:** Dissemination – documented in Interim Report and outlined briefly by Patricia Noonan Walsh.

**Work Package 3:** Powerpoint presentation given by Marja Veenstra reviewing selection of indicators and translation process.

**Open discussion regarding translation process** – Comments from partners:

Jan Tossebro – Lack of expertise in disability apparent in first translation. This was to be expected and did not cause a difficulty.

Alexandra Carmen Cara – Only a few changes – sentences lengthy.

Geert Van Hove – translators may have assumed respondents would be professionals in the field.

Tuomo Maatta – questionnaire ‘wordy’ – simplification of items needed.

Luis Salvador – Need to explain questions.

Meindert Haveman – even though Austria & Germany speak the same language, they differ with regard to their use of German.

Mike Kerr & Jon Perry – some minor changes needed to wording – questionnaire works well.

Patricia Noonan Walsh – remarkable achievement to have the questionnaire translated and validated at this stage. Agreement from Luis Salvador.

Arunas Germanavicius – need to validate Russian questionnaire for use in Lithuania – Significant proportion of those living in Lithuania speak Russian

**Open discussion regarding ethnic minorities**

Meindert Haveman 10% of people in Germany from migrant community, many of whom do not have a parent who speaks German. Should we include this group of people?

Mike Kerr – In the UK this issue is addressed by having a translator present – e.g. a non-English speaking Asian participant could have a relative present who speaks English.

Jan Tossebro – not sure whether this is a task for the Pomona project. The response rate is typically low from this group. A deep commitment would have to be given to this task

Mike Kerr – UK ethics committee raised the issue of how researchers will include people from a minority community – on this basis the UK will include this group, irrespective of how small the group may be.

Meindert Haveman – there is also an additional financial aspect to including this group.

Charles Aussilloux – if you have a large minority it would be necessary to include them, but not for a small minority

Mike Kerr – Not acceptable in the UK to purposefully exclude a group

Patricia Noonan Walsh – Pomona cannot be responsible for claiming representation of population

**Work Package 4:** Member State Reports; Lead Partner Ireland

Patricia Noonan Walsh – didn't realise when we devised this work package in the project proposal that other projects would be seeking similar information such as WHO Atlas etc. Professor Luis Salvador is involved in this WHO initiative. The Pomona project has now completed this task and the reports are presented in the Interim Report.

Luis Salvador – at least three to four other projects that would find this information useful – they will be able to access this information when the report goes live on the Europa Website.

### **Work Package 5: Pilot Study; Lead Partner UK**

Jon Perry gave a presentation on the progress of this work package noting the time slippage due to delays in submissions to ethical committees. To date, evaluation forms from 6 countries, data from 4. Call to partners to submit evaluation form and data as soon as possible.

Findings to date – ethical approval took longer than expected.

Changes requested to survey – minor.

Assurances about confidentiality and training of interviewers requested.

Access to data by participants mentioned – anonymisation of data makes this task impossible and ethics boards accepted this rationale.

Content of questionnaire fine – testament to how well it was constructed.

In some places the range of responses wasn't wide enough – need to add value labels.

Suggestions from partners – additional items that could be included – autism spectrum disorder, nutrition.

Also suggestion of adding 'satisfaction with treatment/health professional' option.

Time taken to complete questionnaire – 1 hour with person with disability; 45 minutes with proxy respondent

SPSS statistical coding sheet worked well – string variables need extending.

Some points regarding consistency between questionnaire & data form.

Next step – await full pilot data – establish small working group to iron out anomalies

Mike Kerr – need to consider implications of returning to ethics committees. Include item on satisfaction with services.

Christine Linehan – issue of adding new indicators such as ASD – can we agree in principle at this meeting whether this is something we should do?

Jon Perry – Suggested waiting till full pilot data is in.

Patricia Noonan Walsh – Findings will have implications for returning to ethical committees

Mike Kerr – project must respond to pilot findings.

Meindert Haveman – diagnostic issues regarding ASD –

### **Open discussion regarding medication indicator**

Jon Perry – issues around medication item – suggestion to revert to psychotropic medication

Mike Kerr – partners will need to code data locally

Meindert Haveman – why is psychotropic medication the focus?

Mike Kerr – known over prescription – agrees with Jon Perry – revert to psychotropic

Christine Linehan & Mike Kerr to work on psychotropic issue & circulate proposal

Meindert Haveman – we will have information on all medications from the pilot

Charles Aussilloux – medication a function of level of ability; lower ability on higher quantities of meds. If we can gather this type of data, we should.

Mike Kerr – need to be careful in interpretation – high level of medication does not reflect poor standard  
 Barbara Brehmer – Austrian ethical committee suggested adding an item on ‘review of medication in previous 12 months’  
 Arunas Germanavicius – are we looking only at prescribed medication?  
 Mike Kerr – the medications of interest are prescribed – compliance in taking medication is almost impossible to quantify. Non prescribed medications are not an indicator.  
 Arunas Germanavicius – may need to document if psychotropics can be given to an individual without prescription as this can happen in Lithuania  
 Jan Tossebro – this doesn’t happen in Norway  
 Mike Kerr – need to document this type of medication use

**Open discussion regarding deadline for pilot**

Jan Tossebro – what is the new deadline for the pilot data  
 Jon Perry – what is reasonable for the collection of this data  
 Jan Tossebro – mid September  
 Patricia Noonan Walsh – need to co-ordinate this deadline with the coordinator of work package 6 – sample selection (Germany & Netherlands)  
 Mike Kerr – important for UK to have clear ‘end’ to their work package  
 Christine Linehan – could partners work to beginning of October – all data must be returned to UK at that point, as resubmission to ethics might be needed  
 Geert Van Hove – also need reliability data from pilot  
 Meindert Haveman – suggested date End of September – agreed.

**Any Other Business**

Patricia Noonan Walsh – Professor Matt Janicki, editor of the Journal of Policy and Practice in Intellectual Disabilities has requested an update article on Pomona  
 Mike Kerr – important to recognise the contribution of all those working on the project, not just partners  
 Patricia Noonan Walsh – important to note substitutions at meetings – also note possible change to Slovenian partnership – awaiting advise from European Commission  
 Christine Linehan – reminder to partners to check their travel allowance as extra travel grants were awarded to new partners and to partners who are co-ordinating work packages. Christine to ask UCD accountant to advise on how partners submit subcontracting claims.

**Thursday 3<sup>rd</sup> August**

11.00-00.30 IASSID Europe Pomona Symposium:

Four papers outlining progress to date presented by Christine Linehan, Marja Veenstra, Dr Jon Perry & Professor Patricia Noonan Walsh. Extensive questions & answers session followed chaired by Professor Patricia Noonan Walsh

15.30-18.30 POMONA Meeting

**Attendees:**

Austria: Barbara Brehmer representing Professor Germain Weber  
 Finland: Dr. Tuomo Maatta  
 France: Professor Charles Aussilloux representing Dr. Bernard Azema

Germany:	Professor Meindert Haveman
Italy:	Dr. Serafino Buono
Ireland:	Professor Patricia Noonan Walsh/Christine Linehan/Marie O'Connor
Lithuania:	Dr. Arunas Germanavicius
Netherlands:	Dr. Henny Van Schrojenstein Lantman de Valk/Marja Veenstra/Astrid Meis
Romania:	Dr. Alexandra Carmen Cara
Slovenia:	Dr. Dasa Moravec Berger
Spain:	Professor Luis Salvador
Wales, UK:	Professor Mike Kerr/Dr Jon Perry
Apologies:	Belgium: Professor Geert Van Hove – apologies, attending IASSID meeting
	Norway: Dr. Jan Tossebro – apologies – attending IASSID meeting

## Agenda

### 5. Regional Meetings

#### Regional Meetings 2006

Provisional attendees at regional meetings – partners to confirm if this provisional list is acceptable

Finland: Helsinki 12-15 October

Tuomo Maatta, Patricia Noonan Walsh, Meindert Haveman, Dasa Moravec Berger, Christine Linehan

Lithuania: Vilnius 9-12 November

Arunas Germanavicius, Mike Kerr, Henny Van Schrojenstein Lantman de Valk, Jan Tossebro, Germain Weber, Christine Linehan

Romania: Bucharest 23-26 November

Alexandra Carmen Cara, Fino Buono, Bernard Azema, Geert Van Hove, Raphael Martinez representing Luis Salvador, Christine Linehan

This list will be circulated to partners to confirm availability.

#### Regional Meetings 2007 & All Partner Meeting 2008

Luis Salvador noted that there is a related conference in Croatia in October 2007

Christine Linehan noted that regional meetings have to date been held in partner countries – this facilitates the inclusion of invited speakers from participating countries

Patricia Noonan Walsh – meetings don't all have fall at the same time – suggested places which have not hosted a meeting for Pomona II include:

Belgium

France

Germany

Norway

UK

Jan Tossebro noted that there is an IASSID Special Interest Group Ageing conference in Oslo in May (20-22 May) – this could be an ideal opportunity to coincide with a Pomona meeting.

Patricia Noonan Walsh will liaise with these countries to decide on regional meetings for 2007

All partner meeting 2008 scheduled for Dublin. This meeting was originally scheduled for April 2008 however the project ceases at the end of April – in order to maximise the findings of the meeting, it should be pushed back to earlier in the year. Patricia Noonan Walsh will circulate suggestions to the group.

### **Work Package 6: Sample Selection**

Presentation by Henny Van Schrojenstein Lantman de Valk - Suggestions from coordinators – approximately 80 people will be surveyed from a limited geographical area. Information on non-respondents will be gathered.

### **Open discussion on non-respondents**

Mike Kerr – essential that we define exactly what we mean by ‘non-respondents’ as there is an ethical issue regarding the presentation of demographic information on people who have not given consent – at what point in the process of recruitment do we define non-respondents and do we have ethical approval to use this information? People have to consent to the dissemination of even limited information.

Meindert Haveman – there is a two stage process. Firstly, there is a sampling frame within the service provider from which people will be invited to participate. Information can be gained on those who do not wish to participate.

Mike Kerr – Concern that those who say no, are then detailed.

Henny Van Schrojenstein Lantman de Valk – didn’t realise the diversity among countries on this issue

Mike Kerr – non-response should only apply from the recruitment step forward.

Henny Van Schrojenstein Lantman de Valk – will the UK receive a sampling frame similar to that described by Meindert?

Mike Kerr – probably not.

Meindert Haveman – need to document non-respondents for publication purposes

Charles Aussilloux – two processes of non-response. Firstly there are those who do not give consent. Secondly, there are those who give consent, but do not complete the entire/part of survey. It is important to know the latter group.

Marja Veenstra – total non-response occurs when a person doesn’t complete any of the survey. Item non-response occurs when a person doesn’t complete some items. It is important to know the reason a person refuses – but this isn’t possible in this situation.

Meindert Haveman – How many times do we go back to a person who doesn’t complete a survey? For example, if a person is in hospital at the initial approach, do we try again?

Mike Kerr – Might be possible to ask the ‘recruiters’ regarding the numbers of people who refuse – without getting demographic information. Then greater detail could be obtained on those who consent but don’t complete the form. A proposed classification could be (1) how many people were recruited? (2) how many people agreed to the researchers contacting them? (3) how many people agreed to take part?

Luis Salvador – two concepts (1) sampling (2) representativeness – Pomona never intended to be representative. If we are only looking at the feasibility of the items and of collecting the data, then Mike Kerr’s suggestion is appropriate

Mike Kerr – scientific question posed at symposium – is there a bias regarding those who consent and those who don’t – that those with very good health or those with very poor health would be more motivated to take part than those with average health.

Meindert Haveman – yes, this bias is likely and for this reason it’s important to sketch the sampling process. Also important to define the limited geographical

area – Meindert will seek information on this from partners. Also important to determine if the criteria of residential provision (home & care) age (18-34; 35-54; 55+) and level of ID (mild, moderate & severe, profound) is realistic for partners. In some countries for example, finding people with ID over 55 years may be difficult.

Alexandra Carmen Cara – In Romania it's difficult to find people with mild ID who are attached to services. This group of people may not be 'registered' with the Handicap Commission, but their GP would know they have ID – agreement by the group that these people should be included.

Meindert Haveman – Meindert & Henny will send criteria again and ask feedback from partners. Perhaps a help desk could be set up on sampling?

Mike Kerr – recommend a visual flow chart to guide researchers on options for sampling at different levels in the process – partners should refer back to Meindert & Henny on their progress.

### **Work Package 9: Training**

Presentation by Henny Van Schrojenstein Lantman de Valk – Initial review of the Work Package 4 Country Reports revealed three themes – (1) specific types of training required e.g. autism, Down's syndrome, ethics. (2) identification of groups requiring training e.g. physicians, psychiatrists, etc., (3) levels of training e.g. Masters, doctoral, mandatory etc.

Aim of Work Package 9 is to make recommendations to the Commission on training.

Mike Kerr – should raise this issue at regional meetings. Also, SIRGs are looking at training – Pomona should link with these groups.

Henny Van Schrojenstein Lantman de Valk – cannot make a statement covering all countries.

Mike Kerr – should make a statement linked directly to the survey – different recommendations for different parts.

### **Any other business**

Christine Linehan – Commission have asked that partners' names be forwarded to Competent Authorities in each country – Christine still awaiting response from some partners – please email

### **Publications**

Patricia Noonan Walsh –

invitation by JPPID to submit a second updated Brief Report on the project  
informal talks regarding other publications

Christine working on HIS HES paper

Paper on survey – to be discussed by Christine, Patricia, Henny & Marja

Need a formal strategy on this – to be discussed at regional meetings

Meindert Haveman – need to consider analysis of data – what are the issues we wish to address?

Mike Kerr – recommends one high impact article on the project. Also need to consider how we present the findings at IASSID Cape Town in 2008

Jon Perry – important to consider that psychometric data would be required for a paper on the questionnaire – need to collect validity and reliability data now.

Luis Salvador – should also consider a paper on feasibility, accessibility and practicalities of conducting a survey

Patricia Noonan Walsh – topics to be discussed at regional meetings;

Sampling

Training

Publication Strategy

Luis Salvador – keen to develop relationship between Pomona and other working groups such as Idresnet, World Health Organisation, WHO Regional Mental Health Group – Luis will come back with some suggestions

Henny Van Schrojenstein Lantman de Valk – would like to produce a disability friendly brochure on the project to disseminate findings

Barbara Brehmer – Austria has produced a similar document we could use as a template

End of Meeting