

# ANNEX IV: 1<sup>st</sup> REGIONAL PARTNER MEETING, BARCELONA

**1<sup>st</sup> Regional Meeting – 6-9 October 2005**

**World Trade Center, Barcelona**

Friday 7 October 2005

## **Agenda**

### **Welcome**

**Thank you to Luis for his assistance in making arrangements**

- 1 Minutes of the Partners' Meeting in Rome – May
- 2 Review - management of the project in Month 6
  - detailed budgets
  - 30% funds received from European Commission
  - partners claim travel and subsistence from UCD
  - timesheets have been sent to all partners and all are advised to keep records carefully
  - regional meetings 2005
- 3 WP 3 – Henny Lantman
- 4 WP 4 – *Country Reports* – all partners will complete one
- 5 WP 5 – progress report from Mike Kerr and Jonathan Perry
- 6 Plans for Maastricht August 2006

AOB

Friday 7 October 2005

**Present:**

Bernard Azema  
 Luis Salvador-Carulla  
 HMJ van Schrojenstein Lantman-de Valk  
 Patricia Noonan Walsh  
 Germain Weber

**1 Notes**

The partners appreciate the excellent opportunities for disseminating information about Pomona at MHMR in Barcelona. Luis placed the *Pomona* logo in the conference Abstract book and also on the Website.

**2 Graz** (November 2005)

Can we include Pomona on the EUPHA conference website? (Luis) – we should develop links with EUPHA, which is an umbrella organization:

- Could POMONA have legal status?
- We could register as member of EUPHA?
- Agreed: to discuss this point at Graz

**3 WP 5 (MK)** – pilot studies – each country should be exploring the processes involved in sampling/carrying out pilot studies and gaining ethical consent

- Agreed to circulate Mike's work to all partners

**4 WP 3 (HMJvSLdeV) – Protocol**

- Draft questionnaire and questions posed by Henny
- ADL (Katz) measure (of activities of daily living) to be included within demographic data
- Aim is to include measures that compare our population to other studies about people with intellectual disabilities and also to the general population

*Bernard:*

Note different terms used across the 14 countries – shall we propose a *Glossary*? (BA). This could be applied in the Member State Reports. The IDRESNET Glossary is available.

*Luis:*

European Mental Health/Economics Network (31 countries)

IDRESNET – 2: Develop system for ID populations

**Propose:** a symposium/meeting that would bring together initiatives on health and ID in Maastricht, August 2006

### Discussion – Henny’s documents for Work Package 3

*Overview:* Demographic domain includes life expectancy and Bernard comments that we must give further reflection to how we shall define this indicator. Henny notes that some indicators reflect system or population data and we have yet to define these.

BMI: Henny suggests that we ask for nutrition data to be available prior to interview.

- *ADL – Katz?* Other? What measures are used in MS? Partners should consult and report to Henny.
- Living arrangements – we have Norway questions – ‘where do you live? GW and BA proposed some detail on environment/size/density of housing.
- ‘respite’ – should this item be included within ‘living arrangements’
- *Income:* how to gather data? HES/HIS measures? Perhaps each country can provide average minimal wage, pensions, and disability benefits. This information should be included in the Member State Reports (WP 4). We need to know (a) how much money is in the hands of the individual; and (b) what are the transfers at national level?
- Measure characteristics/facilities in the living arrangements so that the residential settings of PWID may be compared with those of other citizens in each MS and with PWID in other MS
- How shall we gather data about *oral health*? DMFT – how to we gather this – and when?
- Use items from Bob Davis’s questionnaire (Aus) – CHAPP – and also from Mike Kerr’s instrument (Wales) - PEARL. We can ask whether the person has hearing/visual impairments (and correlate our findings with age and other variables).
- *Reminder:* we are developing a questionnaire to survey information and not carrying out a more costly clinical study.
- *Physical activity* – Henny will consult Eric Emerson and others about measures that might enable us to compare POMONA data with data about general population..
- *Medications:* BA notes that asking this question might raise ethical issues of confidentiality. We must underscore the point that we are gathering anonymized data. GW suggested presenting a list of classical conditions and typical medications. There are two distinct items: (a) what medication does the person actually take; and (b) why the person thinks he/she takes that medication.
- *Checks* – note variation in what checks are available for general populations in the MS
- BA: who will gather data on N=60 participants in each country – will that person require training, and if so, how will this take place?
- Consider funding a training session for the 14 researchers?
- Mental health – shall we use proportion with psychiatric disorder? This is as negative interpretation. How to measure health? GW suggests measuring risks to mental health – we can ask informant if using PAS-ADD, which has been used widely and translated. It is a European instrument, validated in European countries.

Henny will continue to revise the protocol and circulate to all partners. Partners are invited to provide comment. We must offer reasons for selecting each measure.

## Saturday 8 October

### Present:

Bernard Azema  
 Serafino Buono  
 Luis Salvador-Carulla  
 HMJ van Schrojenstein Lantman-de Valk  
 Patricia Noonan Walsh  
 Germain Weber

### 1 IASSID-Europe Conference in Maastricht (August 2006)

All partners may attend the conference and the registration fees are in the Pomona budget.

It was agreed that Pomona would ask HMJvSL-deV to help the group submit two symposia: Abstracts are due 1 December 2005.

Symposium 1		Symposium 2	
1	Ethical issues	1	<i>Country Reports</i> – 1-4
2	Developing the protocol	2	<i>Country Reports</i> – 5 - 9
3	Pilot study	3	<i>Country Reports</i> – 10-14

### 2 WP 4 – *Country Reports*

Each partner will prepare a *Country Report* using a common template. PNW will send information about how to use a template, probably drawing on the IDRESNET project report (all partners have this report in pdf) as a model.

### 3 Regional Meetings 2006

The group agreed that the regional meetings are useful – for example this meeting at Barcelona was helpful as it -

- a. encouraged productive, good discussion in a smaller group
- b. enabled partners to meet other colleagues, attend conference sessions and also disseminate the work of *Pomona*
- c. provided opportunities to meet policy makers and other experts in Spain and the region of Catalunya

### Suggestions for 2006:

Dublin

Helsinki <sup>1</sup>

Romania

Montpellier/Paris

The meeting concluded.

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<sup>1</sup> Tuomo Maatta met colleagues in Helsinki on Friday 7 October in order to discuss (a) data collection for *Pomona* in Finland and (b) plans to invite the *Pomona* group to hold a regional meeting in Helsinki in 2006 to advise the Finnish government on policy for the health of people with intellectual disabilities. Tuomo joined the *Pomona* group in Barcelona on Saturday afternoon.