

# ANNEX V: 2nd REGIONAL MEETING



## Regional Meeting of Partners - Vilnius 9-12 2006

### Crowne Plaza, Vilnius

**Friday 10<sup>th</sup> November 2006**

**Attendees:**

Lithuania	Dr Arunas Germanivicius & Mindaugas Cesulis
Ireland	Prof Patricia Noonan Walsh & Christine Linehan
Germany	Prof Meindert Haveman
Netherlands	Dr Henny van Schrojenstein Lantman de-Valk
Belgium	Diane Smet (for Prof Geert Van Hove)
Norway	Anna Kittelsaa (for Dr. Jan Tossebro)
United Kingdom	Prof Mike Kerr (from afternoon) Dr. Jon Perry

**9am – Presentation by invited guest:**

Prof Dainius Puras, Head & Associate Professor, Centre for Child Psychiatry and Social Paediatrics, Vilnius University. Prof Puras outlined the history of reform of the psychiatric services following Lithuania's independence from the Soviet Union. A recent publication by Prof Puras on this topic was disseminated to attendees.

**(1) Minutes of 1<sup>st</sup> Regional Meeting in Helsinki, October 2006.**

Patricia – brief review of minutes at Helsinki. Christine will ensure that powerpoint presentations from invited speakers at all regional meetings will be put on the website.

**(2) Changes in EU structure for POMONA**

The Working Party for Mental Health has now been dissolved. POMONA II is now classified under the Task Force on Major and Chronic Diseases. NIVEL, based in the Netherlands, is now responsible for monitoring this working group. Christine will attend a meeting of this working group on December 13<sup>th</sup> at the European Commission. POMONA is one of the few projects within this working group that have been invited to make a presentation to the group at Luxembourg.

**(3) Review – Project Management - Budgets**

Both the technical interim report and the financial interim report submitted in July 2006 have been accepted by the European Commission. The second tranch of funding is now being disseminated to partners. To date, partners have received 30% of their budget (less travel which is centralised from Dublin) at the beginning of the project. Recently a further 20% of the budget has been disseminated following the European Commission's acceptance of the 2006 interim report. A second interim report is required for July 2007 and a further 20% of the budget is released following acceptance of this report. The final 30% of the budget is released on approval of the final report. Christine recommended partners review the original POMONA contract as there are specifications as to the level of necessary spending required by partners before the Commission release further tranches.

Patricia will provide information on budgets to partners following discussion with UCD administrators and accountants after the regional meetings.

Arunas questioned the mechanism of invoicing colleagues in the University of Lithuania for their role as 'external' (non-partner) consultants. Christine will discuss this matter with the accountants in UCD to see what methods are available for invoicing.

Christine reminded partners to keep accurate records of their budgets – partners are reminded to review the original budget sent to them at the beginning of the project to ensure their spending is in line with their budget. Christine recommends that each partner meet with their accountant to review their spending and their input of days worked. The project is over half way through its three-year duration and a review of accounts would be beneficial at this point. Partners need to ensure that both they and their researchers are working the required number of days stated in the budget.

Payment for travel is based on receipt of invoices for travel and expenses presented to Dublin. This system is working well however Christine reminded partners to keep copies of all travel documentation as the project will be audited by the European Commission most likely by work package or by partner. University College Dublin now require that the information on invoices from partners be typed and include partners signature.

#### **(4) Work Package 4: Country Reports**

Christine will be using these reports as the basis for a short (5 minute) presentation to the European Commission at the Task Force on Major and Chronic Diseases on December 13<sup>th</sup> 2006.

Meindert has WHO (2002) documentation on prevalence figures for disability which will be of interest to partners. Meindert will send this documentation to Christine for dissemination to partners. Meindert also suggested that a one-page summary of the project, harmonised across all partners, would be useful to disseminate to interested parties. Henny & Meindert will work on a statement for our project regarding the definition of ID we are using in our research and how this impacts on prevalence figures.

## **(5) Work Package 9: Training for Health Professionals**

Henny presented some of the key issues related to work package 9 – training of health professionals. ‘Which kind of training is necessary, at what level, for which professionals?’ There was debate regarding which professionals should be included or excluded in this work package.

Henny suggested that to restrict health professionals to medical practitioners would be inappropriate and would reflect only the medical model of disability. Patricia suggested that asking each partner to examine numerous health professional training courses would be impractical given the funding and time constraints of the project. Christine suggested that partners could be asked to identify one or two ‘models of best practice’ within their own country – in Spain, for example, undergraduates in physiotherapy receive a course module from Special Olympics with onsite visits to health check centres at Special Olympic villages.

Patricia suggested that the European Credit Transfer System (ECTS) may be a useful framework to identify European training courses which are open to all citizens. For further information see: ([http://ec.europa.eu/education/programmes/socrates/ects/index\\_en.html](http://ec.europa.eu/education/programmes/socrates/ects/index_en.html)).

Patricia described a system currently being used in Ireland where dental students in one university in Dublin will receive accredited disability lectures from a second university.

Meindert asked whether the POMONA survey data would highlight training needs in each country. Christine suggested that data analysis will be at the conclusion of the project and therefore is unlikely to be available to guide work package 9. Henny suggested that information from work package 4 (Country Reports) and the extensive literature review conducted as part of the POMONA I Final Report would be used to guide work package 9.

A review of the objectives of work package 9 revealed: “partners will meet and advise contacts in their MS with particular responsibility for devising and delivering curricula for health professionals and share knowledge and information directly”. Jon Perry suggested that small national conferences with key stakeholders may achieve this aim. Patricia suggested that a ‘translational’ international meeting (transfer of knowledge about the health of people with intellectual disabilities) at the final All Partner Meeting in Dublin (scheduled March 2008) may provide an opportunity to achieve this objective. Invited speakers could include Peter Kramers (ECHI project), etc. Henny suggested that Marie Curie grants may be a possible source of funding for this activity.

Partners agreed that while work package 9 does not commence for some time, preliminary decisions on the methodology and outcomes of this work package should commence.

### **LUNCH**

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

Presentation by Prof Meindert Haveman (Powerpoint slides will be placed on the website)

The ultimate goal of POMONA is the collection of survey data on approximately (n=80) individuals with intellectual disability in each of the 14 participating countries. Each partner is asked to identify a given ‘health area’ within which the data will be gathered. The area may represent a city, an administrative area, etc. Where possible, population based data should be

available for the health area. In addition, partners are asked to identify those providing services to people with intellectual disability in the health area and to provide estimates on the numbers of people in receipt of those services. Steps identifying and selecting a sample are outlined on the powerpoint presentation which will appear on the POMONA website.

Meindert reminded partners that overall 40% of participants should have severe/profound levels of ability. This number is necessary for statistical purposes.

Partners discussed the issue of consent to participation, particularly in cases where adults are unable to give consent due to levels of ability. Christine explained the situation in Ireland where no person (e.g. proxy) can give consent on behalf of another person over the age of 18 years. In previous studies, the issue of consent has been addressed in Ireland using the following guidelines: Firstly, the issue of whether the person with intellectual disability is deemed able to consent has to be addressed. Where the person is deemed able to give consent, s/he will be invited to participate. Where a person is deemed unable to give consent (this group is likely to comprise at least 40% of the sample who have severe/profound disabilities) the next of kin is asked to give ‘assent’ or ‘agreement’ to their relative taking part. In cases where no next of kin are known, a health professional who knows the person is asked to provide ‘assent’ or ‘agreement’. If this source is also unavailable, the Chief Executive Officer (CEO) of the service provider may be asked to give ‘assent’ or ‘agreement’.

All partners are requested to document the consent process carefully and to submit their deliberations to Meindert Haveman or Henny van Schroyen Lantman-de Valk.

A ‘helpdesk’ (phone support) is available to partners seeking advice on sampling. Meindert and Henny will respond to queries.

Christine outlined some of the challenges implementing the sampling strategy in Ireland.

- (1) the ‘health’ area chosen for the selection of a sample includes many organizations providing services – only the largest two have been requested to take part in the survey – we don’t have the resources to liaise with the remaining ones which are small in scale
- (2) Population based prevalence figures are available on at ‘health board’ regional level – however the two organizations provide services in a number of health board regions.
- (3) Figures of those receiving services from the two organisations who have agreed to take part in the study will include a substantial proportion of people receiving services outside the health area.
- (4) As such there will be ‘overlapping’ figures from different levels – health board, service provider organisation, health area etc.
- (5) Stratification will probably only occur at two levels in Ireland – (1) residential setting – home versus residential care (2) level of ability (60% mild/moderate and 40% severe/profound). It is unlikely that age as a stratifier can be included as the numbers would be so small that there may be ‘empty’ cells in some stratifying cells.

Partners are reminded to provide as much detail as possible when outlining their sampling structure as this information will be needed to validate the sampling process.

The issue of randomization within strata was discussed. How will individuals within each strata (e.g. X number of people will be required to complete the survey who live in a home setting and who have severe/profound levels of ability)?

Mike Kerr suggested that a common method of randomization should be agreed by all partners. Also the randomization should be undertaken by partners (using an anonymised list where

partners do not have access to names) – this would avoid sources of bias where some partners are completing the randomization process using random number tables and others are relying on service providers to complete the randomization process using different methods. Partners agreed that asking untrained service provider personnel to undertake the randomization process could result in bias.

Christine suggested that partners outline the feasibility of using Meindert’s sampling strategy in their country and forward to Henny & Meindert for comment. Henny & Meindert will then produce a final sampling document on the basis of the responses.

### **Saturday 11<sup>th</sup> November 2006**

Attendees:

Lithuania	Dr Arunas Germanivicius, Mindaugas Cesulis
Ireland	Prof Patricia Noonan Walsh, Christine Linehan
Germany	Prof Meindert Haveman
Netherlands	Dr Henny van Schrojenstein Lantman de-Valk
Belgium	Diane Smet (for Prof Geert Van Hove)
Norway	Anna Kittelsaa (for Dr. Jan Tossebro)
United Kingdom	Prof Mike Kerr & Dr. Jon Perry

#### **(7) Work Package 5: Pilot Study**

Dr Jon Perry presented the most recent draft of the POMONA survey protocol based on (1) findings from the pilot study and (2) a meeting in Cardiff attended by Jon Perry, Mike Kerr & Christine Linehan

Jon reported that, in general, the survey protocol was successfully completed. Feedback from partners based on the pilot have now been incorporated into the new draft, mindful of the fact that major changes may require a second application to ethical committees.

Changes to the SPSS/Excel file have also been suggested and these will be completed by Christine and Frances in Ireland.

Lithuania has yet to begin the pilot study as ethical approval is pending.

Of the 26 reliability interviews expected (2 from each country bar Lithuania), only 8 were submitted in time for analysis. This figure is low and reliabilities will be required for the main data collection study. Partners were requested to conduct INTER rater reliability – that is, to conduct two interviews on behalf of the same individual with intellectual disability. The reliability analysis is used to indicate whether the data from two different raters is the same; that is, reliable. The raters may include the person with ID, a parent, a staff member, a health professional, etc. Inter rater reliability is an important issue for our project as proxy respondents will be used to complete interviews on behalf of people who have more severe levels of intellectual disability and will require a proxy respondent to complete the survey on their behalf.

Of the 8 reliability interviews carried out by POMONA partners, only 4 were correctly completed as INTER rater reliability. The remaining 4 reliabilities were carried out as INTRA reliability. INTRA rater reliability refers to cases where the same measurement is completed on two different

occasions by one rater. This data, while not requested, is helpful but is not required for the main data collection.

Jon stated that preliminary analysis of the reliability data indicated that the protocol is reliable. Full analysis of this reliability pilot data will be completed by the UK team responsible for the pilot study.

Jon recommended that reliability analysis for the main sample should be conducted on approximately 5 participants in each country. That is, the survey protocol should be completed by two raters on behalf of five individuals participating in the survey in every country. Regarding the selection of the participants for reliability analysis, Jon suggests that partners will first have to identify which partners can be included for reliability analysis – that is, that there are two raters available to complete the protocol. From this group, the five participants selected for reliabilities should be identified by random selection.

The issue of a dispute between responses from a person with ID and a family member/staff member/etc was discussed. A decision was agreed that where such a dispute arises, the matter should be discussed with both parties and an agreement sought. In cases where an agreement cannot be found, the response of the family member/staff member/etc., will be taken. This decision is now written at the top of the survey protocol. The rationale behind this decision is that all but one or two items on the protocol require factual information (not self report). Information regarding visits to hospitals, diagnosed conditions, etc., is most likely to be known by family members/staff members/etc. Partners are asked to qualitatively document any disputes of this kind when submitting their data to Ireland. Partners are requested to submit any academic literature they have that addresses this substantive issue where different responses are provided by people with intellectual disability and people completing measures on their behalf.

Defining ‘urban’ and ‘rural’ – this information is requested on the survey protocol. Christine stated that most health interview surveys ask for this information, but that it is ‘self reported’. We will also ask participants to ‘self report’ whether they live in an urban or rural area. In addition to this information Christine has received information from the European Commission which codes the NUTS 3 classification of regions (previously sent to all partners) by urban and rural.

A ‘don’t know’ option has been added to all questions in the response ‘unable to answer/unclear response’. The coding of these responses will change on the next draft of the survey protocol to reduce the size of the data file. These responses can be cross tabulated by respondent (person with intellectual disability or proxy) and by level of ability (mild, moderate, severe, profound).

The issue of ‘residence’ has been clarified. A participant’s residence refers to the place where s/he resides for the majority of the week. That is, for a person who spends weekdays in a residential centre and spends the weekend in the family home, the residence should be identified as the residential centre.

Items on income, and education & day care facilities have been removed from the current draft of the survey protocol. The pilot study revealed major difficulties in the interpretation of these items.

The question ‘do you have a job?’ is retained but now includes a job at open employment, supported employment, sheltered employment or day care – the question is therefore self-

reported. A related item on the survey protocol asks if the participant is paid for his/her job and the amount of money (net – after tax) received for this work.

### **(8) Medication**

Mike Kerr and Christine Linehan worked on this document. The pilot revealed that it is possible to collect data on all prescribed medications taken by the participant. There are many possible methods of analysis for this data. However this area is very labour intensive for analysis. It was therefore suggested that initial assessment could be (1) the number of prescribed medications taken and (2) the number of prescribed anti-psychotics taken. Further analysis of all medication can be conducted thereafter. There was a debate regarding the analysis of antipsychotic or psychotropic medications – no decision was made at the time of the meeting. In order to examine the medication data, partners are requested to submit a list of available prescribed anti-psychotic or psychotropic medication to Christine for data analysis.

#### Interview Guidelines

Meindert recommended that guidelines be prepared on the recommended methodology for conducting interviews. Patricia will check standardized scales such as ABS to see if they provide guidelines for carrying out interviews. Christine asked if Meindert would prepare a short one page document of guidelines for partners – outlining factors to be taken into consideration when interviewing participants e.g. recording who is present etc.

#### Training

Meindert also suggested that information should be recorded about the interviewees – have they received training in interviewing people with ID. Mike suggested that researchers' previous experience interviewing people with ID should also be included.

### **(9) Presentations**

Christine will present information on POMONA at

(1) the EUPHA conference in Montreux, Switzerland 16-18<sup>th</sup> November – the European Union Public Health Association provides an opportunity to dissemination of the project beyond the ID field. Henny will email Peter Kramer (ECHI) who is attending to tell him that Christine will be presenting

(2) the European Commission Task Force on Major and Chronic Diseases meeting on December 13<sup>th</sup>

### **(10) Publications**

Currently there is one POMONA I paper in preparation authored by Patricia, Christine, Mike & Henny – the paper details work carried out during POMONA I on the inclusion of people with ID in over 50 major Health Interview and Health Examination Surveys conducted in Europe (HIS/HES)

Two papers are currently in preparation for POMONA II –

A paper on the development of the survey protocol being prepared by Christine

An invited paper to the Journal of Policy and Practice in Intellectual Disability on the current status of the paper being prepared by Patricia

A suggested publication strategy was discussed whereby partners would inform the POMONA group of their interest in a given area in which they wish to publish. These partners could be the first authors on the paper but would include other partners as co-authors.

Mike asked that all those involved in POMONA be acknowledged in the reports presented to the European Commission. Christine suggested that she will send a list of contributors to partners for review prior to submitting reports – this system worked well for the 2006 report.

#### **(11) Regional Meetings 2007**

Patricia recommends two venues for regional meetings in 2007 as opposed to the three meetings held in 2005 and 2006. These two meetings are connected to IASSID conferences – one on Health & ID which will take place in Prato, Italy May 21-23 2007 – the second is a conference on Ageing & ID which will take place in Oslo, Norway, 31 May – 1 June. Christine reminded partners that there is no funding with the POMONA budget to cover the cost of registration for these conferences.

Patricia will write formally to both conferences to see how POMONA might be included on the agenda.

The final all partner meeting will be held in Dublin in 2008.

#### **Invited Speaker**

The meeting concluded with a presentation by Dr. Med Jovita Petrulyte, Director of the Child Development Centre in Vilnius. Dr Petrulyte showed a video of the centre and outlined current issues influencing service provision for children with intellectual disabilities in Lithuania. A question and answers session followed.

#### **Final Comments**

Partners thanked our Lithuanian colleagues, especially Dr. Arunas Germanivicius, for their kind hospitality in hosting this successful meeting. Thanks also to Prof Puras and Dr Petrulyte for their contribution to the meeting.

#### **Close**