

ANNEX V: 2nd REGIONAL PARTNER MEETING, GRAZ

2nd Regional Meeting – 10-13 November 2005

Hotel Europa, Graz, Austria

**Friday 11 November 2005
14.00 – 17.00**

Chair: Professor Mike Kerr

- 1 Introduction –
Professor Mike Kerr
- 2 Review of minutes of the 1st Regional Meetings in Barcelona –
Prof Germain Weber
- 3 Preliminary Discussion: Work Package 3 – Review of Questionnaire; Work Package 5 – Pilot
Study
Professor Mike Kerr

**Saturday 12 November 2005
9.00 – 12.00**

Chair: Christine Linehan

- 4 Continuation of Discussion: Work Package 3 – Review of Questionnaire; Work Package 5 – Pilot
Study

12.00 – 13.30 Lunch Break

- 5 Work Package 4 – Member State Reports – templates
- 6 Work Package 6 – Sampling Frames
- 7 Opportunities for dissemination/awareness of Pomona Update – IASSID 2006
- 8 General Housekeeping: Budgets, timesheets & claims
- 9 Any other business

1 Introduction

Attendees

- (1) Prof Mike Kerr, Wales
- (2) Dr Jon Perry, Wales
- (3) Dr Jan Tøssebro, Norway
- (4) Prof Germain Weber, Austria – apologies for leaving lunch time Saturday
- (5) Ms Kathrin Gruning, representing Prof Meindert Haveman, Germany
- (6) Dr. Arunas Germanavicius, Lithuania
- (7) Christine Linehan, Ireland – apologies for not attending Friday afternoon as presenting a paper on the Pomona Project at the 13th Annual EUPHA Conference (European Public Health Association), Graz.

2 Review of minutes of the 1st Regional Meetings in Barcelona

By Professor Germain Weber who attended the meeting in Barcelona reviewed the outcome of this meeting

3 Work Package 3 – Review of Questionnaire

Administration Issues:

Questionnaire will be completed by face-to-face interview with:

Person with Intellectual Disability

Person with Intellectual Disability & Other (for part or all of interview)

Proxy (person with intellectual disability not present)

It was noted that some items may be sensitive (e.g. toileting). This should be stated to the person with intellectual disability at the beginning of the interview and it is his/her choice to answer these questions or not or alternatively allow a proxy respondent to address these issues.

As some information is archival (e.g. medication) it may be worth considering posting out the questionnaire in advance of face-to-face interview or allowing respondent to post questionnaire after the interview.

To ensure reliability of the data, a proportion of data (suggestion 10%) will have to be collected twice.

Demographic Indicators

Preference for unique ID code over name– using digit for country, regional code etc.

Need information on whether the individual with intellectual disability is present for the interview.

Note any discrepancy between opinion of person with intellectual disability and carer – Always record opinion of person with intellectual disability

Birth year only

Nationality & ethnicity should be recorded.

Level of Disability & Activities of Daily Living: Suggestion to remove the IQ question & use the short ABS and not the Katz scale. Aetiology question should be restricted to Down's Syndrome yes/no

Living arrangements - “Change to Living & Social Issues”

Living Issues: Should include two items:

- (1) Who do you live with?
- (2) What is the residence location? – residential area?

Omit bathroom items.

Social Issues: Need something on Social Networks – non-resident friendships – possibility of a question on Eurostat regarding contact with people other than co-residents.

Daily occupation: Suggest including education & day centre options as well as open & supported employment

Income item – suggestion to include 2 items from Eurostat (23 & 24, 2000 version) – also wish to analyse using national minimum/average wage.

Health Status Indicators

Epilepsy: Use ILAE (International League Against Epilepsy) criteria

Diagnosis – 2 or more unprovoked seizures. Active cases: one seizure or more irrespective of AEDs in the last 5 years. Inactive case on medication – on AEDs in last 5 years.

AEDs – keep in this section. Hospitalisation for epilepsy – keep in this section

Oral health – ask Professor June Nunn.

Debate: We don’t ask whether a person brushes their teeth, yet we ask about their physical activity. To keep consistency we should be including items on health promotion – what is the individual doing to promote good health? – include ABS item on brushing teeth.

In general agreed that items need to:

- (1) determine health status – e.g. oral health status
- (2) assess health promotion – e.g. does person brush teeth
- (3) health screening questions should go with the item (e.g. visit to dentist should be in question on oral health)

Vision/Hearing/Mobility: Use ABS questions for consistency to determine health status – then look at health promotion & health screening

Health Determinant Indicators

Physical activity: Questions may be too difficult to code as the source is not stated it's difficult to ascertain validity – Try EUROSTAT alternative

Also, can we get an index of empowerment – what prevents you exercising?

Medication: Revert to original idea of psychotropic for this section – list of antipsychotic medication and dosage.

After considerable discussion we decided to also collect information on self-reported major health problems & medications in a separate section of the questionnaire (5-6 using the Special Olympics Horwitz report & Germain to provide list from ESAW project). The rationale was that some of the major causes of morbidity & mortality among people with intellectual disability, and some of the major health disparities between people with intellectual disability and the general population are not covered by the questionnaire. Therefore there was concern that individuals could appear healthy when in fact they may have major health problems and be administered large quantities of medication.

Challenging behaviour: Difficulty in validating the questions from CHAPP questionnaire – suggestion to examine short form of Aberrant Behaviour Checklist.

The issue of copyright was raised – if we use standardised tests – e.g. ABS, ABC, Pasadd etc., do we need to contact publishers and pay? Germain suggested that minor modifications to the questionnaire would mean it was no longer copyright. Christine suggested that we need to cite sources for items in our final report which may pose difficulties. Prof Patricia Noonan Walsh as Principal Investigator would need to make the final decision here.

Health System Indicators

Hospitalisation and contact with Health Care Professionals: These items can be lifted from Eurostat's European Community Household Panel survey using the same 12 month period – this will harmonise responses with the general public.

Health check ups – may need to increase blood sample time period – Henny might advise here what the source of the 12 month item is. There was a suggestion to examine the outcome of these medical check ups however this was dropped in favour of the new self-reported major health problems & medications.

Women's health screening should be matched with men's issues.

Smoking & Alcohol – use European Community Household Panel items.

4 Work Package 5 – Pilot Study

Need to finalise questionnaire soon as this will need to be incorporated into the proposal for ethics.

A pilot study will need to be completed in all participating Member States – not just one or two. Jon Perry outlined the differences between external and internal pilot studies. External pilot studies exclude pilot data for the main study while internal pilot studies include this data. Jan Tossebro suggested that the data should be included in the main study unless substantial changes were made to the questionnaire. If additional information is required this could be collected again.

Jon Perry suggested that he produce a summary evaluation sheet to be completed by researchers outlining their experiences with pilot data.

Of particular interest in the pilot will be information regarding the logistics of collecting data, consent procedures etc., and the validation of survey items

Data from a sub-sample will be collected twice to ensure validity and reliability.

5 Work Package 4 – Member State Reports – templates

A 10-15 page review of the status of people with intellectual disability in each Member State will be produced. This document will assist in providing data at systems level – that is, the estimated prevalence of intellectual disability and how this is determined. Christine will send out headings for these reports and some templates that may be useful in the New Year when this module begins.

6 Work Package 6 – Sampling Frames

There was considerable debate regarding suitable sampling frame. Mike Kerr suggested that a convenience sample of 60-100 individuals with Intellectual Disability should comprise the sample on the basis that Pomona II is an opportunity to test the indicators – the success of the project being measured in terms of whether the data can be collected. Christine suggested that a rationale would be required on two grounds; (1) would it be empirically sound to select a quota sample of individuals in receipt of a specific type of service? (e.g. people with Down’s Syndrome in supported employment) (2) partners will require some guidance in selecting their samples. Suggestions for a rationale included (1) restrict the population to people with intellectual disability in receipt of services (2) include adults across the full level of ability – severe, profound, mild, etc (3) try to have some representation of individuals by residential provision as this seems to be a major determinant of quality of life for people with intellectual disability (e.g. institutionalised care, independent community based care with staff, living with family etc.) – from an epidemiological perspective some over sampling may be required in Member States where some provision is restricted. Kathrin Gruning reminded partners that Professor Meindert Haveman would be giving this issue his attention following the meeting.

7 Opportunities for dissemination/awareness of Pomona Update – IASSID 2006

Partners questioned whether there was enough information to justify two symposia at this conference. The second symposia – on member state reports – was considered the weaker and a suggestion was made that only one paper be presented on this material during the first symposium.

Partners’ preference was to hold the Pomona meetings during the conference, not before or after.

8 General Housekeeping: Budgets, timesheets & claims

Partners were reminded to keep accurate timesheets as there will be an audit by the European Commission at the end of the project. Reimbursement for travel was discussed. Partners were asked to keep copies of all travel tickets etc., submitted to Ireland for payment. Issues regarding payments from the European Commission should be discussed between the accounts departments of the various universities & agencies.

9 Any other business

Christine will try to have a 3rd draft of the questionnaire for discussion at the 3rd meeting in Ljubljana 1-4 December. Christine will liaise with Henny regarding this draft.