

# ANNEX VI: 3rd REGIONAL MEETING



Regional Meeting of Partners – Bucharest 23-26 December 2006

National Centre of Family Medicine, Bucharest

24<sup>th</sup> November 2006

Present

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Italy: Dr Serafino Buono & Eleonora di Fatta (translator)

Austria: Professor Germain Weber

France: Dr Bernard Azema

Romania: Dr Alexandra Carmen Cara

Ireland: Christine Linehan

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The meeting commenced with a presentation by Dr Alexandra Carmen Cara on Romania, its history and landscape.

Christine outlined a review of the overall budget for POMONA and an overview of progress on the 9 work packages comprising the project.

### **Work Package 1 – Coordination: Budget**

Partners were informed that the first interim technical report and financial report were submitted to the European Commission in July 2006 and have both been approved. The Commission have released the second tranch of funding and this is now being disseminated to partners by the accountant personnel at University College Dublin. This tranch accounts for 20% of partners overall budget – except travel and expenses which is held centrally in Dublin for administration purposes. Partners received 30% of their budget at the beginning of the project and have therefore now received 50% of their budget. A further 20% is received following the European Commission's approval of the second Interim Report (due July 2007) and a final amount of 30% is due on approval of the Final Report (at the end of the project).

All partners are encouraged to meet with their accountants to review their budget as the project is now over half way through its three year duration. Partners should familiarise themselves with the timetable of payments from the European Commission and should monitor closely the number of days they contribute to the project ('matched funding') and the number of days work carried out by their researchers. Partners should review the detailed budget sent by Christine at the beginning of the project which outlined the number of days work required by each partner and their researcher and additional funds for travel, subcontracting etc.

Please note that when submitting travel and expenses claims on prepared invoices disseminated by either Christine or Marie O'Connor, University College Dublin now requests that the information presented on these forms be typed.

Problems with payment of reimbursement for IASSID registration fee at Maastricht – Christine to check with Marie

- (1) Fino's payment
- (2) Barbara Bremner's payment
- (3) Alexandra's cheque.

Dr Bernard Azema mentioned an additional spend necessary for France that has not been required by other partners that is related to ethical approval. The procedure for gaining ethical approval is lengthy in France where ethical committees are regionalised around universities and hospitals. In addition, at national level there is also a Ministry of Research & Teaching who monitor the feasibility & statistical appropriateness of each study. Bernard was asked by the National Informatic Committee to present POMONA before the Ministry. While currently France has all the ethical approval required, the POMONA study is classified as a 'medical study' and as a consequence a fee of 1,500 euro is required (15 euro per person) for each participant in the study. Germain suggested that Patricia write formally to the European Commission asking them to define the study as primarily social and not medical and that this correspondence and a similar letter from Patricia be sent to Bernard – this may be helpful in reclassifying POMONA.

In Italy the ethics committee is established in OASI – POMONA was admitted to the ethical committee with no problems. Similarly ethical approval was obtained in Romania, Austria & Ireland without difficulty.

### **Work Package 3 & 5: Development of Protocol and Pilot Study:**

The latest draft of the protocol was presented and reviewed item by item. The following points were discussed in detail:

Urban versus rural item – partners had difficulties in defining this as a self report item. Christine explained that many Health Interview Surveys use an urban-rural item that is 'self reported'. In addition, there is a second related question that may be useful. The question on 'region' is coded according to the European Commission NUTS 3 coding – e.g. UK123A – each of these regions have been coded by the EC as urban/rural – Christine has these classifications.

Partners stated that the 'self report' urban rural item needs a common criterion to be specified – this could be achieved by the level of 'industrialisation' of a region – this may include the level of access to services – concentration of services – population spread – etc. Alexandra recalls using a similar coding which defined the criterion for a village versus a city – Alexandra will pass this on to Christine.

Bernard mentioned a general point regarding the difficulty of having different time spans specified throughout the survey. Bernard conducted two of the interviews in France and found that participants had difficulty remember issues one year ago, two years ago, five years ago etc. Bernard suggested that for POMONA III a common timespan be specified. Christine explained that the time periods used in survey

questions are devised on the basis on either (1) definition (e.g. active epilepsy is defined in cases where an individual has experienced a seizure in the previous five years) or (2) best practice in clinical medicine (e.g. annual health checks; health screening for specific conditions on a three yearly rotation etc.) – however the presentation of these items in the survey may alleviate some of the difficulties noted by Bernard.

There were a number of items for discussion regarding the medication table:  
An addition to the medication table is suggested:

It would be useful to know how long a person has been taking specific prescribed medications.

Is there an option for Slow Release Depot drug? – Christine to ask Prof Mike Kerr about the inclusion of medication taken using ‘depot’ route.

Partners also called for a short section on the interview setting – how many people are present, what type of building, is their privacy, does the person seem relaxed, etc. subjective?

Prof Germain Weber outlined a strategy for training interviewers which is currently being carried out by the Austrian team who are enrolling psychology students to conduct the interviews. A series of two interview sessions will be undertaken for interviewers – ten psychology students. The first session has already taken place which comprised an introduction to people with ID, the POMONA project, ethical issues, informed consent etc. A video was made of one interview and was viewed for comment. A second session will be organised when the protocol is completed. The training aims to ensure that all ten interviewers have a similar standard of training. Training sessions comprise only five people in each group who each complete two half day training sessions.

Christine explored whether video conferencing facilities are available to partners as a possible vehicle for training. This technology is only available in Italy and therefore may not be a viable option – equally, Bernard explained that his interviewers would be unlikely to speak English and it would be difficult to conduct this training via translators.

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

Christine will make a presentation in Luxembourg to the European Commission at the Task Force on Major and Chronic Diseases on December 13<sup>th</sup> 2006. POMONA is now classified under this new Task Force as the former Task Force on Mental Health is disbanded. Christine will present information on the situation of people with ID across Europe. This presentation will be based on the Country Reports. It is noted however that one Country Report is outstanding and that a number of Country Reports remain in their local languages.

#### **Work Package 9: Training Health Professionals**

Bernard also mentioned his interest in expanding the expertise of training on health and disability beyond the POMONA group. In France possibly only five dedicated professionals work in this field. It would be useful to start a network of such expertise. Similarly, courses in ID and health could be shared across partner

countries. Fino is currently exploring options to organise a European Masters in Disability – possibly specialising in the assessment & treatment of adults with ID. Bernard suggests making a recommendation to the European Commission to develop a Masters in Intellectual Disability & Health. Christine recommends that both Bernard and Fino contact Henny with their suggestions as this information is valuable for work package 9 which Henny leads.

### **Saturday 25<sup>th</sup> November 2006**

#### Attendees

Italy: Dr Serafino Buono & Eleonora di Fatta (translator)

Austria: Professor Germain Weber

France: Dr Bernard Azema

Romania: Dr Alexandra Carmen Cara, Cristina Filip (medical student)

Ireland: Christine Linehan

#### **Work Package 9: Presentation by Alexandra on survey of family physicians**

Alexandra has conducted a survey of family physicians in Romania to examine their training needs. Alexandra will present these findings to Henny as they will be helpful in directing Work Package 9. Family Physicians in Romania undertake an additional three years specialisation. As the family physician is one of the primary points of contacts for families who have a family member with ID, they are in an ideal position to comment on training needs. The survey comprised 40 family physicians all bar one of whom had people with ID on their caseload of patients. From this sample, 75% were not aware of how disability is measured. Information was sought on legislation, educational options for children with ID and training options for health professionals. All respondents believed people with ID should be institutionalised and only require consultations with psychiatrists if they have an additional pathology. A discussion followed on differences in service provision for people with ID in different participating countries.

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

Christine presented Prof Meindert Haveman's powerpoint presentation from the regional meeting at Vilnius. A copy of this presentation will be placed on the website. Christine stated that the sampling procedure is a vital element of POMONA. While POMONA cannot make any claims on the representativeness of a sample, the sampling procedure has been the subject of most queries about POMONA at both ID specific conferences (e.g. IASSID) and non ID specific conferences (e.g. EUPHA).

Christine urged partners to send information on their 'health area', population statistics available for this health area, ID statistics for this area (if available), information on service providers etc. This information should be sent by each partner to Meindert and Henny as soon as possible.

Christine outlined how the collection of this information in Ireland is 'overlapping'. That is, information on population statistics covers different boundaries to that available on ID statistics etc.

In the discussion it was pointed out that national health statistics in general give representative figures. The same stands for statistics generated in health areas. As

POMONA-2 data is not collected in terms of representativeness the question was raised how we can mirror or compare figures from representative samples and non representative samples. This should be clarified before we start to work on representative health area data.

### **Work Package 2: Dissemination**

Christine – to write to partners outlining an agreed strategy for publications and presentations for the dissemination of POMONA. A draft outline is included below. Christine asks that all partners review this proposal and return feedback on this proposed dissemination strategy.

Please note that all dissemination activities must acknowledge the financial contribution of the European Commission.

Possible dissemination activities include:

- (1) Full international dataset: Definition - this dataset will include survey data on up to 100 adults with intellectual disability in the 14 participating countries. This dataset will be used when presenting data in the Final Report for the European Commission. Following the presentation of this dataset to the European Commission, this dataset can then be used by partners to disseminate findings.
- (2) Partners may wish to publish academic/scientific articles on key themed areas: for example medication, women’s health, mental health, typology of service provision etc. In these circumstances it is recommended that the partner who takes the lead role in preparing the article is assigned first author. Other partners should then be listed as co-authors. In some journals only a limited number of authors are permitted. In this case, the partner who prepares the paper is listed as lead author and the term ‘on behalf of the POMONA partners’ should be used to acknowledge the contribution of partners. It is acknowledged that many partners, especially those employed in university settings, require these publications as evidence of research activity.
- (3) Where the full dataset is used to publish material in a non-scientific journal the same recommendations apply as in (2)
- (4) National dataset – Definition: this dataset will include survey data on up to 100 adults with ID in one participating country. Partners agreed that where a paper is written primarily concentrating on the findings on one country but comparing it with the combined dataset of the remaining 13 countries, this type of paper should be considered a ‘national data set’ paper.
- (5) Where a ‘national dataset’ paper is submitted to a scientific journal, the paper should be authored by the partner with all remaining partners listed as co-authors.
- (6) Where a ‘national dataset’ paper is submitted to a non-scientific journal, the paper should be authored by the partner with the term ‘on behalf of the POMONA partners’
- (7) It is the responsibility of each partner to disseminate information about POMONA within his/her own nationality. Christine is encouraging partners to disseminate information in each country’s language as this will help ensure local dissemination.
- (8) In order to avoid the duplication of publications, partners are requested to forward information on proposed publications to Dublin.

- (9) Publications prepared throughout the duration of the project should be forwarded to Dublin where they will be placed on the POMONA dataset. The coordination of publications following the ending of the project should also be coordinated by the Principal Investigator Professor Patricia Noonan Walsh.

Any suggestions for circumstances where two or more but not all countries are reported? Any suggestions where only two countries are prepared?

#### Recommendations for the Final Report

Bernard's suggestions:

- (1) Final Report – brief summary – 2-3 page summary translated into every language
- (2) Easy to read version for people with disabilities like Eric Emerson (may not be in time for commission report but could be placed on website)
- (3) Interim Report in one pdf.
- (4) Final Report should present logo for each university at 2<sup>nd</sup> page – Christine asks that all partners now send their logos to Dublin

Christine suggests that a similar system of acknowledgement is used in the 2<sup>nd</sup> Interim Report and Final Report as was used in the 1<sup>st</sup> Interim Report where Christine requests a list of those to be acknowledged from each partner. It is the partner's responsibility to forward this information to Dublin.

Presentations –

International presentations should include all authors where possible – or 'on behalf of POMONA partners'. National presentations should cite the national author and the term 'on behalf of POMONA partners'. The funding of the European Commission must be acknowledged.

#### **Regional Meetings 2007**

Suggested regional meetings at Helsinki and Vilnius

- (1) Prato, Italy – Physical & Mental Health SIRG of IASSID
  - (2) Oslo, Norway – Ageing Group SIRG of IASSID
- (Christine reminded people that there is no funding in the POMONA budget for these conferences)

Partners queried why the three regional meetings were restricted to two meetings when compared with three meetings in previous years. If a third meeting is possible, Germain suggests it should occur in the Autumn.

Partners stated that their preference would be for one all partner meeting next year as opposed to a number of regional meetings. Partners stated that information from the regional meetings was disjointed as decisions were made in the absence of all partners being present. In particular partners would have welcomed an opportunity to link directly with the partners responsible for Work Package 6 – sampling strategy. Partners argued that there would be no budgetary difference between an all partner meeting and three regional meetings. If there is agreement for an all partner meeting in 2007, Germain offered Vienna as a meeting place. The meeting would then be scheduled for month of September, venue place University of Vienna.

### **All partner meeting scheduled for Dublin 2008**

Partners suggested that this meeting provide an opportunity to present data from the health survey. Recommendations based on these findings should also be presented. Germain suggested that invited guests from each country (e.g. ‘competent authorities’ such as government officials, statistical bodies, health professionals etc.) could be formally invited to attend by Patricia and the European Commission/DG Sanco. Germain used this strategy for an ageing conference and despite the lack of funding for invited guests, many competent authorities attended. Partners would need to supply the names of competent authorities to Patricia. Independent speakers should be invited to direct the discussion at the conference – these speakers should work within the field but should be independent of POMONA.

Following Christine’s experience at EUPHA (European Public Health Association) at Montreux in November 2006, where the inaugural meeting of the Mental Health Group argued that Intellectual Disability should not be included in this group, the final POMONA meeting in Dublin should provide an opportunity to disseminate information about health and ID beyond those who work in the ID field.

### **Deadlines.**

While acknowledging the delay experienced in the pilot study and production of a final protocol – largely due to the process of obtaining ethical approval – data collection will still be on schedule for the summer of 2007.

Christine can now prepare the final protocol and make the necessary changes to SPSS file and EXCEL file. While every effort has been taken to incorporate partners’ suggestions, the final decision regarding changes will rest with the Principal Investigator, Prof Patricia Noonan Walsh.

### **Any Other Business**

Germain has kindly offered to host either a 3<sup>rd</sup> regional meeting next year – the suggestion is for September 2007 or to host an all partner meeting next year instead of three regional meetings. The University of Vienna could provide meeting facilities for POMONA. Germain suggests that at this stage in the project, preliminary data analysis it would be very important that all partners meet together to discuss the implications of the findings.

In addition, the proposal of joining a POMONA meeting with IASSID conferences was not endorsed by partners. Partners stated that the all partner meeting in Maastricht this year – also combined with an IASSID conference – was not ideal. Partners had to decide whether they would attend POMONA business or IASSID business and thus were distracted from the POMONA meetings.

Partners therefore suggest that POMONA be represented at both the Health SIRG in Prato and the Ageing SIRG in Oslo but that these venues should not be used as regional POMONA meetings. Final proposal – all partner meeting in Vienna in September 2007.

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The meeting closed with thanks to our host Dr. Alexandra Carmen Cara for all of her assistance in organising this meeting. Our thanks to the National Centre for Family Physicians for allowing us the use of their meeting room. Thanks also to Alexandra's son Vlad Sarzea for his valuable support and to Cristina Filip for her attendance.