

ANNEX III: ALL PARTNER MEETING ROME

Pomona-2

Health Indicators for People with Intellectual Disability: Using an indicator set

Public Health OJ 2004/C62/04

Project funded 2005-2008 by:

Health & Consumer Protection DG
Directorate C – Public Health and Risk Assessment
C2-Health Information

Minutes 1st Meeting of Partners San Raffaele Foundation, Rome, 26-29 May 2005

Attendees:

Austria:	Professor Germain Weber
Belgium:	Dr. Dieter Windels representing Professor Geert Van Hove
Finland:	Dr. Tuomo Maatta
France:	Dr. Bernard Azema
Germany:	Professor Meindert Haveman
Italy:	Dr. Serafino Buono/ Ms. Eleonora Di Fatta
Ireland:	Professor Patricia Noonan Walsh/Ms. Christine Linehan/Ms. Marie O'Connor
Lithuania:	Mr. Robertas Povilaitis representing Dr. Arunas Germanavicius
Netherlands:	Dr. Henny Van Schrojenstein Lantman-de Valk
Norway:	Dr. Jan Tossebro
Romania:	Dr. Alexandra Carmen Cara
Slovenia:	Dr. Dasa Moravec Berger
Spain:	Professor Luis Salvador
Wales, UK:	Professor Mike Kerr

Thursday 26 May

Accommodation for Partners: Hotel Pisana Palace
via della Pisana 370,
00163 Rome

Friday 27 May

9:00 Welcome

Thanks to San Raffaele Foundation and our colleagues for their support

Introductions – by the partners

Review of *Pomona-1*

- Final Report website
- Prospective papers for publication:
 - brief report to new IASSID journal JIPID
 - Submission to EUPHA, WHO, etc.
 - submission to national publications in Member State languages

9:45 Pomona-2 (Powerpoint presentation by Professor Patricia Noonan Walsh)

Background – new EU Public Health Strategy

Activities since submission of the proposal April 2004 until May 2005

Research Question agreed by partners: What is the health situation of people with intellectual disability in the participating Member States as measured by a set of health indicators using standardised assessments?

10:30 Review of the work plan 2005-2008

11:00 Coffee/ tea

11:30 Budget - Powerpoint presentation by Christine Linehan

Overview of the shared-cost model and how each partner's budget was computed

Funding is linked to the work packages

Partners are responsible for documenting their time and their expenditure

Time in days – no other resources: this includes the time that partners contribute by attending meetings

Evidence for the daily rates must be produced (2008)

Actual costs of receipted travel are in the budget for attending 3 partner meetings and 3 regional meetings: taxis and car mileage are **not** covered.

Subsistence is paid at a *per diem* rate for the country visited using EC guidelines

There is a budget for partners to register at the 2nd European Conference of IASSID in Maastricht, August 2006 - when our partners meeting will also take place.

12:30 Lunch

1.30 Work Packages 1-9 Powerpoint presentation by Professor Patricia Noonan Walsh

Work Package 3 – Presentation & discussion of indicators lead by Dr. Henny Van Schrojenstein Lantman-de Valk

Small group discussion of possible Operationalisation of Indicators from POMONA 1:

Demographics: Jan Tossebro has experience of examining residential setting in Norway taken from the National Living Conditions Survey. Also similar items for Daily Occupation.

Health Status: Mental Health – not interested in classifying by disorder – recommend PASADD for psychiatric screening. BMI – as Pomona 1. Oral Health – may need expertise – Professor Walsh to ask Professor June Nunn – issues around ethics of ‘health examination’ vs. health interview. Mobility – select one option from Pomona 1 list. Sensory – Eurostat working on ‘easy’ question. Dr Dasa Moravec Berger suggested these items included ‘can you see someone across the street?’ Epilepsy – Mike Kerr to advise.

Issue for Health Status:

Assessment vs. Questionnaire – need a flowchart identifying data to be collected by:

- (1) survey
- (2) archival
- (3) assessment

Health Determinants: Physical Activity – use top item from Pomona 1; Challenging Behaviour – use full scale of BPI, ABC or ABS 2; psychotropic medication – use EUROHIS proforma list with BNF identification or ATC code and daily dose. Possibility of asking if RA (1) saw medication (2) saw prescription (3) self report only.

Health Systems: need to examine data at three levels – local, national, international.

Recommendation of colour coded indicators as in previous EU work:

Red, amber & green.

Timeplan recommended by Dr. Henny Van Schrojenstein Lantman-de Valk:

3 months – develop questions & obtain consensus

2 months – translate

1 month – obtain consent/ethics – may need to start ethics earlier

Professor Germain Weber recommends a user manual from work package 3 that could be put on the website.

5:00 End of session

Saturday 28 May

9:30 Welcome

Housekeeping - **Hotel:** The first night was paid for in advance for everyone. Partners were asked to pay for any extras – such as the minibar.

WP 4 Member State Reports

Each country will prepare a short report (10 pages) describing the current situation for people with ID. Patricia and Christine will draft an outline and send this to all partners by September 2005. Partners may then send their comments, and discuss progress at the regional meetings. The reports will be completed by April 2006 (Month 12). It would be valuable to have a matrix to summarize the main points so that the 14 countries (for example, Wales) may be compared with each other.

WP 5 Pilot

Mike Kerr and his expert advisor will prepare a document outlining how the pilot phase of the study might happen. He will send this proposal to all the partners for comment. Topics include field testing, sampling, etc. Mike suggests that while **all partners** will take part in the pilot study, not every country must do the same elements. For example, some countries may reflect on the ethical issues.

Mike could send the pilot questionnaire to the ethical committee for the UK for an informal opinion about how the final protocol might be considered and approved.

Partners may also consult advocacy groups or ngos in their countries to seek advice on ethical issues and how to gain informed consent. It is likely that these procedures will be different across the 14 countries.

WP 6 Sample Selection

Meindert and Henny will lead this Work Package.

Meindert suggests that we sample in a particular region, perhaps 50 kilometres wide, with three or more facilities with 100 residents. We should make sure that the area includes people with severe ID, challenging behaviour and elderly persons aged over 60 years.

Each country should consider what is the most representative form of residence for persons with ID and what is the most simple way to identify people with ID in that country. In some countries, we sample through residential service provision (NL), and in other countries, we sample through health providers (Wales). And in other countries, sampling will take place through municipalities (Norway).

We can make a total list of residences in the area, and number from 1 ...n, and select randomly n=70 persons in order to identify n=60.

Some points: Can we get data on individuals in rural areas (France)?

In Lithuania there will be only one approach – institutions. It would be very difficult to identify people who live with their families.

In Norway there is no difficulty in finding rural and urban areas.

Can we sample by gender, rural/urban, whether the person lives in a residential centre or in the family home? Note that the sample procedure will be different for each setting.

Meindert suggests that we do not stratify at the beginning; rather, we pool the data and analyze later by important variables related to health.

Is it possible for each country to identify people with ID living at home?

Luis notes the EPSILON study of schizophrenia which sampled only in urban areas.

WP 6 will be completed in September 2006 (months 13-17).

10:30 Coffee

10:50 Regional Meetings 2005

1-Graz Link with EUPHA conference – 10-12 November

2-Lahti Link with MAMH conference and consultation with
Department of Health, Finland

25-27 August 2005 – Congress of MAMH
www.whocares.fi

Tuomo and Mike will attend this conference.

If this August meeting is too soon, then we could arrange a regional meeting in Finland later in 2005 or March 2007.

Ljubljana January 2006 ??

3 – Barcelona MHMR

Vth European Congress - Mental Health in Mental Retardation

6-8 October 2005
www.mhmrbarcelona.com

The Abstract must be submitted NOW

Luis suggests that there could be a symposium on health indicators and that POMONA could sponsor this symposium. This gives ‘added-value’ to the project.

11:15 Agree plan of work 2005-2006 (1st year)

11:30 Publications

Pomona-1

We shall prepare a Brief Report with authorship by all partners and submit to **Journal of Policy and Practice in Intellectual Disabilities**. If it is accepted, this will appear in the September 2005 issue. It is suggested that the partners try to translate this article for dissemination in their countries. Henny, Mike, Christine and Patricia will plan further publications also.

Pomona-2

Some topics for articles:

- 1 – operationalizing the indicators
- 2 – a summary of the Member States reports (all partners)
- 3 – results
 - There may be a paper with data from 14 countries, and also a paper with focus on one country, such as Austria.
- 4 – results
- 5 – ethical issues
- 6 – WHO journal – recommendations for policy (all partners)
- 7 – Also – each partner could write an article for the **country**, naming the their partners. For example, an article by B. Azema in France, writing ‘for the Pomona group’, and an article in Italy by S. Buono, writing ‘for the Pomona group’.

Could there be articles with 3-4 authors as opposed to ‘for the Pomona Group’?

In principle, the lead author is the person who leads the writing task.

Meindert suggests that we do **not** place our data on the internet.

Be cautious putting powerpoints on the internet also – they may be used inappropriately without our knowledge.

Put Final Report in PDF on the website.

Consider public and private access to website – password protection for POMONA Partners?

Include some variables of level of ability? IQ indication? Adaptive Behaviour? Possibly use the ABS – only some items from this scale
ICF scale by WHO as another classification system?

Luis to provide information on ABS

Research Assistant

When & how can recruitment begin?

UCD (University College Dublin) to send confirmation that there is a budget for this person.

Each partner will receive an exact timetable of number of days for each RA by each workpackage

Recruitment & payment – UCD will need to provide a letter for each partner to authorise this – this will allow partners recruit.

Research Assistants are welcome to join any meeting – but there is not a budget.

Regional Meetings

Budget is for travel & subsistence –

Logo – should keep original

Workplan for this year:

Germain proposes to support Henny on ‘operationalising the indicators’

TO do:

WP 3 – Henny will send document to partners within the next 2-3 weeks for comment – how specific partners can provide support

WP 4

WP 5

THE END.

Finish of Meeting