

POMONA

HEALTH INDICATORS FOR PEOPLE WITH INTELLECTUAL DISABILITIES

INTERIM REPORT
MAY 2006 – APRIL 2007

The POMONA project is carried out by a working group with financial support of the European Commission 2004130

ACKNOWLEDGEMENTS

The authors are grateful to all those who have participated in this project to date; people with intellectual disability, their family, friends & advocates; service providers, policy makers and other stakeholders; project partners and researchers.

The authors would also like to specifically acknowledge the contribution of their colleagues in POMONA I; Mr. Frank Ulmer Jørgensen, Landsforeningen LEV; Professor Charles Aussilloux, Service de Médecine Psychologique Enfants Adolescents Peyre Plantade, CHU Montpellier; Dr. Raymond Cessotto, Fondation Association des Parents D'enfants Mentalement Handicapés; Dr Monica Björkman, Landstingets Hjärnskadecenter.

The authors retain full responsibility for any inaccuracies that may appear.

June 2007

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EXECUTIVE SUMMARY

POMONA II Health Indicators for People with Intellectual Disabilities: Using an Indicator Set is a European Commission project funded from May 2005 to April 2008. This 2nd Interim Report outlines progress from May 2006 to April 2007.

POMONA II aims to develop and test a set of health indicators specific to people with intellectual disabilities (also termed learning disabilities in the United Kingdom and mental retardation in the United States). It is hoped that these indicators will contribute to health information surveys conducted across the European Union. To date, people with intellectual disabilities remain invisible in such surveys. The omission of this population in health monitoring activities is most unsatisfactory given the considerable evidence from smaller-scale studies illustrating major health disparities between people with intellectual disabilities and their age related peers.

Progress on all nine work packages comprising POMONA II is reviewed in detail in this Interim Report. Work Package 1 ‘Coordination’ and Work Package 2 ‘Dissemination’ span the three-year duration of the project. Coordination activities are detailed in the minutes of four project meetings held in the Netherlands, Finland, Lithuania and Romania. Dissemination activities, comprising over 50 different activities including peer reviewed academic articles and oral conference presentations, are outlined in detail.

Work Packages 3 to 6 have been completed during the reporting period of this Interim Report. Work Package 3 ‘Operationalising the Indicators’ comprised the development, production and translation of the POMONA Protocol, a health interview survey for adults with intellectual disabilities, now available for use in fourteen European countries. Work Package 4 ‘Member State Reports’ involved the production of reports on the historical and current situation for people with intellectual disabilities residing in each participating country and where available, a review of data sources on epidemiology and health status. Work Package 5 ‘Pilot Study’ required clearance from ethical committees in the majority of participating country. Applications to ethical committees, while both necessary and valuable given the pioneering nature of the survey, did result in a delay in the commencement of the Pilot Study as partners awaited ethical clearance. Despite such delays, the Pilot Study is now complete and has resulted in constructive amendments to the POMONA Protocol. Work Package 6 ‘Sample Selection’ has culminated in partners identifying appropriate local sampling frames from which people with intellectual disabilities were invited to participate.

Activity for the final year of the project (May 2007 – April 2008) focuses on the remaining three Work Packages 7 to 9. Work Package 7 ‘Data Collection’ is complete in

five participating countries. Other partners are either in preparation or are actively in the field collecting data. Partners are requested to submit all data to the Project Manager by September 2007 for discussion at an All Partner Meeting in Barcelona. Work Package 8 'Data Analysis' will commence when the Project Manager has received all anonymised data. The final work package, '9: Training of Health Care Professionals' falls outside of the current reporting period and is due to commence in October 2007. The final All Partner Meeting in Dublin scheduled for March 2008 has been suggested as a possible opportunity to invite international interested parties to brainstorm training issues.

In summary, despite some time slippage, year two of the POMONA II project has culminated in the completion of four key work packages. Data collection is ongoing for year three, the final year of the project, which will also include work packages on data analysis and the identification of mechanisms for the training of health care professionals. In addition to the completion of these work packages, year three must address the broader context of the POMONA agenda. Can the set of health indicators for people with intellectual disabilities developed by POMONA be incorporated into national health interview surveys? Is the European Health Survey System's proposed European Special Health Interview Survey a possible vehicle for such a survey? Does the work of the United Nation's Washington Group and EUROSTAT's Disability and Social Integration Module provide mechanisms for identifying representative samples of people with intellectual disabilities to participate in a POMONA survey? Collaboration with these and similar groups is essential if the inclusion of people with intellectual disabilities in omnibus health interview surveys at European level is to be achieved.

June 2007

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1. BACKGROUND

1.1 OVERVIEW OF EUROPEAN COMMISSION HEALTH POLICY

While European Member States have prime responsibility for the health and well being of their citizens, there are a number of health related issues where it may be more efficient for Member States to cooperate under the auspices of the European Union. The European Treaty specifically identifies the role of the European Commission in the field of public health as one of ‘complementing’ Member States by promoting research, providing health information and fostering policy coordination among Member States (article 152).

In 1993 the European Commission presented the ‘Communication on the Framework for Action in the Field of Public Health’ as an initial strategy document to develop public health initiatives within the European Union. The programme, which covered a six year duration from 1996-2002, adopted and financially supported public health initiatives in eight key areas; (i) health promotion (ii) rare diseases (iii) pollution related diseases (iv) injury prevention (v) AIDS and communicable diseases (vi) cancer (vii) drug prevention and (viii) health monitoring. Key outputs of the programme included the establishment of European public health networks, (such as the European Public Health Alliance, EPHA); European surveillance systems, (such as the European Home and Leisure Accidents Surveillance System (EHLASS)); and the development of comparable health indicators and shared data systems across the European Union. An evaluation of the Framework for Action conducted by Deloitte (2004) reported that the programmes had achieved ‘an overall positive added value’ of European intervention in the field of public health (p. v) and called for continual investment.

In 2002 the European Parliament and the Council adopted a new ‘Framework of Community Action in the Field of Public Health 2003-2008’. The new programme is based on three objectives: (i) health information, (ii) reaction to health threats and (iii) the prevention of disease and illness. This second public health framework is one of the core elements of the new European Community Health Strategy (for details of the strategy see <http://europa.eu/scadplus/leg/en/cha/c11563.htm>).

The total budget of the 2003-2008 programme is 354 million euro. Project applications for funding from the programme are assessed against their contribution to the three objectives outlined above. By 2006, a total of 270 projects have received funding from the programme, details of which are presented on the Europe website at

http://ec.europa.eu/phea/calls/call_for_proposals_en.html#projects_list. A breakdown of the projects by theme and year is presented in the table below.

TABLE 1: Projects funded through Programme of Community Action in the Field of Public Health (2003-2008)					
Theme	2003	2004	2005	2006	TOTAL
Health Information Strand	32	31	21	23	107
Health Threat Strand	20	15	11	12	58
Health Determinant Strand	20	27	29	29	105
TOTAL	72	73	61	64	270

In 2005, a third Public Health programme was agreed. The ‘Community Programme for Health and Consumer Protection 2007-2013’ was originally proposed to address the three objectives of the 2003-2008 programme, and an additional three strands but, following an alignment of budgetary considerations, only the original three objectives were proposed: (i) to improve citizens’ health security (ii) to promote health for prosperity and solidarity (iii) to generate and disseminate health knowledge.

1.2 EUROPEAN HEALTH SURVEY SYSTEM

A major focus of the public health programmes is the establishment of a European wide information system producing comparable data on health, health-related behaviour, diseases and health systems. Termed the European Health Survey System (EHSS), the EHSS will employ an agreed set of European-wide health indicators, many of which were proposed during the first Framework for Action in the Field of Public Health (1996-2002) and are being further developed during the current Framework of Community Action in the Field of Public Health (2003-2008). Of particular mention is the development of ECHI, a set of European Community Health Indicators for the general population.

Grounded in the work of ECHI and other related projects, the European Core Health Interview Survey (ECHIS) has been established as a core survey of the proposed European Health Survey System (EHSS). ECHIS will comprise five components: (1) an annual survey to be completed in all Member States, (the Mini European Health Module), the first wave of which is expected in 2007 (ii) a European Module on Health Status (iii) a European Health Determinants Module (iv) a European Health Care Module and (iv) a European Background Module. A sub-sample of participants may also be invited to take part in a health examination survey pending an ongoing feasibility study. The European

Statistical System (comprising Eurostat and statistical offices, ministries, agencies and central banks that collect official statistics in EU Member States, Iceland, Norway and Liechtenstein) will manage these components of the EHSS.

A complementary set of European Special Health Interview Surveys is also envisaged to focus on more specific populations (e.g. adolescents), health conditions (e.g. chronic disease) or health themes (e.g. health service utilisation). Three topics have been identified for special attention (i) functional topics as defined by the International Classification of Functions (ICF), (ii) mental health and quality of life (iii) drug use. In order to make these surveys comparable, components of the ECHIS above are likely to be included. The Framework of Community Action in the Field of Public Health (2003-2008) will have responsibility for the coordination of these surveys.

2. POMONA I

2.1 THE PREVALENCE OF INTELLECTUAL DISABILITY

According to the World Health Organisation (2001a), an estimated one to three per cent of the world's population have an intellectual disability. The Report acknowledges that 'the prevalence figures vary considerably because of the varying criteria and methods used in the surveys, as well as differences in the age range of the samples' (p.35). Despite such challenges a crude prevalence estimate, extrapolated from the 490 million citizens of the 27 Member States comprising the European Union, suggests that five million to fifteen million citizens of the European Union are estimated to have an intellectual disability.

2.2 DEFINING INTELLECTUAL DISABILITY

Intellectual disability is the preferred term for a condition that is referred to as 'mental retardation' in the United States, and 'learning disability' in the United Kingdom. Intellectual disability is defined by ICD 10 (World Health Organisation's International Classification of Diseases, Version 10, 1992) as 'a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period'. DSM IV (American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, Version IV, 1994) provides a similar definition; 'a developmental condition that is characterized by

significantly lower than average level of general intellectual functioning’. Both ICD10 and DSM IV definitions note that deficits in intellectual functioning must be accompanied by deficits in ‘adaptive behaviour’, defined as age appropriate functioning in everyday activities such as communication, self care, education, work, leisure time and health.

This dual-criterion approach (Schalock et al., 2007), emphasizing deficits in both intellectual functioning and in adaptive behaviours was pioneered by the American Association on Intellectual and Developmental Disabilities (formerly the American Association of Mental Retardation) whose current definition of intellectual disability is ‘a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18’ (Luckasson, 2002, p1).

Changes in definition reflect the transition from a medical approach to disability, where the disability is perceived as a person-centered trait (typically referred to as a ‘deficit’) to a more ecological approach, where a disability is defined in the broader context of the interaction between the person and his/her environment, and the supports that are required by the individual to enhance this interaction (Schalock et al., 2007). The World Health Organisation’s (2001b) International Classification of Functioning, Disability and Health promotes this ecological approach by emphasising the impact of an individual’s disability in the broader social context, as opposed to a more traditional focus on the aetiology of the disability.

2.3 INTELLECTUAL DISABILITY AND HEALTH

A large body of research attests to the marked disparity in health between people with intellectual disability and the general population (Horwitz, 2000; US Public Health Service, 2001; Fisher 2004; Ouellette-Kuntz 2005; Krahn et al., 2006). The observed poorer health status is thought to reflect a combination of factors including, for example, genetic predispositions to certain health conditions, less favourable social circumstances typically experienced by people with intellectual disabilities, reluctance or inability to utilise generic health services, omission from public health awareness campaigns and residential circumstances that foster inactivity and poor lifestyle choices. Many of the disparities in health experienced by individuals with intellectual disability can be classified using Whitehead’s (1990) taxonomy as constituting a ‘health inequity’; that is, a disparity in health that is avoidable, unnecessary, unjust and unfair. Whitehead (1990) notes “the crucial test of whether the resulting health differences are considered unfair seems to depend to a great extent on whether people chose the situation which caused the ill health or whether it was mainly out of their direct control” (p.6).

2.4 POMONA: HEALTH INDICATORS FOR PEOPLE WITH INTELLECTUAL DISABILITIES IN THE MEMBER STATES

POMONA is a European Commission public health funded project that aims to develop and implement a set of health indicators specific to Europeans with intellectual disabilities. The project is one of many indicator-based projects, all of which hope to contribute to the emerging European Health Survey System (EHSS).

The inclusion of people with intellectual disabilities in European health surveys of the general population has been identified by IASSID (International Association for the Scientific Study of Intellectual Disability) as an important mechanism for the identification of health disparities among this population. IASSID state “Surveys and data systems should identify persons with ID [intellectual disability], as recognition can then be used to facilitate measurement of all aspects of health and reduce health disparities” (Scheepers et al., 2005, p.250). More specifically the position paper states “Persons with ID should not be subsumed into a broad “disability population” definition, because additional factors, which may affect health outcomes, play significant roles that require specific attention to the needs of people with a range syndromes, but having in common cognitive difficulties” (p.250).

POMONA I was funded by the ‘Communication on the Framework for Action in the Field of Public Health’ from 2002 to 2004 during which time partners, expert in the field of intellectual disabilities and representing 13 European countries, agreed upon a set of 18 key health indicators specifically relevant for people with intellectual disabilities. Details of the indicator set and the methodology employed in their selection are presented in the project Final Report (Linehan et al., 2004) which appears on the project website <http://www.pomonaproject.org/report.php>) and in a recent peer review publication by Van Schrojenstein Lantman de Valk et al., (2007) in the Journal of Intellectual Disability Research. The indicator set is presented in **Annex I** and uses the ECHI project framework of classifying indicators by demographics, health status, determinants and health systems. A list of project partners in POMONA I appears in **Annex II**.

In addition to the development of these indicators, POMONA I concluded that no systematic monitoring of the health of people with intellectual disabilities is currently undertaken at European level. A review of recent health interview and health examination surveys carried out in European countries revealed that people with intellectual disabilities are rarely included in health surveys of the general population. This work is ongoing by POMONA II partners and has recently been presented at a major conference of the Special Interest Health Group IASSID (International Association of the Scientific Study of Intellectual Disability) and is now being prepared for publication (Linehan et al., 2007). In contrast to these large omnibus surveys, data evidencing the diminished health status of people with intellectual disabilities is typically gathered on an ad hoc basis, from small sample sizes of people in receipt of services, and rarely includes

a sample of the general population for comparative purposes. People with intellectual disabilities are therefore doubly disadvantaged; despite considerable evidence of health disparities between their health and that of their age-related peers, they are additionally excluded from the very health monitoring mechanisms that are established to identify such disparities.

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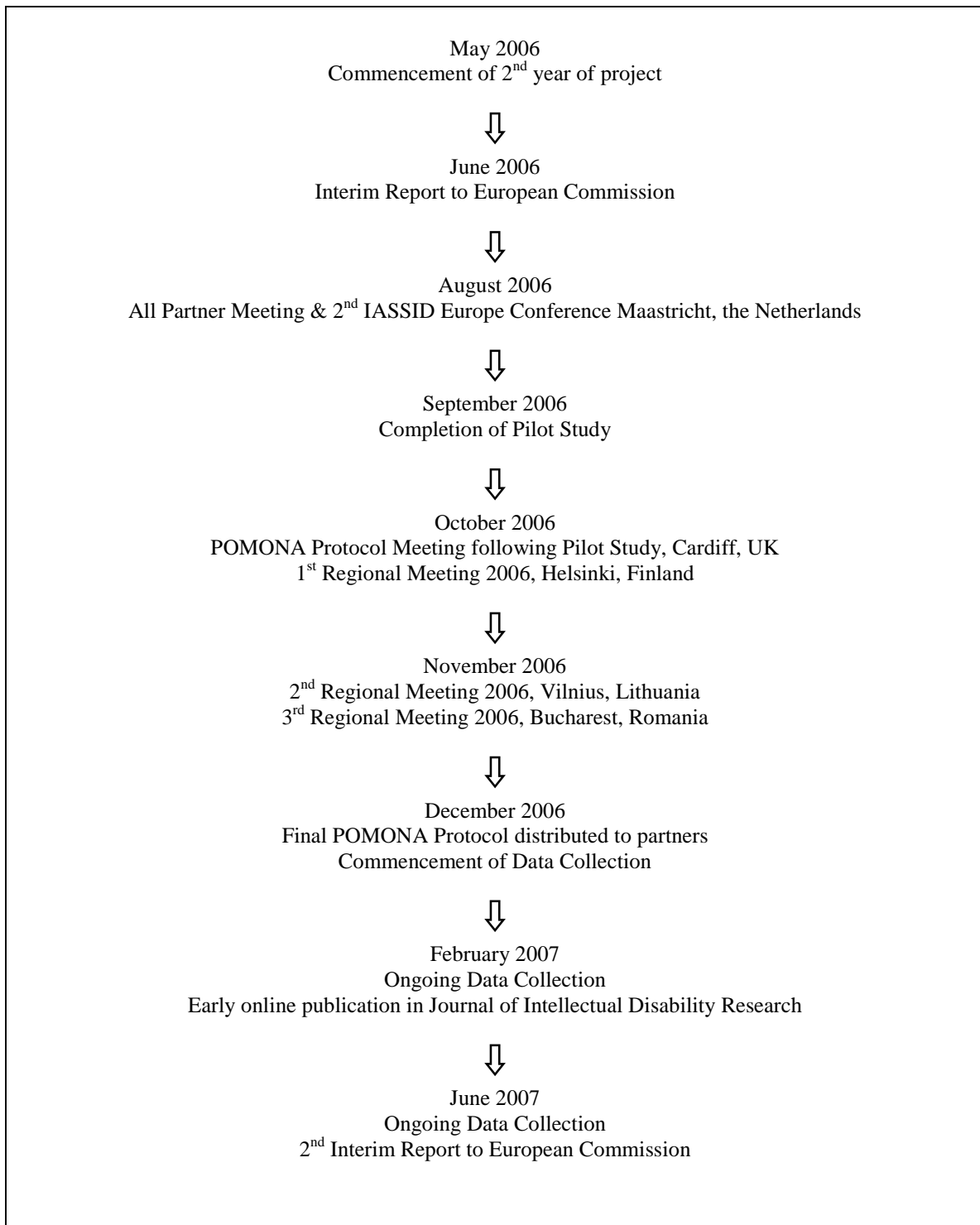
3. POMONA II

3.1 POMONA II OBJECTIVES

The over-arching aim of the POMONA II project is to promote the quality of life and health of people with intellectual disabilities in Europe by the provision of accurate health information and knowledge regarding this population. POMONA II will apply measures to identify the health status and needs of people with intellectual disabilities and contribute evidence to the public health programme that will potentially be applicable among other groups experiencing inequalities. General objectives of the project are:

- To build on experience and evidence gathered in a previous Community-funded project, POMONA which developed a set of health indicators for people with intellectual disabilities.
- To operationalize these indicators by gathering data from participants with intellectual disabilities across participating European countries using a POMONA Protocol developed by project partners
- To build and establish ways to sustain the flow of information about the health of people with intellectual disabilities within countries, the Community and internationally using contacts at all levels.

3.2 POMONA II PROGRESS: MAJOR DEVELOPMENTS



3.3 POMONA II PROGRESS TO DATE – WP1 COORDINATION

Work package n° 1 – Coordination

This work package is linked directly to achieving the overall aim of this project: to operationalize and apply a set of health indicators for people with intellectual disabilities and to prepare useful reports at member state, regional and international levels.

Lead Partner: University College Dublin, Ireland

Progress to Date: ONGOING to 2008

Coordination of the project from May 2006 to April 2007 was conducted via a combination of ongoing email contact and annual meetings comprising one all partner meeting and three regional meetings.

The main activities undertaken in this reporting period comprise three work packages.

- Work Package 6 ‘Sample Selection’, led by partners in the Netherlands (Dr Henny van Schrojenstein Lantman-de Valk & Marja Veenstra, University of Maastricht) and Germany (Prof Meindert Haveman and Kathrin Gruening, University of Dortmund)
- Work Package 7 ‘Data Collection’, led by partners in Wales, United Kingdom (Prof Mike Kerr and Dr Jon Perry, Cardiff University).
- Work Package 5 ‘Pilot Study’ also led by partners in Wales, United Kingdom (Prof Mike Kerr and Dr Jon Perry, Cardiff University). It should be noted that this work package was originally scheduled to be concluded prior to May 2006 however delays were experienced due to the lengthy process of obtaining ethical approval in some participating countries. This delay had a ‘knock-on’ effect, as without the pilot study a final POMONA Protocol could not be finalised.

Each of the four meetings of POMONA partners was hosted in a participating country. Partners are extremely grateful to their colleagues Dr. Henny Van Schrojenstein Lantman de Valk (the Netherlands), Dr Tuomo Maatta (Finland), Dr Arunas Germanivicius (Lithuania) and Dr Alexandra Carmen Cara (Romania) for their warm hospitality and assistance in organising the meeting venues, visiting speakers, accommodation and a variety of social activities during each of the meetings. A brief review of the content of each meeting is presented below.

3.3.1 All Partner Meeting, Maastricht, the Netherlands (2-5 August 2006)

The 2006 All Partner meeting of POMONA Partners was scheduled to coincide with the 2nd International Congress of IASSID (International Association for the Scientific Study of Intellectual Disabilities) Europe. Every four years IASSID hosts a World Congress (the next at Capetown in 2008) and a European Congress (the next at Rome in 2010). These Congresses are considered the premier international events for research presentations, keynote addresses and networking opportunities for those working in the field of intellectual disabilities.

In addition to attending the POMONA Partnership Meeting, partners were funded to attend the IASSID Europe conference. POMONA partners presented a full symposium of four papers, outlining progress to date and arising issues. The papers are available on the project website www.pomonaproject.org. The symposium was well received by a packed audience with a stimulating questions and answers sessions chaired by Professor Patricia Noonan Walsh. The symposium provided an ideal opportunity to inform colleagues in the field about the project and in addition, provided partners with valuable independent evaluations from expert colleagues on the methodology, progress and proposed outcomes of POMONA.

The All Partner POMONA meeting (minutes of which are presented in **Annex III**) commenced with an update of each of the nine work packages comprising POMONA II. Professor Patricia Noonan Walsh reviewed progress on Work Packages 1 and 2, which are concerned with the coordination and dissemination of the project. Discussions concerning Work Package 3 ‘development of a survey protocol’ focused on partners’ validation of the protocol based on a professional translation undertaken by Dublin City University, Ireland. Partners expressed general satisfaction with the translated surveys. Modifications were required, as translators, while expert in their field, would not have a similar level of expertise in disability. For this reason, partners were forwarded a detailed validation methodology, which necessitated the assistance of colleagues who are expert in the field of disability, to evaluate the translated protocol. Work Package 4 ‘Country Reports’ was discussed in the context of the World Health Organisation’s forthcoming World Atlas of Intellectual Disability. Professor Luis Salvador, a POMONA partner, is involved in this initiative.

Dr Jon Perry, UK, was lead discussant regarding Work Package 5, the pilot study. Dr Perry outlined how unavoidable delays in obtaining ethical approval for data collection had resulted in an extension of the proposed duration of this work package. A revised deadline of September 2006 was agreed. Dr Henny Van Schrojenstein Lantman de Valk chaired the discussion of Work Package 6, ‘Sample Selection’. Much of the discussion focused on non-respondent issues. Partners suggested that details regarding those who do not consent to participation should be strictly limited to quantifying this group. Those who consent and are at a later point unable to participate in the study are also deemed

‘non respondents’ however partners agreed that this group differ from those described above as, having consented, they can be considered as having been ‘recruited’ to the survey. Therefore anonymous information on this group concerning age (as per agreed age-bands), type of residential provision (out of home/family) and level of ability may be available to allow some statement regarding this group of non-responders. Dr Van Schroyen Lantman de Valk also chaired a session on Work Package 9 ‘Training of Health Care Professionals’. Partners suggested that training recommendations should be directly linked to the survey protocol and its emerging data.

The meeting closed with a discussion on publication and presentation strategies. In particular, the IASSID World Congress hosted in Cape Town during August 2008 was identified as the premier conference to showcase POMONA outcomes. The timing of the conference is fortuitous as it coincides with the production of the POMONA Project Final Report.

3.3.2 1st Regional Meeting, Helsinki, Finland 12-15 October 2007

Partners from Finland, Ireland and Slovenia attended the Finnish POMONA Regional Meeting at the invitation of the Rinnekoti Foundation, Helsinki. A review of progress on each of the pertinent work packages was undertaken with feedback from attendees on progress to date and arising issues. In particular, partners discussed their experiences of data collection during the pilot study. The detailed minutes of this meeting are presented in **Annex IV**.

Invited Finnish guests, expert in the field of intellectual disabilities, presented information on the epidemiology and circumstances of people with intellectual disabilities, and on the availability of health care services for this population in Finland. Speakers, who are international experts in the field of disability, included Dr Markus Kaski, Rinnekoti Foundation, Dr. Matti Iivanainen, also Rinnekoti Foundation and University of Helsinki and Dr Marja-Leena Hassinen, City of Helsinki Health Centre. The benefits of inviting national speakers to regional meetings are multiple. Firstly, the speakers provide POMONA partners with an insight into national policies and service provision options for people with disabilities. In addition, these invitations also fulfil a dissemination function by creating awareness of the POMONA project among national colleagues working in the field of disabilities.

3.3.3 2nd Regional Meeting, Vilnius, Lithuania 9-12 November 2007

Attendees comprised partners from Lithuania, Belgium, Germany, Ireland, the Netherlands, Norway and Wales, United Kingdom. **Annex V** comprises the full minutes of this meeting, a summary of which is presented below.

The meeting commenced with a presentation by Professor Dainius Puras, Head & Associate Professor, Centre for Child Psychiatry and Social Paediatrics, Vilnius University who outlined the history of reform of the psychiatric services in Vilnius following Lithuania's independence from the Soviet Union.

Dr Henny Van Schrojenstein Lantman de Valk chaired a session on Work Package 9 'Training for Health Professionals'. Partners discussed the scope of the term 'health professionals' and the possibilities afforded by using the European Credit Transfer System as a mechanism to provide training at European level. Dr Jon Perry noted that a key objective of this work package is cited in the project proposal as 'to meet and advise contacts in Member States with responsibility for devising and delivering curricula for health professionals'. Possibilities of inviting key stakeholders to a conference coinciding with the final All Partner Meeting in Dublin were discussed.

Professor Meindert Haveman presented a powerpoint presentation on Work Package 6 'Sample Selection'. Professor Haveman suggested that partners identify a sampling frame within a given 'health area' from which approximately N=80 adults with intellectual disabilities would be randomly selected to participate. Population statistics should be provided for the health area. A helpdesk with phone support was proposed to assist partners in constructing their sampling frame, as local differences in each participating country must be acknowledged. Partners were invited to submit draft sampling strategies to the Work Package co-ordinators for comment.

A final presentation by Dr Jon Perry reported on Work Package 5 'Pilot Study'. Feedback from partners was generally positive. Amendments to the protocol were outlined following a meeting between Christine Linehan, Prof Mike Kerr and Dr Jon Perry in Cardiff University.

3.3.4 3rd Regional Meeting, Bucharest, Romania

This meeting was hosted with the support of the National Centre of Family Medicine, Bucharest and included partners from Romania, Austria, France, Italy, and Ireland. The minutes are presented in full in **Annex VI**.

Dr Alexandra Carmen Cara, hosting the meeting, gave a brief presentation outlining the role of family physicians in providing services for people with intellectual disabilities in Romania. In addition, as with previous regional meetings, progress to date, administrative and budgeting issues were reviewed. Partners have been reminded at all meetings to monitor their budgets and record their time commitment to the project.

Dissemination activities were discussed at length. Partners were agreed that a clear publication strategy is required to disseminate findings from the data gathered from the

POMONA protocol. Partners suggested that the respective partner for each country should disseminate information pertaining to national datasets. Where the data from all participating countries is combined, a dissemination strategy among partners will be required to ensure that partners do not publish duplicate findings.

Participants debated the merits of regional meetings. Certainly, these smaller working groups provide an opportunity for partners to become acquainted with practices in other countries. In addition, those partners who host meetings are encouraged to invite colleagues to meet with the POMONA partners, thereby establishing important collegial networks. One disadvantage however of smaller working groups is that decisions made at one regional meeting are made in the absence of all partners. Equally, partners who are responsible for key work packages, in particular Work Package 6 ‘Sample Selection’ and Work Package 7 ‘Data Collection’ are only available for discussion at one of the three regional meetings. For these reasons, partners suggested that the three regional meetings (scheduled for late 2007) be subsumed into one all partner meeting. As each partner is funded to attend one meeting there is no budgetary issue as to whether the partner attends a small working group or an all partner meeting. For this reason the regional meetings of 2007 have been subsumed into one meeting which will be held during September 2007 in Barcelona, hosted by Prof Luis Salvador, with the support of Spanish intellectual disability organisations AEECRM and Sant Joan de Deu. In addition, an invitation has been extended to the Minister for Health, Catalonia, Mrs Geli, to address this meeting.

3.3.5 Coordination of Project Activities 2005-2006

The following key activities have been coordinated during the second year of the project and are presented in further detail from Section 3.4 below

- Work Package 1: **ONGOING** coordination, attendance at meetings, updates via email
- Work Package 2: **ONGOING** dissemination activities
- Work Package 3: **COMPLETED**: Production of Final POMONA Protocol based on pilot feedback
- Work Package 4: **COMPLETED**: Production/translation of Country Reports not included in 1st Interim Report
- Work Package 5: **COMPLETED**: Collection and analysis of Pilot data in participating countries
- Work Package 6: **COMPLETED**: Identification of sampling frames in each participating country
- Work Package 7: **ONGOING**: Data collection in participating countries
- Work Package 8: **Scheduled May 2007-January 2008** (Data Analysis) slight slippage due to ongoing data collection
- Work Package 9: **Scheduled October 2007-April 2008** (Training for Health Professionals) Discussions for conference in Dublin March 2008

3.4 POMONA II PROGRESS TO DATE – WP2 DISSEMINATION

Work package n° 2 – Dissemination

This work package is linked to a core objective of this project and a priority for the Health Information Strand within the EU Public Health Programme (2003-2008). Project activities aim to inform relevant bodies at member state, regional and international levels about evidence and best practice in applying health indicators among people with intellectual disabilities.

Lead Partner: University College Dublin, Ireland

Progress to Date: ONGOING to 2008

Within the first year of the project (2005-2006) over 35 dissemination activities were identified with an additional ten activities planned. This year a total of 55 dissemination activities, 13 pending and 42 completed are recorded and are detailed in Table 2 below. These activities include book chapters, peer reviewed articles, oral presentations at conferences, invited addresses, poster presentations, meetings, workshops, lectures, newsletters and information sessions.

Dissemination of project activities to the Working Party on Morbidity and Mortality (WPMM), Task Force on Major and Chronic Diseases (TFMCD) include a presentation of the project's activities to the Task Force in December 2006, an outline of the project for publication in the March 2007 (Vol. 2) edition of the WPMM Newsletter and attendance at a progress meeting of WPMM TFMCD in June 2007.

In addition, an opportunity exists for some project partners to liaise with delegates from EUROSTAT and the United Nations' Washington Group on Disability Statistics at an international meeting hosted in Dublin during September 2007. These groups are charged with developing an international short set of questions to identify people with disabilities in censuses or nationally based surveys. POMONA partners attending these events will be invited to provide feedback to the next All Partner Meeting in Barcelona.

In addition to these activities, partners are currently debating dissemination strategies for the complete POMONA dataset. Recall that this dataset will contain anonymous data on approximately 80 adults with intellectual disability in 14 European countries (an estimated 1120 participants). In order to coordinate dissemination activities of this data, partners have been circulated a dissemination form. Partners are asked to identify areas of dissemination that they are interested to lead. Some partners, for example, have specific expertise in primary care, aging, or epilepsy, etc., and have nominated themselves to take responsibility for disseminating data related in these sectors.

A POMONA website was created for the first POMONA project (2002-2004) and is updated on an ongoing basis to include the activities of POMONA II. The website can be accessed at www.pomonaproject.org. The table below presents POMONA II dissemination activities undertaken or prepared during the period May 2006 – April 2007.

TABLE 2: DISSEMINATION ACTIVITIES

Type of presentation (e.g. publication, conference presentation, poster presentation, invited address, meeting, workshop etc)	Presenter(s)/ Author(s) (* denotes speaker at oral presentation)	Title of publication/presentation	Name of publication/ conference/ organisation where meeting held	Date of publication/ conference/ meeting
FORTHCOMING From June 2007				
Paper in preparation	Buono S et al.	Indicatori di salute negli adulti con DI: il Progetto POMONA	Life Span and Disability	In preparation
Paper in preparation	Buono S, Mongelli V, Carrubba A, Di Fatta E, Mascali G, Trubia G.	The condition of adults with id: a comparative study on health and life status	Life Span and Disability	In preparation
Research in progress	Buono S and the Dept. of Psychology, Oasi	Self-injury in adults with ID.		In progress
Manual	A.M. Mazzelli, V. Mongelli, G. Mascali, G. Trubia, L. Dana, S. Buono	Day Habilitation Manual		In progress
Book Chapter	Satgé D., Azéma B., Culine S. & Sasco A.	Cancers in Persons with Intellectual Disability: Current Data	Mary V. Charleton (ed.) “Mental Retardation Research Focus” - Hauppauge NY, Nova Science Publishers Inc.	Publication 3rd Quarter 2007

Book Chapter	Azéma B.	Des indicateurs de santé pour les personnes vivant avec une déficience intellectuelle: le projet européen POMONA	Zribi G et al. (dir.) “La santé des personnes handicapées” (provisional title) submitted January 2007.	To be published by Editions Ecole Nationale de Santé Publique
Poster presentation	Linehan, C., & Walsh, P.N., on behalf of the POMONA Project	Measures of Adult Mental Health in Europe	6th European Congress of Mental Health in Intellectual Disabilities, Zagreb, Croatia.	October 11-13, 2007
Conference Presentation	Brehmer, B & Weber, G	Frailty syndrome and mental health issues in an older population with intellectual disability – preliminary findings from the Austrian POMONA sample	6 th European Congress of Mental Health in Intellectual Disabilities, Zagreb Croatia	October 11-13 2007
Conference Presentation	Buono S.	Indicatori di salute negli adulti con DI: il Progetto POMONA	Seminar addresses to professionals dealing with people with ID.	September 2007
Conference Presentation	Buono S	Indicatori di salute negli adulti con DI: il Progetto POMONA	Master: Valutazione e intervento nelle disabilità intellettive, IRCCS Oasi Troina, Università KORE Enna	6 July 2007
Invited Address	Azéma B	The European Approach on Health in Intellectual Disability and the Pomona Project	The future national Inter-Universities Diploma (“Diplôme Inter Universitaire”: Lyon, Paris, Rennes & Montpellier) “Déficience Intellectuelle-Handicap Mental”, Hôpital La Pitié Salpêtrière, Paris, Pr Vincent Des Portes (Coord.)	2007-2008

Invited Address	Linehan, C	Health Disparities and People with Intellectual Disabilities: A European Perspective.	Health Service Executive, North Western Area. LHO Area Conference for Learning Disability Services, Sligo.	October 2007
Peer Reviewed Publication (in preparation)	Linehan, C., Walsh, P.N., Van Schroyen Lantman de Valk, H., Kerr, M., Dawson, F., on behalf of the POMONA Project	Monitoring the Health of People with Intellectual Disabilities in European Health Interview and Health Examination Surveys	Submission to generic Public Health journal summer 2007	Summer 2007
COMPLETED April 2006-May 2007				
Peer Reviewed Article	van Schroyen Lantman-de Valk, H., Linehan, C., Kerr, M.P., Walsh, P., N.	Developing health indicators for people with intellectual disabilities. The method of the Pomona Project	Journal of Intellectual Disability Research. Vol. 51, (6), 427-434	2007
Peer Reviewed Abstract	Linehan, C* & Walsh, P.N on behalf of POMONA Project	Piloting a set of Health Indicators for People with Intellectual Disability in 14 European States 2005-2008	European Journal of Public Health, 16 Suppl, 1, 20 (Abstract)	16-18 November 2006
Peer Reviewed Abstract	Linehan, C* Buono, S., Moravec Berger, D., Salvador Carulla, L., Tossebro, J.,	Monitoring the Health of Adults with Intellectual Disabilities in Europe	Journal of Applied Research in Intellectual Disabilities, Vol 19, 3, 248. (Abstract)	2-5 August 2006
Peer Reviewed Abstract	Veenstra, M., * van Schroyen Lantman- de Valk, H., Azema, B., Cara, A., Maatta, T.	Applying a set of health indicators for people with intellectual disabilities across 14 European countries: Developing a survey instrument	Journal of Applied Research in Intellectual Disabilities, Vol 19, 3, 248. (Abstract)	2-5 August 2006
Peer Reviewed Abstract	Weber, G., van Hove, G., Walsh, P.N*.,	Gathering information about the health of people with intellectual disabilities: Ethical issues	Journal of Applied Research in Intellectual Disabilities, Vol 19, 3, 248. (Abstract)	2-5 August 2006

Peer Reviewed Abstract	Perry, J* Kerr, M Germanavicius, A., Haveman, M., Linehan, C.	Applying a set of health indicators for people with intellectual disabilities across 14 European countries: Implementing a pilot study.	Journal of Applied Research in Intellectual Disabilities, Vol 19, 3, 248. (Abstract)	2-5 August 2006
Conference Presentation	Haveman, M.	Health Indicators for Adults with Intellectual Disabilities in Europe	IASSID Special Interest Research Group Roundtable on Ageing and Intellectual Disabilities, Oslo	30 May – 1 June 2007
Conference Presentation	Kittelsaa, A.	Ageing, Health and Intellectual Disabilities: Pomona II, a Health Survey in 14 European Countries	Nordic Conference on Ageing in People with Intellectual Disabilities	29-30 May 2007
Conference Presentation	Haveman, M.	Health Indicators for Adults with Intellectual Disabilities in Europe	State of the Science in Aging with DD: Charting Lifespan Trajectories and Supportive Environments for Healthy Community Living, Atlanta, Georgia	21-22 May 2007
Conference Presentation	Câra, A.	POMONA II Importanța indicatorilor de sănătate pentru evaluarea stării de sănătate a persoanelor cu dizabilitate intelectuală- Boli cronice și nevoi de îngrijire POMONA II	Conferinta cu Participare Internationala: Managementul Bolilor Cronice în Practica Medicilor de Familie (The Management of Chronic Disease in Family Doctors' Practice) Palatul Copiilor, București.	17-20 May 2007
Conference Presentation	Linehan, C*, Walsh, P.N., Van Schrojenstein Lantman-de Valk, H., Kerr, M., (2007) on behalf of the POMONA Project	Monitoring the Health of People with Intellectual Disabilities within European Health Surveys	IASSID Special Interest Research Group Conference on Physical Health: Chronic Disease Management in People with Intellectual Disability. Prato, Italy,	21-23 May 2007

Conference Presentation	Van Schroyen Lantman-de Valk, H., Straetmans, J., Schellevis, F., Dinant, G., (2007)	Health Monitoring through GP Databases	IASSID Special Interest Research Group Conference on Physical Health: Chronic Disease Management in People with Intellectual Disability. Prato, Italy,	21-23 May 2007
Conference Presentation	Kerr, M., & Perry, J* (2007)	Surveying the Health of People with Intellectual Disabilities	IASSID Special Interest Research Group Conference on Physical Health: Chronic Disease Management in People with Intellectual Disability. Prato, Italy,	21-23 May 2007
Conference Presentation	Buono S.	Le disabilità intellettive: aspetti psicologici e socio-sanitari	Convegno sul Centenario dell'Università di Palermo	22 May 2007
Conference Presentation	Buono S, Musumeci M, Linehan C, Noonan Walsh P.	Il progetto POMONA: indicatori di salute negli adulti con disabilità intellettiva	III Convegno Internazionale dell'Associazione Mediterraneo senza Handicap. La Valletta. Malta	23-25 April 2007
Conference Presentation	Weber, G & Brehmer, B	POMONA Project: Aims, methodology and cooperation plan	Umbrella Organisation of Social Service providers of the City of Vienna, 1070 Wien, Schottenfeldgasse 29	1 February 2007
Conference Presentation	Perry, J. & Kerr, M.	Pomona: Monitoring the Health of Adults with Intellectual Disabilities in Europe	Bro Morgannwg NHS Trust, Clinical Governance half day	13 December 2006
Conference Presentation	Buono, S.,* Walsh, P.N., Linehan, C., & Musumeci, M.	Indicatori di Salute Nelle Disabilità Intellettive.	VII Congresso Nazionale. Promuovere Benessere Con Persone Gruppi Comunità. Cesena, Italy	28-30 September 2006

Conference Presentation	Kerr, M.	POMONA II Health Indicators for Adults with Intellectual Disability.	Kingston University Kingston Ontario Canada	15 September 2006
Conference Presentation	Câra, A.	Monitorizarea stării de sănătate a persoanelor cu dizabilitate intelectuală POMONA 2 Monitorising the health of people with intellectual disability-POMONA 2 European perspective	Health Trade- Conference For Doctors: Another Kind of Dialogue for Health. Organised by CNSMS(National Center of Studies for Family Medicine), ROMEXPO Bucharest	10-11 June 2006
Conference Presentation	Buono, S.	Indicatori di salute nelle disabilità intellettive. Il progetto Pomona II	Master “Le disabilità Intellettive” Università di Messina Italia	20 May 2006
Conference Presentation	Van Schroyen Lantman- de Valk, H Veenstra, M	POMONA:gezondheids-indicatoren voor mensen met verstandelijke beperkingen.	Pepijn en Paulus	15 May 2006
Invited Address	Buono S.	Indicatori di salute nelle disabilità intellettive.	7° Congresso Nazionale Disabilità, Trattamento, Integrazione. Padova (Italy)	7-9 June 2007
Invited Address	Van Schroyen Lantman-de Valk, H., Veenstra M.	Gezondheidsindicatoren voor mensen met verstandelijke beperkingen. Heeft de AVG daar wat aan?	Symposium afstuderen AVG opleiding EUR Rotterdam	2 February 2007
Invited Address	Linehan, C. on behalf of the POMONA Project	Intellectual Disability: A European Perspective.	Task Force on Major and Chronic Diseases; European Commission, Luxembourg	13 December 2006
Invited Address	Linehan, C. on behalf of the POMONA Project	Health Monitoring for People with Intellectual Disability in the European Union.	Special Olympics Youth Games Symposium, Rome.	1 October 2006

Invited Address	Azéma B	Espérance de vie, santé et qualité de vie des personnes handicapées : quels suivis de santé au long cours pour les personnes handicapées ?	23èmes Journées Nationales de formation des personnels des Maisons d'Accueil Spécialisées et des Foyers d'Accueil Médicalisés" Angers -France	17-19 May 2006
Brief Information	Azéma B & Weber G.	Le Projet Pomona	Congress : Le vieillissement des personnes handicapées : des constats aux propositions ». Guest speaker Germain WEBER La Grande Motte, France.	November 2006
Brief Information	Azéma B.	Le Projet Pomona	Regional Congress: Autisme : recherches et pratiques en Languedoc Roussillon", Narbonne, France	19 June 2006
Poster presentation	Buono S, Mongelli V, Carrubba A, Di Fatta E, Mascali G, Trubia G.	The condition of adults with id: a comparative study on health and life status	16 th SIRGAID Roundtable conference, Oslo (Norway)	30 May-1 June 2007
Poster	Perry, J. & Kerr, M.	POMONA-2: Operationalisation & piloting a set of health indicators for people with intellectual disabilities	Seattle Club Meeting, Kendall, UK (Conference of ID researchers)	11-12 December 2006
Workshop	Aussilloux C & Bartheye E.	Le Projet Pomona. Une étude soutenue par le CREAI Languedoc Roussillon au niveau européen.	ANCREAI (National Association of the Regional Centres, the CREAI) Paris.	30 November 2006
Workshop	Azéma B.	La santé des personnes handicapées. L'intérêt du projet Pomona	GAMAS (regional working group of professionals in severe, multiple & profound disabilities. CREAI Languedoc Roussillon	June 2006

Lecture	Azéma B.	La santé des personnes handicapées vieillissantes. (Brief information on the Pomona Project)	University Course, Professional Master in Gerontology, Faculté de Médecine de Montpellier-Gerontoclef, Montpellier.	March 2007
Lecture	Azéma B.	La santé des personnes handicapées. (Brief information on the Pomona Project)	University Course, Professional Master in Psychology. Faculté de Lettres, Université Paul Valéry, Montpellier.	18 and 25 April 2007
Meeting	Walsh, P.N., & Linehan, C	Meeting with competent authorities	Health Service Executive, Dublin	13 November 2006
Meeting	Azéma B	Présentation du projet européen d'une enquête de santé sur les personnes avec déficience intellectuelle : le projet POMONA	Rencontre CREAM Languedoc Roussillon Montpellier- France	23 June 2006
Meeting	Linehan, C.	Pomona II Project	Special Olympics Europe / Eurasia, Brussels	9 May 2006
Weblink	NHS National Library for Health	http://www.library.nhs.uk/learningdisabilities/ Search POMONA	NHS National Library for Health	Since June 2006
Newsletter	Submitted by Linehan, C. on behalf of the POMONA Project	Pomona II Project – Health Indicators for People with Intellectual Disabilities http://ec.europa.eu/health/ph_information/implement/wp/morbidity/docs/wpmm_02_en.pdf	Working Party on Morbidity and Mortality Newsletter, March 2007 Number 2, p.3. European Commission, Luxembourg.	March 2007
Newsletter	Azéma B.	Des indicateurs de santé pour les personnes ayant une déficience intellectuelle : le projet européen POMONA II.	Le Pélican, 171, 4-9.	May 2006,
Newsletter	Linehan, C.	Health Monitoring in European for People with Intellectual Disability	Include Europe Newsletter of Inclusion Europe, Bruxelles	April 2006

3.5 POMONA II PROGRESS TO DATE – WP3 OPERATIONALISING THE SET OF INDICATORS

Work package n° 3 – Operationalising the agreed set of indicators

This work package is central to the development and operationalization of a set of European health indicators for people with intellectual disability. Completion of this work package will provide all partners with an agreed protocol to use in a small pilot study in each participating MS prior to the major survey planned for 2006.

Lead Partner: University of Maastricht, the Netherlands

Progress to Date: WORK PACKAGE COMPLETED

This task comprised the main focus of activity for the first year of the project (May 2005-2006). During this time a draft POMONA Protocol was devised based largely on the set of 18 health indicators identified in the Final Report POMONA I (Linehan et al., 2004). The POMONA Protocol comprises three elements:

- (1) Part One: Items related to demographics, health status, health determinants and health system utilisation adopted from current European Health Interview Surveys, suggestions from partners and intellectual disability specific sources.
- (2) Part Two: The PAS ADD Checklist (Moss, 2006) an intellectual disability specific measure of mental health for which a licence was sought and obtained.
- (3) Part Three: The Aberrant Behaviour Checklist (Aman & Singh, 1986) an intellectual disability specific measure of challenging behaviours for which permission was sought and obtained.

Dublin City University Language Services was commissioned by the Project Manager to translate this version of the POMONA Protocol into a total of 13 European languages. In addition, partners in Austria and Belgium took responsibility for adapting the translated protocol into Austria German and Flemish Belgian versions.

The translated versions of the POMONA Protocol were then subject to a process of validation in each country whereby three experts in intellectual disability, two monolingual and one bilingual (native and English speaker) were asked to review the translation from Dublin City University Language Services. Amendments made to the POMONA Protocol following the Pilot Study (Work Package 5) will be reviewed below under Work Package 5.

3.6 POMONA II PROGRESS TO DATE – WP4 REPORT ON SYSTEMS IN PARTICIPATING MEMBER STATES⁸

Work package n° 4 – Reports on Systems in participating Member States

This objective aims to gather data on health systems in participating MS as these apply to individuals with intellectual disability. It is linked to an information priority stated in the Official Journal 27.2.2004, section 2.1. It will result in a set of 14 reports to share with Competent Authorities in participating MS, while the over-arching critical summary will be the first of its kind and thus valuable within MS and also as evidence to inform policy at Community level.

Lead Partner: University College Dublin, Ireland

Progress to Date: WORK PACKAGE COMPLETED

This work package comprised the production of short reports by each partner on the circumstances of people with intellectual disability in each participating country. The Project Manager circulated a brief outline of the report requesting information on three key areas:

- **Background:** historical context of service development for people with disabilities; definitions of intellectual disability; prevalence estimates; data sources.
- **Service Provision:** eligibility criteria; educational services; residential services; sources of income.
- **Health Service Utilization:** health service provision, research data on health status, disability training for health professionals

Annex VII presents additional reports that were completed or translated since May 2006. These include:

- ❖ An English translation of the Austrian report (**Annex VII 1**)
- ❖ An English translation of the Italian report (**Annex VII 2**)
- ❖ An English translation of the Lithuanian report (**Annex VII 3**)

Reports for all other countries were presented in the 1st Interim Report of the POMONA project and can be located on the project website at www.pomonaproject.org

⁸ The term ‘Member State’ is employed here to include all POMONA partners – Member States prior to January 2007 enlargement, New Member States, EFTA Member States and Applicant States

3.7 POMONA II PROGRESS TO DATE – WP5 PILOT SURVEY

Work package n° 5 – Pilot Survey

This work package is linked to the main objective of the project, that is, to conduct a survey across participating Member States using the agreed set of health indicators for people with intellectual disability.

Lead Partner: Cardiff University, Wales, United Kingdom

Progress to Date: WORK PACKAGE COMPLETED

3.7.1 Ethical Approval

A pilot study was scheduled to take place between the 10 and 12th month of the project, concluding in April 2006. As reported in the 1st Interim Report of this project, a protracted process of obtaining the necessary ethical approval required by participating countries delayed the commencement of this work package. A list of Ethics Committees is presented below illustrating the diversity of organisations throughout Europe who preside over ethical judgments of this nature. In Germany, for example, no ethical approval was required on the grounds that the POMONA Protocol is a non-invasive health interview survey. In contrast, application was required to three separate organisations in France to obtain the necessary ethical approval. Organisations responsible for granting approval included universities, statutory bodies, hospitals and voluntary bodies.

TABLE 3: ETHICAL COMMITTEE APPLICATIONS

	Affiliation	Ethics Committee
Austria	Department of Clinical, Biological and Differential Psychology, Faculty of Psychology, University of Vienna, Universitaetsstrasse 7, Vienna, Austria	Board of the Faculty of Psychology, University of Vienna
Belgium	Department of Orthopedagogics, Ghent University, Henri Dunantlaan 2 9000 Ghent, Belgium	Ethical Committee of the Faculty of Psychology and Educational Sciences (Ghent University)

Finland	Joint Municipal Authority for Kainuu, Health Care and Social Welfare/Service Centre of Kuusanmäki, Pölyvaarantie 3, Kajaani 87250 Finland	The Joint Municipal Authority for Kainuu
France	CREAI Languedoc Roussillon (Centre Régional pour l'Enfance et les Adultes Inadaptés) 135 Allée Sacha Guitry, BP 35567, 34072 Montpellier Cedex 3, France	Comité Consultatif de Protection des Personnes dans la Recherche Biomédicale (CCPPRB); Commission Nationale de l'informatique et des Libertés (CNIL); Comité consultatif sur le traitement de l'information en matière de recherche dans le domaine de la santé
Germany	Fakultät Rehabilitationswissenschaften (Faculty of Rehabilitation Sciences), University of Dortmund, Emil-Figge-Str.50, Dortmund 44221, Germany	Not required
Ireland	UCD Centre for Disability Studies, School of Psychology, University College Dublin, Belfield, Dublin 4, Ireland	University College Dublin
Italy	Unità Operativa di Psicologia, IRCCS OASI MARIA SS, Via Conte Ruggero 73, Troina, Sicily, Italy	Comitato Etico dell'IRCCS Oasi Maria SS
Lithuania	Research and Training Centre for Social Psychiatry at Psychiatric Clinic of Faculty of Vilnius University, Vasaros 5 Vilnius LT 2055, Lithuania	Lithuanian Committee for Bioethics
Netherlands	Department of General Practice, CAPHRI Care and Public Health Research Institute, University of Maastricht, PO Box 616 Maastricht 6200MD, the Netherlands	Medical Ethics Committee of the Academic Hospital of Maastricht
Norway	Department of Social Work and Health Science, Norwegian University of Science and Technology, N7491, Trondheim, Norway	The Norwegian Social Science Data Services, The privacy Issue Unit; The Regional Committee for Ethics in Medical Research
Romania	Sc Medfam Apolo Srl, Luceafarului No 13 Bl G1 Sc 1A, Ap 3, Călărași 8500 Romania	Comisia De Bioetica Colegiul Medicilor din Romania
Slovenia	Inštitut za varovanje zdravja Republike Slovenije (Institute of Public Health of the Republic of Slovenia), Trubarjeva 2, Ljubljana, Slovenia	Komisija za medicinsko etiko (Medical ethics commission) Inštitut za klinično nevrofiziologijo (Institute for clinical neurophysiology)

Spain	Asociación Española para el Estudio Científico del Retraso Mental (AEECRM), Sede Autónoma de Andalucía, Plaza San Marco 6, 11403, Jerez (Cádiz), Spain	Ethics Committee of the Spanish Association of Professionals on Intellectual Disabilities (AEECMR); Sant Joan de Deu Mental Health Services; ICAS Hospital Ethics Committee.
Wales United Kingdom	Welsh Centre for Learning Disabilities, Cardiff University, Neuadd Meirionnydd, Heath Park, Cardiff, CF 14 4YS Wales, United Kingdom	Central Office for Research Ethics Committees (COREC)

3.7.2 Collection of Pilot Data

Following the approval of ethical committees, where required, a pilot study was conducted under the leadership of project partners from Wales, UK, Professor Mike Kerr and Dr Jon Perry. Guidelines were sent to all partners in February 2006 regarding sample size (approximately N=8) and structure (two reliability interviews if possible).

Pilot interviews were conducted during the summer and autumn of 2006. A total of N=84 interviews and N=10 reliability interviews, totaling 94 interviews were conducted by partners during this time. Findings were fed back to the UK team via a comprehensive evaluation form, which requested information on ethical approval, sample selection, consent procedures, items comprising the POMONA Protocol, data entry and clarity of the User Manual, which provides guidelines for data entry.

3.7.3 Amendments to POMONA Protocol based on Pilot Study Feedback

At a meeting in Cardiff University in October 2006 Professor Mike Kerr, Dr Jon Perry and Christine Linehan produced a revised draft of the POMONA Protocol based on pilot feedback from partners. The revisions were largely omissions of items that were unreliable or had questionable validity. Items on financial income, for example, were removed on the basis that the data were not comparable across countries. Some participants, for example, had included the cost of their care as part of their income. Their stated income was therefore considerably larger when compared to those who presented only ‘disposable income’. Other amendments included the provision of more explicit definitions for some items (e.g. ‘residence’ is defined as the setting where an individual resides for the majority of the week) and a simplification to the medication chart. In general, the modifications were minor reflecting positive experiences by partners in conducting the pilot interviews. A draft of the amended POMONA Protocol was presented to all partners at the regional partner meetings throughout October and November 2006. The Final POMONA Protocol was disseminated to all partners in early December 2006.

3.8 POMONA II PROGRESS TO DATE – WP6 DRAW SURVEY SAMPLES IN EACH PARTICIPATING MEMBER STATE

Work package n° 6 – Draw survey samples in each participating Member State

Identifying an appropriate sampling frame is an essential step in undertaking the main objective of the project, the collection of health indicator data on people with intellectual disability in participating Member States.

Lead Partners:

University of Maastricht, the Netherlands

University of Dortmund, Germany

Progress to Date: WORK PACKAGE COMPLETED

Lead partners for this work package, Dr Henny Van Schrojenstein Lantman de Valk and Professor Meindert Haveman along with colleagues Marja Veenstra and Kathrin Gruening produced guidelines for project partners outlining the sampling procedures for POMONA II.

The guidelines highlight that it is not the goal of POMONA II to provide a valid profile of the distribution of health among adults with intellectual disabilities in each of the participating countries. With regard to the goals of POMONA II and within the time and budgetary constraints, a representative sampling procedure is neither necessary nor feasible. Rather, the goal of the project is to test the validity of the POMONA Protocol.

Partners were instructed to identify a ‘health area’ that was large enough to ensure a broad representation of typical living circumstances for adults with intellectual disabilities but which would also be of a size that would be manageable for partners to conduct face-to-face interviews. The health area should be specified by population demographics (number of residents, age and gender profiles if available), by service provision for people with intellectual disabilities (organisations providing residential, educational, employment provision etc.,) and if possible, data regarding the number of people with intellectual disability resident in the region.

From this health area, approximately 80 adults with intellectual disabilities should complete the POMONA Protocol. This sample size would result in approximately N=1,120 interviews completed across all 14 participating countries. Partners were advised to undertake the following steps, where local situations permitted, to recruit their sample:

- Service providers, family organisations, local decision makers, etc., were informed about the POMONA Project, its goals, methods and the potential consequences of the study.
- Service providers within the health area were then identified and listed by location, name, and number of service users.
- People with intellectual disability living in the family home or alone were identified from a variety of sources including service providers, family organisations, and support groups such as Special Olympics.
- A best-informed estimate was generated of the proportion of people in the health area with intellectual disability resident in either (1) family/individual housing or (2) residential settings. Where possible, samples should represent these proportions; for example, if 20% of people with intellectual disabilities in the health region reside in the family home, then approximately 20% of the sample of N=80 should be resident in the family home and the remainder 80% resident in out of family placements.
- In addition to sampling participants by residential type, partners were also asked to consider age (noting the groupings 18-34 years, 35-54 years, 55 years and older) and level of ability (if possible, approximately 40% of the sample should have a level of ability within the severe to profound range).

Mindful of the above criteria, a review of partners' sampling frames revealed that almost all partners employed service providers' registers as a suitable frame from which a sample of participants living in 'out of family placements' could be identified. Many partners also availed of service providers' registers to identify samples of potential participants living in the family home or alone. In these circumstances participants typically received day services from the service provider but were responsible for their own living arrangements.

While the vast majority of participants to date have been identified and recruited through service provider registers, a minority of partners identified samples through additional sources. These included family support organisations (used by one partner), multidisciplinary community teams (also N=1) family physician networks (N=1), and disability organisations (N=2).

The effectiveness of these recruiting options can only be truly assessed at the conclusion of the data collection process. In the meanwhile, interim feedback from partners regarding sampling procedures and the data collection process is presented in the next section.

3.9 POMONA II PROGRESS TO DATE – WP7 DATA COLLECTION IN PARTICIPATING MEMBER STATES[‡]

Work package n° 7 – Data collection in participating Member States

This is the core activity in the project. It will involve all partners in gathering information with the set of health indicators in the agreed protocol. Each partner will aim at gathering data on about 100 persons, giving due regard to local practices on how to obtain access to suitable participants, informed consent and management of related ethical or professional issues. The lead partner, who has considerable experience in carrying out data collection in collaboration with health professionals and service providers, will co-ordinate and monitor data collection activity and receive data in a single format (Excel).

Lead Partner: Cardiff University, Wales, United Kingdom

Progress to Date: ONGOING

This work package, ‘Data Collection in Participating Member States’ is the substantive activity of the project, culminating in people with intellectual disabilities in 14 European countries completing the POMONA Protocol. The data gathered from this exercise will be used to test not only the validity of the POMONA Protocol but also the feasibility of identifying and surveying a sample of participants in each country.

It is important to note that the POMONA Protocol is at this time, intended for completion by individuals who are over 18 years of age. The rationale supporting this age restriction was presented in POMONA I (2002-2004) during the development of the indicator set. Project partners agreed that children with intellectual disabilities have differing needs from adults and require a unique set of health indicators specific to their own needs. It is hoped that the successful implementation of the current indicators for the adult population of people with intellectual disabilities will allow for further development of the indicators for those who are under 18 years of age.

Data collection was originally scheduled to take place over a nine-month duration from August 2006 (Month 16) to April 2007 (Month 24). Unavoidable delays in securing ethical approval in participating countries resulted in a ‘knock-on’ delay for the subsequent work packages. The Pilot Study (Work Package 5) was completed in September 2006 and a final POMONA Protocol, reviewed by partners at all three regional meetings, was disseminated to partners in December 2006. As a consequence of these delays the time schedule for the collection of data has now been extended to

[‡] The term ‘Member State’ is employed here to include all POMONA partners – Member States prior to January 2007 enlargement, New Member States, EFTA Member States and Applicant States

conclude in August 2007 (Month 28), an addition of four months to the original deadline for this work package.

This new time frame allocates the same nine-month duration for data collection as originally planned and coincides with the All Partner Meeting scheduled for September 2007 in Barcelona. Partners will be requested to submit all data to the Project Manager prior to this meeting. The timing is fortuitous, as it will allow partners collectively discuss preliminary findings from the data and most especially, discuss the presentation of indicator data for dissemination purposes.

An update of data collection within participating countries is presented below and reveals that while data collection is completed in some participating countries, it is ongoing in the majority.

TABLE 4: DATA COLLECTION UPDATE		
Country	Status	Approximate Response Rates
Austria	COMPLETED	1%
Belgium	COMPLETED	Not possible to determine; invitation to participate made by service providers
Finland	COMPLETED	50%
France	COMPLETED	35%
Germany	ONGOING	90% (only available for those in residential facilities)
Italy	ONGOING	0%
Ireland	ONGOING	10%
Lithuania	– data collection to commence July	-
Netherlands	ONGOING	80%
Norway	ONGOING	78%
Romania	ONGOING	0%
Slovenia	Full sample successfully recruited – data collection to commence	42%
Spain	COMPLETED	0%
Wales, United Kingdom	ONGOING	40%

Response rates vary considerably between countries, with Italy and Spain reporting no individuals declining to take part in the survey and Germany, the Netherlands and Norway reporting refusal rates in excess of 75%. The reasons why individuals decline to participate have important consequences for the successful implementation of the survey. Unfortunately, in many cases the reasons cannot be estimated, largely because the invitation to participate in the survey was initiated by a service provider, not by the POMONA partner. For the same reason, the exact number of those declining to participate may be unknown as partners are not directly involved in recruiting interviewees.

While this lack of accuracy is undoubtedly a disadvantage of the use of service providers as ‘gatekeepers’ to a survey sample, the advantages of liaising closely with service providers are many. Firstly, case ascertainment is immediate via service providers’ registers. Secondly, participants and proxy respondents have commented that the endorsement of their service provider is reassuring. Finally, the anonymity of participants can be assured prior to their giving consent in cases where service providers make the initial approach to people with intellectual disabilities on behalf of the POMONA researchers.

When partners were asked to suggest reasons why participants may have declined to participate they suggested a variety of issues including a lack of interest in the study, survey fatigue in one country where a similar survey had been recently undertaken, and a lack of information about the survey in cases where POMONA researchers were not involved in the initial approach to potential survey participants. These issues highlight the importance of both the timing of the survey and approach taken when recruiting participants.

Issues concerning the appropriateness of sample selection, recruitment processes, and data collection are scheduled for discussion at the all partner meeting in Barcelona, Spain in September 2007. It is envisaged that data collection will be completed by all partners and data returned anonymously to the Project Manager prior to this meeting.

3.10 POMONA II PROGRESS TO DATE – WP8 ANALYSIS OF DATA

Work package n° 8 – Analysis of Data

This work package is linked to the main objective of the proposed project - to operationalize an agreed set of health indicators in order to collect data related to people with intellectual disabilities in the participating MS and to diffuse the findings at all levels (T-7: Table 7.1, page 4). Consolidating and analyzing data from 14 sources is an essential if challenging element in this process.

Lead Partner:

University College Dublin, Ireland

Service Centre of Kuusanmäki, Finland

Progress to Date: Scheduled to commence May 2007 – revised commencement date August-September 2007

This work package was originally scheduled to commence May 2007. As data collection is ongoing to September 2007, full data analysis cannot commence until that time.

In the interim, an SPSS (Statistical Package for Social Scientists) file, EXCEL file and User Manual were amended to take cognisance of changes to the POMONA Protocol following the pilot study and were then disseminated to partners. Partners who have completed data collection have successfully used both the manual and the statistical files and completed datafiles have already been returned to the Project Manager.

Preliminary data analysis of the full data file comprising anonymised data from all 14 countries will begin in August or September 2007 prior to the Barcelona All Partner Meeting. Essentially, data cleaning and frequency counts can be prepared for presentation and discussion at this meeting. It is envisaged that options for data analysis and presentation of indicator data will be agreed at this meeting. Data analysis, coordinated by partners in Ireland and Finland will continue from this period to April 2008. This re-scheduling retains the nine-month duration of the work package.

It should be noted that all storage, data input and datafiles at European level will be managed in accordance with guidelines from the Data Protection Commission (Ireland). Partners are advised to contact their national Data Protection offices for advice regarding national storage of data.

3.11 POMONA II PROGRESS TO DATE – WP9 TRAINING OF HEALTH PROFESSIONALS

Work package n° 9 – Training of Health Professionals

This work package is linked to a core objective (T-7, Table 7.1, page 4) aimed at contributing evidence about best practices in providing health information and health promotion strategies appropriate for people with intellectual disability to inform Community policy. It is expected that successful results will meet well-established global and Community targets for promoting health and reducing health inequalities (Official Journal 2.27.2004 Workplan Section 1.1 (b) "tackling inequalities in health". This information and knowledge resulting from Pomona-2 will be diffused in an efficient, sustainable procedure, through teaching and learning systems that target health professionals.

Lead Partner: University of Maastricht, the Netherlands

Progress to Date: THIS WORK PACKAGE COMMENCES OCTOBER 2007

This Work Package ‘Training of Health Care Professionals’ is scheduled from October 2007 to April 2008 and therefore falls outside the scope of this report.

The lead partner for this work package, Dr Henny Van Schrojenstein Lantman de Valk, has undertaken preliminary work. Issues concerning the scope of ‘health professionals’ have been discussed at POMONA meetings. Partners have suggested that both medical and allied health professionals be included in the scope of the definition to avoid any over reliance on a medical perspective. An additional suggestion from Dr Jon Perry, UK, is that the final All Partner Meeting scheduled for early 2008 in Dublin might include a conference component. Delegates could include competent authorities in each participating country charged with education and training options for health professionals. A workshop format would allow for open discussion of current educational options. In addition, the feasibility of using European mechanisms such as the European Credit Transfer System could be debated.

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4. CONCLUSIONS

WORK PACKAGE 1 ‘COORDINATION’

STATUS: ONGOING

POMONA II is now embarking on the final year of activity. While there has been some slippage in time frame, the following tasks have been completed in the reporting time period: (1) ongoing dissemination activities (2) production of Final POMONA Protocol (3) production of Country Reports (4) collection and analysis of Pilot Study data and (5) identification of suitable sampling frames. Only three key tasks remain: (1) data collection (2) data analysis and (3) training proposals for health care professionals. These tasks are currently being linked to coincide with upcoming partner meetings. Data collection is scheduled for completion by September 2007 allowing for a full discussion of data analysis at the All Partner Meeting in Barcelona in late September. The final All Partner Meeting in Dublin scheduled for March 2008 is suggested as an ideal venue to invite competent authorities from participating countries to attend a workshop discussion on methods to address the training needs of those health professionals who work in generic health services and require specific training to understand the health care requirements of people with intellectual disabilities

WORK PACKAGE 2 ‘DISSEMINATION’

STATUS: ONGOING

A total of 55 dissemination activities have been undertaken or planned during this reporting period. This is in addition to 35 activities the previous year. The activities include peer-reviewed articles, oral conference presentations, meetings with competent authorities, etc. The sheer volume of activities reflects the partners’ industrious commitment to this project. In addition to similar activities planned for the final year of the project, a dissemination strategy is currently being developed regarding the anonymised dataset that will culminate from the data collection underway in participating countries. Partners have been invited to nominate themes for dissemination (e.g. ageing) they would be willing to coordinate. Dissemination of POMONA activities to those with responsibility for conducting large-scale national health interview surveys is also a priority. It is fortunate that the United Nations’ Washington Group (charged with identifying a set of questions to identify people with disabilities in censuses and national surveys) and EUROSTAT (who are currently developing a European Disability and Social Integration Module (EDSIM)) will meet in Dublin in September 2007. POMONA partners will attend these events and will make representations on behalf of those with intellectual disabilities.

WORK PACKAGE 3 ‘OPERATIONALISING THE SET OF INDICATORS’

STATUS: COMPLETED

A delay was encountered in producing the final draft of the POMONA Protocol. This delay was caused by the lengthy process partners experienced obtaining ethical approval, where required, to conduct the survey in their respective countries. Without this approval the proposed pilot study, which would provide valuable feedback regarding the protocol, could not be undertaken. In hindsight, more time should have been allocated to the task of making representation to ethical committees. In fact, the task may have comprised a full work package of itself. Certainly the experiences of partners, when presented by Professor Patricia Noonan Walsh at the IASSID Europe conference in Maastricht, highlighted considerable variation throughout Europe regarding the composition of ethical committees, the nature of the submissions required and the judgements delivered.

The requirement for approval from ethical committees may however be unique to POMONA in comparison with other omnibus health interview surveys conducted at European level. POMONA is, first and foremost, a project. Partners, who are charged with recruiting and interviewing people with intellectual disabilities, are not statistical officers of their country and are therefore bound, professionally and morally, to seek ethical approval to undertake surveys of this kind. This is not the typical situation where health information surveys are administered by bodies such as the European Statistical System, which comprises EUROSTAT, statutory statistical offices, ministries, and other European based agencies who collect official statistics throughout Europe. These bodies operate under strict statistical legislation at both national and European level. This legislation permits the gathering and analysis of data from all members of the population, including those from vulnerable populations, while taking cognisance of ethical issues such as privacy and recruitment. The issue of whether the delays experienced by partners in the POMONA partnership may impinge negatively on efforts to mainstream the protocol for use in national health interview surveys conducted throughout Europe will be examined during the final year of the project to ensure that the interests of those individuals with intellectual disabilities who participate in a health survey of this nature are kept to the fore at all times, via mechanisms such as ethical committees or the protection afforded by statistical legislation.

WORK PACKAGE 4 ‘REPORT ON SYSTEMS IN PARTICIPATING STATES’

STATUS: COMPLETED

All POMONA partners have now completed reports detailing the circumstances for people with intellectual disabilities in their countries. Background information is provided regarding the historical context of service development for people with intellectual disabilities and how this has influenced current service provision. Epidemiological information regarding prevalence was sought, but findings revealed that national databases are rare, and typically, population estimates are thought to underestimate prevalence rates. Data regarding health status and utilisation of services is equally rare, and largely comprises small-scale ad hoc surveys. The data, while sparse, adds to a small but growing volume of work attempting to define and describe the

circumstances of people with intellectual disabilities. Most recently, the World Health Organisation's World Atlas of Intellectual Disability is currently being compiled and POMONA partners have liaised with WHO colleagues regarding the Atlas.

WORK PACKAGE 5 'PILOT STUDY'

STATUS: COMPLETED

The delay in commencing this work package has been outlined above. The findings from this pilot study were extremely valuable in streamlining the POMONA protocol for use across fourteen European countries. Amendments were minor, but typically resulted in the removal of items that caused confusion in some countries. The underlying attempt to attain 'cultural equivalence' across items was a primary criterion for item selection. Where equivalence of meaning could not be attained, items were removed. The experiences of those partners who have completed data collection suggest that the POMONA protocol was appropriately edited following the pilot study.

WORK PACKAGE 6 'SAMPLE SELECTION'

STATUS: COMPLETED

It is important to emphasise that there is no attempt to recruit a representative sample of people with intellectual disabilities to complete the POMONA protocol in this project. Clearly, this task is beyond the scope of available resources. Given that the purpose of the data collection exercise is to test the validity and reliability of the POMONA protocol on a small sample (<100) of respondents, guidance on sample selection was focused on ensuring that partners had ease of access to a sample, and that specific groups (such as those with more severe levels of intellectual disability) were appropriately represented. Partners typically used service providers' registers to identify their sample. Liaison with service providers was a successful recruitment option, but provides some challenges when compiling non-response statistics, as researchers may not be directly involved in the initial approach made to potential participants.

A debate is required as to proposed methods of obtaining a representative sample in the event that the POMONA protocol is adopted for use at either national or European level. Precedents do exist where, for example, post census surveys can identify representative samples of individuals with specific disabilities. Partners need to consider how realistic options such as this would be for their own country and to propose alternate options if available. Certainly, links with the UN's Washington Group and EUROSTAT's EDSIM group are worth pursuing in this regard.

WORK PACKAGE 7 'DATA COLLECTION'

STATUS: ONGOING

To date, data collection has been completed in five countries. A deadline for completion of data collection for remaining partners is August 2007. This extension reflects time lost earlier in the project but retains the nine-month duration of this work package. All data will be requested from partners prior to the Barcelona meeting in September 2007. This

will allow for preliminary data to be presented at this meeting and options for data analysis and dissemination to be discussed in detail.

WORK PACKAGE 8 ‘DATA ANALYSIS’

STATUS: Originally scheduled to commence May – rescheduled to August 2007

Data analysis will occur from August 2007 to the end of the project in April 2008. Those partners who have returned data to the Project Manager have successfully entered data on template data files as instructed by user manuals distributed to partners. Data analysis will include analysis of reliability data where protocols will be completed by two proxy respondents on behalf of one individual for a small sample of participants.

WORK PACKAGE 9 ‘TRAINING OF HEALTH PROFESSIONALS’

STATUS: Commences October 2007

This work package does not fall into the scope of the current reporting period. Initial suggestions regarding the development of this work package include broadening the definition of health professionals beyond physicians and linking training options directly to specific health indicators. Mechanisms by which training modules could be offered at European level have been suggested such as the European Credit Transfer System. The final All Partner Meeting in Dublin has been suggested as opportunity to invite those charged with training initiatives throughout Europe.

ACKNOWLEDGEMENTS

The authors are grateful to all those who have participated in this project to date; people with intellectual disability, their family, friends & advocates; service providers, policy makers and other stakeholders; project partners and researchers.

The authors would also like to specifically acknowledge the contribution of their colleagues in POMONA I; Mr. Frank Ulmer Jørgensen, Landsforeningen LEV; Professor Charles Aussilloux, Service de Médecine Psychologique Enfants Adolescents Peyre Plantade, CHU Montpellier; Dr. Raymond Cessotto, Fondation Association des Parents D'enfants Mentalement Handicapés; Dr Monica Björkman, Landstingets Hjärnskadecenter.

The authors retain full responsibility for any inaccuracies that may appear.

June 2007

This report was prepared by the Project Manager Christine Linehan, Senior Researcher, UCD Centre for Disability Studies, School of Psychology, University College Dublin, Belfield Dublin 4, IRELAND on behalf of the POMONA Partnership.

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