

# 1. BACKGROUND

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## 1.1 THE HEALTH MONITORING PROGRAMME

The European Commission's communication on the Framework for Action in the Field of Public Health (COM (93) 559 final of 24 November 1993) pioneered funding for eight major public health initiatives throughout Europe from 1996 to 2002 (Deloitte, 2004). One of these programmes, the Health Monitoring Programme focused on the measurement of health status of EU citizens. A total of 54 health monitoring projects were supported in this programme from a budget of €18,200,000.

The rationale behind the Health Monitoring Programme was that effective health policy throughout the European Union should lead to improved health status for EU citizens. Improvements in health status, however, could only be monitored using valid and accurate health indicators standardised across the EU. The Health Monitoring Programme comprised three core activities (i) the establishment of comparable indicators across the European Community (ii) the development of networks throughout Europe and (iii) the development of analysis and reporting tools.

A primary realisation of the Health Monitoring Programme was the development of a number of sets of health indicators for use throughout the Community. A generic set of indicators for the general population was devised, termed ECHI – European Community Health Indicators. ECHI aims to harmonise items for inclusion in typical Health Interview Surveys (HIS) and Health Examination Surveys (HES) conducted throughout the European Community. ECHI 2, completed in June 2005, identifies 48 health indicators classified under four key domains; (i) Demography and Socio-Economic Situation, (ii) Health Status, (iii) Determinants of Health and (iv) Health Systems. Simultaneously to the development of the ECHI indicators, other projects received funding from the Health Monitoring Programme to develop specific indicators for distinct populations. These projects focused on areas such as oral health, perinatal health, environmental health etc.

According to Deloitte (2004) who conducted an evaluation of all eight public health initiatives, Health Monitoring projects “take time ... before the data collection can produce outputs in terms of trends or effects usable for policy decisions. These specific elements have to be taken into account when evaluating realisations and results (Deloitte, 2004; p.48) .... The final product, i.e. valid and comparable data to use for policy decisions, is not yet in sight” (p.49). That is, while the development and identification of suitable health indicators continues, the primary aim of the Health Monitoring Programme, to evaluate the efficacy of health policy throughout Europe, cannot be realised until there is a sustainable framework supporting the ongoing collection of harmonised health data throughout the European Commission.

Reference Deloitte (2004) Final Evaluation of the eight Community Action Programmes on Public Health (1996-2002) Accessed June 2006 at [http://ec.europa.eu/health/ph\\_programme/documents/evaluation/frep\\_evaluation\\_en.pdf](http://ec.europa.eu/health/ph_programme/documents/evaluation/frep_evaluation_en.pdf)

## 2. POMONA I

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### 2.1 PEOPLE WITH INTELLECTUAL DISABILITIES IN EUROPEAN HEALTH MONITORING

In 2002 the final group of projects awarded funding under the Health Monitoring Programme was announced. *POMONA; Health Indicators for People with Intellectual Disability in the Member States* (2002/203496-00<sup>1</sup>) was among the successful applicants. The project proposal argued that while the development of a European set of health indicators (ECHI) was commendable, certain sections of society, specifically people with intellectual disabilities could remain largely excluded from the health monitoring process.

The proposal made reference to the draft set of health indicators produced by ECHI. The draft indicator set produced in 2001<sup>2</sup> contained only two references to people with intellectual disabilities; (i) the incidence of Down's Syndrome, classified as a morbidity indicator under the category 'diseases or disorders of large impact' and (ii) the incidence of Congenital Anomalies specifically including 'mental handicap', classified under a user window of indicators specific to 'Health and Services for Mother and Child'. The Pomona project proposal suggested that the narrow focus on Down's Syndrome and emphasis on mother child interaction excluded many European citizens with intellectual disabilities from participating in the health monitoring program.

### 2.2 PEOPLE WITH INTELLECTUAL DISABILITIES: DEFINING THE POPULATION

In the absence of a standard terminology in the field, the term 'intellectual disability' is the preferred term for a condition referred to as 'mental retardation' in the United States, 'learning disability' in the United Kingdom, and previously referred to throughout parts of Europe as 'mental handicap'. The disability is outlined in both ICD 10 (World Health Organisation, 1992) and the DSM IV (American Psychiatric Association, 1994). The American Association on Intellectual and Developmental Disabilities (formerly the American Association of Mental Retardation; personal communication June 2006) provides the following definition<sup>3</sup>:

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<sup>1</sup> [http://ec.europa.eu/health/ph\\_projects/2002/monitoring/monitoring\\_2002\\_05\\_en.htm](http://ec.europa.eu/health/ph_projects/2002/monitoring/monitoring_2002_05_en.htm)

<sup>2</sup> [http://ec.europa.eu/health/ph\\_projects/1998/monitoring/fp\\_monitoring\\_1998\\_frep\\_08\\_en.pdf](http://ec.europa.eu/health/ph_projects/1998/monitoring/fp_monitoring_1998_frep_08_en.pdf)

<sup>3</sup> [http://www.aamr.org/Policies/faq\\_mental\\_retardation.shtml](http://www.aamr.org/Policies/faq_mental_retardation.shtml)

*Mental retardation 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.*

*Five Assumptions are considered essential to the application of the definition:*

- 1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.*
- 2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.*
- 3. Within an individual, limitations often coexist with strengths.*
- 4. An important purpose of describing limitations is to develop a profile of needed supports.*
- 5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.*

## **2.3 PEOPLE WITH INTELLECTUAL DISABILITIES – HEALTH DISPARITIES**

There is a growing body of empirical research indicating that people with intellectual disabilities experience poorer health than the general population (Krahn, Hammond & Turner, 2006). The conceptual difference between disability on the one hand, and ill health on the other is however relatively recent (Krahn, 2003). Previously, illness and disability were presumed equivalent. More recently, the impact of physical and social environments in which people with intellectual disabilities reside is being explored as a contributing factor towards their health status (Bickenback et al., 1999). According to Krahn et al., 2006:

*“The observed poor health of the population of people with intellectual disability is seen as resulting from a combination of factors; genetic factors that contribute to higher rates of associated conditions and their subsequent sequelae (e.g. thyroid problems associated with Down’s Syndrome); social circumstances that are characterised by low income, social isolation, vulnerability to abuse, and inadequate attention of care providers to health needs; environments (e.g. exposure to unhealthy levels of lead or other contaminants; environments physically inaccessible for people using wheelchairs); individual behaviours that contribute to secondary conditions because of inadequate knowledge about health-promoting lifestyles (e.g. oral health care, nutrition), cognitively inaccessible treatment programmes for high risk behaviours (e.g. smoking, alcohol and drug use, anger management), and residential settings that support inactivity and poor nutrition; and inadequate health care access that contributes to poor management of associated conditions (e.g. seizure disorders), comorbid conditions (e.g. latestage diagnosis of cancers, untreated caries) and secondary conditions whose occurrence or impact could be minimised with better care (e.g. recurrent pneumonia, bowel obstruction, depression)” (Krahn et al., 2006; p.71)*

A special edition of the Journal of Applied Research in Intellectual Disabilities (2005) was recently devoted to the issue of health disparities among this population. Ouellette-Kuntz’s (2005) contribution defines health disparity in accordance with Whitehead’s (1992) definition as “population-specific differences in health indicators” (p. 114). Furthermore, a health disparity is considered by Braveman & Gruskin (2003) as ‘inequitable if it is systematically associated with social disadvantage in a way that puts an already disadvantaged social group at further disadvantage ... equity in health has an ethical value, inherently normative, grounded in the ethical principle of distributive justice and consonant with human rights principle ... [It] cannot be assessed without comparing how better off or worse off social groups are faring in relation to each other” (p.256).

## **2.4 THE NEED FOR HEALTH MONITORING**

Despite the “abundant evidence that people with intellectual disabilities are more likely to live in poor health and die earlier than those who do not have intellectual disabilities (Bittles et al., 2002; Durvasula & Beange 2001; Ouellette-Kuntz, 2005)” (Emerson & Durvasula, 2005; p. 95), people with intellectual disabilities are often hidden in public health monitoring surveys (Walsh et al., 2005). People with intellectual disabilities are therefore doubly disadvantaged by likely health inequalities and by their exclusion from health monitoring activities. Walsh, Kerr & van Schroyen Lantman-de Valk, (2003) propose that without a coherent, evidence-based strategy for monitoring the health of people with intellectual disabilities in the Member States, thereby permitting comparisons between this population and their peers without disabilities “attempts to implement European policies and thus promote the healthy ageing of Europeans with intellectual disabilities will falter” (p.48)

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

A total of 13 partners participated in the original Pomona project, which was carried out over an 18-month period from November 2002 to May 2004. A list of project partners is presented in ANNEX I. Three aims directed project activities:

- To determine what health indicators, if any, are in place across the Member State related to the health of people with intellectual disability
- To consult on practices, referring to scientific evidence, about optimal indicators for this population
- To propose a set of health indicators for people with intellectual disability across the Member States

*Aim 1:*

*To determine what health indicators, if any, are in place across the Member State related to the health of people with intellectual disability*

The first aim was examined through a number of sources. Firstly, literature pertaining to health indicators specific to people with intellectual disabilities was reviewed. Only one relevant source was identified – the Core Indicator Project in the United States. Given the homogeneous nature of data collection across the United States in comparison with the myriad of different health systems utilized across the European Union, this valuable project is of limited use as a template within a European context.

Secondly, generic sets of health indicators, such as ECHI, were reviewed to determine whether they could be adopted for use among a sample of people with intellectual disabilities. The use of such generic sets of indicators for those with intellectual disabilities was considered inappropriate by project partners on the grounds that the indicators themselves tend to exclude people with intellectual disabilities and also because health issues specific to people with intellectual disabilities are not included as indicators.

Thirdly, partners were asked to identify national registers of intellectual disability that could be linked to health data thereby providing a mechanism by which health monitoring could occur. Only two partners, Ireland and the Netherlands, have such databases and these are considered of limited use for health monitoring purposes. The Irish database, for example, is a voluntary register and specifically states that it is not designed as an epidemiological tool.

Fourthly, health interview and health examination surveys at Member State level were examined. The European Health Interview & Health Examinations Surveys (HIS HES) database<sup>4</sup>, the

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<sup>4</sup> <https://www.iph.fgov.be/hishes/>

culmination of another project funded by the European Commission, provides full details of all omnibus health surveys conducted throughout the European Union. An examination of the items of all surveys conducted in participating Member States (N=54) and contact with survey managers revealed that bar the “Handicaps, Disabilities and Dependency Survey” in France and the “Impairments, Disabilities and Health Status Survey” in Spain, all other surveys either exclude people with disabilities completely from their coverage, or include this population under the umbrella of the person having a ‘longstanding or chronic condition’. As it is not possible to identify those with intellectual disabilities from those with other ‘longstanding or chronic conditions’, it is not possible to currently use these surveys as a vehicle to monitor the health of people with intellectual disabilities. With the inclusion of additional partners in POMONA II, the examination of health surveys in other participating European Member States (Lithuania & Slovenia), Applicant States (Romania) and EFTA Member States (Norway) continues. Progress to date appears in **ANNEX II**.

Finally, partners were requested to collate recent research examining the health of people with intellectual disabilities in their countries. Findings indicated major variability among the availability of health data in each region. Such variability would render the use of such data for monitoring purposes invalid.

*Aim 2:*

*To consult on practices, referring to scientific evidence, about optimal indicators for this population*

Four key criteria were identified to guide the selection of indicators. These criteria were:

- (i) Importance – does the indicator address a key area of concern for this population?
- (ii) Disparity – does the indicator highlight a disparity between this population and the general public?
- (iii) Usefulness – is the indicator a useful tool in resource allocation?
- (iv) Information – is there sufficient information available at Member State level?

At the conclusion of the project, partners agreed that the ‘disparity’ and ‘information’ criteria were most helpful in discriminating among indicators. Given the expertise of the POMONA partners, virtually all indicators proposed for inclusion were deemed ‘important’ and ‘useful’.

The ‘disparity’ criterion was considered a key criterion throughout the project’s deliberations. Partners agreed that the continual monitoring of health indicators indicating a disparity between the health status of people with intellectual disability and the general population would provide an opportunity not only to benchmark the initial disparity between the two groups, but also to observe any change in this disparity overtime.

The ‘information’ criterion posed a number of challenges. Clearly, routine health data is not available on behalf of people with intellectual disability in Member States. The POMONA partners agreed that the project was charting new territory in this regard and that clinically important

indicators could not be excluded on the grounds that sufficient information is not currently available at country level. While candidate health indicators for this population are not currently monitored in any systematic fashion, small-scale scientific studies within each country provide useful and valid templates for how such indicators could be incorporated into large omnibus health surveys.

*Aim 3:*

*To propose a set of health indicators for people with intellectual disability across the Member States.*

The final aim addresses the substantive issue of generating a set of indicators specific to people with intellectual disabilities. A total of 18 health indicators were recommended and these are presented in Table 2.1 below. Indicators are presented using the classification framework employed by ECHI comprising Demographics, Health Status, Health Determinants and Health Systems. An extensive literature search accompanied each indicator in the Final Report (Linehan et al., 2004)

**TABLE 2.1: FINAL SET OF HEALTH INDICATORS PROPOSED BY POMONA**

Demographics	1.1 Prevalence
	1.2 Living Arrangements
	1.3 Daily Occupation
	1.4 Income/Socio-Economic Status
	1.5 Life Expectancy
Health Status	2.1 Epilepsy
	2.2 Oral Health
	2.3 Body Mass Index
	2.4 Mental Health
	2.5 Sensory
	2.6 Mobility
Determinants	3.1 Physical Activity
	3.2 Challenging Behaviour
	3.3 Psychotropic Medication Use
Health Systems	4.1 Hospitalisation & Contact With Health Care Professionals
	4.2 Health Check
	4.3 Health Promotion
	4.4 Specific Training For Physicians

Linehan *et al.*, (2004) presented a proposed operationalisation for each of the indicators outlined above. The proposed operationalisation for Indicator 2.4 – *Indicator of Mental Health for People with Intellectual Disability*, for example, was ‘the prevalence of psychiatric disorder’ as measured by standardised assessment tools such as the Reiss Screen for Maladaptive Behaviour (Reiss, 1988) or the PAS ADD (Moss *et al.*, 1993). Similar suggestions were presented for the remaining health indicators.

POMONA concluded in 2004 outlining recommendations for a set of 18 health indicators specific to European citizens with intellectual disabilities. Linehan *et al.*, (2004) concluded:

*“In conclusion, the population of people with intellectual disability are disadvantaged in terms of likely health inequalities, and are excluded from current public health monitoring. It is timely and appropriate therefore to act and address these important issues at Community level” (p. 191).*

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## 3. POMONA II

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### 3.1 POMONA II OBJECTIVES

*Pomona II Health Indicators for People with Intellectual Disabilities: Using an Indicator Set* has received funding from the European Commission 2003-2008 Public Health Programme<sup>5</sup>. The project is classified under the stream 'Improving information and knowledge for the Development of Public Health' and runs from 1<sup>st</sup> May 2005 to 30<sup>th</sup> April 2008.

The general objectives of the project are:

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

The specific objectives of the project are:

- To operationalise a set of health indicators for people with intellectual disabilities
- To gather information on current health systems within participating Member States as these relate to people with intellectual disabilities and prepare reports
- To gather data using health indicators, consolidate data and prepare reports at international, regional and member state levels
- To diffuse findings at all levels – using contacts so as to build sustainable development of health information systems
- To inform training of health professionals in Member States with evidence generated by project activities

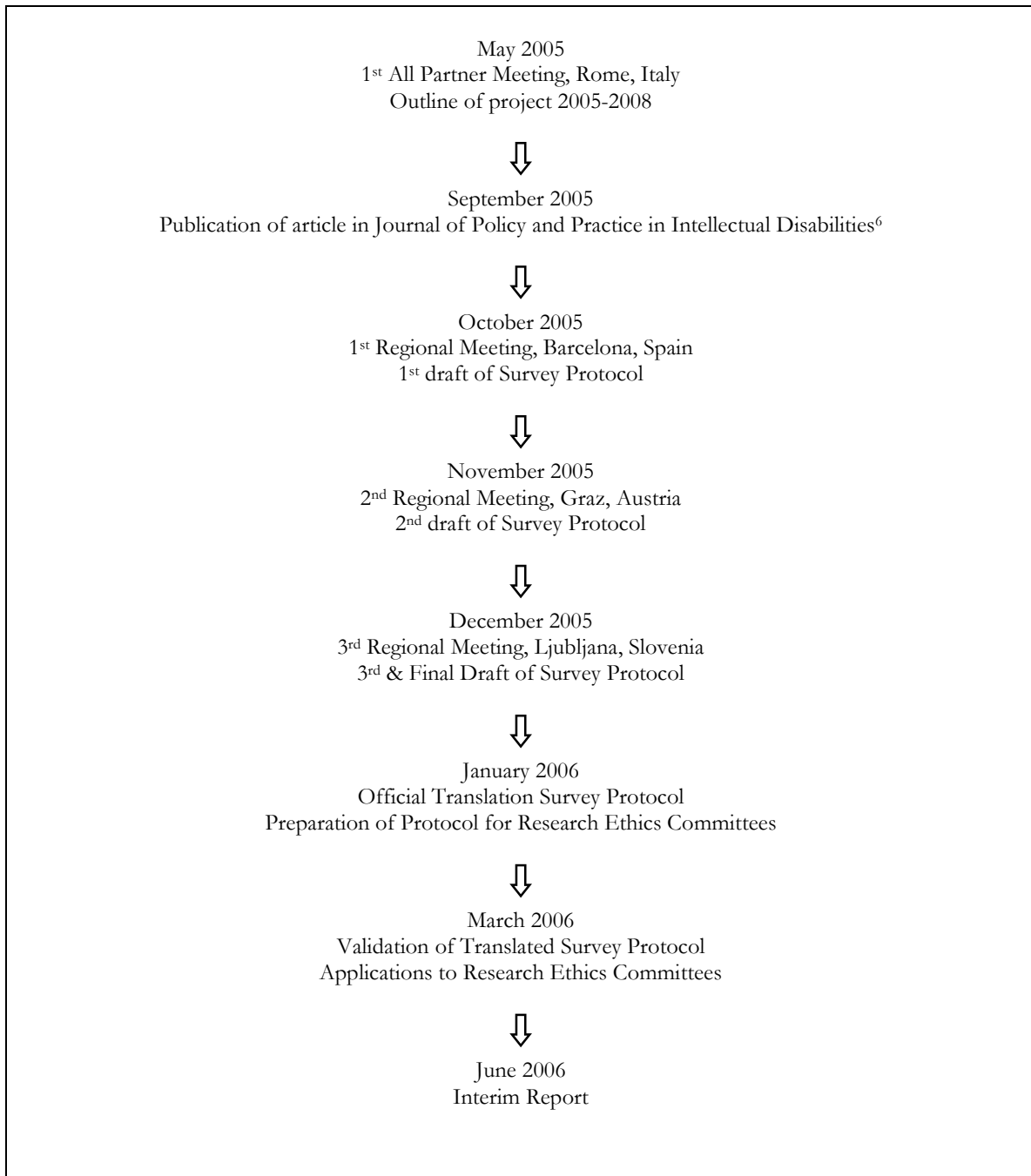
The following methods are outlined to achieve these objectives:

- (a) Preparation of common protocol;
- (b) Translation into appropriate languages (testing by back-translation);
- (c) Pilot studies in participant MS;
- (d) Drawing samples of people with intellectual disabilities in the MS;
- (e) Gathering data;
- (f) Consolidation and analysis of data;
- (g) Preparation of reports.

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<sup>5</sup> [http://ec.europa.eu/health/ph\\_projects/2004/action1/action1\\_2004\\_14\\_en.htm](http://ec.europa.eu/health/ph_projects/2004/action1/action1_2004_14_en.htm)

### 3.2 POMONA II PROGRESS TO DATE



<sup>6</sup> Walsh et al., (2005)

### 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 THROUGHOUT DURATION OF PROJECT***

The lead partner Professor Patricia Noonan Walsh, NDA Professor of Disability Studies, Centre for Disability Studies, University College Dublin, coordinates POMONA II. Christine Linehan, Senior Researcher, Centre for Disability Studies, University College Dublin, carries out day-to-day management.

The project comprises nine work packages, each outlining a specific task and led by nominated project partners. This report outlines progress to date on each work packaged scheduled between 1<sup>st</sup> May 2005 and 30<sup>th</sup> April 2006.

The project is coordinated via annual partner meetings and email correspondence. A total of four partner meetings are scheduled for each year of the project; one meeting is attended by all partners, the remaining three regional meetings are attended by small working groups of partners. A brief summary of the four meetings held within the first year of the project is presented below.

#### **3.3.1 All Partner Meeting, Rome, Italy**

The all partner meeting for 2005-2006 was held at the San Raffaele Foundation, Rome, Italy from 26-29 May 2005. POMONA II acknowledges and thanks the San Raffaele Foundation for their valued support in hosting this inaugural meeting. The full minutes of this meeting including attendees and activities are presented in **ANNEX III**.

Briefly, this meeting provided an opportunity for partners to become acquainted and to be fully briefed on the schedule of activities for the three-year duration of the project. All nine-work packages were outlined in detail and partners were invited to comment on the proposed schedule. The logistics of conducting a health survey among adults with intellectual disabilities within each participating country were discussed and comparisons and contrasts between countries noted. Partners were requested to consider the recruitment process of a part-time Researcher and to give consideration to the operationalisation of the proposed indicators.

#### **3.3.2 1<sup>st</sup> Regional Meeting, Barcelona, Spain**

The 1<sup>st</sup> regional meeting was held in Barcelona, Spain. Partners representing Austria, Finland, France, Ireland, the Netherlands and Spain attended. This meeting coincided with the 5<sup>th</sup> European

Congress of Mental Health in Mental Retardation (MHMR) “Integrating Research into Practice” held in Barcelona between 6-8<sup>th</sup> October. This conference provided an excellent networking opportunity for POMONA partners who were also delegates at the conference.

A first draft of the Survey Protocol, developed by Dr Henny Van Schroyen Lantman-de Valk, the Lead Partner for Work Package 3, and Researcher Marja Veenstra, was presented for discussion. Partners were invited to comment on the draft, which was then circulated via email to all partners following the meeting for discussion. The full minutes of this meeting including attendees and activities are presented in **ANNEX IV**.

### **3.3.3 2nd Regional Meeting, Graz, Austria**

The 2<sup>nd</sup> regional meeting was held in Graz, Austria and comprised attendees from Austria, Germany, Ireland, Lithuania, Norway and Wales. This meeting coincided with the 13<sup>th</sup> European Conference on Public Health (EUPHA) where a paper on POMONA was presented entitled “The development of a European Set of Health Indicators for People with Intellectual Disability”<sup>7</sup>. The full minutes of this meeting are presented in **ANNEX V**.

A modified version of the draft Survey protocol developed by Dr Henny Van Schroyen Lantman-de Valk and Marja Veenstra was discussed. The group suggested that the survey protocol could be completed during face-to-face interview with a variety of respondents, dependent on the level of ability of the interviewee. The interview could be completed with (i) the person with intellectual disability only, (ii) the person with intellectual disability and a nominated other – for part or the entire interview, (iii) a proxy respondent. To ensure reliability of the data, a proportion of data should be collected twice.

As some items were deemed sensitive (e.g. scales on challenging behaviour, mental health) and were devised to be completed by a third party, partners agreed that these parts of the survey protocol should be posted in advance to be completed by a nominated other prior to the interview. Copyright issues regarding the use of these scales were also discussed. The group agreed that Christine Linehan would devise a 3<sup>rd</sup> draft of the survey protocol based on these discussions for presentation at the final regional meeting in Ljubljana, Slovenia. This draft would also be circulated to all partners for comment.

### **3.3.4 3rd Regional Meeting, Ljubljana, Slovenia**

The 3<sup>rd</sup> regional meeting was held in Ljubljana, Slovenia and comprised attendees from Belgium, Ireland, Italy, Romania & Slovenia. The meeting was hosted by the Institute of Public Health of the Republic of Slovenia. POMONA partners acknowledge and thank the Institute for the kind hospitality extended to POMONA partners during this meeting.

A third draft of the survey protocol devised by Christine Linehan was presented at this meeting. Partners agreed that the inclusion of generic items from European Health Interview and Examination Surveys in this draft of the survey protocol would facilitate comparisons between the health of adults with intellectual disabilities and the health of the general population. In addition, the

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<sup>7</sup> Linehan et al., (2005)

use of standardised scales such as the PAS ADD (a scale of mental health) and the Aberrant Behaviour Checklist (a scale of challenging behaviour) were agreed pending copyright.

This meeting also provided a valuable opportunity for Slovenian colleagues working in the field of intellectual disability to meet with the POMONA partners. Presentations regarding services for people with intellectual disability in Slovenia were given by Dr. Nik Tevz-Gizej a Physician with the Draga Centre and by Dr. Tomaz Jereb a Parent Representative from Sožitje. The full minutes of this meeting are presented in **ANNEX VI**.

### **3.3.5 Coordination of Project Activities 2005-2006**

The following activities have been coordinated during the first year of the project and are presented in further detail from Section 3.5 below

- (1) Production of an agreed Final Survey Protocol - December 2005
- (2) Permission to include copyrighted scales in Final Survey Protocol – January 2006
- (3) Research Ethics Protocol devised by Project Manager sent to partners – January 2006
- (4) Template of Country Report (Work Package 4) devised by Project Manager sent to partners – January 2006
- (5) Translation of Final Survey Protocol conducted by Dublin City University Translation Services – January 2006. The protocol is now available in the following languages:
  - (1) Dutch
  - (2) English
  - (3) Finnish
  - (4) Flemish
  - (5) French
  - (6) German
  - (7) Italian
  - (8) Lithuanian
  - (9) Norwegian
  - (10) Romanian
  - (11) Russian
  - (12) Slovenian
  - (13) Spanish
- (6) Guidelines on validation process of translation devised by Project Manager sent to partners – February 2006
- (7) Guidelines of Pilot Study (Work Package 5) devised by Professor Mike Kerr & Dr Jon Perry, Wales sent to partners – February 2006
- (8) Agreement of meeting schedule for 2<sup>nd</sup> year of project: The All Partner meeting is scheduled to coincide with the 2<sup>nd</sup> International Congress of IASSID in Maastricht in early August 2006. Three regional meetings will be held in October and November 2006 in Lithuania, Romania & Finland.

### 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 THROUGHOUT DURATION OF PROJECT***

The Commission regularly invites project co-ordinators to join meetings in Luxembourg where they have opportunities to discuss their activities with colleagues who have expertise in diverse areas of public health throughout Europe.

The co-ordinator of POMONA II was appointed as member of the Mental Health Working Party (2003-2006). At the 4th meeting of the Working Party convened in Luxembourg 20 February 2006, this party was devolved, in line with re-structuring of SANCO. The Pomona project will now be attached to the new EU-Platform on Mental Health through Strand 1, 'Morbidity and expectancies'.

The Project co-ordinator, Patricia Noonan Walsh, is Vice-President of IASSID – *International Society for the Scientific Study of Intellectual Disabilities* <[www.iassid.org](http://www.iassid.org)>. Her brief is to liaise with global health bodies such as WHO and PAHO in order to raise awareness and build knowledge about the health of persons with intellectual disabilities. She attended the White House Conference on Aging in Washington DC in December 2005 as an invited international expert, and thus had an opportunity to bring the POMONA II project to a wider audience. In April, she presented a report on the project to a Roundtable of international experts on intellectual disability at the University of Toronto, Canada. Currently, she is involved in planning a high-level conference on the quality of life and human rights of persons with intellectual disabilities that will take place in Santiago de Chile in 2007, working in collaboration with regional organizations and also with PAHO – Pan American Health Organization.

Finally, the partners wished to sustain their fruitful contacts with persons with intellectual disabilities, family members, professionals and policy-makers in their countries, and with representative groups. To translate the evidence gathered during POMONA II project investigations into policy and practice, the partners designed a multi-level dissemination strategy. The aim of each activity – local, national, regional and global - is to build sustainability of the outcomes of POMONA II after the life of the current project

A POMONA website was created for the first POMONA project (2002-2004) and has been update to include the activities of POMONA II. The website can be accessed at [www.pomonaproject.org](http://www.pomonaproject.org).

The table below presents POMONA II dissemination activities that have been carried or prepared during the period May 2005 – April 2006.

<b>TABLE 3.1: DISSEMINATION ACTIVITIES</b>				
Type of presentation (e.g. publication, oral presentation, poster presentation, meeting, workshop etc)	Presenter(s)/ Author(s)  (* denotes speaker at oral presentation)	Title of presentation	Name of conference/ Organisation where meeting held	Date of conference/ meeting
<b>FORTHCOMING</b>				
Peer Reviewed Publication (Accepted Forthcoming 2006).	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.	Accepted for Publication
Oral Presentation (Accepted Forthcoming 2006).	Buono, S., Linehan, C.,* Moravec Berger, D., Salvador Carulla, L., Tossebro, J.,	Monitoring the Health of Adults with Intellectual Disabilities in Europe:	IASSID Maastricht, the Netherlands	August 2-5 2006.
Oral Presentation (Accepted Forthcoming 2006).	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	IASSID Maastricht, the Netherlands	August 2-5 2006.
Oral Presentation (Accepted Forthcoming 2006).	van Hove, G., Walsh, P.N., Weber, G. *	Gathering information about the health of people with intellectual disabilities: Ethical issues	IASSID Maastricht, the Netherlands	August 2-5 2006.

Oral Presentation (Accepted Forthcoming 2006).	Germanavicius, A., Haveman, M., Kerr, M., * Linehan, C.	Applying a set of health indicators for people with intellectual disabilities across 14 European countries: Implementing a pilot study	IASSID Maastricht, the Netherlands	August 2-5 2006.
Oral presentation (Accepted Forthcoming 2006).	Kerr, M.	POMONA II Health Indicators for Adults with Intellectual Disability.	Kingston University Kingston Ontario Canada	
Oral Presentation (Accepted Forthcoming 2006).	Linehan, C.	POMONA II Health Indicators for Adults with Intellectual Disability.	Health Service Executive, North Western Area. LHO Area Conference for Learning Disability Services, Sligo.	November 29 <sup>th</sup> 2006
Oral Presentation (Accepted Forthcoming 2006).	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	EUPHA European Public Health Association Conference, Montreux , Switzerland	November 16-18 2006.
Oral Presentation (Accepted Forthcoming 2006).	Buono, S.,* Walsh, P.N., Linehan, C., & Musumeci, M.	Indicatori di Salute Nelle Disabilita Intellettive.	VII Congresso Nazionale. Promuovere Benessere Con Persone Gruppi Comunita. Cesena, Italy	September 28-30 2006
Oral Presentation (Accepted Forthcoming 2006).	Linehan, C.	Health Monitoring for People with Intellectual Disability in the European Union.	Special Olympics Youth Games Symposium, Rome.	October 1 <sup>st</sup> 2006
<b>COMPLETED</b>				
Peer Reviewed Publication	Walsh, P.N., Linehan, C., Kerr, M.P., van Schrojenstein Lantman-de Valk, H., Buono, S., Azema, B., Aussilloux, C., Määttä, T., Salvador-Carulla, L., Garrido-Cumbrera, M., van Hove, G., Björkman, M., Ceccotto, R., Kamper, M., Weber, G., Heiss, C., Haveman, M., Ulmer Jørgensen, F., O'Farrell, L.	Brief Research Report: Developing a Set of Health Indicators for People with Intellectual Disabilities: Pomona Project.	Journal of Policy and Practice in Intellectual Disabilities, Vol 2, Number 3-4, 260-263	September/ December 2005

Paper	Azéma B	Les indicateurs de santé pour les personnes avec déficience intellectuelle : le projet européen Pomona II 4-9	In Informations CREA Languedoc Roussillon - Le Pélican, 2006 May, 171, 4-9.  This paper is quoted in the national disability data network and the National Disability Research Centre, CTNERHI <a href="http://www.ctnerhi.com.fr/ctnerhi/pagint/centre_d oc/base_donnees/saphir.htm">http://www.ctnerhi.com.fr/ctnerhi/pagint/centre_d oc/base_donnees/saphir.htm</a>	2006-05
Publication	Linehan, C.	Health Monitoring in European for People with Intellectual Disability.	Include Europe Newsletter	April 2006
Publication	Linehan, C.	POMONA: European Set of Health Indicators for People with Intellectual Disability	IASSID (International Association for the Scientific Study of Intellectual Disability) Health Special Interest Group Newsletter	January 2006
Publication	Veenstra, M & van Schroyen Lantman-de Valk, H	Pomona 2 project: Europees onderzoek naar zorgaanbod voor mensen met een verstandelijke beperking	Op één Lijn, magazine of Department of General Practice, University of Maastricht	November 2005
Publication	Walsh, P.N., Linehan, C.	Europeans with intellectual disabilities: A public health perspective.	European Union Parliament Magazine, Issue 210	3 October 2005

Oral 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
Oral presentation	Buono, S.	Indicatori di salute nelle disabilità intellettive. Il progetto Pomona II	Master “Le disabilità Intellettive” Università di Messina Italia	20 May 2006
Oral presentation	Azéma B	Espérance de vie, santé et qualité de vie des personnes handicapées : quels suivis au long cours pour les personnes handicapées ?	23 <sup>ème</sup> Congrès National des MAS et FAM Angers -France	17-19 May 2006
Oral presentation	van Schroyen Lantman- de Valk, H Veenstra, M	POMONA:gezondheids-indicatoren voor mensen met verstandelijke beperkingen.	Pepijn en Paulus	15 May 2006
Oral Presentation	Walsh, PN	Measuring health status, determinants and outcomes with health indicators: the Pomona project	14 <sup>th</sup> SIRGAID Roundtable on Aging and Intellectual Disability, University of Toronto, Canada	27 April 2006
Oral Presentation	Walsh, PN	Best practices and healthy outcomes for people with intellectual disabilities: A European perspective	One-Day Conference Aging and Living Well Organized for Province of Ontario, Canada	26 April 2006
Oral presentation	Weber, G.	Pomona II Project	Lebenshilfe Österreich General Assembly Vienna,	21 April 2006
Oral presentation	Buono, S.	Indicatori di salute nelle disabilità intellettive. Il progetto Pomona II	Corso di formazione “Programmi di abilitazione per adulti con disabilità gravi”. IRCCS Oasi Maria SS Troina. Italia	30 March 2006

Oral presentation	van Schroyen Lantman- de Valk, H. & Veenstra, M	POMONA:gezondheids-indicatoren voor mensen met verstandelijke beperkingen.	CAPHRI-dag (Care and Public Health Research Institute, University of Maastricht)	30 March 2006
Oral presentation	Weber, G.	Pomona II Project	Förderheim der Stadt Wien, Ybbs (Lower Austria)	16 March 2006
Oral presentation	Veenstra, M & van Schroyen Lantman- de Valk, H	POMONA:gezondheids-indicatoren voor mensen met verstandelijke beperkingen. een Europees project.	Toetsgroep Clausule (Pepijn en Paulus) (for Physicians for people with ID)	21 February 2006
Oral presentation	van Schroyen Lantman- de Valk, H & Veenstra, M	POMONA:gezondheids-indicatoren voor mensen met verstandelijke beperkingen	Meeting researchers cooperating in programme Intellectual Disabilities at UM	7 February 2006
Oral Presentation	van Schroyen Lantman- de Valk, H & Veenstra, M	POMONA:gezondheids-indicatoren voor mensen met verstandelijke beperkingen. een Europees project.	Ministry of Health, Welfare and Sports	22 November 2005
Oral Presentation	Linehan, C,* Walsh, P.N., Kerr, M., Van Schroyen Lantman-de Valk, H.	The Development of a European Set of Health Indicators for People with Intellectual Disability (2002-2004).	EUPHA European Public Health Association Conference	10-12 November 2005
Oral Presentation	Veenstra, M & van Schroyen Lantman- de Valk, H	POMONA	FORUM, at Department of General Practice, University of Maastricht	01 November 2005
Oral Presentation	Walsh, PN	A European Public Health perspective on aging and health for people with intellectual disabilities	Keynote presentation at Annual Disability Conference, Michigan, Grand Rapids Michigan USA	8 November 2005
Oral Presentation	Walsh, PN	Healthy Aging of People with Intellectual Disability: A European public health perspective.	Gerontological Society of America - Annual Scientific Meeting, Orlando, Florida USA	20 November 2005

Oral Presentation (to be published in a book in French)	Azéma B	Des indicateurs de santé pour les personnes vivant avec une déficience intellectuelle : le projet européen POMONA	Journée d'études sur le handicap : « Accès aux droits à la santé et aux soins des personnes handicapées » Université de Luxembourg. Fonds National pour la Recherche du Luxembourg & Fondation APEMH	25 October 2005
Oral Presentation	Linehan, C.	Health Disparities among People with Intellectual Disability.	Personal Outcomes Conference, Health Services Executive, Tullamore	October 25 2005
Oral Presentation	Walsh, PN	Healthy Aging: A European perspective	Colloquium on Aging, Wayne State University, Detroit Michigan USA	15 October 2005
Oral Presentation	Walsh, PN	Promoting the health of people with intellectual disabilities: Health indicators	Public Lecture at University of Ulster, Belfast, N. Ireland (UK)	10 October 2005
Oral Presentation	Walsh, PN	Health Indicators for People with Intellectual Disabilities	14 <sup>th</sup> Roundtable on Aging and Intellectual Disability, University of Dortmund, Germany	May 2005
Poster Presentation	Weber, G., Fritsch, A., Brehmer, B., & Oppenauer, C.	POMONA-II Gesundheit von Menschen mit intellektueller Behinderung	Austria EU Presidency conference: Ageing and Disability /Disability an Ageing Organisers: EU Level: ARFIE, EASPD, EDF, Inclusion Europe AGE EURAG National level :	8 - 9 June 2006  346 Participants from 25 European countries.  Including participation of high officers from

			Lebenshilfe Österreich, Steirische Behindertenhilfe, Universität Wien	DG Social Affairs and DG Research
Poster Presentation	Kerr, M., Walsh, P.N., Linehan, C., & van Schrojenstein Lantman-de Valk, H.,	Health Indicators for People with Intellectual Disabilities in the Member States: Pomona 1 & 2.	Welsh Centre for Learning Disabilities, 30 <sup>th</sup> Anniversary	13 September 2005
Meeting	Azéma B	Présentation du projet européen d'une enquête de santé sur les personnes avec déficience intellectuelle : le projet POMONA	Rencontre CREAI Languedoc Roussillon Montpellier- France	23 June 2006
Meeting	Linehan, C.	Pomona II Project	Special Olympics Europe / Eurasia, Brussels	9 May 2006
Meeting	van Schrojenstein Lantman- de Valk, H & Veenstra, M	Gezondheid van mensen met een verstandelijke beperking.	Maasveld, living facility for people with ID	11 November - 2005
Meeting	Azéma B	Les Travaux du Groupe POMONA	ANCREAI (Association Nationale des Centres Régionaux pour les Enfants et les Adultes Inadaptés) « Journées de formation des Directeurs et Conseillers Techniques » Pompadour - France	19-21 September 2005
Website Link	Azéma B	ANCREAI (Association Nationale des Centres Régionaux pour les Enfants et les Adultes Inadaptés)	<a href="http://www.ancreai.org/rubrique.php?id_rubrique=65">http://www.ancreai.org/rubrique.php?id_rubrique=65</a>	Website Link

### 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: OPERATIONALISATION PROCESS COMPLETED, TRANSLATED & VALIDATED SURVEY NOW AVAILABLE IN 13 LANGUAGES**

#### 3.5.1 Operationalisation of the Indicators & Development of the Survey Protocol

A set of eighteen health indicators was identified in the Final Report of the first POMONA project (Linehan et al., 2004). A sample of possible operationalisations for each indicator was provided. The final operationalisation of indicators is a key objective for POMONA II. Following three regional meetings, partners reached consensus on this task.

The final operationalisations are contained within the Survey Protocol that will be administered to a sample of adults with intellectual disability in each participating country. The Survey Protocol comprises three parts:

- (1) Part I: Items extracted from a variety of sources including current European Health Interview Surveys; suggestions from partners, intellectual disability specific sources
- (2) Part II: The PAS ADD Checklist (Moss, 2006)
- (3) Part III: The Aberrant Behaviour Checklist (Aman & Singh, 1986)

The Survey Protocol is divided into a number of sections, each denoted by a letter. Table 3.2 presents these sections, their respective health indicator area and the sources for the items contained in the section:

**TABLE 3.2: COMPONENTS OF HEALTH SURVEY**

Section	Part	Number of Items	Content	Indicator	Source
A	I	11	Administration	NA	
B	I	2	DOB Nationality	Demographics	EUROSTAT 2001 European Community Household Panel 2001, Wave 8
C	I	4	Residential Setting	Living & Social Arrangements	Larkin et al., (2003). Selected changes in Residential Service Systems over a Quarter Century 1977-2002. <i>Mental Retardation</i> , 41,4, 303  Barron, S., Mulvany, F., (2003) National Intellectual Disability Database. Health Research Board, Dublin
D	I	4	Socialisation	Social Support	EUROSTAT 2001 European Community Household Panel 2001, Wave 8
E	I	8	Activity	Daily Occupation	Devised by Project Manager
F	I	5	Finance	Income & SES	EUROSTAT 2001 European Community Household Panel 2001, Wave 8  Emerson, E., Malam, S., Davies, I., & Spencer, K., (2005) <i>Adults with Learning Disabilities in England 2003/2004</i> . London: Department of Health
G	I	1	Aetiology	New	Suggested by POMONA partner
H	I	11	Level of Ability	Demographics	Emerson, E., Malam, S., Davies, I., & Spencer, K., (2005) <i>Adults with Learning Disabilities in England 2003/2004</i> . London: Department of Health
ID	I	2	Level of Ability	Demographics	Devised by Principal Investigator
ADL	I	5	Level of Ability	Demographics	Devised by Principal Investigator
I	I	17	General Health	New	The European Health Interview Survey (EHIS) – also covers items in Horwitz Special Olympic Report on Health Morbidities and Mortalities among people with intellectual disability
J	I	1	Self Reported Health	New	EUROSTAT 2001 European Community Household Panel 2001, Wave 8

Section	Part	Number of Items	Content	Indicator	Source
K	I	2	Smoking	New	European Commission (2003). Health in Europe: results from 1997–2000 surveys. Luxembourg, European Commission  Also recommended by EUROHIS (Denmark 2002 survey, Q.139)
L	I	2	Alcohol	New	European Commission (2003). Health in Europe: results from 1997–2000 surveys. Luxembourg, European Commission  Also recommended by EUROHIS (Denmark 2002 survey, Q.139)
M	I	3	Epilepsy	Epilepsy	International League Against Epilepsy. Commission of Epidemiology and Prognosis, International League Against Epilepsy, 1993. Guidelines for epidemiological studies on epilepsy. <i>Epilepsia</i> , 34, 592-596
N	I	4	Oral Health	Oral Health	Recommendation by International Expert in Dentistry & Special Needs
O	I	4	Vision	Sensory	European Commission (2003). Health in Europe: results from 1997–2000 surveys. Luxembourg, European Commission
ALD	I	1	Vision	Sensory	Devised by Principal Investigator
P	I	2	Hearing	Sensory	European Commission (2003). Health in Europe: results from 1997–2000 surveys. Luxembourg, European Commission
ALD	I	1	Hearing	Sensory	Devised by Principal Investigator
Q	I	1	Mobility	Mobility	European Commission (2003). Health in Europe: results from 1997–2000 surveys. Luxembourg, European Commission
ALD	I	1	Mobility	Mobility	Suggested by POMONA partner
R	I	3	Physical Activity	Physical Activity	De Bruin A, Picavet HSJ. (1996) Health interview surveys: towards international harmonization of methods and instruments. (WHO Regional Publications, European Series, No. 58) Copenhagen: WHO Regional Office for Europe. (p.76)
S	I	4	Hospitalisation	Hospitalisation & contact with Health Care	European Commission (2003). Health in Europe: results from 1997–2000 surveys. Luxembourg, European Commission  Suggested by POMONA partner

Section	Part	Number of Items	Content	Indicator	Source
T	I	16	Check up	Health Check Ups	European Commission (2003). Health in Europe: results from 1997–2000 surveys. Luxembourg, European Commission  Suggested by POMONA partner  ECHI 2 - European Community Health Indicators (Phase 2  FINRISK 2000 Survey – from Health Information Survey Health Examination Survey Database
BMI	I	2	BMI	Body Mass Index	EUROSTAT 2001 European Community Household Panel 2001, Wave 8
MEDS	I	18	Medication	Psychotropic Medication Use	Taken from previous study: Walsh, P.N., Linehan, C., Hillery, J., Durkan, J., Emerson, E., Robertson, J., Hatton, C., Gregory, N., Kessissoglou, S., Hallam, A., Knapp, M., Järbrink, K., & Netten, A.,] (2000). The Quality and Outcomes of Residential Supports provided for Irish Adults with Intellectual Disabilities. Summary Report. Centre for the Study of Developmental Disabilities, National University of Ireland, Dublin.
PASADD	II	25	Mental Health	Mental Health	Moss, S., (2006). The Mini PAS ADD Interview Pack. Pavilion Publishing, Brighton
ABC	III	58	Challenging Behaviour	Challenging Behaviour	Aman, M. G., & Singh, N. N. (1986). Aberrant Behavior Checklist Manual. East Aurora, NY: Slosson Educational Publications
<b>FROM MEMBER STATE REPORTS</b>					
Prevalence		These indicators cannot be extrapolated from individual data Information, where available, is included in the Member State Reports (Work Package 4)			
Life Expectancy					
Health Promotion					

An English version of the Survey Protocol is presented in **ANNEX VII**. Only Part I is presented in this report. Part II and Part III are copyrighted material, and while permission has been granted to use these scales as part of the above survey (as a measure of mental health and challenging behaviour), their inclusion in a report that will appear in the public domain would breach copyright legislation. The protocol is now available in a number of languages (detailed in the next section). The first page of the protocol in each language is presented in the Annexes to provide an indication of the variation across languages.

### 3.5.2 Translation & Validation of the Survey Protocol

Following agreement on the content of the Final Survey Protocol, the English version of the protocol was sent to Dublin City University Language Services for translation into the top ten languages presented. In addition, two other languages are available following translations by POMONA partners. Professor Germain Weber & colleagues in Austria translated a German version of the protocol while a Flemish version of the protocol was adapted from the Dutch translation by Professor Geert Van Hove & colleagues in Belgium. The protocol is now available in thirteen European languages listed below:

1. Dutch
2. English
3. Finnish
4. Flemish
5. French
6. German
7. Italian
8. Lithuanian
9. Norwegian
10. Romanian
11. Russian
12. Slovenian
13. Spanish

A first translation is however only one in a number of steps of validation and translation. In order to complete this task partners were given the instructions provided in Table 3.3. Typically a full written backward translation by a second translator is conducted following translation of a questionnaire. Back translation is the process whereby a second bilingual person is asked to translate the translated questionnaire (e.g. French) back into the source language (e.g. English). Both versions – the original English version and the back translation – are then compared and discrepancies resolved.

The process of a full written back translation was not availed of on this occasion for a number of reasons. Firstly, given the level of expertise in the field of intellectual disability required for the validation task, it was felt that partners should be involved in this process as opposed to a second professional translation company. Secondly, the process of back translation has received criticism on the grounds of being ‘circular’ – that is, an initial poor first translation will by definition result in a second poor translation (Johnson, 1998; Harkness 1996; Deutscher 1973). Thirdly, emphasis was placed on ‘Conceptual Equivalence’, the degree to which a particular concept has identical meaning within two or more cultural groups (Okazaki & Sue, 1995; Hui & Triandis, 1985) as opposed to ‘lexical equivalence’, which places emphasis on words, rather than meaning (Deutscher, 1973). Finally, the cost of a second back translation conducted by a professional organisation would have been beyond the scope of the study.

The verification strategy employed for POMONA involved three experts in intellectual disability; two monolingual and one bilingual (native and English speaker) reviewing the original translation. Following these deliberations, the final judgement on ‘conceptual equivalence’ rested with the project partner as an expert in the field of intellectual disability. This verification process has now been completed and final versions of the Survey Protocol have been sent to the Project Manager.

**TABLE 3.3: VALIDATION PROCESS**

**VERIFICATION**

When you receive your translation of the survey, you will need to verify that it is ‘conceptually equivalent’ to the original English version of the survey. Conceptual equivalence (Johnson, 1998) means "the degree to which a particular concept has identical meaning within two or more cultural groups" or "items exhibit identical meaning across two or more cultures after translation". To be clear – we need to ensure that the items in the translated versions have the same meaning as the original English version.

The following process is recommended to determine conceptual equivalence:

**STEP 1:**

In many cases the translators have left the English text beside the translation. You should read the translation and identify any terms or concepts in the items that you think are not conceptually equivalent to the English version of the items.

If you are unsure of the meaning of the original English version of the item – please email me at [christine.linehan@ucd.ie](mailto:christine.linehan@ucd.ie) or phone me on 00 353 716 4645

Examples of terms that are NOT conceptually equivalent may include terms such as ‘neighbourhood group’ on Item D1. The term ‘neighbourhood group’ in the English version of the survey means a local community group. You may decide that the translation of ‘neighbourhood group’ does not mean a local community group in your culture. If so, you should record this item as ‘conceptually NOT equivalent’. Please keep a record of all ‘conceptually NOT equivalent’ items and make suggestions to change the item.

**STEP 2:**

If you have received a translation that has both the original English version and the translated version, please make a copy of the translation and delete the English text.

Now ask a colleague working in the field of intellectual disability who is monolingual (is NOT a fluent English speaker) to read the survey item by item in their own language. For each item you should ask them "What do you think this question asks?" Your colleague should be able to state the question to conceptual equivalence. Please keep a record of all ‘conceptually NOT equivalent’ items and ask your colleague to suggest changes to the item.

**STEP 3:**

Ask a bilingual person (fluent in English) to meet with you to discuss the survey. Give the person the English version of the survey and ask him/her to read each item in English. Then ask the person to tell you what the item means in your own language. Compare the answer they give to the item with the item in the translated version of the survey you have received. You need to determine whether the response given by the bilingual person is conceptually equivalent (that is, has the same meaning) to the survey you have received. Please keep a record of all ‘conceptually NOT equivalent’ items and ask your colleague to suggest re-wording the item.

**STEP 4:**

Examine all the items from STEP 1, STEP 2 and STEP 3 that are NOT ‘conceptually equivalent’. As an expert in the field of disability, you will make the final decision on which suggestion you will use to change the item. When you have finished making the changes, you should ask another colleague who is monolingual (not a fluent English speaker) to read the complete survey. You should ask the person to evaluate the survey for ‘readability’ – that is, how easy it is to read.

**STEP 5:**

Email your completed survey to me at [christine.linehan@ucd.ie](mailto:christine.linehan@ucd.ie)

### 3.6 POMONA II PROGRESS TO DATE – WP4 REPORT ON SYSTEMS IN PARTICIPATING MEMBER STATES<sup>8</sup>

*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: REPORTS FROM ALL PARTNERS COMPLETED***

The Project Manager circulated a template, outlining the material to be included in these reports, to all partners in January 2006. The guidelines are presented below in Table 3.4.

The production of Member State reports aimed to meet a number of objectives. Firstly, the compilation of material for these reports provided an opportunity for partners to familiarise themselves with the overall context for people with intellectual disability resident in their own country. This process will be useful for partners when selecting an appropriate sampling frame from which participants may be invited to take part in the health survey.

Secondly, the reports will provide a highly useful portrait of comparisons and contrasts between service care delivery for people with intellectual disabilities throughout Europe. Partners will have an opportunity to review the reports from other countries and discuss comparisons and contrasts at future POMONA meetings.

Thirdly, the reports provide a valuable resource for partners to present to Competent Authorities both within and beyond their own countries.

The Member State reports are presented in **ANNEX VIII**

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<sup>8</sup> The term ‘Member State’ is employed here to include all POMONA partners – Member States prior to May 2004 enlargement, New Member States, EFTA Member States and Applicant States

**TABLE 3.4: TEMPLATE FOR MEMBER STATE REPORT**

The aim of Work Package 4 is to present a description of each participating Member State, prepared to a common template. Given the time limit of the task, each Member State Report will comprise approximately 10-20 pages (excluding references) and should be guided using the following headings:

**BACKGROUND**

- (1) What definitions of Intellectual Disability are typically used in your Member State?  
Is there an 'official' definition?
- (2) What is the historical context in which services have developed in your Member State?
- (3) Are there specific legal rights afforded to people with intellectual disability? Education, disability specific service provision, etc. Situations where rights may be revoked on the basis of incapacity?
- (4) What is the estimated prevalence figure for intellectual disability in your Member State? Both in terms of an estimated 1-3% of the population who have an IQ is less than 70, and in terms of known service users. Is there any published material on prevalence studies?
- (5) What databases/sources are available in your Member State that might provide information on prevalence? Medical or social benefits; disability databases etc.

**SERVICE PROVISION**

- (6) What is the criterion for eligibility for intellectual disability services?
- (7) What type of service provision is currently offered to adults with intellectual disability?  
Educational, day service, residential, etc
- (8) What sources of income are available for people with intellectual disability?  
Benefits – provide some index of national minimum wage as a reference point

**HEALTH SERVICES & UTILISATION**

- (9) What health services are currently offered to adults with intellectual disability?
- (10) Is there a body of research in your Member State on the health of adults with intellectual disability? Cite main researchers and areas of research they investigate (not the specific studies themselves – just direct the reader to where the information can be found)
- (11) Is there any data on life expectancy among this population in your Member State?
- (12) Can you provide comparative information on the following for both people with intellectual disability and the general population – prevalence of epilepsy, forms of health promotion such as screening for blood pressure, blood cholesterol, breast screening, cervical screening, testicular cancer screening. Are there other forms of health promotion screening available to people with intellectual disability (such as medication use, oral hygiene, contraception etc.) and how is this information available – in written form, pictures, television adverts etc.
- (13) Is there any disability specific training for health professionals – such as modules on undergraduate programmes etc? GP, Dental, Psychiatry -

The following sources will be helpful:

- (1) World Health Organisation -  
The WHO Atlas Reports may be useful in providing generic information on health systems in Member States. The Regional Office provides a profile of many countries:  
<http://www.euro.who.int/countryinformation>
- (2) Idresnet – the Idresnet Project produced an excellent document 'Intellectual Disability in Europe Working Papers'

[http://www.kent.ac.uk/tizard/research/research\\_projects/idresnet\\_working\\_papers\\_%202003.pdf](http://www.kent.ac.uk/tizard/research/research_projects/idresnet_working_papers_%202003.pdf)

While our focus is more health related, this document provides a very useful template of the type of report we would like to produce.

(3) EU Monitoring & Advocacy Program Country Reports

<http://www.eumap.org/group1/silva2/topics/inteldis/index>

A series of excellent reports in 14 Member States which again, do not focus on health specifically, but provide excellent background information.

### 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: PROCESS OF OBTAINING ETHICAL APPROVAL COMPLETED OR PENDING IN ALL PARTICIPATING MEMBER STATES; DATA COLLECTION IN PROGRESS WHERE ETHICAL APPROVAL HAS BEEN OBTAINED***

The aim of the pilot study is to test the Survey Protocol on a small sample of adults with intellectual disability in each participating country prior to the roll out of the main survey. The pilot survey provides an opportunity to examine the logistics of gathering data, the process of obtaining consent, the appropriateness of individual survey items, and the coding and entering of survey data etc.

Given the vulnerability of the population in question - adults with intellectual disability - health data cannot be gathered without due regard for the requirement of Research Ethics within each participating country. Partners were advised by the Project Manager to identify a suitable Research Ethics Committee and to prepare and submit an application for review. A Research Ethics Protocol, devised by the Project Manager for submission to the Irish Research Ethics Committee – at University College Dublin - was forwarded to partners as a template. Partners were advised that local differences may result in minor variations to partners' applications. The protocol comprised the following elements:

- Abstract & Background Information
- Aims of POMONA II
- Methodology for Data Collection
- Pilot Study
- Sample Selection Criteria & Sample Recruitment
- Data Collection
- Confidentiality and Data Protection
- Data Handling & Storage
- Insurance
- Dissemination

This template document was forwarded to partners in February 2006 at the commencement of Work Package 5: the Pilot Study. Table 3.5 below outlines the progress to date regarding Research Ethics. The table illustrates considerable variation in the requirements for ethical approval in participating countries. Some countries, such as Germany, do not require ethical approval for non-invasive observational research. In contrast, the POMONA health survey is classified as ‘biomedical research’ in France on the basis that data are health related and therefore sensitive. The biomedical classification results in a rigorous vetting of the research protocol by a number of organisations including research ethics, data protection and protection of participants.

The status of research ethics applications in all participating countries is outlined below. The majority of partners have received approval, and a minority are pending. To date, no research ethics application has been rejected. While ethical approval is a necessity in the majority of participating countries, and is an important issue when conducting a survey with a vulnerable population, the process of application and review has delayed the completion of the pilot study. This delay is beyond the remit of project partners, project management and the European Commission. Without appropriate ethical approval, any collection of data on behalf of people with intellectual disability would be considered a breach of best practice in the field.

The delay has however provided partners with an opportunity to undertake preliminary consultations with service providers and Competent Authorities who can assist in the recruitment of participants for the main survey. A number of partners have now completed these negotiations and have secured agreement from appropriate authorities to invite people with intellectual disabilities to take part in the survey. As such, part of Work Package 6 – Sample Selection, has been completed while awaiting a decision from the various Ethical Committees.

Partners in Wales, UK – Prof Mike Kerr and Dr Jon Perry – are lead partners for the Pilot Study work package. In February 2006 guidelines regarding the structure of the pilot study were disseminated by Dr Perry & Prof Kerr to all partners. The guidelines recommend that the pilot sample should be restricted to the same geographical area from which the main sample will be drawn. The aim should be to achieve a pilot sample of 8 people in each Member State who should be aged 18 or over. Four of these should live in the family home and four should live in residential care. Of the four people living with their families, two should have a severe intellectual disability (i.e., few or no language skills and few independent living skills). The other two people living with their families should have mild to moderate intellectual disabilities. Similarly, two of the four people living in residential care should have severe disabilities and two should have mild/moderate disabilities. Recommendations are also provided regarding the issue of consent to participation. While consent procedures vary throughout Europe, the approval of an appropriate Research Ethics Committees ensures that best practice is adhered to regarding this aspect of the survey.

The main data collection phase of POMONA – as outlined in Work Package 7 – commences in August 2006. The 2<sup>nd</sup> All Partner POMONA meeting is scheduled for the first week in August coinciding with the 2<sup>nd</sup> International Congress of IASSID (Europe) the *International Association for the Scientific Study of Intellectual Disability*. It is hoped that partners will have completed their pilot study by this meeting in August and that the transition from pilot study to main data collection will occur smoothly on the grounds that much of the sample selection procedures outlined in Work Package 6 have been completed as partners await a response from Ethical Committees.

**TABLE 3.5: RESEARCH ETHICS COMMITTEES**

Country	Affiliation	Ethics Committee	Decision
<b>Austria</b>	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	<b>Approved</b>
<b>Belgium</b>	Department of Orthopedagogics, Ghent University, Henri Dunantlaan 2 9000 Ghent, Belgium	Ethical Committee of the Faculty of Psychology and Educational Sciences (Ghent University)	<b>Pending</b>
<b>Finland</b>	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	<b>Approved</b>
<b>France</b>	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); <i>COMMISSION NATIONALE DE L'INFORMATIQUE ET DES LIBERTÉS (CNIL);</i> Comité consultatif sur le traitement de l'information en matière de recherche dans le domaine de la santé	<b>Approved</b> Comité Consultatif de Protection des Personnes dans la Recherche Biomédicale (CCPPRB); <b>Pending</b> CNIL
<b>Germany</b>	Fakultät Rehabilitationswissenschaften (Faculty of Rehabilitation Sciences), University of Dortmund, Emil-Figge-Str.50, Dortmund 44221, Germany	Not required	<b>Not Applicable</b>
<b>Ireland</b>	Centre for Disability Studies, University College Dublin, Belfield, Dublin 4, Ireland	University College Dublin	<b>Approved</b>

<b>Italy</b>	Unità Operativa di Psicologia, IRCCS OASI MARIA SS, Via Conte Ruggero 73, Troina, Sicily, Italy	Comitato Etico dell'IRCCS Oasi Maria SS	<b>Approved</b>
<b>Lithuania</b>	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	<b>Pending</b>
<b>The Netherlands</b>	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	<b>Approved</b> (pending signature)
<b>Norway</b>	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	<b>Approved</b>
<b>Romania</b>	Sc Medfam Apolo Srl, Luceafarului No 13 Bl G1 Sc 1A, Ap 3, Călărași 8500 Romania	Comisia De Bioetica Colegiul Medicilor din Romania	<b>Approved</b>
<b>Slovenia</b>	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)	<b>Pending</b>
<b>Spain</b>	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.	<b>Pending</b>
<b>United Kingdom</b>	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)	<b>Approved</b>

### 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: THIS WORK PACKAGE COMMENCES MAY 2006***

Work Package 6, which commences beyond the reporting period of this report – May 2006, is concerned with the identification and sourcing of a suitable sample of adults with intellectual disabilities to participate in the health survey.

The lead partners, Professor Meindert Haveman and Dr van Schroyen Lantman-de Valk, circulated preliminary information on this work package to partners for discussion in November 2005. The document outlines the aims of data collection and notes that:

*“a representative sampling procedure in which each person of a population has a chance (mostly the same chance) to be selected in a sample, or a quota sampling procedure in which persons are matched in a quantitative model like the distribution in the population, is not necessary for WP 3”*

The document suggests that while a representative sample is not required for the purposes of testing the standardisation and validity of the indicators, some pre-stratification of important variables should be attempted. Suggested variables include level of ability, type of residential provision and age. Instructions regarding possible sampling frames and the need to over-sample some sub-groups (such as older persons) are also outlined.

As stated previously, some partners have begun the process of liaising with service providers and families to invite adults with intellectual disability to participate in the survey. The period awaiting ethical approval has provided many partners with an opportunity to begin this task.

### 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: THIS WORK PACKAGE COMMENCES AUGUST 2006***

This task is scheduled to occur outside the reporting period of this Interim Report. Work Package 7 is scheduled to take place between August 2006 and April 2007.

The POMONA All Partner meeting, which coincides with the 2<sup>nd</sup> International Congress of IASSID *International Association for the Scientific Study of Intellectual Disability* Europe in Maastricht, takes place in the beginning of August. Results from the pilot study and the commencement of the main survey will be key points for discussion at this 2<sup>nd</sup> All Partner meeting.

A series of three regional meetings will provide opportunities for discussion and appraisal of the data collection process during this time. The three regional meetings are provisionally scheduled for:

- (1) Helsinki, Finland: 12-15 October 2006
- (2) Vilnius, Lithuania: 9-12 November 2006
- (3) Bucharest, Romania: 23-26 November 2006

### 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 Kuusankoski, Finland*

***Progress to Date: THIS WORK PACKAGE COMMENCES MAY 2007***

This task is scheduled to occur outside the reporting period of this Interim Report. Work Package 8 is scheduled to take place between May 2007 and January 2008.

The collection and input of data for Work Package 5, the Pilot Study, has required some preliminary work to be carried out on this work package. To date, researchers in Ireland have produced a data file for partners using SPSS (Statistical Package for Social Scientists).

Currently, the SPSS file is being converted to EXCEL. Both packages are compatible and partners report that EXCEL is the preferred package of choice for those who do not have an SPSS license. These data files will be forwarded to co-lead partners in Finland for comment.

A user manual outlining the appropriate variable and value labels is also being produced in Dublin. This manual will ensure standardized coding of data to ensure compatibility when merging data files from all participating countries.

Consultations with the Data Protection Commission (Ireland) have also been ongoing regarding the anonymisation, storage and sharing of health data throughout Europe. The Commission's advice was of major benefit when compiling a Research Ethics Protocol suitable for dissemination throughout Europe.

### 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 (I-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 task is scheduled to occur outside the reporting period of this Interim Report. Work Package 9 is scheduled to take place between October 2007 and April 2008.

Dr. Henny van Schrojenstein Lantman-de Valk is lead partner for this work package. Dr. van Schrojenstein Lantman-de Valk has considerable expertise in the educational needs of health professionals regarding intellectual disability.

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## 4. POMONA II FUTURE WORK

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POMONA I provided considerable evidence that people with intellectual disabilities are typically excluded from health interview surveys and are rarely considered in major public health campaigns. Campaigns such as those advocating for greater health care screening or campaigns addressing significant determinants of health such as smoking or obesity, for example, are largely targeted at the general population and do not meet the needs of those with intellectual disabilities. This exclusion is evident despite a known disparity in health status and access to health care services between people with intellectual disabilities and their age related peers.

POMONA II provides a pioneering opportunity to gather standardised European-wide health data on behalf of this population. A survey protocol has now been developed that – following testing in the POMONA II project - will permit the participation of adults with intellectual disabilities in health surveys conducted throughout Europe. The use of items from previous European health surveys, and recommendations from EUROHIS, is intended to facilitate comparative analyses between responses from people with intellectual disabilities and responses from the general public. Such a comparison will highlight health disparities and inform health care providers for this population.

In addition to the production, translation and validation of a survey protocol ready for use in all 14 participating countries, Member State reports have been completed, Research Ethics Committee applications have been submitted and partners have engaged in a variety of opportunities for dissemination such as peer reviewed publications, presentations at leading conferences and attendances at project meetings. The completion of these tasks within a relatively short time span of twelve months was made possible through the expertise and enthusiasm of project partners.

Throughout the coming year (May 2006-April 2007), the substantive task of data collection will be undertaken in participating countries. This task commences in August 2006 – a timely starting date that coincides with the 2<sup>nd</sup> POMONA All Partner Meeting, which will be held during a major conference in the field of intellectual disability, the 2<sup>nd</sup> International Congress of IASSID Europe (*the International Association for the Scientific Study of Intellectual Disabilities*). The data collection phase is due to be completed by April 2007 – coinciding with the reporting period for the second Interim Report.

By the third year of this project the data gathered between 2006-2007 will be analysed. This data will provide a unique opportunity to determine the validity and appropriateness of the health indicators. The final year of the project will also provide an opportunity for project partners to examine the issue of training and disability awareness among health care professionals.

This first year of the project has seen the completion of tasks necessary to begin data collection proper. The second and third year will see the realisation of this work and produce a unique dataset that will contribute to a greater awareness and recognition of the needs of people with intellectual disabilities.