

5. POMONA - Results

The project can best be evaluated by returning to the original aims of the project. These aims were stated as:

- To determine what health indicators, if any, are in place across the Member States
- 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

5.1. Aim 1 Results:

Determining what health indicators, if any, are in place across the Member States.

As indicated in Chapter 4, multiple sources were examined to determine what health indicators, if any, are in place across the Member States that examine the health of people with intellectual disability. Results pertinent to each data source are reported below along with an assessment of each sources' appropriateness as a resource for health indicator data for persons with intellectual disabilities.

5.1.1. Literature pertaining to health indicators for people with intellectual disability

A comprehensive literature search and consultation among project partners identified a dearth of published material regarding health indicators for people with intellectual disability. Material that was identified, such as the Core Indicator Project, originate in the United States and rely on homogeneous data collection procedures across participating States. The validity of adopting such a model across the European Union, where a diversity of health care systems exists, is questionable. In addition, limited material was identified regarding health targets for people with intellectual disabilities. The Welsh Health Gain Protocol for Mental Handicap/Learning Disability (1992) is an example of such documents and illustrates how this type of material is of limited value to the current project as it is aspirational in nature and does not specify health indicators per se.

5.1.2. Health indicators employed for the general population

In the absence of specific health indicators for people with intellectual disabilities, the possibility of applying generic health indicators to this population was explored. The European Community Health Indicators (ECHI) are recognised as the most current and definitive set of health indicators. A review of these indicators,

however, revealed only one indicator specific for people with intellectual disability: the incidence of Down’s Syndrome. While the ECHI contains several indicators that appear in the final POMONA draft list (e.g. Body Mass Index) there are several reasons why it cannot be used per se as the draft list of indicators. These reasons include (a) the ECHI indicators are not comprehensive with many of the final POMONA list absent, (b) the operationalisation of the ECHI indicators does not address difficulties in measurement present in people with intellectual disabilities, such as behavioural disorder, and (c) ECHI makes no attempt to identify people with intellectual disability, therefore with the exception of Down’s Syndrome, the population is essentially invisible.

5.1.3. National population statistics regarding intellectual disability

The possibility of identifying health indicators from current intellectual disability database systems was also explored. Project partners were requested to identify the presence of national registers of intellectual disability or the presence of local service registers, and the potential to link these data, if available, with health services data. The findings from this survey are presented below. As the survey reveals, only two Member States of those who responded have a national register of intellectual disability. Of these, only one Member State, the Netherlands, can link this data to centralised health data records. It should be noted, however, that this database is no longer in operation and as such the data is archival. The possibility of using national register data linked to health data in an attempt to construct health indicators for people with intellectual disability is therefore extremely limited and realistically could not be undertaken on behalf of people with intellectual disability residing in the European Union.

Another implication of the lack of national registers throughout the European Union is the fact that basic population statistics, necessary for the development of indicators such as those developed by ECHI, are unavailable for most Member States. Proportional indicators, where the numerator is part of the denominator (e.g. number of persons aged under 18 years/number of persons in the population), cannot be computed for this population. In the absence of this type of population data, it is likely that data on prospective health indicators will rely on smaller scale sample surveys being conducted in each Member State.

Table 5.1: Survey of National Registers among participating Member States							
Country	National register	Linked to health data	Local service register	How ID is identified	Linkable to health service data	ID recorded on health sources	Tests
Belgium	No	N/A	Yes		No	No	WISCR+ others
Denmark	No	N/A	Yes	No	Yes by CPR number		
Finland	Only most disabled	Technically yes	Yes	AAMR ICD 10	Possibly with ethics	No ICD 10 only	WISCR and others
Ireland	Yes (n=27000)	No	Yes		No	No	No standard

Italy	No	N/A				No	
Luxembourg	No	N/A	Yes	AAMR ICD 10	N/K	No	IQ and others
Netherlands	Yes (n=27000)	Only using anonymised identifiers	Yes	Social care	Yes by CPR number	No	IQ ABS SRZ
Spain	No	N/A	Yes		No	No	
Sweden	No	N/A	Yes	Social care	No		IQ
UK	No	N/A	Yes	Social care need	Yes linkage with ethics	ICD10 only	

5.1.4. Health interview and health examination surveys at Member State level that may contain information regarding the health of people with intellectual disability

While no health monitoring systems were identified that specifically examine the health of people with intellectual disability in Member States in the European Union, the possibility of this population being included in generic health monitoring systems was also explored. Throughout the European Union an extensive, if not yet cohesive system of health monitoring exists. Each Member State engages in Health Interview Surveys (HIS; conducted by interview with participants) and Health Examination Surveys (HES; conducted through physical examination) to determine the health of the nation. Typical sample sizes for such surveys exceed 10,000 individuals. The European Commission's Health Monitoring Programme promotes the standardisation of these surveys in due course. At present these omnibus surveys occur at different time periods in each Member State. That is, while some Member States may conduct a given survey every five years (termed 'waves'), other Member States may conduct 'one time only' surveys or change the emphasis of the survey on different waves. In addition, the questions and measures employed in these surveys are not standardised across Member States. That is, data on such variables such as Body Mass Index may be classified differently in surveys rendering any comparison across states invalid. Despite such challenges, HIS and HES surveys provide valuable information for policy makers and health service providers in Member States. The current inclusion of people with intellectual disability in such surveys was therefore explored as a possible data source of health indicators for this population.

An examination of all HIS and HES surveys conducted in participating Member States was undertaken to determine whether these surveys provide information regarding the health of people with intellectual disability. The most comprehensive inventory of health surveys in Europe is the European Health Interview & Health Examination Surveys Database and is available via the Internet at <https://www.iph.fgov.be/hishes/>. The database is the outcome of a European Union Health Monitoring Programme project conducted in 2000. The project, 'Health surveys in the European Union: European Health Interview & Health Examination Surveys (HIS and HIS/HES) evaluations and models (Phase 1 and Phase 2)' can be accessed at <http://europa.eu.int/comm/health/>.

The European Health Interview & Health Examination Surveys Database defines health surveys using the following criteria:

- Surveys aiming to give a complete picture of health, medical consumption, lifestyle and preventive behaviour.
- Surveys with a significant health or health related component, like surveys on impairment, disability and handicaps.
- Multipurpose surveys.
- Living conditions surveys.
- Health related questions of the European Community Household Panel (ECHP) and the Eurobarometer.

All Health Interview Surveys and Health Examination Surveys from Member States participating in the current project were extracted from the database and individually searched. Fifty-four surveys (of which some included both HIS and HES components) from the 13 participating Member States were examined. Where previous versions of a contemporary survey were cited, the most recent version of the survey was examined. Each survey was examined to determine:

(1) Does the survey contain questions addressing the identified set of health indicators generated by this project?

To address this query, the full questionnaire as presented on the HES HIS database website was manually searched for questions which addressed the health indicators generated by this project. Surveys that did not contain items pertinent to these health indicators were deemed not be of use to this project. Surveys that did contain pertinent items (e.g. BMI, sensory impairment, etc.) were further examined as stated in (2) below.

(2) Can data be extracted from the survey solely on people with intellectual disability?

The HIS HES website provides information regarding the sample selection for each survey. Two selection criteria are of relevance to the current project:

- a. The HIS HES database provides information on whether or not respondents were included from 'institutions for the mentally handicapped'
- b. The HIS HES database also provides information on whether or not proxy respondents were employed where adults were 'not at home' or 'unable to reply' – Dr. Jean Tafforeau, Scientific Institute of Public Health, Brussels, who coordinates the HIS HES database confirms that intellectual disability is one reason why proxy respondents are employed.

The table below identifies HIS and HES surveys in each of the participating Member States in the current project. Each survey was assessed on the two criteria outlined above: firstly, does the survey address health indicators that have been selected in the current project, and secondly can information from this survey be extracted specifically on the health of people with intellectual disability. Where the latter question can be addressed, a valid comparison can be made between the health of those with intellectual disability and the health of those in the general population. Any identified disparity in health status between the two populations would, therefore, be apparent. For this reason, HIS and HES surveys could provide a useful vehicle to monitor health disparity. A full report on this survey is presented in Appendix H

SURVEY OF HEALTH INTERVIEW SURVEYS AND HEALTH EXAMINATION SURVEYS

CONDUCTED IN PARTICIPATING MEMBER STATES

Member State	Survey	Does survey examine health indicators of interest?	Can information on people with intellectual disability (ID) be extracted?
Austria	1.1 Disabled Persons' Survey	Yes	No
	1.2 Sports, Leisure Time and Home Accidents	No	N/A
	1.3 Microcensus	Yes	No
Belgium	2.1 Health Interview Survey	Yes	No
	2.2 General Socio-Economic Survey	No	N/A
Denmark	3.1 Danish Health & Morbidity Survey	Yes	Yes, but less than 7 respondents with ID
	3.2 Health & Morbidity in Denmark	Yes	No
Finland	4.1 Living Conditions Survey	Yes	No

	4.2 Finnish Health Care Survey	Yes	No
	4.3 FinRisk 97	Yes	No
	4.3.1 FinRisk Health Examination Survey	Yes	No
	4.4 Health 2000	Yes	Yes, but only 10-20 respondents with ID
	4.4.1 Health 2000 Health Examination Survey	Yes	Yes, but only 10-20 respondents with ID
	4.5 Survey on Health Behaviour	Yes	No
	4.6 European Community Household Panel	Yes	No
	4.7 Health Behaviour Survey among the Elderly	No	No
	4.8 Health Behaviour Survey among the Adult Population	Yes	No
	4.9 The National FinRisk Survey	Yes	No
	4.9.1 FinRisk Health Examination Survey	Yes	No
France	5.1 Health and Care Interview Survey	Yes	No response from co-ordinator at time of printing: Recommend further investigation - however it should be noted that any possible sample of PWID† excludes those in institutionalised care and those requiring a proxy respondent.

† PWID = 'people with intellectual disability'

	5.2 Health and Social Protection Survey	Yes	<p>It was not possible to contact the coordinator at the email address provided:</p> <p>Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care and those requiring a proxy respondent.</p>
	5.3 Handicaps, disabilities and dependency survey	Yes	No
	5.4 Health Barometer	Yes	<p>No response from co-ordinator at time of printing:</p> <p>Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care and those requiring a proxy respondent.</p>
	5.5 French Survey on Living Conditions and Aspirations	No	N/A
	5.6 Continuous survey on household living conditions	Yes	<p>It was not possible to contact the coordinator at the email address provided:</p> <p>Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care and those requiring a proxy respondent.</p>

	5.7 Survey on Household Living Conditions	No information provided	It was not possible to contact the coordinator at the email address provided: Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care and those requiring a proxy respondent.
	5.8 National Survey on Health and Health Insurance	Yes	It was not possible to contact the coordinator at the email address provided: Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care and those requiring a proxy respondent.
Germany	6.1 Survey on Living Conditions, Health & Environment	Yes	No response from co-ordinator at time of printing: Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care and those requiring a proxy respondent.
	6.2 German National Health Interview Survey	Yes	No response from co-ordinator at time of printing: Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care and those requiring a proxy respondent.

	6.2.1 German National Health Examination Survey	Yes	No response from co-ordinator at time of printing: Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care and those requiring a proxy respondent.
	6.3 Questions on Health	Yes	No
	6.4 Questions on Health Microcensus	Yes	No
Ireland	7.1 Survey of Lifestyle, Attitude and Nutrition (SLAN)	Yes	No
	7.1.1 SLAN Health Examination Survey	Yes	No
	7.2 Living in Ireland Survey	Yes	No
Italy	8.1 Aspects of Daily Life	Yes	No response from co-ordinator at time of printing: Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care.

	8.2 Health Conditions and the Use of Health Services	Yes	No response from co-ordinator at time of printing: Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care.
Luxembourg	9.1 Eurobarometer	Yes	No
	9.2 Panel Living in Luxembourg	Yes	No
	9.3 European Community Household Panel	Yes	No
	9.4 Socio-Economic Panel living in Luxembourg	Yes	No
	9.5 2002 LFS ad hoc module employment of people with disabilities	No	N/A
Netherlands	10.1 Continuous Quality of Life Survey	Yes	Survey Coordinator is currently on maternity leave. Recommend further investigation - however it should be noted that any possible sample of PWID excludes those in institutionalised care.
	10.2 Patient Survey – Second Dutch National Survey of General Practitioners	Yes	No
	10.3 Netherlands Health Examination Survey	Yes	No

Spain	11.1 National Health Survey	Yes	No
	11.2 Impairments, Disabilities and Health Status Survey	Yes	Yes.
Sweden	12.1 Living Conditions Survey	Yes	No response from co-ordinator at time of printing.
United Kingdom	13.1 Health & Lifestyle Survey	Yes	No
	13.2 Survey of Psychiatric Morbidity		Yes, but in a non-institutionalised setting only
	13.3 The Scottish Health Survey	Yes	Yes – but numbers of respondents with ID would be very small and unrepresentative.
	13.3.1 The Scottish Health Examination Survey	Yes	No
	13.4 Disability Survey	Yes	No – however data may be available from a 1986 version of this survey conducted in institutions.
	13.5 Health Education Monitoring Survey	Yes	No
	13.6 Health Survey for England	Yes	No

	13.6.1 Health Survey for England Health Examination	Yes	No
	13.7 General Household Survey	Yes	Possible – however the sample would be biased towards those with higher levels of ability
	13.8 Census (2001)	No	No

Overall findings from the survey revealed that the majority of HIS and HES surveys could not provide data on the health of people with intellectual disability in the European Union. While it was not possible to contact the survey coordinator for all 54 surveys, representatives from 41 surveys were contacted and provided information on those who participated in the surveys. The vast majority of these coordinators stated that it would not be possible to extract information from these surveys on people with intellectual disability. Some surveys have included a proportion of respondents with intellectual disability, however the number of respondents would be so small (<20 individuals) as to render the information unrepresentative. One survey does, however, merit attention: the Impairments, Disabilities and Health Status Survey conducted in Spain. Correspondence with the coordinator of this survey indicates that it is possible to extract information specifically on the health of respondents with intellectual disability and compare their responses with those of the general population. Further investigation of this survey is required to determine the possibilities of incorporating a representative sample of people with intellectual disability in a national omnibus health survey.

Several important methodological issues were identified during the analysis on HIS HES survey data.. Firstly, many surveys were based on a sampling system using the 'household' as the unit of sampling. As a proportion of people with intellectual disability do not reside in traditional household settings, it is likely that they would be excluded from such surveys. Secondly, difficulties arose in identifying respondents with disabilities who participated in such surveys. Generally 'filter' questions were employed to determine whether any person in the household 'has a disability', 'has difficulty learning' or is in receipt of a specific social service benefit eligible to those with a disability. Whether such questions constitute a valid measurement of disability is open to debate and is currently being addressed by the United Nations (www.cdc.gov/nchs/citygroup.htm). Finally, generic health surveys, by definition, focus on health issues pertinent to the general population. It became apparent that health issues specific to people with intellectual disability were unlikely to be addressed given that they would be deemed irrelevant for the majority of respondents. Despite such challenges, current HIS and HES surveys may provide an opportunity for the collection of comparable health data on both the general population and those with intellectual disability. Further consideration of the model employed in Spain is certainly indicated.

5.1.5. Data at Member State level regarding POMONA health indicators for people with intellectual disability

A final exploration of health data was undertaken by requesting project participants to identify any recent research conducted in the field of intellectual disability that related to the selected health indicators. That is, while no systematic monitoring of the health of people with intellectual disability may occur in participating Member States, the possibility existed that health issues specific to people with intellectual disability, such as obesity or health screening, may have been extensively investigated by people working within the field of intellectual disability using a variety of methods including sample studies, examination of registers from those with intellectual disability attending services, or through the use of social service databases. The possibility may then emerge that similar studies conducted in different Member States would allow for the comparability of this data across states.

The data submitted by partners is presented below in summary format. A full report of the findings is presented in Appendix I.

It should be noted that partners submitted a wealth of additional information in conjunction with the information presented in this current document. Much of this additional information relates to indicators that were subsequently removed during the final selection of health indicators. The outstanding information is retained by the Steering Committee and provides a valuable portrait of health status and health care provision for people with intellectual disability in Member States.

When submitting their data, partners were requested to identify a data source. These data sources could include data from population-based census surveys, population-based disability surveys, population-based health registers, or intellectual disability specific registers (usually in the form of Service Provider registers). In the absence of these robust data sources, partners were asked to identify sample surveys that, while not ongoing sources of data, may provide information regarding the prevalence of health indicators in each Member State.

The tables below presents a summarised format of the type of data submitted by partners. A definition of terms is presented in the first table.

The following abbreviations are employed:

Abbreviations for Member States:

AT: Austria	BE: Belgium	DK: Denmark	FIN: Finland
FR: France	DE: Germany	IRL: Ireland	IT: Italy
LUX: Luxembourg	NL: Netherlands	SP: Spain	SW: Sweden
UK: United Kingdom			

<i>Estimate</i>	Prevalence figure has been generated by extrapolating generic prevalence figure from population base
<i>Population based data (+ID)</i>	Population based data: while data specifically on intellectual disability has rarely been extracted from these databases, such data may be available.
<i>Population based disability data (+ID)</i>	Population based data of those with disabilities: while data specifically on intellectual disability has rarely been extracted from these databases, such data may be available.
<i>Population based disability data (-ID)</i>	Population based data of those with disabilities from which data specifically on intellectual disability cannot be extracted.
<i>Population based ID Service User data (+ID)</i>	Population based data of those with intellectual disabilities attending services.
<i>Social Service/Insurance data (+ID)</i>	Central or regional administrative data of those in receipt of benefits available to people with intellectual disability
<i>Regional disability data (-ID)</i>	Regional administrative data of those with disabilities attending variety of services (not ID specific)
<i>Regional ID data (+ID)</i>	Regional administrative data of those with intellectual disability attending variety of services
<i>Regional institutionalised ID data (+ID)</i>	Regional administrative data of those with intellectual disability in institutional care
<i>Sample Survey (+ID)</i>	One off sample survey – typically includes unrepresentative quota sample of service users.
<i>No data</i>	No data source identified by partners (or in rare cases a database containing information on the general public from which no disability specific information was collected)

DEMOGRAPHIC HEALTH INDICATORS

<i>Indicator</i>	<i>AT</i>	<i>BE</i>	<i>DK</i>	<i>FIN</i>	<i>FR</i>	<i>DE</i>	<i>IRL</i>	<i>IT</i>	<i>LUX</i>	<i>NL</i>	<i>SP</i>	<i>SW</i>
<i>Prevalence</i>	No data	Population based disability data(-ID)	Social Service /Insurance data (+ID)	Social Service /Insurance data (+ID)	Population based disability data (+ID)	Population based disability data (-ID)	Population based ID Service User data (+ID)	Estimate, Regional disability data (-ID) Sample Survey (+ID)	Estimate, Regional institutionalised ID data (+ID)	Estimate	Population based disability data (+ID)	Estimate
<i>Living Arrangements</i>	Regional ID data (+ID)	Regional disability data (-ID)	Regional institutionalised ID data (+ID), Regional ID data (+ID)	Population based ID Service User data (+ID)	No data	Regional ID data (+ID)	Population based ID Service User data (+ID)	No data	Regional institutionalised ID data (+ID)	Regional institutionalised ID data (+ID), Population based ID Service User data (+ID)	No data	No data
<i>Daily Occupation</i>	Sample Survey (+ID)	No data	Regional ID data (+ID)	Population based ID Service User data (+ID)	No data	Sample Survey (+ID)	Population based ID Service User data (+ID)	Population based disability data (-ID)	Population based disability data (-ID)	Population based disability data (+ID)	Population based disability data (+ID)	Estimate
<i>Income</i>	No data	No data	Regional ID data (+ID)	Social Service/ Insurance data (+ID)	No data	Social Service/ Insurance data (+ID)	Population based disability data (-ID)	Population based disability data (-ID)	Social Service/ Insurance data (+ID)	Social Service/ Insurance data (+ID)	No data	No data
<i>Life Expectancy</i>	No data	No data	Population based disability data (+ID)	Population based disability data (+ID)	Population based disability data (+ID)	No data	Population based ID Service User data (+ID)	No data	No data	Regional institutionalised ID data (+ID)	No data	Sample Survey (+ID)

HEALTH STATUS INDICATORS

<i>Indicator</i>	<i>AT</i>	<i>BE</i>	<i>DK</i>	<i>FIN</i>	<i>FR</i>	<i>DE</i>	<i>IRL</i>	<i>IT</i>	<i>LUX</i>	<i>NL</i>	<i>SP</i>	<i>SW</i>
<i>Epilepsy</i>	Sample Survey (+ID)	No data	Estimate	Population based data (+ID) & Sample Survey (+ID)	No data	Estimate	Sample Survey (+ID)	Sample Survey (+ID)	No data	Regional ID data (+ID)	Sample Survey (+ID)	Sample Survey (+ID)
<i>Oral Health</i>	No data	Sample Survey (+ID)	No data	No data	Sample Survey (+ID)	Population based disability data (-ID)	Population based data (+ID)	No data	Regional ID data (+ID)	No data	Sample Survey (+ID)	No data
<i>Body Mass Index</i>	Sample Survey (+ID)	No data	No data	Sample Survey (+ID)	No data	No data	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	No data	No data
<i>Mental Health</i>	Sample Survey (+ID)	No data	Sample Survey (+ID)	Sample Survey (+ID)	No data	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Regional ID data (+ID)	Sample Survey (+ID)	Sample Survey (+ID)
<i>Sensory Impairment</i>	Sample Survey (+ID)	No data	Sample Survey (+ID)	No data	No data	Population based disability data (+ID)	Sample Survey (+ID)	No data	Sample Survey (+ID)	Regional ID data (+ID)	Sample Survey (+ID)	Sample Survey (+ID)
<i>Mobility</i>	Sample Survey (+ID)	No data	No data	No data	No data	No data	No data	No data	Sample Survey (+ID)	Population based ID Service User data (+ID)	Sample Survey (+ID)	Sample Survey (+ID)

DETERMINANTS OF HEALTH INDICATORS

<i>Indicator</i>	<i>AT</i>	<i>BE</i>	<i>DK</i>	<i>FIN</i>	<i>FR</i>	<i>DE</i>	<i>IRL</i>	<i>IT</i>	<i>LUX</i>	<i>NL</i>	<i>SP</i>	<i>SW</i>	<i>UK</i>
<i>Physical Activity</i>	Sample Survey (+ID)	No data	Sample Survey (+ID)	No data	Sample Survey (+ID)	No data	Sample Survey (+ID)		No data	No data	No data	No data	No data
<i>Challenging Behaviour</i>	Sample Survey (+ID)	No data	No data	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	No data	No data	Sample Survey (+ID)	No data	Sample Survey (+ID)
<i>Medication</i>	No data	Regional ID data (+ID)	No data	No data	No data	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	Sample Survey (+ID)	No data

HEALTH SYSTEM INDICATORS

<i>Indicator</i>	<i>AT</i>	<i>BE</i>	<i>DK</i>	<i>FIN</i>	<i>FR</i>	<i>DE</i>	<i>IRL</i>	<i>IT</i>	<i>LUX</i>	<i>NL</i>	<i>SP</i>	<i>SW</i>	<i>UK</i>
<i>Hospitalisation & contact with health care professionals</i>	No data	No data	No data	Population based disability data (-ID)	No data	Population based disability data (+ID)	Population based disability data (+ID)	Population based disability data (+ID) & Population based disability data (-ID)	No data	No data	Population based disability data (+ID)	Population based disability data (+ID)	Population based disability data (+ID)
<i>Health Check</i>	No data	No data	No data	No data	No data	No data	Sample Survey (+ID)	No data	Sample Survey (+ID)	No data	No data	No data	No data
<i>Health Promotion</i>	No data	No data	No data	No data	Campaign on (1) sex education (2) oral health	No data	No data	No data	No data	No data	Campaign on (1) oral health	No data	No data
<i>Training</i>	Evidence of training	Evidence of training	Evidence of training	No data	No data	No data	Evidence of training	Evidence of training	No data	Evidence of training	Evidence of training	No data	Evidence of training

The tables above illustrate the current availability of data in participating Member States for each of the selected health indicators. The variability in types of data is evident. While some states have national disability databases from which basic population statistics can be extracted, others have prevalence estimates. Similarly while data relating to the occurrence of hospitalisation among people with intellectual disability can be extracted from generic databases of inpatient care in some Member States, others have no data regarding the use of these health care facilities by people with intellectual disability.

The aim of this survey was to determine whether, in the absence of systematic health monitoring for people with intellectual disability, the possibility existed that data pertaining to the set of identified health indicators in this project would be available at national level through less robust sources such as sample studies, service user registers, etc. As the tables above reveal, the currently available data is heterogeneous in nature and could not be employed in any meaningful way as a valid indication of the health status or health care utilisation of people with intellectual disability resident in the European Union.

5.1.6. Conclusion: Determining what health indicators, if any, are in place across the Member States that examine the health of people with intellectual disability.

To reiterate, a number of sources were examined to determine what health indicators, if any, are in place across the Member States that examine the health of people with intellectual disability. Each shall now be briefly reviewed to determine whether they provide a useful data source from which the health of people with intellectual disability can be monitored.

- Literature pertaining to health indicators specific to people with intellectual disability:

There is a dearth of material regarding health indicators for people with intellectual disability. Material that was identified was deemed inappropriate for the present study. Specifically, models of health monitoring for this population in the United States cannot be adopted in the European Union due to the varying health systems and availability of data across the EU. Other material identified throughout this search was largely ‘aspirational’ in nature and called for health targets for this population to be met without identifying the mechanism through which such targets would be measured.

- Health indicators employed for the general population.

The use of a generic set of health indicators, specifically ECHI, to monitor the health of people with intellectual disability was examined and rejected on a number of grounds. The ECHI indicators exclude health indicators specific to people with intellectual disability; they do not address the difficulties in measurement posed by people with intellectual disability; they do not specifically identify people with intellectual disability other than those with Down’s Syndrome thereby excluding a large proportion of people with intellectual disability.

- National population statistics regarding intellectual disability.

Partners were requested to identify the presence of national registers of intellectual disability that could be linked to health data thereby providing a mechanism through which the health of people with intellectual disability could be monitored. Only two partners identified a national register, and of these one cannot be linked to health data (Ireland) and one is no longer in operation (Netherlands). The ability to link national registers with health data is not currently possible in Member States and cannot be considered as a viable method to monitor the health of this population.

- Health interview and health examination surveys at Member State level that may contain information regarding the health of people with intellectual disability.

The possible inclusion of people with intellectual disability in Health Interview Surveys and Health Examination Surveys conducted in each participating Member State was examined. A total of fifty-four such surveys were examined. The vast majority of these surveys do not include people with intellectual disability in their sample selection. While some surveys do include this population, the small sample size would render any information unrepresentative. One survey however, the Impairments, Disabilities and Health Status Survey, Spain, may provide a useful framework as correspondence with the survey coordinator indicates that it is possible to extract information on behalf of respondents with intellectual disability and to compare this data with responses from the general population. Further exploration of this survey is recommended.

- Data at Member State level regarding POMONA health indicators for people with intellectual disability.

A final exploration of health data was undertaken by requesting project participants to identify any recent research conducted in the field of intellectual disability relevant to the selected indicators. A review of the material submitted by partners revealed major variation in the availability of data for each indicator. This variability would render the use of such data for monitoring purposes invalid.

To conclude, of the five investigations conducted above, no systematic monitoring of the health of people with intellectual disability was identified throughout the participating Member States of the European Union. Health data for this population are largely based on sample studies, of varying sample sizes and methodologies, which cannot be compared with the general population. However, while no such system currently exists, this investigation has identified potential methods by which such data may be collected. The current call for more standardised HIS and HES surveys throughout the European Union may provide a useful framework to incorporate the health monitoring needs of those with intellectual disability. Further investigation of these surveys, and their potential inclusion of a representative sample of people with intellectual disability is recommended.

5.2. Aim 2 Results:

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

Through the consensus of all partners, four key criteria developed by the Steering Group were employed in the selection of health indicators. These criteria were:

- ❖ Importance – is the health indicator an important issue for the health of people with intellectual disability?
- ❖ Disparity – is there evidence of differing prevalence rates of the health indicator among those with intellectual disability when compared with the general population?
- ❖ Usefulness – is the health indicator a useful tool for the resource allocation?
- ❖ Information – is data regarding the health indicator available in Member States?

Partners' evaluation of the health indicators presented in ECHI during the All Partner Meetings indicated the relative merit of these criteria. The power of criteria such as 'Importance' and 'Usefulness' for example, to discriminate among health indicators was limited. Partners agreed that most indicators were, to some extent at least, either 'important' or 'useful'. The remaining two criteria, 'Disparity' and 'Information' were more applicable in the selection of health indicators, but as outlined below, may have raised more issues than provided solutions to the selection of health indicators for this population.

Disparity is a key theme throughout this project. The continual measurement of health indicators revealing a disparity between the health of individuals with intellectual disability and those in the general population will provide an opportunity not only to benchmark the ongoing health of people with intellectual disability but moreover will provide an opportunity to determine any reduction in health disparity between people with intellectual disability and the general population. Clearly, where disparities emerge between the health of individuals with intellectual disability and those in the general population extra resources are required.

The 'information' criterion is also a dominant theme throughout the project. Partners agreed that information pertaining to the health of individuals with intellectual disability is extremely limited and that the POMONA project was charting new territory in this regard. Partners discussed potential candidate indicators in depth on the basis that while they were perceived to be of considerable clinical importance, their inclusion as a health indicator using the criteria above was challenging. Firstly, some clinically important health issues cited by partners had little empirical backing. That is, while 'vaccination' was presented as a key issue for people with intellectual disability, and an issue that would reflect a disparity between those with intellectual disability and those in the general population, the search for empirical based literature supporting these contentions yielded a dearth of material. Partners agreed that it would not be appropriate to exclude clinically important candidate indicators that had received little attention in the literature. In fact, partners commented that the inclusion of such indicators may in fact stimulate debate concerning these areas and thereby increase the evidence base.

Secondly, the challenge of measuring many of these clinically important candidate indicators was discussed at length by partners. Consider for example the indicator 'income'. All partners agreed that financial income and socio-economic status were important correlates of health. In addition, partners' clinical experience strongly supported the contention that the income of those with intellectual disability is lower than those in the general population. The issue of how such an indicator could be measured was however challenging. People with intellectual disability can potentially receive income from a number of sources; family, social benefit, employment, to name a few. The diversity of income for people with intellectual disability both within and

between Member States in the European Union would however make comparable data collection extremely difficult. Clearly further work is required regarding the piloting of such indicators.

Finally, partners were cognisant of the lack of basic prevalence data regarding people with intellectual disability in Member States. Recall that only two Member States have core information on prevalence rates from National Database sources. The remaining Member States typically calculate prevalence estimates extrapolated from an expected 1% prevalence rate. Partners suggested that until such time as standardised datasets are available in Member States, the measurement of health indicators for this population is most likely to be determined from sample surveys.

5.3. Aim 3 Results:

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

The final set of 18 health indicators are outlined below.

Final Set Of Indicators – September 2004

Demographics	<ul style="list-style-type: none"> 1.1 Prevalence 1.2 Living Arrangements 1.3 Daily Occupation 1.4 Income/Socio-Economic Status 1.5 Life Expectancy
Health Status	<ul style="list-style-type: none"> 2.1 Epilepsy 2.2 Oral Health 2.3 Body Mass Index 2.4 Mental Health 2.5 Sensory 2.6 Mobility
Determinants	<ul style="list-style-type: none"> 3.1 Physical Activity 3.2 Challenging Behaviour 3.3 Psychotropic Medication Use
Health Systems	<ul style="list-style-type: none"> 4.1 Hospitalisation & Contact With Health Care Professionals 4.2 Health Check 4.3 Health Promotion 4.4 Specific Training For Physicians

The following section provides further detail on each of these indicators. Firstly, a literature review is presented supporting each indicator. Where possible, the literature reviews cite prevalence figures, highlight disparity and illustrate why the indicator is an area of importance with regard to the health of people with intellectual disabilities. Secondly, a proposed ‘operationalisation’ of each indicator is presented.