

EXECUTIVE SUMMARY

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

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

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

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

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

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

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

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