

2 The Task Force on Major and Chronic Diseases

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Summary:

The Task Force on Major and Chronic Diseases (TFMCD) is one of the implementing structures of the Health Information and Knowledge Strand of the EU Public Health Programme 2003-2008. At the core of the TFMCD are the major and chronic diseases related projects funded under this Programme. The general purpose of the TFMCD is to help building the EU Health Information and Knowledge System on major and chronic diseases, which can be regarded as a matrix: different actions are needed at different levels in national and supranational public health monitoring systems, and this needs to be done for multiple diseases and conditions. Therefore, the TFMCD projects are involved in a wide array of activities, which are related to identification of data needs, indicator development, data collection and analysis, quality assurance, and dissemination and promotion of outcomes. In these activities, both morbidity and mortality aspects are taken into account. There are close links between the work done in the TFMCD and activities of the Working Party on Health Indicators related to the ECHI indicator lists.

1 Context and mandate

There is an increasing demand for health information for political decision-making, not only at national level, but also at European level. It was therefore decided to create a comprehensive and sustainable health monitoring and information system in the EU Public Health Programme 2003-2008, in order to establish comparable quantitative and qualitative indicators on health and health-related behaviour of the population, diseases and health systems at Community level: the "EU Health Information and Knowledge System". This System has been developed and operationalised in the Health Information and Knowledge Strand, which was one of three Strands within the EU Public Health Programme 2003-2008. The other two Strands were Health Threats and Health Determinants.

Several implementing structures were established for the Health Information Strand at the beginning of the Programme, among which seven Working Parties (see figure 1, and the DG SANCO website: http://ec.europa.eu/health/ph_information/implement/implement_en.htm). One of these is the Working Party on Morbidity and Mortality (MMWP). The purpose of the MMWP is to provide a forum for discussion and exchange of views and experience on information and knowledge in the fields of Morbidity and Mortality at National, Sub-national and European Union level. The MMWP serves as an expert group to advise on information and knowledge for monitoring Community policies and other initiatives in the field of morbidity and mortality.

The availability of high quality, comparable data is vital especially in the field of major and chronic diseases, which represent a heavy burden of disease for the EU citizen and which use a great deal health care resources. The European Commission therefore decided to establish, as a substructure of the MMWP, a Task Force on Major and Chronic Diseases (TFMCD), to specifically help building the EU Health Information and Knowledge System on major and chronic diseases. In addition to the TFMCD, other substructures of the MMWP are the Task Force on Rare Diseases and the Task Force on Health Expectancies. The latter has the specific task to ensure the proper implementation of the EU structural indicator Healthy Life Years (HLY).

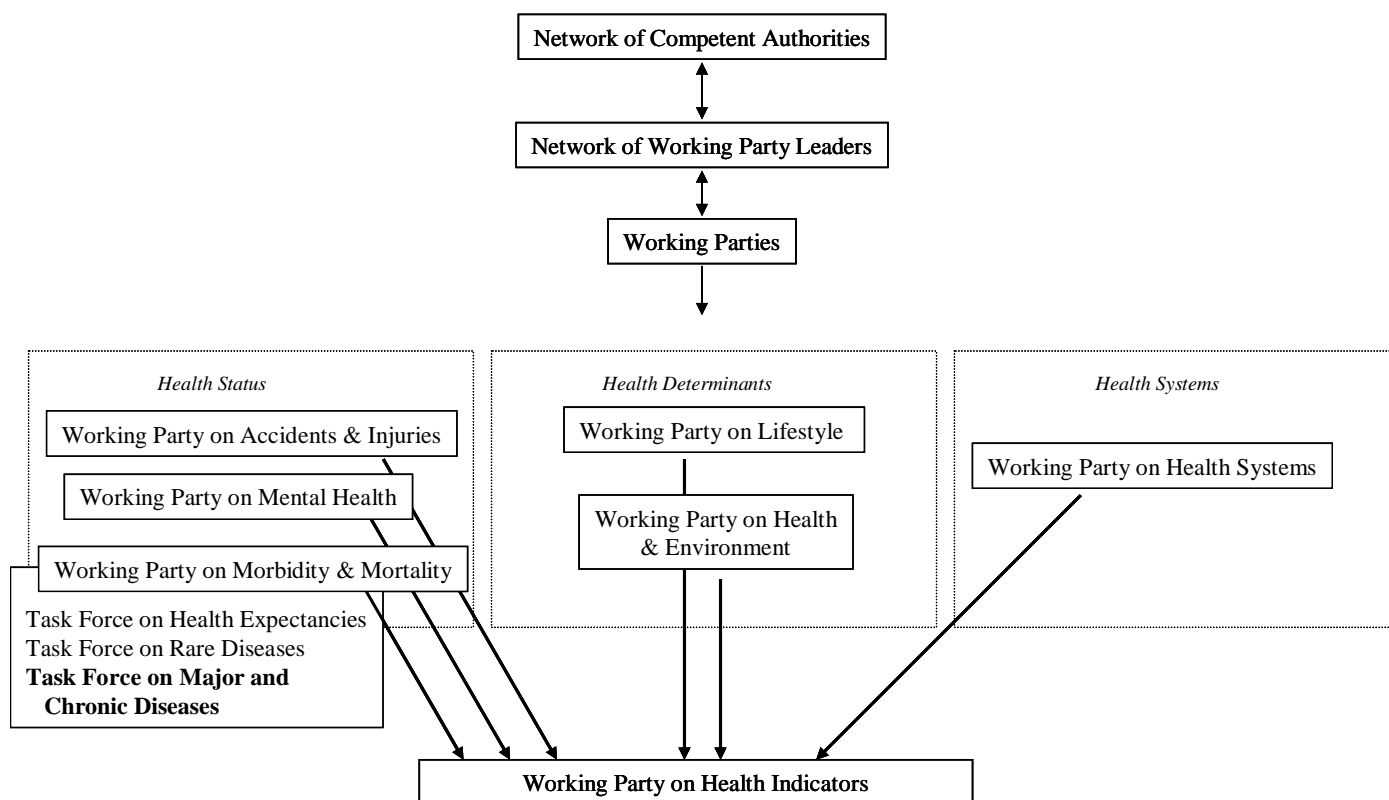


Figure 1 Implementing structure of the Health Information and Knowledge Strand of the Public Health Programme 2003-2008 (at the beginning of the Programme), and the place of the TFMCD within this structure

The TFMCD consists of project leaders of major and chronic diseases projects under the Public health Programme 2003-2008 and former project leaders from the previous public health programmes, national experts in major and chronic diseases, and representatives of Non-Governmental Organisations (NGOs). The major aims of the TFMCD are:

- to advise and assist the European Commission Public Health Directorate promoting optimal epidemiological information and collecting information on prevention, diagnosis and treatment of major and chronic diseases in Europe, in recognition of the unique added value to be gained for major and chronic diseases through European coordination.
- To provide a forum for discussion and exchange of views and experience on issues related to major and chronic diseases and conditions defined in the Community Public Health Programme and annual Work Plans.

Under the Public Health Programme 2003-2008, the TFMCD met twice a year in Luxembourg. The full mandate of the TFMCD is available at the website of DG SANCO: http://ec.europa.eu/health/ph_information/implement/wp/morbidity/taskforce_chronic_en.htm

2 Activities of TFMCD projects

The TFMCD helps building the EU Health Information System for MCD in a comprehensive and sustainable way. The structure underlying the System can be regarded as a matrix: collecting and disseminating comparable, valid data requires different actions at different levels in national and supranational public health monitoring systems, and this needs to be

done for multiple diseases and conditions. In the former Public Health Programme the development of indicators for different groups of diseases and conditions has received ample attention. Building on these results sustainable operation of the EU Health Information and Knowledge System has been emphasized under the Programme 2003-2008. Existing data sources have been used as much as possible in setting up this System. Making an inventory of available data (such as from morbidity registers, health surveys, hospital discharges etc.) and making these data more comparable (e.g. by harmonising coding practices) is, therefore, one of DG SANCO's priorities.

With regard to the above-described first axis of the matrix, the specific objectives TFMCD projects should aim for are described in the Task Force's mandate:

- To widen access to high quality information on causes, diagnosis, screening methods, counseling, treatment and care for major and chronic diseases;
- To promote the availability of high quality comparable major and chronic diseases epidemiological data across Europe regarding incidence, prevalence, survival and inequalities within and between countries;
- To promote the development of improvements in the classification and coding system for major and chronic diseases to supplement the International Classification of Diseases, in liaison with WHO;
- To promote the development of improvements in the methods of collection of data and Europeans classifications and coding systems for major and chronic diseases used by the European Statistical System;
- To promote effective surveillance and early warning and cluster response in relation to changing risk factors for major and chronic diseases;
- To promote the exchange of ideas and information regarding quality of life issues, and regarding patient preferences and choice;
- To assist in the diffusion of "good and best practice" by means of presentation and comparison of national health information;
- To advise the Commission services in the implementation of disease or morbid conditions modules in the Commission Eurobarometer survey or in other components of the European Health Survey System.

These objectives are being achieved through a wide array of project activities, among which: the refinement of existing indicators; the development of new indicators in fields so far not yet adequately covered; building networks of expertise; the development of tools and (best practice) guidelines and the organisation of trainings and workshops for proper implementation of these products; setting up databases and data collection systems; and designing adequate reporting strategies. Dissemination of project results is usually done through different means targeting specific audiences, e.g. papers in scientific journals, policy health reports and public websites. The (projects of the) TFMCD, furthermore, provides expert input for DG SANCO policy developments (e.g. annual Work Plans, Communications) and contributes to European health reporting. A full listing of TFMCD projects is available at the TFMCD website: <http://www.nivel.eu/EC/TFChronicDiseases>. This website contains links to project websites, if available, and to more detailed project information at the website of DG SANCO.

3 Contribution of TFMCD to ECHI indicator system and the European Health Interview/Examination Survey

The European Community Health Indicators (ECHI) are at the core of the EU Health Information and Knowledge System. The ECHI project under the Health Monitoring Programme (1997-2002) has developed a comprehensive list of indicators, including their operational definitions, in close co-operation with many other projects under the Health

Monitoring Programme. At the end of the Programme, the list contained approximately 400 items/indicators. There was a strong wish from the European Commission to develop a shortlist, in order to prioritise work for harmonisation of data collection by EU Member States. ECHI undertook the task of selecting the indicators for the shortlist in close collaboration with the project leaders, Working Parties and the Commission departments involved. Thus, the so called ECHI shortlist was created (2004), containing a total of about 100 indicators on demographic and socio-economic factors, health status, health determinants, health services, health interventions and health promotion. For about 40 shortlist indicators data are readily available and reasonably comparable. All the ECHI indicators, which were not selected for the shortlist, remain on the so called ECHI long list, to be implemented in the future. Currently, preparations for the implementation of the shortlist in all EU Member States are ongoing. The short and long lists, as well as metadata tables, which contain definitions of the shortlist indicators and an overview of available data sources per indicator, are available at the ECHIM website: <http://www.echim.org>. ECHIM is the scientific secretariat for the Working Party on Health Indicators (see below).

It is impossible to collect data and produce ECHI indicators without a very good basis in the form of EU instruments to gather this information. Therefore, EU action, through the different projects in the different Working Parties, focuses on improving the quality and the comparability of these instruments (health surveys, disease registers, hospital activity, health accounts, etc.) to make it easier for Member States, European networks and ECHI to compare and analyse information (see above; 'activities of TFMCD projects'). So, Working Parties' and Task Forces' expertise is used for all phases of data management related to the ECHI indicators: the analysis of data needs in their respective area; definition of indicators and quality assurance; technical support for national efforts; data collection at EU level; reporting and analysis; and promotion of the results.

The development and implementation of the ECHI indicator system is coordinated by the Working Party on Health Indicators, which is, therefore, a cross-cutting Working Party, exchanging relevant developments and activities with all other Working Parties (see figure 1). The contribution of the TFMCD to the ECHI indicators system is specifically related to the indicators on health status. There is a continuous exchange of information between the TFMCD and the Working Party on Health Indicators, e.g. on project outcomes (data, tools) related to the ECHI short list and long list, and on the update of the shortlist, which took place in 2007. This exchange is systematically operationalised through having ECHI representatives attending the TFMCD meetings and vice versa, and through biannual overviews of ECHI indicator system related project output, which are made by the TFMCD's Scientific Assistance Office (a in 2005 funded project, see: http://ec.europa.eu/health/ph_projects/2005/action1/action1_2005_9_en.htm).

3.1 Health interview/examination surveys related projects

It is envisaged that in future European Health Interview Surveys (EHIS) and European Health Examination Surveys (EHES) will constitute an important source of information for part of the ECHI indicators, among which the health status indicators. Eurostat plays a vital role in the development, jointly with DG SANCO, of the European Health Survey System (EHSS), which entails both EHIS and EHES. Data for EHIS will be gathered through the European Statistical System. The first data collection round for the so called core modules of EHIS is planned for 2009. Currently, DG SANCO is exploring the possibilities for EHES as an additional source of information in the future. More information on the EHSS is available at the website of DG SANCO:

http://ec.europa.eu/health/ph_information/dissemination/reporting/ehss_en.htm.

Under the EU Public Health Programme 2003-2008 there are two Health Interview/ Examination Survey related projects, which are crosscutting projects for the Working Party on Health Indicators and the TFMCD. These are:

▷ The 2004 funded EUHSID project (European Union Health Surveys Information Database). Its general aim is updating the Health Interview Survey (HIS)/Health Examination Survey (HES) database. This database was established under the Health Monitoring Programme 1997-2002 and represents an inventory of nationally and internationally administered health surveys in EU Member States, EFTA countries and some countries of other regions (USA, Canada and Australia) from 1991 onwards. The database contains practical information related to the survey (institutions, contacts) as well as content related information (e.g. questions used, methodologies applied). Besides adding the latest surveys carried out in the European region, EUHSID specifically focuses on: refining the coding of survey instruments and the search capacities of the database; documenting recommendations for new standardized instruments to be used in population health surveys in Europe; and comparing the content of the questionnaires and examination protocols used in population health surveys in Europe with the recommendations. The HIS/HES database is available at: <https://hishes.iph.fgov.be>

▷ The FEHES project (Feasibility of a European Health Examination Survey). Its main objective is to examine and analyse the feasibility of carrying out a European HES or repeated national HESs in EU Member States. This goal will be reached through: the creation of a network of experts and institutes for implementing HES in all EU Member States; the description and analysis of the feasibility of models of HES with different intensity and costs; the collection and assessment in all EU-countries of information on factors affecting feasibility of HES; making proposals and recommendations for the future of HES in the EU and all Member States; and the preparation of a proposal for a European HES pilot, to be carried out both in Member States with and without previous national HES experience. More information is available at the project website: <http://www.ktl.fi/fehes/>

4 Mental health

Mental health is an integral and important part of population health: it is estimated by WHO that one fourth of the 'population burden of disease' is due to mental ill health. The International Labour Organization (ILO) estimates that mental ill-health costs are 3-4 % of GDP, mainly through lost productivity (Gabriel & Liimatainen, 2000). Good mental health is increasingly important for economic growth and population well-being in Europe. The transformation of Europe into an information society and technological changes in working life cannot successfully be achieved without giving population mental health special consideration. Mental health information is, therefore, an important field within the European health information system.

A core aim of any mental health policy is to create knowledge and raise awareness on the extent of mental health problems in the population (including among specific groups in the population) and to develop population-level mental health promotion and mental disorder prevention. To be able to act on these aims, mental health policy is dependent on a sound mental health information system with a good coverage. Regrettably, most current regional, national and international health information systems are weak in the field of mental health. The European Commission has therefore supported improvement of mental health monitoring in several grants from the public health programme (Lehtinen 2004).

The Working Party on Mental Health was one of the seven working parties for health information created in 2003. However, the working party was discontinued in 2005 due to re-organisation of mental health issues within DG SANCO, when the responsibility for mental health issues was transferred from the health information unit to the health determinants unit.

Currently mental health projects co-funded by the Public Health Programme are allocated either to the TFMCD or to the Health Determinants Unit C4.

The MINDFUL project (see www.stakes.fi/mindful), coordinated by the Finnish National Research and Development Centre for Welfare and Health STAKES, aimed at improving population mental health monitoring in EU by defining a common set of mental health indicators, analysing availability and preparing of a common European database. Furthermore, it aimed at improving the status of mental health information by widening the scope of the mental health monitoring systems to cover not only mental disorders and mental health systems, but also positive mental health and determinants of mental health, which had previously been rather neglected. Building on existing research and previous development projects, MINDFUL shows that data on mental health-related mortality and on psychiatric hospital use are available to a reasonable extent, but also that huge information gaps exist, notably in the areas of mental health determinants, community-based mental health services and mental health expenditure. The main outcomes of MINDFUL have been reported by Lavikainen et al (2006).

After thorough survey of validity, psychometric properties, availability and policy relevance, the MINDFUL project recommended a final set of 35 mental health indicators (Table 1). 15 of the 35 MINDFUL indicators rely on population surveys for their collection.

The MINDFUL database, consisting of indicator metadata and numerical data for each of the 35 MINDFUL mental health indicators, is freely available for researchers, developers, and the public, through the project website <http://www.stakes.fi/mindful> (click on 'Indicators'). The database covers the period from 1990 onwards. Available data were retrieved from international databases, national statistical offices, survey reports and published scientific articles. In addition to national total population data, the MINDFUL database also contains breakdowns by sex, age and NUTS21 regions where available.

¹ The Nomenclature of Territorial Units for Statistics (NUTS) is defined for the Member States of the European Union. The NUTS is a three-level hierarchical classification, that subdivides each Member State into a whole number of NUTS 1 regions, each of which is in turn subdivided into a whole number of NUTS 2 regions and so on. Because the subdivision depends on the size of the population, both NUTS 1 and 2 are equivalent to the whole country in some smaller countries. These include Cyprus, Denmark, Estonia, Latvia, Lithuania, Luxembourg, Malta, and Slovenia

Table 1 The MINDFUL list of mental health indicators for Europe

GROUP	DOMAIN	INDICATOR
Health status	<i>Cause specific mortality</i>	1a. Suicide
		2a. Deaths of undetermined intent
		3. Drug related deaths
		4. Alcohol related deaths
	<i>Morbidity, disease specific</i>	5. Any anxiety disorder
		6. Major depression
		7. Hazardous and harmful drinking
		8. Suicide attempts
	<i>Morbidity, generic</i>	9. Psychological distress
		10. Mental disorders and adjustment among children and adolescents
		11. Energy, vitality
		12. Happiness
		13. Psychological impairment
Determinants of health	<i>Personal conditions</i>	14. Sense of mastery
		15. Self-Esteem
	<i>Social and cultural environment</i>	16. Social support
		17. Negative life events
Health systems	<i>Prevention, health protection and promotion</i>	18. Childhood adversities
		19. Suicide prevention
	<i>Health resources</i>	20. Mental health promotion
		21. Number of psychiatric beds
		22. Number of psychiatrists
	<i>Health care utilisation; psychiatric care and social services</i>	23. Number of child (and adolescent) psychiatrists
		24. Number of in-patient episodes due to mental health conditions
		25. Number of long-stay patients
		26. Involuntary placements
		27. Use of outpatient services
		28. Self-reported use of mental health services
		29. Use of antidepressants
		30. Use of antipsychotics
		31. Use of anxiolytics
		32. Use of hypnotics
		33. Disability pensions due to mental disorders
		34. Sickness allowance spells due to mental disorders
	<i>Expenditure</i>	35. Expenditure on mental health services

To be able to successfully combat the European epidemic of mental ill-health, the increasing use of psychiatric services, and increases in sick-leave and early retirement due to mental disorders (Järvisalo et al. 2005), policy makers and citizens need information on mental health determinants. The MINDFUL Project has recommended that the EHIS core module should be strengthened in the field of mental health by including data collection on five central psycho-social determinants of health and mental health, i.e. 'Sense of mastery', 'Social support', 'Negative Life-events', 'Self-esteem'; and 'Childhood adversities'.

The MINDFUL Project also scrutinised evidence on childhood determinants of adult mental disorder (Fryers, 2007). Based on the outcomes of this inventory, recommended indicators to capture childhood determinants of adult mental disorder are 'Negative life events' and 'Childhood adversities'. This work is continued in the project "School Children Mental Health in Europe", which is co-funded by the EC Public Health Programme health determinants strand.

Furthermore, the MINDFUL Project analysed feasibility of structural indicators of positive mental health. Using the Delphi methodology, a set of 31 indicators of social and environmental factors that have a positive impact on public mental health was proposed. Further development and data collection in relation to these structural indicators will be performed in the Monitoring Positive Mental Health Environments (MMHE) Project, which is co-funded by the EC Public Health Programme health information strand.

Mental health has individual, social, ethical, economic and societal precursors and consequences that should be addressed in all Member States. Adequate and comparable information on mental health at population level will be an indispensable pre-requisite for tackling these problems, in targeting measures effectively towards required priorities, and in monitoring progress to agreed goals. MINDFUL has demonstrated the need for further development of policy-relevant European mental health monitoring, to support the aims of the Commission's 'Green Paper on Mental Health', the recent Commission initiative to establish an "EU Mental Health Pact", the implementation of the WHO 'Mental Health Action Plan for Europe', and major EC policies, such as the 'Lisbon Agenda'.

MINDFUL has also shown that, in many cases, mental health data are simply not-available. And when available, they are often non-comparable between Member States, due to differences in data collection, indicator definitions and health systems. The current state of mental health monitoring in the EU indicates that there is lack of co-ordination of and support to Member States. Work is needed to support further harmonisation of mental health indicators and to secure the development and retrieval of data on determinants of mental health. Such work can hardly be done within projects, and thus the introduction of a policy-relevant mental health monitoring system requires infra-structure support. A 'European Mental Health Observatory', supported by the Commission, was therefore recommended by the MINDFUL Project to establish leadership and ensure comparability of mental health monitoring in EU. Such an observatory could be associated with the 'European Centre for Disease Control' and closely collaborate with international organisations such as WHO and OECD. Such an Observatory could be built according to the model of the 'European Monitoring Centre for Drug and Alcohol Abuse' (EMCDDA), which has successfully developed and implemented monitoring of drug abuse.

It is essential that mental health indicators are incorporated in the forthcoming 'European Health Survey System' (EHSS). In spite of the magnitude of mental health problems and the importance of positive population mental health, mental health is not sufficiently covered in the current core module of the 'European Health Interview Survey' (EHIS). Special emphasis should be put on policy-relevant indicators, such as indicators of positive mental health, and data on vulnerable groups at risk of developing mental ill-health. Work to develop a structural

mental health indicator should commence and the mental health contribution to the 'healthy life years' indicator needs to be explored in detail.

5 Health of people with intellectual disabilities

Disability is not itself a disease state. However, abundant evidence suggests that people with disabilities are likely to incur secondary health conditions, and thus disparities are evident when people with disabilities are compared with their peers. An emerging perspective is that multiple and complex factors associated with access to care, identification of disease and treatment availability contribute to negative health disparities among people with disabilities.

People with intellectual disabilities comprise a group within the populations of all countries at risk of significant social disadvantage. An estimated five million persons or 1% of the population of the EU 27 Member States have intellectual disability, the preferred term for a condition known as 'mental retardation' in the United States or 'learning disability' in the United Kingdom. Other terms such as 'mental handicap' persist elsewhere. Defined by significant limitations in cognitive and adaptive functioning, intellectual disability is present from birth or the early developmental period.

Today, people with intellectual disabilities have an increased life expectancy. In many of the more developed countries, they will experience middle and older age. Higher rates of obesity, diabetes and epilepsy, and lower rates of cardiovascular fitness and preventative health screening are among the many health disparities that have been identified for this segment of the population. They are at heightened risk of incurring mental health disorders. A growing body of published evidence reports on the risks, characteristics, assessment strategies and treatment outcomes of those described by clinicians as having dual diagnosis: that is, persons who have lifelong intellectual disability and who also have a diagnosis of a mental health condition.

As they comprise an especially disadvantaged group with evident health disparities people with intellectual disabilities should be identified specifically in health information surveys, rather than subsumed under the larger, more diverse group of people with disabilities. Reliable, comparable information about people with intellectual disabilities is needed to determine health status and health care needs and thus promote equity.

The activities of partners in POMONA I (2002-2004) yielded an evidence-based set of 18 health indicators for people with intellectual disabilities, consistent with the ECHI set developed previously for the general population. The main task of POMONA II (2005-2008) is to apply this indicator set. To date, the POMONA 18 indicator set has been operationalized in a comprehensive survey instrument, which has been translated into 13 languages, field-tested and revised. The POMONA 18 survey instrument includes two standardized measures that specifically relate to (a) screening for the presence of psychiatric disorder and to (b) assessment of problem or challenging behaviours among persons with intellectual disabilities.

Ethical approval was secured in all countries where this was a requirement. One element of the project was to investigate whether Health Information Surveys in Europe currently include or potentially might include information about the health of people with intellectual disabilities. Physical and mental health data related to 1300 participants were gathered by November 2007 (<http://www.pomonaproject.org>).

Activities within POMONA II focus on strategies at Community level to gather reliable, comparable and sustainable health information about a large segment of the population with

evident health disparities and social disadvantage. The project shares the stated priorities of the TFMCD in building the EU Health Information System for Major and Chronic Diseases:

- * Reliable, valid methods to gather comparable health data
- * Make available data about health inequalities within and between countries
- * Disseminate results within Member States, at Community level and internationally among health policy makers, health professionals, researchers, advocates and other stakeholders.

6 Mortality related projects

As explained above, the scope of the TFMCD entails both morbidity and mortality aspects. There are several projects within the TFMCD, which focus primarily on mortality. These are:

▷ The 2004 funded ANAMORT project (Analysis of injury mortality in the European Union). It aims to produce relevant indicators, which can be used throughout Europe to account for injury mortality. Its general objectives are: to evaluate the quality and comparability of injury mortality statistics in Europe; and to produce validated results on the causes of death by injury in Europe, allowing comparisons among countries. In the project's analyses the sub-groups on the Eurostat Causes of Death Shortlist, and detailed sub-groups established in the course of the project will be applied. The results will allow the attribution of observed differences in mortality rates either to differences in certification and/or coding, or to real differences in mortality conditions. More information is available at: <http://www.dsi.univ-paris5.fr/AcVC/anamort.htm>

▷ The 2003 funded MONSUE project (Monitoring Suicidal Behaviour in Europe). It aims to reduce the frequency of suicide, suicide attempts and the repetition rate of suicide attempts in various European countries, by assessing the magnitude of the problem (monitoring of suicides and suicide attempts), and by identifying groups at risk, risk factors, and specific variables (methods, "hot spots", time variables etc.), which can be influenced to prevent this behaviour. Based on these findings guidelines for prevention of suicides and suicides attempts will be developed. Read more at:

http://ec.europa.eu/health/ph_projects/2003/action1/action1_2003_31_en.htm

▷ The 2005 funded CANICULE project (Etude de l'Impact de la Canicule d'Aout 2003 sur la Population Européenne). This project aims to determine the magnitude of excess mortality (number of deaths) in Europe during the heat wave of Summer 2003, specifying the countries and periods in question. It then aims to determine its impact on the population of very old people; what fraction died during the summer? This study should assist in understanding better the impact of temperatures on mortality trajectories in the highest ages. According to meteorologists, heat waves may well occur more frequently in the future - more intense and longer. It seems relevant in these condition, therefore, to study the impact of heat waves on the mortality of the very old, whose numbers have increased radically over the past few years. More information on heat wave related mortality is available at the SANCO site:

http://ec.europa.eu/health/ph_information/dissemination/unexpected/unexpected_1_en.htm

Also member of the TFMCD is the HEM project (Closing the Gap - Reducing Premature Mortality. Baseline for Monitoring Health Evolution Following Enlargement), which was funded in 2003. As its name implies, this project aims to close the gap in premature mortality between old EU and new Member States. It does so through, among other things, the creation of a baseline for monitoring evolution of preventable and premature morbidity, disability and mortality risk factors following the enlargement of the European Union in 2004, and favourable modification of major risk factors for diseases, especially alcohol, selected nutritional factors (obesity), and tobacco. The HEM project has contributed to the chapter on Ischemic Heart Disease in this report. More information on (other) project outcomes is available at: <http://www.hem.waw.pl>

7 Other disease/condition based projects

Most projects in the TFMCD focus on a specific disease/condition or disease cluster. The majority of these describe their contribution to the EU Health Information and Knowledge System in one of the following chapters of this report. There are, however, a few disease based projects which are not represented in this report :

▷ The EUNICE project (EU Network for Information on Cancer) has been launched in 2004. The objective of Eunice is to compile, compare, analyze interpret and disseminate information relevant for monitoring the status of cancer burden in the European populations; and planning and evaluating of cancer control measures at national and EU level. It will also help to refine indicators, especially in areas related to cancer screening, treatment and outcome evaluation. It will establish a common database, which will be used to plan programmes of cancer control in the EU (benchmarking and scenario development) and to monitor their outcome. More information on the EUNICE project is available at the website of DG SANCO:

http://ec.europa.eu/health/ph_projects/2004/action1/action1_2004_33_en.htm

▷ The IMCA II project (Indicators for Monitoring COPD and Asthma in the EU), which was funded in 2005, builds on the results of the IMCA I project. During the first phase of the project, a comprehensive list of indicators for respiratory conditions was developed. IMCA II aims to collect routine data on mortality, hospital discharges, health care, human resources and health care utilization costs in order to estimate the indicators defined by the IMCA I project for all countries involved in the project for a period of 10 years. The project will also develop a module on COPD and asthma to be incorporated in European Health Examination Surveys. The module's feasibility will be tested and pilot performance will be assessed in four geographical areas in Spain, Italy, Sweden and Germany. For more information:

http://ec.europa.eu/health/ph_projects/2005/action1/action1_2005_22_en.htm

▷ the ENE project (European Network on Endometriosis) was funded in 2006. It seeks to raise understanding and promote awareness of the impact of endometriosis across the EU and to create an international network of expertise and opportunities for all professionals and individuals dealing with the disease. It will do so by developing a new European Endometriosis Support Alliance (EESA) to coordinate and provide comprehensive support and training to the 4 sectors associated with the condition i.e. individuals, researchers/academics, doctors/nurses and employers; creating an internet based Endometriosis Community Gateway (ECG), that will provide the focal point for all individuals and groups requiring information and support; and completing a comprehensive pan-European epidemiological study of over 10,000 women with endometriosis in order to develop a research-based information and support base. Basic project information is available at:

http://ec.europa.eu/phea/documents/2006_Health_Information.pdf

▷ The NephroQUEST project (European Nephrology Quality Improvement Network), also funded in 2006, focuses on data on renal replacement therapy, which entails both dialysis and renal transplantation. The project aims to ensure EU-wide dissemination of comparable, high-quality renal replacement therapy data collection by the following actions: acceptance of a standardized indicator set, development of standardized information technology for automated data collection and raising the level of new or already existing but less well developed registries to high standards. For more information visit the NephroQUEST website: <http://www.nephro-quest.org>

▷ The last of the TFMCD projects funded in 2006 is the EUROLIGHT project (Highlighting the impact of the headache in Europe). The project's general objective is to gather, in collaboration with NGO's and health care professionals, reliable and comparable information on the global public health impact of headache disorders. For this purpose, a questionnaire will be developed by the project and tested in 10 pilot EU countries. This exercise should serve as the basis for future EU level surveys. Through its activities, the project aims to raise

awareness in policymakers, health professionals and citizens, and to improve patients' quality of life. More information is available at the project website: <http://www.eurolight-online.eu>

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