Major and Chronic Diseases

REPORT 2007
Executive Summary

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Content

During the Public Health Programme 2003-2007 it was decided to build up Working Parties and Task Forces in order to create a cooperation mechanism between the European Commission and the Member States in different areas for health information. The aim of these bodies is to provide a forum for stakeholders, national experts and EU project leaders to discuss initiatives in their area and to disseminate results, outcomes and recommendations coming from projects. Another object of the working parties is to support the Commission in their work and to highlight gaps and special topics in their field of action.

The topics to be discussed in working parties are normally very broad and therefore it was decided to build up subgroups – the so called task Forces. One of the task forces is the Task Force on Major & Chronic Diseases which is a subgroup of the working party Mortality and Morbidity.

In 2006 the Task Force Major & Chronic Diseases decided to give better visibility to their extensive work. One of the outcomes is this report. It was written on voluntary basis by expert members of the Task Force Major & Chronic Diseases.

Many thanks to all the experts and in particular to the Scientific Secretariat, NIVEL in the Netherlands, for their help in making this report a reality.

The report provides an overview of the main topics which were discussed during the different meetings of the Task Force. It also highlights the results and ongoing activities of different projects which were or are funded by the European Commission.

The report on Major and Chronic Diseases will improve information in the area of major and chronic diseases.

I think that this report will give the necessary visibility and attendance that the Task Force on Major and Chronic Diseases worked to achieve.

Andrzej Ryś

1B. Status of the report

This report was produced by the Task Force on Major and Chronic Diseases (TFMCD) at the request of DG SANCO C2 (Health Information). In summer 2007, all leaders of running projects within the TFMCD were approached for contributing to the report on a voluntary basis. Based on the positive reactions of those project leaders, who were able to find the time and resources to contribute (either alone or in cooperation with their expert colleagues), a disease based division of chapters was made. This division was as much as possible in line with the Major and Chronic Diseases information sheets available at the DG SANCO website at that time.

Authors were asked to show the contribution of their projects to European Public Health Information, as much as possible according to a pre-structured template. It was left to the decision of the authors to use those data which were, in their opinion, either of the best quality, or most feasible to use within the time they could make available for writing their contribution to this report. This flexible approach has two major consequences. Firstly, the contents of this report are a reflection of the authors' findings and opinions, and do not necessarily reflect the opinion or the position of the European Commission. Secondly, besides project results, different public (EU, WHO) and scientific data sources have been used. If necessary in terms of copyright, permission for publication was obtained for the non-public materials (tables, figures) used in this report.

The writing of this report was steered and coordinated by an Editorial Board, which consisted of:

Simona Giampaoli, MD

Deputy leader of the Task Force on Major and Chronic Diseases, Istituto Superiore di Sanità, Rome, Italy

Herman Van Oyen, MD DrPH

Deputy leader of the Working Party on Morbidity and Mortality, Scientific Institute of Public Health, Brussels, Belgium

Walter Devillé, MD PhD

Project leader of the Scientific Assistance Office project, NIVEL – the Netherlands Institute for Health Services Research, Utrecht, the Netherlands

Marieke Verschuuren, MD PhD

Researcher for the Scientific Assistance Office project, NIVEL – the Netherlands Institute for Health Services Research, Utrecht, the Netherlands

The Commission gratefully acknowledges the time and efforts dedicated to the realization of the Major and Chronic Diseases Report 2007 by the members of the Editorial Board.

2. The Task Force on Major and Chronic Diseases

Verschuuren M, MD PhD

NIVEL – the Netherlands Institute for Health Services Research, Researcher "Scientific Assistance Office" project (SAO)

Wahlbeck K, MD, Research Professor

National Research and Development Centre for Welfare and Health STAKES, Coordinator «Mental Health Information and Determinants for the European Level" project (MINDFUL)

Noonan Walsh P, PhD, NDA Professor of Disability Studies

University College Dublin, project leader "Health indicators for people with intellectual disabilities: using an indicator set" project (POMONA 2)

Context and activities of the Task Force

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. 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. Information on the Task Force and on all its projects is available at the website of DG SANCO (http://ec.europa.eu/health/index_en.htm) and the website of the TFMCD (http://www.nivel.eu/EC/TFChronicDiseases/).

Mental Health

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 reorganization. From that point on mental health projects were allocated either to the TFMCD or to the Health Determinants Unit C4. Therefore the TFMCD contains several projects dealing with mental health information. One of them is the "Mental Health Information and Determinants for the European Level" project (MINDFUL), which was funded in 2003. This project resulted in a recommended set of 35 mental health indicators. Building on existing research and previous development projects, MINDFUL shows that data on suicides 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. Given the large public health impact of mental health disorders, further development of and support for a European mental health monitoring system is needed.

Health of people with intellectual disability

Disability is not itself a disease state. However, disparities are evident when the health of people with disabilities is compared with that of their peers. Therefore DG SANCO decided to fund "Status of Health Monitoring for Adults with Intellectual Disability in the Member States" phase I and II: the POMONA projects. 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, by applying this indicator set, to develop and test a survey instrument to gather reliable, comparable and sustainable health information at Community level about a large segment of the population with evident health disparities and social disadvantage. A pilot study was completed among N=84 participants in 2007, and the main survey data for N=1300 participants are being analyzed at time of writing (April 2008). While the findings about how age, gender, ability level and residence are related to health status, determinants and use of health systems will be of great interest, it is essential to recall two important points. First, the sample of participants is not population-based, and findings cannot be extrapolated to the population of about 5 million persons with intellectual disabilities in Europe. Second, the project aimed to operationalize the indicator set as a survey instrument, translate this into 13 languages, secure research ethical approval and apply the instrument in data gathering among 14 countries with diverse traditions and characteristics. This is in itself a unique and remarkable outcome. Future work is required to build on these accomplishments at Community level, for example, in building a sustainable system for gathering and sharing reliable and valid health data about the health of this group of citizens. To heighten dissemination globally, a symposium about the project will be presented at the 13th World Congress of IASSID – International Association for the Scientific Study of Intellectual Disabilities – in Cape Town, August 2008.

3. Atherosclerotic Cardiovascular Diseases: Ischaemic Heart Disease and Stroke

Giampaoli S, Palmieri L, Ciccarelli P, Donfrancesco C

Unit of Epidemiology of Cardio and Cerebrovascular Diseases, Istituto Superiore di Sanità, Rome, Italy, EUROCISS Project Coordinating Centre

Zatonski W

Cancer Epidemiology and Prevention Division, The Maria Sklodowska-Curie Memorial

Cancer Center and Institute of Oncology, Warsaw, Poland

Cardiovascular diseases (CVD) are one of the leading causes of death and hospitalization in both genders in nearly all countries of Europe. The most frequent CVD are those of atherosclerotic origin, mainly ischemic heart disease (IHD) and stroke. CVD clinically manifest itself in middle life and older age, after many years of exposure to unhealthy lifestyles (unhealthy diet, physical inactivity, and smoking habit) and risk factors (high blood pressure, dislipidemia, diabetes, obesity). Although CVD prevalence is very high, its occurrence is largely preventable remaining risk factors at favourable level during life span.

Even though the clinical onset is mainly acute, CVD often evolve gradually, causing substantial loss of quality of life, disability, and life long dependence on health services and medications. They also result in premature deaths (20-64 years). CVD are associated with adverse outcomes in elderly people, including cognitive impairment, dementia and decreased physical performance. The societal costs of CVD are substantial and include not only those directly related to health care and social services, but also those linked to illness benefits and retirement, impact on families and caregivers, and loss of years of productive life.

Since 1970 CVD mortality, mainly IHD and stroke, has been decreasing in the majority of Western European countries, but increasing in Eastern Europe; during recent years mortality has also been decreasing in Eastern European countries, except in Balkan countries for stroke. Declines could be due to changes in environmental risk factors, such as diet and smoking habit, and improvements in modern cardiovascular treatments, responsible of both decreasing morbidity and increasing survival.

Great differences exist in hospitalizations for all CVD,

IHD and stroke in European Union (EU) countries: contrary to common belief, more than half of hospitalizations are not for myocardial infarction or stroke. Actually, in recent years there has been a notable increase in the number of hospitalizations for heart failure and arrhythmias, which are common complications of myocardial infarction and require frequent hospitalizations; data on hospital discharges for these conditions could be useful to improve understanding of the patterns of morbidity and future trends in medical care, but are generally not available.

Falling mortality rates have resulted in longer life spans; however, it is recognized that trends do not change equally across countries. Innovations in medical, invasive and biological treatments contribute substantially to the escalating costs of health services and it is therefore urgent to have reliable information on the magnitude and distribution of the problem both for adequate health planning and clinical decision making with correct cost-benefit assessments.
Prospective epidemiological studies emphasized that known risk factors account for more than ¾ of cases of CVD; individuals with favourable risk profile during life live longer and are eligible for low medical care expenditures in the last years of life. Across Europe with its ageing population there is a pressing need to cope with costs increase and make prevention and treatment a priority to reduce the growing health burden and lessen the socio-economic impact of CVD.

In 2007, the European Heart Network, in cooperation with the European Commission and the WHO launched the first European Heart Health Charter designed to prevent CVD in Europe and invited international and national organizations to sign the Charter, to commit to combating early death and suffering from CVD through prevention and to act on the 2000 Valentine's Declaration: «Every child born in the new millennium has the right to live until the age of at least 65 without suffering from avoidable cardiovascular disease".

4.   Autism Spectrum Disorders

Ramirez A, Dr

Project leader of the "European Autism Information System" (EAIS) project

Posada de la Paz M, Dr

Fundación para la Cooperación y Salud Internacional Carlos III, Spain

Knapp M, Professor; Romeo R

Institute of Psychiatry, King's College London

Morgan, H

Autism Cymru, Wales

Infantile Autism as a clinical condition is characterised by a profound lack of affective contact and repetitive, ritualistic behaviour of an elaborate kind. Over the past decades, it has been recognized that there is a wider and complex group of diseases/conditions, which are known as Autism Spectrum Disorders (ASDs). ASDs include the above described classical Infantile Autism, and other clinical conditions like Asperger's syndrome, Fragile X Syndrome, Landau-Kleffner Syndrome, Rett syndrome, childhood disintegrative disorder, and PDD-NOS (pervasive developmental disorder not otherwise specified). ASD is a lifelong neuro-developmental disorder due to neurobiological conditions.

Controversy about the plausible interaction between genetic and environmental risk factors for ASD is still unresolved. In ASD several conditions have been found to be potential risk factors, though methods and populations differ across studies which hampers the comparability of outcomes. In the 2006 Public Health Programme, a the European Network for Surveillance of risk factors on Autism and Cerebral Palsy (ENSACP) project was selected for co-funding. This network will develop guidelines for identification of ASD and Cerebral Palsy pre- and perinatal risk factors.

The incidence of autism and other pervasive developmental disorders (PDD) was studied in the United Kingdom1 over the period 1998 to 2001. There were changes in the age-standardised incidence ratios from 35 in 1991 to 365 in 2001. The increase for PDD was around ten-fold; but the increase in autism was

also striking. The authors conclude that better ascertainment of diagnosis is likely to have contributed to this increase but that a real increase cannot be ruled out. Prevalence rates have been estimated in different European countries but due to the different methodologies and definitions used, it is not possible to make comparisons. A systematic review of prevalence studies has contributed to explaining some of the influences on variation among prevalence estimates. Over half of the variation among study estimates can be explained by the age of the children screened, the diagnostic criteria used, and the country studied. The impact of these known factors should be further investigated as they may be acting as proxies for other influences on prevalence.

No comparable data on morbidity in ASD in Europe are available. An epidemiological survey conducted by Fombonne[2] mentions epilepsy as the most frequent co-morbid condition followed by hearing or visual impairments, cerebral palsy, Downs Syndrome, tuberous sclerosis and Fragile X Syndrome, among others. These co-morbid conditions are the cause of higher mortality rates among people with ASD as compared to the general population.

Currently no reliable data on health service usage for ASD per Member State is available. It has been observed that there are very wide inequalities in terms of waiting lists for diagnosis, in countries where such services exist, often in the private sector and through Parents' Groups.

The central aim of the European Autism Information System (EAIS) project, which started its work in 2006, is to have an agreed information system to record ASD data. To reach this aim, a final protocol will be developed and piloted that will enable the obtainment of valid and comparable information on ASD prevalence in several European countries, as well as harmonized methods for planning an ASD prevalence study in Europe.

It is well accepted in the scientific community that early and intensive education can help children with ASD to develop and learn new skills. The second aim of the EAIS project therefore is related to strengthening the early diagnosis of ASD. For this purpose, all available tools for early diagnosis will be evaluated and evidence-based arguments will be proposed to operate from a single and unified diagnostic approach.

In a recent report by one of the project partners, the economic consequences of Autism in the UK were calculated[3]. The findings reveal that children with autism cost £2.7 billion (Euros 3.8 billion) annually, yet for adults the figure is £25 billion (Euros 36.2 billion) - over eight times as much. The EAIS project will study the financial burden of ASD on a European scale, as this Europe-wide information at present is lacking.

The European Autism Alliance (EAA) is an association to be created as part of the EAIS project, as a strategy to continue the work of the project in a sustainable manner and to ultimately provide a centre of scientific excellence. The role of the EAA will include: training, distribution of software and information systems, and providing a forum for all stakeholders. The EAA will be run as a non-profit organisation, financed by membership fees, income-generating services (such as training activities) and grants.

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2 Fombonne, E., (2005). Epidemiology of autistic disorders and other pervasive developmental disorders. Journal of Clinical Psychiatry 2005, 66 (suppl. 10)
3 Knapp M, Romeo R, Beecham J, (2007). The economic consequences of autism in the UK. Foundation for People with Learning Disabilities, London.
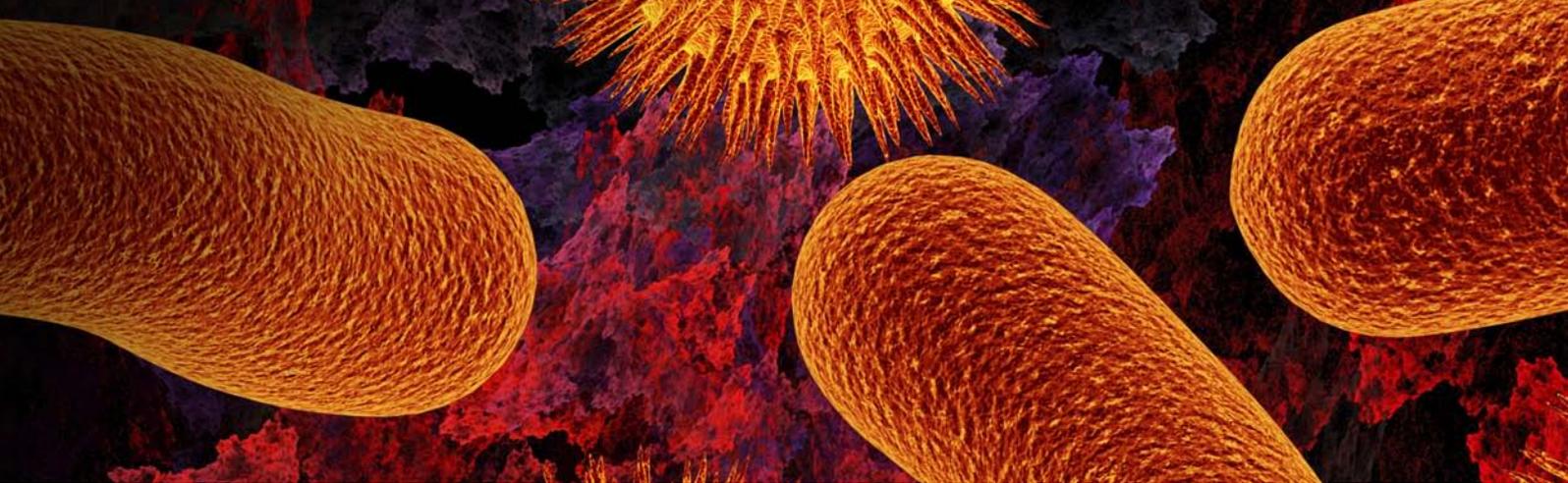
5. Cancer

Baili P, Casella I, Amati C, Micheli A

Descriptive Epidemiology and Health Planning Unit, Fondazione IRCCS "Istituto Nazionale dei Tumori",

Via Venezian, 1, 20133 Milan, Italy. Tel: 00390223902869. Fax: 0039 0223903528. eurochip@istitutotumori.mi.it

the EUROCHIP Working Group[1]

Cancer affects around 3,2 million Europeans each year, the most common forms of the disease being lung, colorectal and female breast cancer1. Due to the ageing of the population in Europe, cancer incidence cases are expected to increase1 thus constituting a major public health issue for Europe. Cancer prevalence, the measure of live persons with a past cancer diagnosis, grows with incidence and with the percentage of survival. In Europe we can estimate a total of prevalent cancer cases in 2002 of nearly 14 million.

The European Commission subsidized various projects in order to define a list of health indicators to be collected in all Member States (MSs). More information is available on cancer than for other diseases, thanks to a long established tradition of cancer registration in the majority of MSs. A list of cancer health indicators was developed by the EUROCHIP-1 project2.

These indicators show that the picture of cancer in Europe offered large regional inequalities in incidence, survival and mortality, reflecting the difficulties of European MSs to modify health systems to reduce the risk of cancer, improve control, and bring research results to a benefit for all citizens and patients. EUROCHIP-2 activated specific studies in the majority of EU MSs with focus on European cancer health inequalities3. EUROCHIP-2 promoted in the network a discussion on cancer control priorities and provided feedbacks and reports covering the following key points for European Cancer Control Policies:

• cancer control needs an integrated cancer information system in all MSs and cancer registries are the heart of this system

• primary prevention is no longer a high priority only for wealthy countries, but it has become one for all European countries. Eastern European countries have to promote actions against tobacco following the experience of other European countries and put attention to increasing trends in male cancer mortality. Attention to healthy diet

and physical activity should be promoted in all EU countries

• organised screening programmes (for cervical, colorectal, and female breast cancers) have to be subsidized and implemented in all MSs, first of all in Eastern Europe

• cancer prevalence is dramatically increasing. Hence:

o the needs of cancer patients and prevalent cancer patients (especially elderly patients) are increasing. For this reason it is necessary to have full knowledge of the variation of health services demand as a function of cancer type, patient age and rehabilitation requirements. Once the demand for services is accurately assessed, services can be provided rationally according to available resources[4]

o the demand for resources to follow-up cancer patients and identify and treat cancer recurrences is increasing. While this is happening, new knowledge is being acquired by genetic research and the reality of cancer is changing. A list of few major killer diseases changed into a long list of different rare diseases, each requiring a specific treatment. These are the problems that an integrated and effective cancer control policy for Europe has to face[4].

1. Ferlay J et al. Estimates of the cancer incidence and mortality in Europe in 2006. Ann Onc 18: 581–92. 2007
2. Micheli A et al. Cancer control in Europe: a proposed set of European cancer health indicators. Eur J Public Health 13(3 Suppl):116-8. 2003
3. http://www.tumori.net/eurochip
4. Micheli A et al. Strategies for cancer control in Italy. Tumori. 2007 93(4):329-36. 2007

6. Dementia

Gove, D
Information Officer, Alzheimer Europe
Georges, J
Executive Director, Alzheimer Europe

The term "dementia" is used to describe various kinds of brain disorders which all involve the progressive damage and death of brain cells. It is not actually a disease but rather a syndrome (a pattern of symptoms) which may be caused by an almost infinite number of cerebral and extra-cerebral diseases.

A great deal of research is being carried out all over Europe into the mechanisms involved in the development of dementia, risk factors/protective factors and possible future treatments. At this moment in time, there is no curative treatment for dementia although there are a few drugs which treat the symptoms of the disease and temporarily slow down the rate of cognitive decline.

These are donepezil, rivastigmine, galantamine and memantine. All four drugs are authorised and reimbursed in 16 EU member states (of the EU-27) but information is lacking on the situation in Estonia and Latvia and none are reimbursed in Bulgaria and Malta. In four countries certain drugs are not authorised i.e. galantamine in Hungary and Romania, donepezil in the Netherlands and rivastigmine in Lithuania. Similarly, galantamine is not refunded in Lithuania and Poland and neither is memantine in Italy, Poland and the United Kingdom.

The estimated number of people with dementia in Europe (EU-27), based on calculations made using prevalence rates provided by the EURODEM group (Hofman et al., 1991) and Ferri et al. (2005), is 5,526,488 and 6,120,842 respectively. This represents 1.13% and 1.25% respectively of the total population (EUR-27). The actual incidence of dementia per 1,000 was estimated by Ferri et al. (2005) as being 8.8 for Western Europe, 7.7

for countries in Eastern Europe with a low adult mortality rate and 8.1 for countries in Eastern Europe with high adult mortality rate.

Concerning possible risk and protective factors, it is most probable that the cause of dementia is multi-factorial in the vast majority of cases. It is difficult to monitor how many people with dementia are admitted to hospital and how many people die with dementia as many people are not diagnosed and for those who are, their dementia is not necessarily recorded in hospital admission records and on death certificates.

"Recommendations for the diagnosis and management of Alzheimer's disease and other disorders associated with dementia: EFNS guideline" (Waldemar et al., 2007) were recently published by the European Federation of Neurological Societies. Some other guidelines have been identified in individual countries in the framework of Alzheimer Europe's ongoing EuroCoDe project e.g. in Estonia, Finland, France, Germany, Greece, Hungary, Italy, the Netherlands, Poland, Romania, Slovenia and the United Kingdom but as the EFNS guidelines are relatively new, it is not yet known which countries will eventually adopt them.

As the disease progresses, people with dementia are gradually disabled by cognitive and physical impairments but such disability is not always officially recognised. Access to services and support may be dependent on an assessment of needs, old age, living alone and/or having limited financial resources. In some countries, when disability-orientated criteria are adopted, they are not adapted to people with dementia who consequently find that they are excluded from timely access to appropriate support.

Alzheimer Europe and its member associations are keen to emphasise the importance of an early diagnosis, equal access to anti-dementia drugs for Alzheimer's disease throughout Europe and recognition of dementia as a disability requiring appropriate services and support.

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Hofman, A. et al. (1991), The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings, International Journal of Epidemiology, Volume 20, No.3, pages 736-748.

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7. Depression

Alonso J, Bruffaerts R, Gabilondo A, Haro JM, Kovess V, and Vilagut G
For the ESEMeD/MHEDEA 2000 Investigators[1]

Mood disorders are one of the most common diseases in the world but it's only recently that they have been considered of major public health concern. The most frequent mood disorder is major depressive disorder (MDE), characterized by a lasting distinct change of mood, a loss of the ability to experience pleasure and accompanied by several psychophysiological changes, interfering considerably with the ability to develop daily life activities. This disorder can often become chronic or recurrent leading to substantial impairment in functioning. It has been suggested that MDE accounts for nearly 45% of suicides (Arsenault-Lapierre G, 2004). Although these disorders can be properly diagnosed in primary care, they often remain undetected or not properly treated (Pignone MP, 2002).

The European study of the Epidemiology of Mental Disorders (ESEMeD) was one of the largest general population surveys to collect relevant information on the epidemiology of mental disorders in 6 European countries (Belgium, France, Germany, Italy, the Netherlands, and Spain) in a joint collaboration with the World Health Organization.

Between 9.9 and 21.0% of the general adult population depending on the country reported a lifetime history of any mood disorder. Women were almost twice as likely to have had any mood disorder in a given year. The highest likelihood of depression was found for the youngest age group (18–24 years old), with a significant decline with age. Comorbidity was highly prevalent, and almost 45% of the individuals with mood disorders also met the criteria for another mental disorder, especially anxiety disorders. The median age of onset of MDE was found to be late 30s in most countries.

People suffering from mood disorders showed a substantial decrease in the quality of life and were consistently associated with substantial functional impairment. The impact of depression on disability and quality of life seemed at least similar or even stronger than the impact of common chronic physical disorders. Health-related stigma also showed to be common among individuals with mental disorders and significant disability experiences.

MDE and dysthymia were the first cause of mental health consultation in the ESEMeD countries especially those presenting comorbidity with anxiety disorder. Women, divorcees, people with higher educational level, and those living in urban areas were more likely to go for a consultation. 28.8% to 52.1% of lifetime cases of

mood disorders (depending on the country) had made their treatment contact within the year of disorder onset. On average only 36.5% of those with 12-month mood disorders had made contact with the health services in the year before. In addition, only 57.4% of those with MDE receiving treatment in specialized care, and 23.3% of those receiving treatment in general medical care complied with the criteria of minimally adequate treatment. About 3% of the overall sample had an unmet need for mental healthcare. This was highest in the youngest cohort (18–24 years).

In ESEMeD, lifetime prevalence of serious ideation of suicide was 7.8% while that of making a serious attempt of suicide was 1.8%. Suicidal ideation and gestures were found to be more prevalent among women, younger individuals, and people living in large urban areas. Major depressive episode appeared to be the most important risk factor for lifetime suicide attempts. The lifetime prevalence of suicide attempts could be cut by almost one-third by preventing major depression. Some country differences are existent, with Germany and France having the highest, and in Italy and Spain the lowest risk of suicidal ideation.

Mood disorders are frequent, mainly major depression, affecting more than 28 million people in the ESEMED countries at some time in their lives and more than 9 million every year. Despite the impact of mood disorders, consultation rates and treatment adequacy in general medical care remains very low. A better identification of mood disorders and its risk factors through further efforts in continuing medical education at general practice level could help health professionals to recognize and treat these disorders in an early stage. Additional measures such as increase in service provision, access and educating individuals in need for mental healthcare could alter the proportion of individuals who will ever develop a mood disorder. There is also a need for more qualitative research to improve the knowledge about stigma and other possible reasons for the underuse of mental healthcare services.

1: Jordi Alonso, Matthias Angermeyer, Sebastian Bernert, Ronny Bruffaerts, Traolach S. Brugha, Giovanni de Girolamo, Ron de Graaf, Koen Demyttenaere, Isabelle Gasquet; Josep Maria Haro, Steven J. Katz; Ronald C. Kessler, Viviane Kovess, Jean Pierre Lépine, Johan Ormel, Gabriella Polidori, and Gemma Vilagut.

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Kovess-Masféty V, Alonso J, Brugha TS, Angermeyer MC, Haro JM, Sevilla-Dedieu C, the ESEMeD/MHEDEA 2000 Investigators (2007). Differences in lifetime use of services for mental health problems in six European countries. Psychiatric Serv; 58: 213-220.

8. Diabetes

Carinci F, Stracci F

On behalf of the BIRO Collaborators[1]

Storms F

On behalf of the EUCID project

Diabetes Mellitus (Diabetes) is characterised by an elevated blood glucose level and is a growing burden for all the countries in the world. There are two types of diabetes: type 1, characterised by the absence of insulin production and type 2 diabetes characterised by an insensitivity to insulin and a relatively decreased production of insulin. Type 1 has to be treated by insulin from the start and type 2 can be treated by life style intervention, tablets en insulin consecutively. Not only the diagnosis of diabetes and the treatment of the elevated blood glucose are important in the burden of diabetes in the society, but especially also the complications of diabetes, like kidney function decrease and myocardial ischemia. A growing number of all populations in the world is at risk for developing diabetes. Official figures on Diabetes burden are lacking in most Member States of the EU.

DG-SANCO Diabetes projects

BIRO

"Best Information through Regional Outcomes" (BIRO) is a three-year project run by seven partners since late 2005 to build "a common European infrastructure for standardized information exchange in diabetes care, for the purpose of monitoring, updating and disseminating evidence on the application and clinical effectiveness of best practice guidelines on a regular basis" (http://www.biro-project.eu).

EUDIP/EUCID

"European Core Indicators in Diabetes" (EUCID) is a two-year project whose goal is "to make available the national facts of Diabetes Mellitus and it's risk factors from countries in the European Union". The project involves 19 countries and delivered diabetes indicators for 2005 in February 2008 (www.eucid.eu)

Health Determinants/risk factors

Overweight and obesity are considerable problems in Europe and need growing attention from public health care. Very little data on impaired fasting glucose as a risk factor for the development of diabetes are available and this should be one of the items to be discussed for the future.

Incidence/Prevalence

Not all EUCID countries have data available on the incidence of childhood diabetes. Within the EU there are considerable differences, from 6 to 60 / 100.000

children. The incidence of type 2 diabetes in these children is growing, but proves not to be a considerable percentage in 2005 for the countries where data were available. Prevalence for the age above 25 years ranged from 3.3 to 7.3%, with an increasing prevalence by age.

Clinical management

Clinical management in diabetes uses a well defined set of data to intervene above certain cut off points. These vary from blood glucose management with HbA1c as indicator, blood pressure, blood lipids, kidney functions and microalbuminurea and many more. The EUCID data include process (% available data) and outcome data (% below the threshold) for many of these indicators.
Disability
Diabetes has many long term complications. These can be divided in microvascular (end stage renal failure, blindness and diabetic foot) and macrovascular (Stroke, Myocardial Infarction and also diabetic foot). EUCID has collected data for several of these end points.

Mortality

Mortality data for diabetes are not very reliable. Death through acute complications of diabetes like hyperosmolar and ketoacidotic coma are reliable and can be retrieved from national death registers. The incidence however is low.. Since most diabetic patients die from macrovascular complications, diabetes will normally not be the primary cause of death but a secondary cause. In only a few countries regional (Scotland) or national (Denmark) databases are in place of people with diabetes that can look for the combination of death and diabetes while being alive. Primary causes of death on death certificates will be very reliable, but secondary causes and concomitant diseases will be less reliable

Towards the construction of a European Diabetes Register
The EUCID project allows establishing a core set of diabetes indicators that could provide the means for monitoring EU achievements in the coming years. Meanwhile, increasing emphasis is put on the establishment of a European Diabetes Report that should be produced on a regular basis. BIRO provides the basis for the statistical estimations needed for such a Report and the fundamental software engines required for its routine publication.

By acknowledging the importance of an increased cooperation for the construction of a European Diabetes Registers, both BIRO and EUCID Consortia have decided to merge into a common initiative called "EUBIROD". The plan is to spread the use of a unique system of online indicators in as many regions as possible all over Europe, allowing a regular update of EUCID indicators and the periodic release of a EU Report based on the BIRO template.

Conclusion

Diabetes care indicators differ considerably amongst the European countries. Some differences can be explained by medical causes, but many have no obvious reason. The organisation of care can be one of the explanations. For this reason it is important that health systems are provided with targeted indicators results, on a routine basis, to help them optimise the organisation of health care for people with diabetes.
Paradoxically, key indicators that are crucially needed to plan diabetes care, like prevalence of impaired fasting glucose and death with diabetes as primary or secondary cause are still inconsistently available at the moment, but will be available in the future.
Identifying solutions to make all key indicators available at all levels can be highly effective to reduce the burden of diabetes both in economical and clinical terms, especially since a growing number of clinical data are available through the use of electronic medical records and the possibility to merge these data.
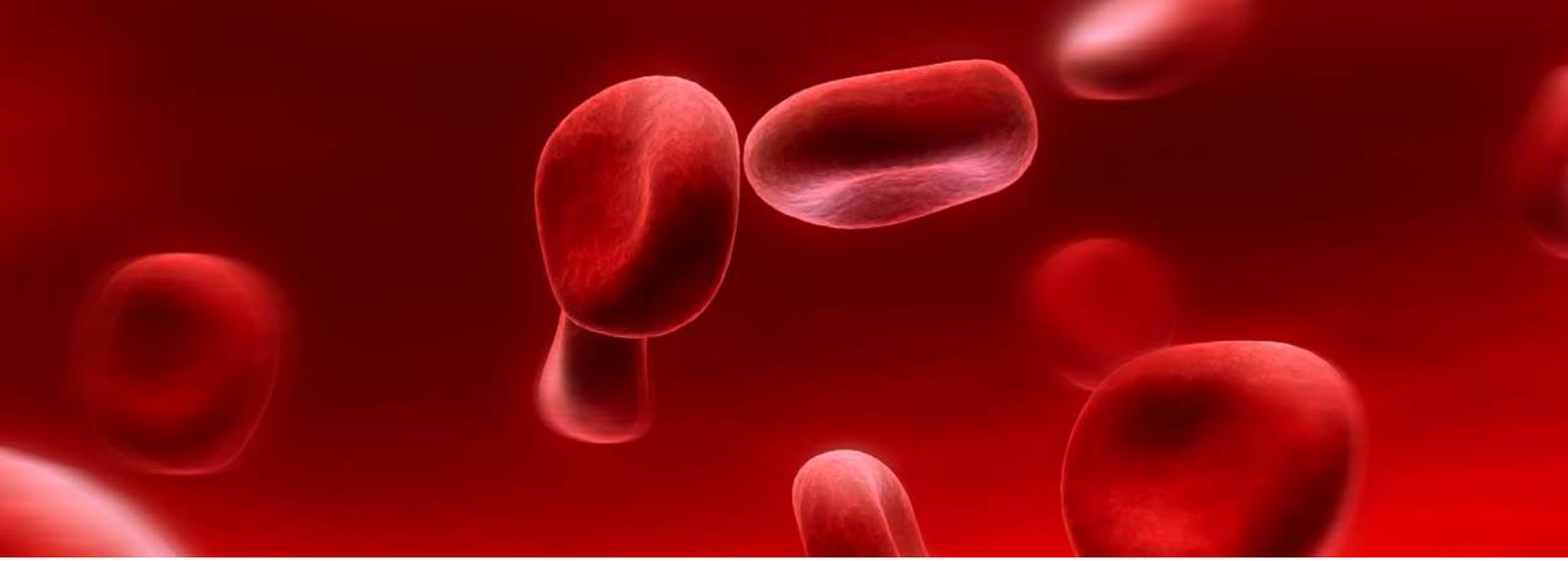
9. Haematological Malignancies

Sant M, Allemani C, Tereanu C, Giraldo P, Maynadiè M, De Angelis R
The HAEMACARE Project

Introduction

Haematological malignancies (HMs) constitute a large fraction of all blood diseases in adults. Leukaemias and non-Hodgkin lymphomas (NHL) are the commonest haematological malignancies accounting for 6% of all cancer deaths in the EU.

Several studies indicate that incidence and mortality for most HMs are increasing. Survival is also increasing, however, due to recent evolutions in the HMs classification and to the availability of new treatments, intercountry and overtime comparisons are difficult.

Incidence, mortality and survival across Europe

In 2002, there was a considerable variation in the incidence, mortality and survival of HMs across Europe. Generally men had higher HMs incidence and mortality than women for all HMs. From the beginning of 1990s to early 2000s survival increased for all HMs, especially for Hodgkin lymphoma (HL) (from 73% to 83%) and NHL

(from 48% to 54%).

NHL were the most frequent HMs in the Western European countries (age-standardized incidence rate in men 11/100,000; mortality 5/100,0000). For patients diagnosed in 1995-99, the mean European Age-adjusted 5-year relative survival was 55%.

The regional variation in incidence of all Leukaemias considered together ranged from 10/100,000 in Western Europe to 8/100,000 in Eastern Europe, with no important difference by geographic area in mortality. Overall people affected by Leukaemias had rather poor survival (42,5%). The highest survival was for Chronic Lymphatic Leukaemia (68%), the poorest for Acute Lymphatic Leukaemia (31%)

The incidence of Hodgkin lymphoma was similar across the European regions, the age-standardized rate being approximately 2/100,000. The mortality age-standardized rate varied from 0.4/100,000 in Western Europe to 1.2/100,000 in Eastern Europe. The mean European age-standardized 5-year relative survival was the highest of all HMs, ranging from 80% in EUROCARE west (France, Germany, Italy, the Netherlands, Spain, Switzerland and the National Registries of Iceland and Malta); to 75%

in EUROCARE east (the Polish Registry of Warsaw and the National Registries of the Czech Republic, Estonia, Slovakia, and Slovenia)[1].

The age-standardized incidence (4/100,000) and mortality (2,5/100,000) of Multiple Myeloma (MM) in men was double in the Northern and Western European countries compared to the Eastern European countries. MM Multiple Myeloma had extremely poor survival (35%).

Incidence and mortality trends for all HMs except HL are increasing in all European countries. It is more accentuated in the West and the North of Europe compared to the East. Thus, in the future an increase of the number of patients diagnosed with HMs is expected.

 Major developments in the treatment of HMs

Effective treatments for Hodgkin lymphoma are available since the end of 1970s, based on conventional chemo- and radio-therapy. In recent years, the discovery of innovative molecular targeted treaments - such as Imatinib for subtypes of myeloid chronic leukaemia – likely will modify the natural history of these diseases, and improve prognosis in the near future. However, the high cost of these new treatments may generate inequalities in availability and access to treatments, which should be carefully monitored.

The HAEMACARE project

Comparison of incidence, prevalence and survival for HMs across countries and over time is difficult, due to changes in the classification of HMs, which now makes use of morphologic, immunologic and genetic criteria. Furthermore, most studies on HMs are carried out on selected series of patients, so that results may not be generalisable to the entire population.

Funded by the EU in 2005, HAEMACARE aims to increase the availability, standardization and comparability of Cancer Registries' data on HMs, through the revision of coding procedures used by Cancer Registries. HAEMACARE has developed a categorisation of ICD-O morphology codes, into groups with prognostic significance that have been validated on the EUROCARE (European Cancer Registry-based Study of Survival and Care of Cancer Patients; www.eurocare.it) and SEER (Surveillance, Epidemiology and End Results; http://seer.cancer.gov) data. A manual for coding HMs is in preparation

and will be diffused to all the European registries. Further objectives of HAEMACARE are to improve public health use of clinical data, through integration of data from population Cancer Registries and clinical networks on HMs.

1 Allemani C, Sant M, De Angelis R, Marcos-Gragera R, Coebergh JWW and the EUROCARE Working Group «Hodgkin disease survival in Europe and the U.S.: Prognostic Significance of Morphologic Groups». Cancer 2006; Jul 15;107(2):352-60.

10. Maternal and Child Health

Zeitlin J, Zimbeck M, Cans C, Gissler M and the EURO-PERISTAT Steering Committee[1]
EUROPERISTAT project

A Maternal and perinatal health

A European priority

• Of the over five million babies born in Europe every year, an estimated 23,000 are stillborn, 22,000 die in their first year and over 40,000 experience severe impairments, many of perinatal origin. Maternal deaths are rare (5 to 15 cases per 100,000 live births), but up to half of them may result from substandard care. Poor perinatal health outcomes are more common among women and babies of lower social status.

• The consequences of poor health extend beyond the perinatal period: impairments in children are a long term burden for individuals, their families and society. Perinatal complications increase the risk of major adult illnesses, such as hypertension and diabetes.

• Technological advances introduce new risks and ethical dilemmas. For instance, progress in neonatal intensive care increases survival at the limit of viability, but exposes these babies to risks of surviving with disabling impairments.

• A key challenge is to benefit from new medical technology where appropriate without over-medicalising pregnancy and childbirth.

The EURO-PERISTAT project

To improve the surveillance of perinatal health on the European level, the EURO-PERISTAT project developed an indicator set based on existing indicators and a consultation process with clinicians, epidemiologists and statisticians from European member states and Norway. EURO-PERISTAT indicators cover four themes: fetal, neonatal and child health, maternal health, population characteristics and risk factors, and health services. Unfortunately, many of the EURO-PERISTAT indicators cannot be derived from the existing international databases (e.g. EUROSTAT, WHO and OECD) and thus the development of the EURO-PERISTAT health information network will be essential for better surveillance in this area. The indicators which can be computed from readily available data are described below.

Maternal age

Both younger and older mothers are at higher risk of poor perinatal health outcomes and it is thus pertinent to compare the extremes of the age distribution. For young mothers the increased risks of perinatal mortality are associated with social and health care factors, including lack of antenatal care, unwanted or hidden pregnancies, poor nutrition and lower social status. In a large number of EU countries, births to young mothers constitute only between 2% and 4% of all births. In others, principally countries that have recently joined the EU, they represent

a greater proportion of all births (between 6% and 13%). Differences between the new and old member states are also apparent with respect to childbearing at older ages. Risks of adverse outcomes are higher among older women, starting from around 35 years of age onwards. There is a trend towards later childbearing in the 15 old member states, while this trend is much less evident in the new member states.

Neonatal health outcomes

Neonatal mortality varies from about 2 per 1,000 births in Sweden, Luxembourg, Czech Republic, Norway and Finland to over 5 per 1,000 in Bulgaria, Latvia and Romania. Similar disparities are observed for mortality in the first year of life (from 2 to 15 per 1,000), as well as for fetal mortality (from 2 to 8 per 1,000). Among countries who joined prior to 2004 (the original 15 members) and Norway, the median rate of neonatal mortality in 2004 was 2.7 per 1,000 births. This median rate was higher (4.4/1,000) among countries that joined the EU in 2004 (Czech Republic, Cyprus, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovenia, and Slovak Republic), and was more than three times greater (8.5/1,000) among countries that acceded in 2007 (Bulgaria and Romania). Babies with a birthweight less than 2500 grams constitute between 4 and 9% of all live births. These babies include those that are preterm, with normal or low birthweights and babies born at term with growth restriction; all these groups are at higher risk of having longer-term impairments in childhood than term babies with normal birthweight.

Cerebral palsy

Cerebral Palsy (CP) is the indicator chosen by PERISTAT for monitoring longer term childhood health impairments due to its frequent association with adverse perinatal events. It is the commonest disabling condition in childhood; it occurs in 1.5 to 2.5 per 1000 live births, and the disabling condition is permanent during the life of the affected children.

EURO-PERISTAT works with the SCPE (Surveillance of Cerebral Palsy in Europe) Network which includes 24 CP registers in 13 countries. Prevalence rate of CP among children born with normal birthweight is around 1 per 1000, among children born with a birthweight 1500 to 2499g the rate is around 1 per 100, and among children born with a very low birth weight (<1500g) the rate is around 6 per 100. Multiple born infants have a four times higher risk of developing CP than singletons, this higher risk being mainly related to the higher risk of preterm birth in multiples.

Maternal mortality

The maternal mortality ratio (MMR) in the European Union has declined from 20 maternal deaths per 100,000 live births in the early 1980s to 7 deaths per 100,000. Currently there is substantial variation between countries in Europe. In small countries, MMR are generated using a small number of events and thus trends must be observed over longer periods.

Priorities for the future

These data reveal large differences in risk factors and out-comes within Europe. EURO-PERISTAT is working to compile more extensive information on perinatal health in order to improve our understanding of these variations. Many key indicators exist nationally, but have not been standardised for international comparisons (multiple birth rates, preterm birth rates, mortality rates for specific gestational age and birth-weight groups) and thus immediate improvement is possible. For other key dimensions of perinatal health such as maternal and neonatal morbidity and pregnancy outcomes for women with lower risk pregnancies, more work on appropriate indica-tors and methods is necessary.

1: The EURO-PERISTAT Steering Committee are: S. Alexander, Université libre de Bruxelles, Belgium W.Zhang, Université Libre de Bruxelles, Belgium H. Barros, Porto Medical School, Portugal M.H. Bouvier-Colle, INSERM, France I. Berbik, Hungarian Society of Obstetrics and Gynecology, Hungary B. Blondel, INSERM, France G. Bréart, Assistance Publique-Hôpitaux de Paris, France S. Buitendijk, TNO Institute Prevention and Health, the Netherlands C. Cans, SCPE Registers, France M. Gissler, STAKES, Finland P. Hlava, Institute Health Information & Statistics, Slovak Republic A. Macfarlane, City University, UK Z. Novak-Antolic, University Medical Centre, Slovenia J. Zeitlin, INSERM, France M. Zimbeck, INSERM, France

10. Maternal and Child Health

Adolf Valls-i-Soler, José I Pijoán, Marina Cuttini, Javier de la Cruz, Carmen R Pallás, Michael Weindling, Henry L Halliday, Carlo Corchia, Mikko Hallman, Virgilio Carnielli, Olivier Claris, Helmut Hummler, Diego Rada and Agueda Azpeitia,
on behalf of the EuroNeoStat Consortium[1]

B Very Low Gestational Age

A neonatal network for data collection on short- and long-term health consequences of VLBW/VLGA infants born in Europe (EuroNeoStat) was financed in 2006 by SANCO as an information system designed to meet the peculiarities of perinatal care in the different MS. A set of standardised perinatal indicators with uniform definitions of perinatal risk and protective factors, neonatal interventions and significant short-term outcomes was developed. A set of indicators to assess health and neurodevelopment status at 24-months was also created by consensus. (Full definitions available at: www.euroneostat.org).

The EuroNeoStat 2006 cohort of VLGA/VLBW infants included babies from 14 neonatal intensive care units from 10 MS (Austria, Czech Republic, Finland, France, Germany, Greece, Italy, Poland, Spain and UK) plus Russia. At this time, sample size (N=1520) is still too small to be considered representative of MS or to establish comparisons between regions or countries. Mean birth weight (BW) and gestational age (GA) were 1152 g and 28.7 wks.

The consequences of "being born too soon, too small" with very low gestational age (VLGA, <32 wks) and very low birth weight (VLBW, <1501 g) are great. Even though those infants constitute only less than 2% of all live births, they have a major impact on perinatal, neonatal and infant mortality. Moreover, extreme prematurity has long-term consequences in terms of compromise of patients' well-being as children and adults, causing stress for families and economic burden for health systems. Prevention of premature delivery has been elusive, so ready access to intensive care for these high risk infants is mandatory to improve their short- and long-term outcomes.

Mortality. The 28-day neonatal mortality rate (NMR) of VLBW/VLGA infants admitted was 10.7% (95%CI 9.1-12.3%) and post-neonatal, pre-discharge mortality 1.8%. Babies dying in the delivery suite represented 3% of all VLBW/VLGA babies born and 20% of all neonatal deaths. Neonatal mortality is highest for those infants who have

the lowest birth weight and gestational age. NMR was higher for male than female infants (13.9% vs. 10.6%).

Morbidity. The most important protective factor was prenatal corticosteroid use, being given to 81.4% of all babies. Caesarean section was done in 70.8% of the infant cohort. 24.8% and 17.4% of babies had an APGAR score at one and five minutes below 5 and 7, respectively. For resuscitation in delivery room the following was used: oxygen (85%), manual ventilation (61.4%), intubation (42.2%), cardiac compression (2.8%) and epinephrine (2.1%). After admission to neonatal intensive care units, the following interventions were used: oxygen (81.4%), continuous positive pressure (62.9%), mechanical ventilation (47.5%), surfactant (51.6%) and some type of major surgery (15.3%).

Rates of complications were: intraventricular haemorrhage grade 3-4 (9.9%), cystic periventricular leukomalacia (3.4%), pneumothorax (3.8%), chronic lung disease (20.8%), necrotising enterocolitis (4.9%), stage 3-5 retinopathy of prematurity (5.9%). While prenatal infection was present in 5.5%, nosocomial infection (or: hospital-acquired infection) was higher at a 25%. At least one major congenital anomaly occurred in 9.5% of all VLBW/VLGA babies.

The EuroNeoSafe initiative was developed to disseminate a culture on patient safety first among European neonatal intensive care units. A free software for voluntary reporting of adverse events has been developed and is available at the website. Outcomes that could be explored for patient safety are based on the wide variability of rates of nosocomial infection among neonatal intensive care units (0 to 41.8%) and pneumothorax (0 to 16.3%).

Since the number of neonatal intensive care units and MS, and thus cases analysed in the 2006 EuroNeoStat cohort is still small, results should be interpreted with caution. Nevertheless, the network is growing fast and so is the number of cases being collected. The aim would be that all European NICUs collaborate in the project.

VLBW/VLGA-specific neonatal mortality rates are associated with overall neonatal mortality, being and excellent indicator of the quality of perinatal care. Their weight-specific mortality rates account for about three quarters of the mortality variance observed among countries and regions. For the above reasons, the authors suggest that WHO should consider including gestational age specific mortality and morbidity among the indicators used to monitor infant health and recommend member states to collect and report such data.

1: Scientific Steering Management Committee of the EuroNeoStat Consortium: Carnielli V, Dept. Paediatrics, Azienda Ospedaliero–Univer, Ancona and Corchia C, and Cuttini M, Ospedale Pediatrico Bambino Gesù, Rome, Italy; Claris O, Edouard Herriot, Lyon, France, President ESN; Halliday H, Royal Maternity Hosp., Belfast, Weindling M, Liverpool Women's Hospital, Liverpool, UK; Hallman M, Oulu Univer. Hosp., Oulu, Finland; Hummler H, Children's Hosp., University of Ulm, Ulm, Germany; Sedin G, Univer. Hosp., Uppsala, Sweden; Stiris T, Ullevaal Hosp,, Oslo, Norway, President ESPR; Pallás CR, de la Cruz Bértolo J, Hosp. Univer. 12 Octubre, CIBERESP, Madrid and Valls-i-Soler, JI Pijoan, Hosp. Cruces, Univer. Basque Country, Bilbao, Spain Other Contributing Members: Bucher H, Neonatology Clinic, Zurich, Switzerland; Gadzinowski J, Ginekologiczno Polozniczyy Kliniczny, Poznan, Poland; Plavka R, General Faculty Hosp., Prague, Czech Republic; Urlesberger B, Klinische Abteilung für Neonatologie, Graz, Austria; Viacheslau L, Children's Hosp. No 1, S. Petersburg, Russia; Virella D, National Branch Portuguese Pediatric Society, Coimbra, Portugal; Xanthou M, Niktari G, Aghia Sophia Children's Hosp., Athens, Greece

11. Multiple Sclerosis

Pugliatti M, Dr
University of Sassari (IT) & University of Bergen (NO) - neurologist and epidemiologist – member of the
MS-ID Scientific Advisory Committee, Chairperson of European Federation of Neurological Societies
(EFNS) Panel on Neuroepidemiology & Public Health
O'Leary, M
European Multiple Sclerosis Platform - MS-ID Project Coordinator

Multiple Sclerosis (MS) is a chronic progressive potentially highly disabling disease. Despite being a relatively rare disease, the socio-economic impact is considerable. It is the major cause of non-traumatic disability in young adults. MS is an immuno-mediated disorder of the central nervous system, characterised by inflammation, demyelination and neurodegeneration. Demyelination is the loss of myelin – the protective insulating sheath surrounding nerves. The loss of myelin disrupts the ability of the nerves to conduct electrical impulses to and from the brain and this produces the various symptoms of MS. The sites where myelin is lost (plaques or lesions) appear as hardened (scar) areas. In MS these scars appear at different times and in different areas of the brain and spinal cord. The term Multiple Sclerosis means, literally, 'many scars'. What causes MS is still unknown.

MS manifests with signs of multiple neurological dysfunctions (e.g. visual and sensory disturbances, limb weakness, gait problems and bladder and bowel symptoms) followed by recovery or alternatively by an increasing disability over time. Less specific symptoms, such as fatigue, can interfere with patients' quality of life and productivity, regardless of the degree of disability.

'Disease-modifying' treatments exist for the management of MS. Symptomatic treatments are also frequently used, especially for controlling bladder problems, pain syndromes, increased muscle tone (spasticity) and fatigue. Rehabilitation in MS implies comprehensive, multidisciplinary, individualised, coordinated programmes.

In Europe, over 500,000 individuals are estimated to have MS. The disease occurs more frequently in northern countries. Women develop MS up to three times more frequently than men. The greatest proportion of individuals with MS is in the 35-49 years age group in Europe. The disease usually manifests itself clinically between the age of 20 and 40 years, occurring rarely in childhood or after the age of 50. Every year approximately 30,000 individuals in Europe manifest signs or symptoms related to MS.

At one point in time, and depending on the populations studied, between 33% and 80% of persons with MS have a mild disease (are able to walk, but present neurological impairment), 13% to 48% require assistance in walking (up to the use of bilateral crutches) for most of the time, and 5% to 39% use wheelchairs or are bed-ridden and require continuous assistance.

MS is associated with an elevated risk of death. The highest mortality rate from MS is reported for the age group 50-69 years and is twice more frequent for women. The life expectancy for MS patients ranges from between 30 and 45 years after disease onset.

Not all persons with MS have the same access to disease modifying and symptomatic treatments across the EU. The extent to which rehabilitation is offered also varies significantly from country to country.

As a result of these variations, a number of key EU policy developments have taken place in recent years that address the rights and quality of life of people with MS. These include a European Parliament Resolution in 2003 on the effects of discriminatory treatment afforded to people with MS in the EU, and the development of a European Code of Good Practice in 2005 that incorporates the most important European consensus documents in the field of MS. The Code is a political instrument that outlines briefly the issues of fundamental importance to people affected by MS. It provides a practical framework that describes in general terms the optimal approach in relation to treatments, therapies and services, research, employment, and empowerment of people affected by MS.

The added value of the Code of Good Practice in MS is twofold:

• It signposts core consensus documents and materials that are endorsed by both the medical and patient community.
• It commits national governments and the European Commission to an independent monitoring system that will feed into the open method of coordination on public health.

The endorsement of the Code of Good Practice in MS by national administrations is of key importance for the MS community. The intention behind annual reporting as outlined in the Open Method of Coordination (proposed in the Code of Good Practice in MS) is to formalise the reporting on progress of national administrations with respect to the impact their policymaking has on people with MS and wider the MS community. The benchmarking of appropriate standards is essential.

The European Multiple Sclerosis Platform (EMSP) is presently coordinating the Multiple Sclerosis Information Dividend (MS-ID) project enhancing the bank of information available on MS across Europe. The MS-ID project - which commenced in January 2007 and will run until September 2009 - involves 1) piloting a model European MS register, 2) promoting the Code of Good Practice in MS and 3) gathering comparative information on the treatment and management of MS, as well as 4) measuring the socio-economic impact of the disease and the quality of life of people with MS. The MS-ID project has six MS societies as official partners with additional support and implementation

through the remainder of EMSP's membership base of 27 national MS societies.

12. Musculoskeletal Conditions

Anthony D Woolf, BSc, MBBS, FRCP

Professor of Rheumatology, Institute of Health Research, Peninsula College of Medicine and Surgery, Universities of Exeter and Plymouth

Consultant Rheumatologist, Royal Cornwall Hospital, Truro, Cornwall, UK

Musculoskeletal problems and conditions are characterised by pain with an effect on function, and they include osteoarthritis; rheumatoid arthritis; osteoporosis and fragility fracture; back pain; and regional pain syndromes including those following injury or activity, such as associated with sports or occupation. Nearly a quarter of adults in Europe report having some form of arthritis or rheumatism. Musculoskeletal conditions (MSC) are often chronic and the main cause of disability in older age groups. They rank in the top 10 causes of disability adjusted life-years (DALY) in Europe and osteoarthritis is the 5th greatest cause of years lived with disability (YLD) in high-income countries.

The major determinants of musculoskeletal health are age, gender, obesity, physical inactivity, smoking, excess alcohol and injuries, either in the home, such as a fall, or related to work or leisure activities. Their incidence and prevalence increase with age, and approximately 10% of the population who are 60 years or older have symptomatic problems that can be attributed to osteoarthritis. MSC are more common in women and some are income related. MSC are the major cause of physical disability across Europe and a major cause of work loss, disability pensions and early retirement.

The burden of these conditions is increasing with aging of the population and with changes in lifestyle risk factors such as obesity and reduced physical activity. The options for prevention and effective management are increasing with better understanding of their causes and successful investment in developing new treatments, both pharmacological and surgical.

There is however a lack of data reflecting their burden in Member States. There are not routinely collected data that measures their occurrence and impact across Europe to enable this burden to be monitored. Hospital discharge data is not often relevant as people with MSC are predominantly managed in primary care or as ambulatory patients. Guidelines exist for the management of most MSC but there is little knowledge of their implementation in Member States. There is also little data on the availability and usage of services and treatments for MSC. Data on the impact on individuals and economic impact on society of MSC as is not readily available.

Recommendations have been made for the prevention and management of MSC (http://ec.europa.eu/health/ph_projects/2000/promotion/fp_promotion_2000_frep_15_en.pdf) and for monitoring these conditions in the European Community. In particular, the recommendations for monitoring MSC are related to incidence / prevalence of major musculoskeletal problems and conditions using agreed case definitions; determinants of MSC; hospital inpatient utilisation (amongst others related to hip and knee arthroplasty and hip fracture); clinical management; treatment; and disability and social consequence of MSC. In general it is recommended that as many of the indicators as possible should be simultaneously collected from each target population to be able to look for linkage. Data collected on treatment and outcome should be related where possible to the reason. This may be more feasible

and valid in registers than surveys. It would provide condition/problem-related data that would enable specific strategies to be developed.
(http://ec.europa.eu/health/ph_projects/2000/monitoring/fp_monitoring_2000_frep_01_en.pdf)
In addition, a depository of clinical guidelines for the various musculoskeletal conditions and information on implementation across the MS is recommended.

13. Oral Health

Bourgeois, D

EGOHID phases I and II project Leader

Dental caries is one of the most prevalent chronic diseases of people worldwide; individuals are susceptible to this disease throughout their lifetime (Selwitz et al, 2007). Decay experience at early and/or later stages of severity assessed by variations of the severity of caries index is accepted globally as a standardized measure of one of the most common oral diseases. It is mainly based on the DMFT (Decayed, Missing and Filled Teeth) index that measures the lifetime experience of dental caries in permanent dentition (Ottolenghi et al, 2007). The burden of oral diseases and the needs of populations over the past 20 years in Europe have changed considerably which has led to good progress with improving oral health in some parts and to extend and build on these to reduce the prevalence and severity of dental caries (Figure 1). In children aged 12 yrs old, there have seen substantial falls in the DMFT index across OECD countries, declining from an average 4.5 in 1980, to 2.6 in 1990, and 1.4 in 2003 for a consistent group of countries with long time series. During that period, 16 of the 19 OECD countries for which data are available saw declines in DMFT of 50% or more. Trends of tooth decay at 12 yrs old underlines convergence of caries

towards a DMFT=1 score, whatever the organization of the oral health system, its financing and prevention mode (Figure 1). This is a substantial public health achievement. Reductions in caries and other dental problems were mainly achieved through diffusion and consumption of fluoride toothpaste along with changing living conditions, disease management, improving oral hygiene and public health measures.

But, despite great achievements in oral health of populations globally, problems still remain in many communities particularly among under-privileged groups. Caries in Europe would concern 10 to 20 % of the children who do not have or hardly benefited from the improvement of dental health of populations observed for the past 30 years. In France (2006), 20% of children aged 12 yrs old represent 72% of tooth decay, 6% of children represent 50% of tooth decay and 56% are caries free. The children at high risk of caries are major elements for the development of health policies turned to the reduction of the disparities, the prevention and the promotion of health integrated into chronic diseases. The significant role of socio-behavioural and environmental factors in oral health is evidenced in an extensive
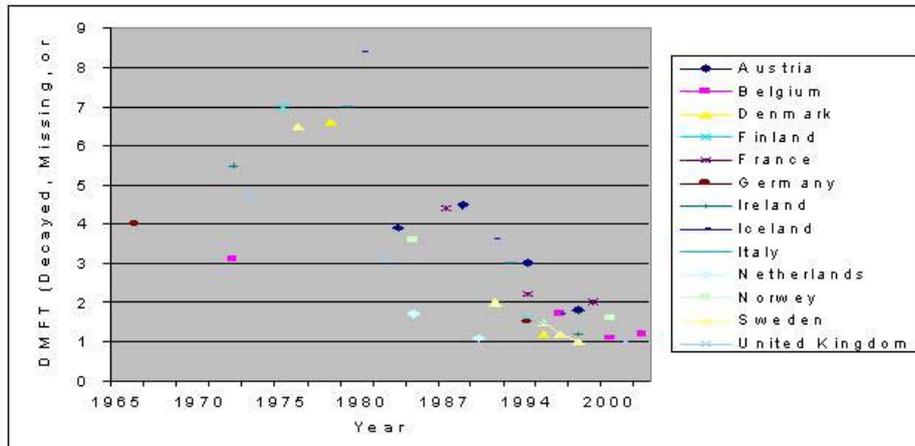
Figure 1 Tooth Decay Trends at 12 yrs old -Data from the World Health Organization

number of epidemiological surveys. The greatest burden of all oral diseases is on the disadvantaged and socially marginalized (WHO, 2003). Children are part of the most vulnerable groups affected and within this age group further difficulties arise for those affected by specific systemic conditions, those with developmental disturbances of tooth structure, the socio-economically deprived, the elderly and the handicapped. It is therefore necessary to focus preventive efforts on these special risk groups of populations from this preventable disease.

The population presenting oral disorders need care adopting a longitudinal perspective, with an emphasis on prevention and health promotion. In dental caries management, the focus has been around preventive caries management for children, but caries is a disease process that needs to be managed over a person's lifetime. The evidence is leading to an international trend in clinical practice, to move away from operative intervention towards prevention of caries. This approach relies on accurate diagnosis of disease and lesions, disease prevention, just-in-time restoration, minimally invasive operative procedures, and prevention of recurrence (Pitts, 2004). An indispensable condition for the political changes to reform the surveillance system to provide adequate information from a European public health surveillance point of view is to take measures so that oral health will be incorporated in policies relating to prevention and taking care of chronic diseases, as well as in policies relating to the health of mother and child (Petersen et al, 2005).

Figure 1 Tooth Decay Trends at 12 yrs old -Data from the World Health Organization – http://www.euro.who.int - Ottolenghi L, Muller-Bolla M, Strohmenger L, Bourgeois D. Oral Health Indicators for Children and Adolescents. European perspectives. Eur J Paediatr Dent. 2007 Dec; 8(4):205-10.

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14. Sexual and Reproductive Health

Oliveira da Silva, M

On behalf of the REPOSTAT 2 project

Sexual and Reproductive Health (SRH) outcomes are important measures of the general health and social well being of a population. The scope of SRH extends across the lifespan and across several Public Health domains. The REPROSTAT-1 project created a common core set of indicators to effectively monitor and evaluate SRH and associated health care in the EU, covering the areas Sexually Transmitted Infections/Sexual behaviour; youth; contraception, fertility and reproduction; abortion; and emerging areas (http://www.fm.ul.pt/reprostat). Building on the results of the first phase, the REPROSTAT-2 project has the following aims: 1) a systematic review of factors associated with teenage pregnancy in European Union, 2) to conduct an ad hoc youth sexual health pilot survey in four Member States, and 3) to build a critical study about the actual feasibility of comparing the existing European SRH indicators.

The results of the systematic review show that the well-recognized factors of socioeconomic disadvantage, disrupted family structure, and low educational level and aspiration appear consistently associated with teenage pregnancy. Evidence that access to services in itself is a protective factor remains inconsistent. Although further association with diverse risk-taking behaviours and lifestyle, sexual health knowledge, attitudes and behaviour are reported, the independent effects of these factors remain unclear.

REPROSTAT-2 conducted in 2006 a sexual youth pilot survey, aimed at young people aged between 16 and 19 years old from Belgium, Czech Republic, Estonia and Portugal. More than 47% of respondents had already had heterosexual intercourse. Mean age at first sexual intercourse ranged between 15.2 in Belgium and 16.4 in Czech Republic. The large majority of respondents used a method to avoid pregnancy at first sexual intercourse. Portugal was the country with the smallest percentage of respondents answering that they had heard about Chlamydia (12%). Apparent differences related to teenage pregnancy were observed: in 2005 rates varied between 6% in Portugal and 1% in Czech Republic. In Portugal there is considerable use of emergency contraception, with sales increasing from 80.000 in 2001 to 220.000 in 2006. This might be an indication that inadequate access to and/or knowledge on regular contraceptives is a cause for the high rate of teenage pregnancy.

The REPROSTAT-2 project also studied whether the SRH indicators are available and comparable in 8 Member States. The total fertility rate appeared to

range from 1.2 in Poland to 1.9 in France. This is below the replacement level of 2.1.

Maternal age at the first child birth ranged from 24.6 years in Romania to 29.2 years in Spain. The postponement of childbearing is continuing, even though it seems that the mean age at first childbearing seems to be diverging in the old EU Member States. Under a Public Health perspective, having the first term pregnancy after 30 years old is a recognized increased risk factor for breast cancer. Number of birth per 1000 women between 15-19 years ranged from 9.3 in France to 33.8 in Romania (2005). The reasons for such a huge discrepancy among different Member States have to carefully be analyzed and critically understood in the context of specific health and cultural contexts.

Socio-Economic Status (SES) and ethnical differences exist among REPROSTAT-2 SRH indicators. For instance, in Portugal, there is a consensual clinical impression that most teenage mothers come from the lower SES and/or from ethnical minorities (African, gypsies). Health professionals agree that young teenage pregnancies should be prevented for health, social and emotional reasons. However, in some Member States (e.g. Portugal and Belgium) the law specifically forbids that national health data can be disaggregated by their ethnical provenance. One understands that this was done in order to prevent racist politics, but from a Public Health perspective this creates serious difficulties for documenting the need for specific interventions targeted at those groups.

In order that sound evidence based policy decisions can be taken on SHR issues, more evidence based knowledge is needed, overcoming existing ignorance and misconceptions. In order to overcome the current information gap, it seems essential to conduct a common survey for all EU countries, including a core module containing questions about SRH. In particular there is a need for pan-European youth SRH surveys. This can be done by extending the current WHO HBSC-survey (Health Behaviour in School-aged Children) to the age group 15-19. Ideally, the population that already dropped-out of school at this age – one of the high-risk groups – should be included.

15. Life Expectancy with Chronic Morbidity

Jagger C

University of Leicester, United Kingdom

Robine JM

INSERM (French National Institute of Health and Medical Research)

Van Oyen H

Scientific Institute of Public Health, Belgium

Cambois E

INED (French National Institute of Demographic Studies)

This chapter brings together all chronic diseases through assessment of life expectancy with and without chronic morbidity in Europe. The generic term for such indicators is health expectancies which are summary measures of population health combining information on mortality and morbidity. Health expectancies have gained prominence within Europe over the last few years through the Healthy Life Years (HLY) indicator, based on a global activity limitation question, and developed in the framework of the European Union Lisbon Strategy.

After a review of the historical background to health expectancies we report comparisons across Europe of life expectancy with chronic morbidity (LEwCM) at age 65. LEwCM is based on the global chronic morbidity question of the Minimum European Health Module (MEHM) in the Statistics of Income and Living Conditions (SILC) survey 2005. Previously developed by the EuroHIS Chronic Physical Conditions Network, the form of the question 'Do you suffer from (have) any chronic (long-standing) illness or condition (health problem)?' with a simple yes/no response. Data was available for 25 countries (Austria, Belgium, Cyprus, the Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands,

Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, United Kingdom). As comparable trend data on global chronic morbidity is unavailable, trends in life expectancy at age 65 are presented since this is an integral part of LEwCM.

Considerable disparities are evident in the prevalence of chronic morbidity in 2005. For men the prevalence ranges from 17.5% (Greece) to 39.9% (Finland) and for women from 21.8% (Greece) to 45.4% (Sweden). The reported prevalence in women is higher than that for men within every Member State though the gender gap varies from 2.1% in the United Kingdom to 8.4% in Sweden. However men and women give the same picture of the diversity of chronic health problems reported in Europe.

Life expectancy at age 65 for the EU25 in 2005 was 16.7 years for men and 20.3 years for women. These average values hide considerable differences with a gap between the highest and lowest values in men of 5.2 years: from 12.5 years (Latvia) to 17.7 years (France); in women a slightly smaller gap of 4.9 years from 17.1 years (Slovak Republic) to 22.0 years (France). The gender gap in life expectancy at age 65 within Member States in 2005 was only 2.1 years for Greece compared to 4.9 years for Estonia.

Life expectancy with chronic morbidity at age 65 for the EU25 in 2005 was 9.6 years for men and 12.4 years for women. The gap in LEwCM between Member States is greater than those for life expectancy being 7.3 years for men (from 5.6 years with chronic morbidity in Denmark to 13.0 years in Finland) and 8.9 years for women (from 7.7 years in Denmark to 16.7 years in Finland). The proportion of remaining life at age 65 spent with chronic morbidity ranged for men from 34.8% of remaining life spent with chronic morbidity in Denmark to 77.0% in Finland and for women from 40.5% in Denmark to 79.6% in Finland. There appears little evidence that Member States with the lowest proportion of unhealthy life (spent with chronic morbidity) are also those with the longest overall life expectancy at age 65.