EUROPEAN COMMISSION
HEALTH & CONSUMER PROTECTION DIRECTORATE-GENERAL

Directorate C - Public Health and Risk Assessment
C2 - Health information

Some elements on the situation of multiple sclerosis in the European Union

(Version 3.0)

Definition

Multiple sclerosis (MS) is a disorder of the central nervous system (brain and spinal cord) caused by lesions in the white matter of the central nervous system that degenerate the myelin sheath, marked by lack of muscle coordination, muscle weakness, speech problems, paresthesia, and visual impairments.

Symptoms

- weakness of one or more extremities
- paralysis of one or more extremities
- tremor of one or more extremities
- muscle spasticity (uncontrollable spasm of muscle groups)
- muscle atrophy
- movement, dysfunctional
- slowly progressive
- beginning in the legs
- numbness, decreased or abnormal sensation in any area
- tingling
- facial pain
- extremity pain
- loss of vision -- usually affects one eye at a time
- double vision
- eye discomfort
- rapid eye movements, uncontrollable
- eye symptoms worsen on movement of the eyes
- decreased coordination
- loss of balance
- decreased ability to control small or intricate movements
- walking/gait abnormalities
- muscle spasms (especially in the legs)
- dizziness
- vertigo
- urinary hesitancy, difficult to begin urinating
- strong urge to urinate (urinary urgency)

- frequent need to urinate (urinary frequency)
- incontinence (leakage of urine, loss of control over urination)
- decreased memory
- decreased spontaneity
- decreased judgment
- loss of ability to think abstractly
- loss of ability to generalize
- depression
- decreased attention span
- slurred speech
- difficulty speaking or understanding speech
- fatigue, tired easily

Additional symptoms that may be associated with this disease:
- constipation
- hearing loss
- positive Babinski's reflex

Symptoms may vary with each attack. They may last days to months, then reduce or disappear, then recur periodically. With each recurrence, the symptoms are as different as new areas affected. Fever can trigger or worsen attacks, as can hot baths, sun exposure, and stress.

At least half of patients with MS suffer from cognitive impairment that may significantly affect their daily functioning and quality of life. The pattern of cognitive impairment usually includes difficulties with information processing speed, learning capacity, and problem-solving behaviours. There is very important to identify cognitive dysfunction as early as possible in patients with MS to minimize the deleterious effects. Neuroimaging has a central role in understanding the causes of cognitive dysfunction and recognizing patients who may be at highest risk for developing this complication of MS.

Causes and risk factors

The cause of MS is unknown. There is considerable variation in the occurrence of MS around the world. This has been ascribed to environmental factors, such as exposure to viruses or ionising radiation, or to genetic factors. Worldwide, multiple sclerosis occurs with much greater frequency in higher latitudes away from the equator, than in lower latitudes, closer to the equator.

The disease involves repeated episodes of inflammation of nervous tissue in any area of the (brain and spinal cord). These episodes occur when the body's own immune cells attack the nervous system. The location of the inflamed areas varies from person to person and from episode to episode. The inflammation destroys the covering of the nerve cells in that area (myelin sheath), leaving multiple areas of scar tissue (sclerosis) along the covering of the nerve cells. This results in slowing or blocking the transmission of nerve impulses in that area, leading to the symptoms of MS.

The exact cause of the inflammation associated with MS is unknown. Geographic studies indicate there may be an environmental factor involved. MS is more likely to occur in northern Europe, the northern United States, southern Australia, and New Zealand than in other area. The "intertropical belt" seems to have much lower rates of this condition. There seems to be a genetic link to the disease, with some families more likely to be affected than others and certain genetic markers are more common in people with MS than in the general population.

An increase in the number of immune cells in the body of a person with MS indicates that there may be a type of immune response that triggers the disorder. The most frequent theories about the cause of multiple sclerosis include a virus-type organism, an abnormality of the genes responsible for control of the immune system, or a combination of both factors.

Types of Multiple Sclerosis

The course of MS is unpredictable. Some people are minimally affected by the disease while others have rapid progress to total disability, with most people fitting between these two extremes. Although every individual will experience a different combination of MS symptoms there are a number of distinct patterns relating to the course of the disease:

- Relapsing-remitting MS (RRMS). The majority of MS patients (approximately 85%) initially present with this form of the disease, characterized by clearly defined disease relapses with full recovery or with sequelae and residual deficit upon recovery. RRMS is not classified as a progressive form of multiple sclerosis, but residual deficits can be established with each exacerbation.
- Secondary progressive MS (SPMS). At least 50% of patients with RRMS will transition into this sub-form, characterized by disease progression with or without occasional relapses, minor remissions, and plateaus.
- Primary progressive MS (PPMS). Approximately 10% of the MS population presents a disease progression from the onset with occasional plateaus and temporary improvements.
- Progressive-relapsing MS (PRMS). The least common form is a progressive disease from onset with acute relapses, with or without full recovery, with periods between relapses characterized by continuous progression.

Estimation of incidence of MS and difficulties for a better data

Estimates of the number of people affected by this disease throughout the world range between 1.1 and 2.5 million. No data on prevalence or incidence in the EU have been collected (except some local or regional surveys) and the number of persons affected is estimated between 350 000 and 405 000 in the EU-15 (approximately 1 out of 1 000 people). The prevalence of multiple sclerosis varies from 20 to 40 per 100 000 for the Mediterranean, to about 150 per 100 000 for the northern parts of the United Kingdom and Sicilia. In the Netherlands, only data for the province of Groningen are available (61.1 per 100 000 in 1986) and a nationwide estimation in Austria has given a prevalence of 98.5 per 100 000 (ref Baumhackl).

Estimations provided by some private organisations based on estimates by national MS societies and others and extrapolations of survey data for regions within the countries, are coincident with these general estimations. However these figures should be used with a lot of caution due to the variety and non comparable sources used in every country.

Country	Estimated number of people with MS	Estimated prevalence per 100 000
Austria	7 000	86.4
Belgium	8 900	87.5
Bulgaria	3 200	39.3
Cyprus	350	46.7
Czech Republic	10 000	97.1
Denmark	6 000	112.0
Estonia	725	51.0
Finland	5 000	98.0

France	50 000	84.9
Germany	120 000	99.0
Greece	5 000	46.7
Hungary	6 600	65.0
Iceland	285	105.1
Ireland	4 500	125.0
Italy	50 000	88.2
Luxembourg	400	94.1
Netherlands	15 000	94.9
Norway	3 800	86.4
Poland	30 000	77.1
Portugal	5 000	50.5
Romania	7 500	33.4
Spain	30 000	76.7
Sweden	12 000	134.8
Turkey	30 000	46.4
UK	85 000	143.8

Source: All About Multiple Sclerosis (http://www.mult-sclerosis.org/)

Women are affected more commonly than men. The disorder most commonly begins between 20 to 40 years old, but can happen at any age. Risks include a family history of MS and living in a geographical area with a higher incidence rate for MS.

However; it is always difficult to measure incidence and prevalence rates for rare conditions with traditional research tools as surveys. For neurodegenerative disorders considered rare as Parkinson's Disease or multiple sclerosis (or even for epilepsy), the sample size required begins to approach the total population size. However, there is a class of diseases for which it is possible, but very expensive, to conduct large population-based surveys. Some diseases in this category have been studied in only a few population-based studies. Often, even the largest studies produce estimates with very wide confidence intervals. In some cases we have only prevalence studies since they do not require longitudinal follow-up. These studies typically produce estimates of single parameters related to the disease of interest (e.g. incidence, prevalence, or associated mortality). The prevalence of a disease in a population is the proportion of that population with the disease at a specific point in time. It is, by definition, a product of the incidence of the disease (the rate at which new cases arise) and the mean duration of disease, which is determined by rates of recovery and mortality. Many chronic diseases are believed to have recovery rates of zero; once affected by the disease, patients' symptoms and progression may be more or less well controlled, but they never return to a disease-free state. For these diseases, prevalence is determined exclusively by incidence of disease and the mortality associated with it. Given the costs of estimating incidence and prevalence for many conditions, there are high returns to statistical analyses that improve estimates of incidence and prevalence. In particular, we can learn much if we can combine data from incidence and prevalence studies. From individual studies of incidence, we can combine the prevalence rates from the baseline survey with the longitudinal incidence rates.

Other existing information on multiple sclerosis in the EU

Eurostat data on mortality due to multiple sclerosis are available only for six countries: Denmark (288 deaths, 1996/99), Iceland (5, 1996/97), Luxembourg (9, 1998/99), the Netherlands (384, 1996/97), Norway (352, 1996/99) and Sweden (287, 1997/99).

Data on hospitalisation for MS has been required for Eurostat in his yearly questionnaire on hospital activity as part of his 59 hospital diagnosis list. Data obtained from the Member States and Candidate Countries proves again the difficulties to assess in an appropriate way the impact of the MS.

However, the Hospital Data Project (HDP) supported by DG SANCO, which has as a main objective to create a MDS (Minimum Data Set) to collect in an improved way data on hospital diagnoses and activity has not included the MS In his 130 diagnosis list.

Level of hospitalisation of MS patients is much related to the systems of reimbursement. MS is considered one of the most expensive diseases for the health systems (as well as the all the neurodegenerative diseases). A recent German study estimates in about 2.3 billion Euros per year the cost of the treatment. The effect is a transmission of responsibilities of care to the families of the patients or to other dependency or home care structures, for which no data on patients treated are available.

Table 1: Total number of hospital discharges due to multiple sclerosis

	DE	ES	FR	AT	PT	FI	S	ENG	BG	CY	MT	RO	SK
1990	:	:	:	:	:	:	2 988	:	:	:	:	2 929	:
1991	:	:	:	:	:	:	3 206	:	:	:	:	2 713	943
1992	:	:	:	:	:	:	2 419	:	:	:	:	2 972	1 062
1993	:	:	:	:	:	:	2 269	:	:	:	:	2 979	1 009
1994	26 946	:	:	:	:	:	2 128	:	:	:	:	3 068	987
1995	29 672	:	:	:	:	:	1 964	:	:	14	:	3 280	1 160
1996	31 572	:	:	:	:	2 404	1 803	:	:	9	:	2 812	1 246
1997	33 007	:	20 596	:	:	2 414	1 641	:	:	6	:	3 094	1 336
1998	36 636	:	19 179	4 677	:	2 627	1 656	15 579	:	7	:	3 108	1 417
1999	41 031	2 969	20 339	:	:	2 638	1 705	16 051	:	:	:	3 247	1 460
2000	:	2 905	21 615	5 257	699	2 665	1 728	15 956	1 676	5	9	3 837	1 605
2001	:	:	:	:	569	2 736	1 615	:	1 822	5	9	5 401	1 845

Table 2: Hospital discharges due to multiple sclerosis per 100 000 inhabitants

	DE	ES	FR	AT	PT	FI	S	ENG	BG	CY	MT	RO	SK
1990	:	:	:	:	:	:	35.0	:	:	:	:	12.6	:
1991	:	:	:	:	:	:	37.3	:	:	:	:	11.7	17.9
1992	:	:	:	:	:	:	28.0	:	:	:	:	13.0	20.1
1993	:	:	:	:	:	:	26.1	:	:	:	:	13.1	19.0
1994	33.1	:	:	:	:	:	24.3	:	:	:	:	13.5	18.5
1995	36.4	:	:	:	:	:	22.3	:	:	1.9	:	14.4	21.7
1996	38.6	:	:	:	:	47.0	20.4	:	:	1.2	:	12.4	23.2
1997	40.2	:	35.4	:	:	47.0	18.6	:	:	0.8	:	13.7	24.8
1998	44.6	:	34.9	57.9	:	51.0	18.7	31.5	:	0.9	:	13.8	26.3
1999	50.0	7.5	34.8	:	:	51.1	19.3	32.3	:	:	:	14.4	27.1
2000	:	7.3	32.8	64.9	6.9	51.5	19.5	32.0	20.5	0.7	2.4	17.1	29.7
2001	:	:	:	:	5.5	52.8	18.2	:	22.4	0.7	2.3	24.1	34.2

Source: Eurostat (NewCronos database)

The neuro-developmental diseases and the EU environmental strategy

The EU Environment and Health Strategy put an emphasis on improving understanding of the links between environmental factors and key diseases and conditions. Neuro-developmental disorders have been identified as a priority disease, together with childhood cancers and respiratory diseases, asthma and allergies. As a first step to come to policy recommendations on indicators and priority diseases a baseline report was drawn up.

In this base-line report on neuro-developmental disorders an overview is given on present knowledge on diseases, environmental factors, exposure and strength of evidence.

The study of environmental risk factors is divided in three groups: Voluntary exposure, Involuntary exposure and Therapeutic exposure. Voluntary and therapeutic exposures are addressed not extensively, because the risks of alcohol, smoking and drugs for the developing brain are well recognized. Therapeutic exposure like anticonvulsants, steroids, diethylstilboestrol and radiation are addressed briefly. Effects in these two groups of exposure can be a warning, because mechanisms of actions can be the same as for other environmental factors. The involuntary exposure is the most important group to address the environmental risk factors and possible effects on neurodevelopment.

Some groups or substances and the evidence of links with neuro-developmental disorders in children are given in different levels. PCBs, dioxins, lead and mercury are proven to be neuro-toxic in humans. Background levels of PCBs and dioxins in several parts of Europe in 1990-1992 had negative effects on neurodevelopment. Levels are decreasing, but still too high.

Medical treatment of MS and hospitalisation

If the level of hospitalization for MS is low if we consider the high severity of the disease it's, certainly, for this effect of 'expulsion' from the structures of the public health system to the families and home or residential care structures. However the impact of the existing treatments in the type of care should be analysed.

Treatments for MS fall into two general groups. The first group addresses the disease itself and the second group includes drugs and techniques to alleviate symptoms. Symptom management is vitally important for living well with MS. Three drugs are currently approved for control of relapsing-remitting MS. These drugs are Betaseron, Avonex, and Copaxone. None of them cure MS. They reduce the frequency and severity of attacks and delay the onset of permanent disabilities. Two of them (Betaseron and Avonex) are forms of interferon beta, a substance the immune system normally makes to regulate itself. The third (Copaxone) is a synthetic that mimics a component of human myelin and may work by serving as a decoy for the MS attack. They are often called the "disease-modifying" drugs, and some people use the term "ABC" drugs. Other possible future therapies are the autologous hematopoietic stem cell transplantation, the use of statin agents, monoclonal antibodies and others.

The evidence is overwhelming that beta interferon can reduce both the number and the severity of relapses that people with MS suffer. Relapses can be distressing, painful and disabling. They vary greatly in severity, but extreme attacks can result in blindness, paralysis and incontinence and may require hospitalisation. It has been shown that people taking beta Interferon need less hospital treatment and that could save money for the health systems. The problem is that Beta interferon does not work for all MS patients, but it estimated that about only half would achieve substantial relief of their symptoms by taking the drugs. A patient taking beta Interferon may have a few less attacks of symptoms early on, but at the end of five years there is no evidence that they are as less likely to be disabled than if they had not taken the drug.

There are no other alternative drugs available and then only services such as rehabilitation or physiotherapy can stop the progress of the disease.

Some recent British studies suggest that if beta Interferon cost £5, £100 or even £1,000 a year, the minor benefit it brings in terms of relieving symptoms might be worthwhile, but because it costs £10,000 per patient per year it is not cost effective. It would cost £250,000 to give beta Interferon to five patents for five years. For the same cost one could employ one, or maybe two MS nurses or physiotherapists who could work on reducing the physical impact of the disease help a far larger number of patients.

However the initial results of the PRISMS (Prevention of Relapses and Disability by Interferon-b-1a Subcutaneously in Multiple Sclerosis, University of British Columbia) provide the most convincing evidence yet that patients with relapsing–remitting MS treated with interferon beta (IFN-b) will develop less permanent disability. Although the PRISMS-4 study may not have been designed with this purpose in mind, the final result is similar to a "randomized start" study design, recommended as the ideal way to demonstrate disease modification in neurodegenerative disorders.

Economic evidence in multiple sclerosis

Despite their differences, all studies in the field of economic evidence of MS highlight clearly the high burden that this disease imposes on society, in terms of production losses by an essentially very young disabled patient population, as well as on families, with a very high need for informal care. They also illustrate very well how different health-care systems provide different levels of services for these types of patients. A systematic review of studies on economic evidence on MS (from *Gisela Kobelt · European Health Economics, Spéracèdes, France published in the European Journal of Public Health*) agrees in some overall findings:

- Costs outside the health-care system, i.e. productivity losses (short-term sick leave and early retirement) non-medical costs (investments, etc.) and informal care by family or friends, dominate the costs of MS. Studies differ, however, in the way in which informal care is calculated (replacement cost or productivity loss) and whether it is considered a direct or an indirect cost. Thus, the proportion of costs estimated for indirect cost varies considerably.

- Indirect costs represent a larger proportion of costs in patients with limited permanent disability (i.e. at lower expanded disability status scale, EDSS levels).

- Males have higher total costs than females, driven by higher productivity losses.

- Inpatient care dominates direct costs (prior to the introduction of the new drugs).

- Costs increase with increasing severity of the disease. Taken individually, age, disease duration, level of disability (measured with the expanded disability status scale EDSS), all are positively correlated with costs, but there is also a clear co-linearity between these variables.

- Costs are higher overall for patients with SPMS than for those with RRMS. However, when controlling for EDSS this is less clear: costs appear to be driven by the level of EDSS rather than by the type of MS, and for patients at the same level of EDSS and in the absence of a relapse, there is no significant difference in costs between the two types of MS.

Table 1

Cost comparison (Germany, Italy, Sweden, UK), cost per patient, PPP€ 2003

	Germany 1999 (Kobelt 2001)	Italy 1996 (Amato 2002)	Sweden 1998 (Henriksson 2001)	United Kingdom 1999 (Kobelt 2000)
Direct costs [a]	10 012	4024	17 933	3973
Out-of-pocket costs and informal care	11 575	6537	20 012[b]	10 637
Indirect costs	15 771	6411[c]	20 657	12 456
Total costs (PPP€,2004)	**37 356**	**16 972**	**58 602**	**27 066**

[a] *Includes interferon use adjusted to national usage at the time of the study, except for Italy where interferon was excluded*
[b] *Includes personal assistants provided by the social service*
[c] *Includes caretaker loss of income*

Table 2

Cost perspectives in Germany (million DM)		
	1999 (Kobelt 2001) Public payer perspective	1999 (Kobelt 2001) Societal perspective
Direct costs	2047	4525
- Inpatient care	750	804
- Ambulatory care	477	556
- Drugs (interferons)	344	365
- Drugs (other)	154	186
- Services, adaptations	322	1664
- Informal care	–	950
Indirect costs	930	3349
- Sickness absence	50	296
- Early retirement	880	3044
Total costs (DM)[b]	**2977**	**7850**
Total costs (€)	***1520***	***4010***

[a] *Adjusted for national interferon use;* [b] *Prevalence 120 000*

Source: European Journal of Public Health, Gisela Kobelt

The shift in responsibilities between the State, the market and the family

All countries are currently discussing and debating how to create an adequate infrastructure to provide long-term care, whether as residential or home care to elderly people as well as to those suffering from neurodegenerative diseases as MS. On average, each individual can expect two to four years dependency on formal care at the end of his or her life (OECD 1999). Policy-makers should to make choices about how to integrate this newly recognised risk into on-going national systems. This involves distributing responsibility for long-term care among the public, private and third sectors as well as the family.

Long-term care was originally considered as being a need to be met by families rather than by governments. Therefore, while there has been a move towards public support for care for the frail elderly, most countries insist that public finances bear only a part of the cost. Provision of long-term care continues to be in large part -- if not primarily --the responsibility of families, and to be provided through informal care and unpaid work.

Such an assumption about the role of the family immediately raises questions about who will do the work within the family. The matter involves empirical and economic questions related to the availability of care-givers and broader issues of justice and equity for women. Women have everywhere been the traditional providers of informal care and are predominant in the formal care activities and the nursing sector (OECD, 1999).

The knowledge about MS in the general public

"The European Year of people with disabilities" in 2003 will promote awareness of disability. The Eurobarometer 54.2 and 60.0 surveys, conducted by the European Commission in 2000 and 2003, asked participants about their attitudes towards disability.

As 57% of Europeans admitted having a lack of knowledge about the 21 types of disabilities named in the questionnaire (the average being based on results collected by each item), it is worth noting that the word "disability" covers a series of deficiencies which generate different levels of information in the population. Knowledge was highest in four large groups: (a) Disabilities due to long lasting illnesses such as cancer (61%), asthma and diabetes (58%), and arthritis (54%) (which are not always considered

as a handicap); (b) Disabilities that correspond to a more widespread perception of handicap such as physical and sensorial disabilities - for instance, 48% of Europeans knew about visual disabilities, 46% about hearing impairments, 43% about cerebral stroke, and only 23% about muscular dystrophy (which is the disability that obtains the lowest score out of the 21 selected type of disabilities); (c) Mental and psychological disabilities are the less well known with only 37% being fairly aware about Alzheimer's disease, 35% about Parkinson's disease and 31% about psychiatric disabilities; and (d) Other types of disabilities with uneven levels of information - brain injury, head injuries and spinal cord injury (25%), multiple sclerosis (32%) and skeletal impairments (30%).

One of the key challenges of the *The European Year of people with disabilities* (EYPD) campaign was to promote a wider understanding and acceptance of the main disability issues. In order to measure in part the success of this campaign, the European Commission commissioned a series of questions about the EYPD campaign and disability issues in the Eurobarometer 60.0 survey in 2003 with the objective to compare 2000 and 2003 results taken through a comprehensive list of disabilities and their 'awareness' of these conditions was assessed (including MS). Views were assessed across the European Union and results are based on a European Union level (where relevant), on a country-by-country level and a socio-demographic analysis which attempts to highlight both the similarities and differences by such varied factors as gender, age, education, occupation, etc. Throughout this survey, it will become increasingly apparent that fundamental variations in attitude are usually based upon a country-by-country view rather than on a particular socio-demographic characteristic such as gender, age, education or occupation although sub-divisions based upon potentially linked aspects such as education, occupation and income do emerge.

How aware are you of the various types of disabilities? Would you say you are fairly aware or fairly unaware of the various types of disabilities?
Multiple Sclerosis

	Fairly aware		Fairly unaware		Don't know	
	2000	2003	2000	2003	2000	2003
B	35	41	59	58	6	1
DK	30	38	58	55	13	7
D WEST	25	36	67	60	8	5
D TOTAL	24	34	68	61	8	5
D EAST	21	27	70	68	9	5
GR	24	43	74	56	3	1
E	21	26	75	61	5	13
F	39	46	59	52	2	2
IRL	41	74	54	24	5	2
I	27	34	66	64	8	3
L	39	57	57	41	5	2
NL	46	54	47	43	7	3
A	55	62	39	35	6	3
P	12	22	81	75	7	2
FIN	40	45	56	54	4	2
S	36	48	58	50	6	2
UK	49	78	45	20	6	2
EU15	33	44	61	52	6	4

Source: Eurobarometer 54.2 (2000) and 60.0 (2003), European Commission

Between 2000 and 2003 across the EU15, the awareness level of multiple sclerosis (MS) increased by a third from 33% to 44% over the three years in question. Substantial increases in awareness were once again noted in the UK where the figures rose from 49% to 78%. A similar pattern was seen in Ireland where the figures jumped from 41% to 74%. Countries with the lowest level of awareness of this condition were Portugal and Spain. In Portugal, although the awareness level had practically doubled from 12% to 22%, MS was still a medical condition of which only one in five was fairly aware. The comparable figure in Spain was 26%. There was a noticeable variation between the two parts of Germany in that, although awareness levels had increased in both, the growth in West Germany from 25% to 36% was substantially greater than that seen in East Germany where there was an increase from 21% to 27%. The Spanish figures once again feature prominently in the 'don't know' statistics. There was a noticeable increase in awareness of this disability with age. While, in 2003, only 35% of respondents aged 15 to 24 were aware of this disability, the figure increases to 47% for those aged 55 or more.

However and despite this substantial improvement on knowledge on MS, this low knowledge in the general public about what is MS constitutes an objective difficulty for any strong political action at national or EU level.

The multiple sclerosis in the existing public health programmes

In 1993, the European Commission adopted eight programmes in the field of Public Health. On February 4th, 1999 the European Parliament and the Council reached an agreement regarding the Programme of Community Action for rare diseases, which was officially approved on April 29th, 1999. For the period 1999-2003 the Decision No 1786/2002/EC of the European Parliament and Council of 23 September 2002 adopting a programme of Community action in the field of public health 2003-2008 includes the rare diseases as an important objective. The rare diseases are those of genetic origin, life-threatening or chronically debilitating diseases which are of such low prevalence that special combined efforts are needed to address them. As a guide, low prevalence is taken as prevalence of less than 5 per 10 000 in the Community.

Even though MS is not a 'rare disease' per se, it' possible to refer to the former EU rare diseases programme, and the Orphanet project (link attached: http://www.orpha.net//consor/cgi-bin/OC_Exp.php?Lng=GB&Expert=802) which sets out clinical data, treatment, research and patient group information concerning multiple sclerosis.

Any project has been submitted to the new Public Health Programme for information on MS.

Future information actions on multiple sclerosis in DG SANCO C-2

Information on neuro-degenerative diseases will be one of the categories covered in the Health information system being established in the EU Public health Programme. A project (European Community Health Indicators or ECHI) is developing a list of health indicators and definitions which will form the basis for this system.

The Working Party Morbidity and Mortality (WPMM) met in Luxembourg on 20-21 January 2004 and had examined how information on neuro-degenerative diseases could be improved in the system based on their significance in terms of disease burden and cost to the public health services. Participants in the WPMM were invited to submit calls for proposals on neuro-degenerative diseases (including MS) in the next wave of the Public Health Programme. The period of submission starts on 27 February 2004 with a deadline of 26 April 2004A call for tender on neuro-degenerative diseases (including MS) and his impact on health systems as well as inventorying the existing information and prevalence data will be submitted to the approval of the WPMM and launched during 2004 or 2005.

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