



Healthier Together

in the European Union



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Luxembourg: Office for Official Publications of the European Communities, 2007

ISBN 92-79-04503-2

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PRINTED IN BELGIUM

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Foreword

Health is important for everyone. But not everyone knows about the role the EU has to play in protecting our health and preventing future health problems. Health is, in part, our individual responsibility – the choices we make, like quitting smoking, eating healthy food, taking exercise and practising safe sex are personal choices. By making healthier lifestyle choices, we can also prevent illness later in life.

At the same time, governments at all levels have a role in making these choices available to citizens, and giving them the information they need to make those healthy lifestyle choices. So, what can the EU do to add value to the action of Member States? This booklet helps to explain.

The EU has a legal obligation under its founding Treaty to protect health. That is because health is a cross-border issue – diseases cross borders, patients cross borders, health professionals cross borders, healthy and unhealthy products cross borders. Tackling infectious diseases and making sure blood donations are safe, are some examples of EU action in this area.

The EU can help to improve health and prevent illness too. This can be through bringing Member States together to discuss what works; for example, in tackling obesity or limiting alcohol-related harm, particularly for young people. In some cases the EU can put legislation in place to help improve the health of citizens, such as by regulating tobacco products and banning tobacco advertising.

This booklet helps to describe the scope of work on health that the EU is carrying out, helping to protect EU citizens and enable them to make healthy choices and live healthier lives.

Markos Kyprianou,
Commissioner for Health

Introduction

Healthy Life Years (HLY):

Indicator to measure how many years individuals live without disability.



The European Union (EU) works to **protect and improve the health of European citizens**. The Treaty establishing the European Community¹ underlines this principle. The aim is to make sure that all Europeans – regardless of who they are or where they live – can enjoy a healthy life until old age. They should be protected from threats to their health, be aware of healthy lifestyle options and, when they fall ill, know and enjoy their rights to treatment at home and abroad.

The EU's role is not to duplicate what has already been done at national level, but to act on issues that cannot be fully addressed by individual countries. The EU covers a population of nearly half a billion in its 27 Member States and a **coordinated response to health challenges can sometimes be crucial**: this is what the EU's "added value" is all about.

Health policy rests mainly in the hands of national governments. However, action at EU level is important:

- to address **health inequalities** across the Union and develop solidarity mechanisms, for example, through the use of financial resources available in regional funds;
- whenever there are **cross-border issues**, such as the fight against communicable diseases or the mobility of patients;
- wherever **key health determinants** can be addressed more strongly with EU direct action;
- when common or **joint actions** can increase the resources and expertise available, for example, to fight rare diseases that affect only a relatively small number of people in any individual country, or to develop research programmes;
- when cooperation and exchange of **best practices** can help Member States respond adequately to complex lifestyle issues;
- when key **global players**, such as large companies or international organisations, are implicated;
- to ensure that all the **different EU policy areas** – environment, economy, industry or social cohesion – **contribute towards improving health**, because human health is affected by so many different factors.

To support its activities, the EU has allocated a budget of €353 million for projects developing and promoting public health across all Member States (period 2003-2008). In addition, other EU investments – for example, through the **Structural Funds or Research Programmes** – help to reduce the major differences in health status (which continue to exist in and between Member States) and contribute to improved access to healthcare in Europe's regions. This reflects the increased awareness that a healthy population is an essential requirement for economic prosperity and growth: the burden of ill health translates into high healthcare and social costs, ranging from sick leave, replacement at work, lower productivity and absenteeism, to early retirement.

1. Article 152 of the EU Treaty states that a high level of human health protection shall be ensured in the definition and implementation of all Community policies and activities.

The **economic and social challenges of an ageing population** are also to be taken into account and it is important that the years during which people stay healthy, energetic and independent are nearly as many as those comprising their total life expectancy.

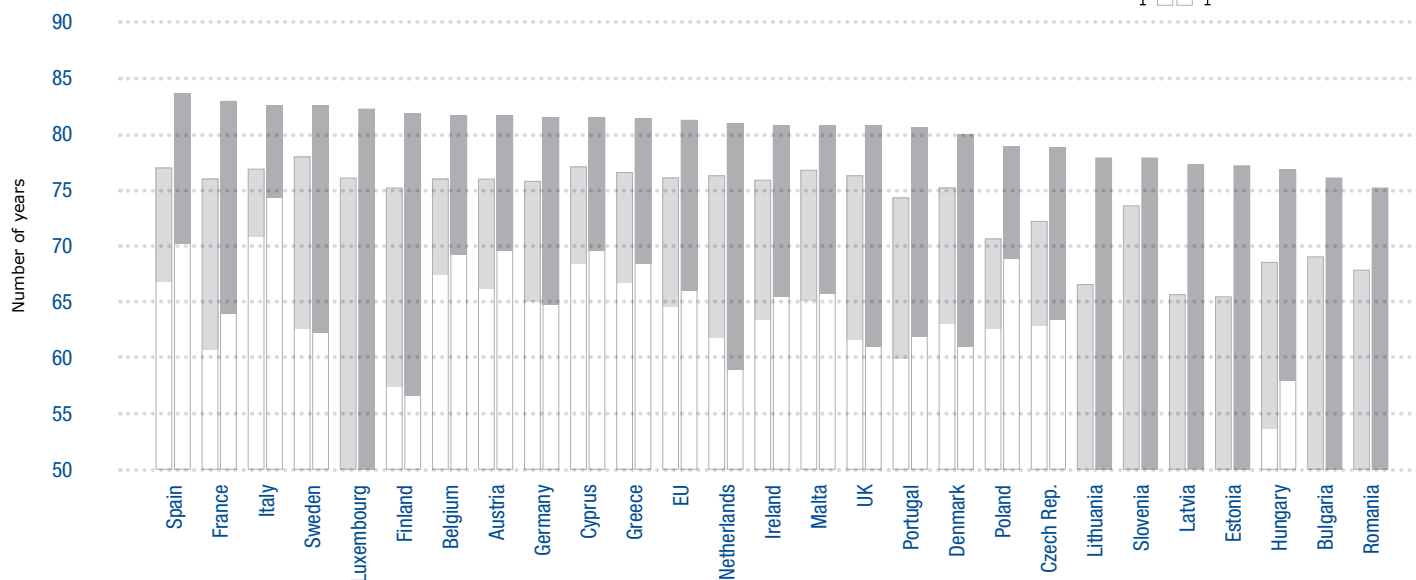
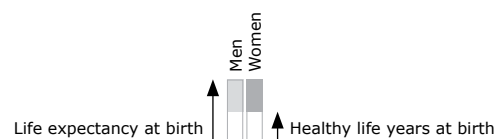
The EU also does a lot of work to promote public health around the world. The world's poorest countries benefit from **EU development funding**, as it supports health systems, infrastructure and training. EU **humanitarian aid** funds emergency medical care during times of crisis. But the EU's global health work is not just about money; it is also about sharing **expertise**, providing **technical assistance**, and **promoting EU health standards and values** around the world.

This brochure aims to highlight some of the **key health policy areas** in which the EU is active. It does not intend to be exhaustive, but illustrative, with a summary of the main facts, objectives and examples of concrete actions for a number of key areas:

- Nutrition, physical activity & obesity prevention
- Alcohol
- Tobacco
- HIV/AIDS
- Blood transfusions and cell & organ transplants
- Rare diseases
- Communicable diseases
- Patient mobility
- Health information

Life Expectancy and Healthy Life Years

Source: Eurostat, 2003



N.B.: Healthy life years at birth (HLY) not available for Luxembourg, Lithuania, Slovenia, Latvia, Estonia, Bulgaria and Romania.

Stay healthy for longer: a major objective for Europe

As part of its strategy to boost growth and employment, the European Union has set a target to increase the “Healthy Life Years” (HLY) of its citizens. Studies indicate that by increasing HLY, people stay in the labour force for longer and so competitiveness rises. This will contribute to the Lisbon Agenda objective of making Europe the most competitive economy in the world by 2010. The average difference between life expectancy and healthy life expectancy is 11 years for men and 16 years for women, but there are great discrepancies between Member States: for example, HLY varies by almost 20 years between Italian and Hungarian men – 72 and 53 respectively. The EU is working to understand more about the reasons for such discrepancies in order to help all EU citizens reach their healthy life potential.

Eat better, exercise more – **fight obesity**



There are over 1 billion overweight adults around the globe, out of which 300 million are obese. In the EU alone, it is estimated that over 200 million adults may be overweight or obese – that is over half the adult population. And, as far as European children are concerned, one quarter are now overweight or obese and this figure is growing by 400 000 each year.

Body Mass Index:

$$\text{BMI} = \frac{\text{Weight in kg}}{(\text{Height in m})^2}$$

Obese or overweight?

A common measure of an obese adult is any individual with a Body Mass Index (BMI) above 30, whereas anyone with a BMI over 25 is classed as overweight.

Fat is unhealthy

The obesity phenomenon is responsible for a series of very **serious physical and mental health problems**, ranging from heart disease, diabetes, cancer, to infertility and psychological disorders. It is estimated that obesity accounts for up to **7% of the EU's healthcare costs**. On top of this, the wider costs to the economy, due to lower productivity and premature death, should be taken into consideration.

Positive changes for healthier living

Nutritional habits have changed significantly over the last decades – people now consume around **500 calories more** than they did 40 years ago. Combine this with a **lack of exercise**, and rising obesity levels hardly seem surprising – EU citizens spend on average over 5 hours a day sitting down and more than one in three does no exercise in their leisure time! Tackling the obesity epidemic requires action to be taken by authorities and industry, along with personal effort by individuals to adopt a healthier lifestyle.

Across Member States, many different organisations, authorities and industry representatives are now engaged in the fight against obesity. The EU's role is to help countries **pool resources** and **share best practices**. It also has an important part to play in food labelling and in the promotion of voluntary action by the food industry.

Improving Food Labels

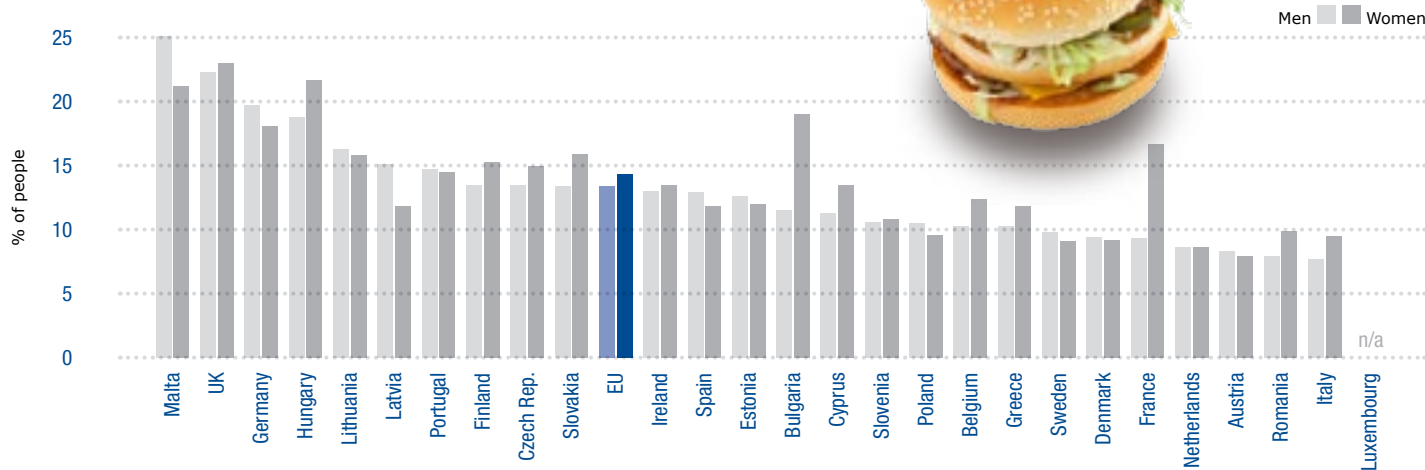
In May 2006, the European Parliament approved new EU-wide **rules on health and nutrition claims** and a new **Fortified Foods Regulation**. Together, these ensure that consumers can rely on food labels for accurate information on health and nutritional value. Health claims such as "good for your heart" have to be scientifically demonstrated, and it is not possible to attach a positive health claim to a product which contains too much salt, fat or sugar.

Encouraging voluntary actions by key EU players

In March 2005, the EU set up the **Platform for Action on Diet, Physical Activity and Health**, bringing together consumer organisations, health NGOs and EU-level industry representatives to tackle the EU's obesity problem. In its first year, **100 new voluntary actions** by 34 key European actors from industry and civil society were triggered, including a **voluntary ban** by the Union of European Beverages Associations (Unesda) on adverts targeting children and a pledge by members of the European Modern Restaurant Association to provide information to customers on the nutritional content of their meals.

Obese people in the over-15 age group

Source: Eurostat, 2003



For **further information** on EU activities relating to **nutrition, physical activity & obesity prevention** visit
 > http://ec.europa.eu/health/ph_determinants/life_style/nutrition/nutrition_en.htm
 or my Lifestyle / Nutrition on the EU Health Portal at > <http://health.europa.eu>
 HELENA project > www.helenastudy.com

Research programmes

Under the **7th Framework Programme 2007-2013**, funding has been allocated for research projects on nutrition and diet-related diseases. This leads on from the **€61 million** already invested by the EU in this field under the **5th and 6th Framework Programmes for Research (1998-2006)**. This has been used, for example, to finance the HELENA project (Healthy Lifestyle in Europe by Nutrition in Adolescence), running between 2005-2008 and involving research groups from institutes across Europe. This will provide factual information about food and nutrients intake, food choices and obesity prevalence among European adolescents.

Support to innovative actions

The EU financially supports many different groups implementing concrete actions to fight obesity. The Shape Up programme, for example, is a 3-year initiative, involving schools from 26 cities across the EU. The scheme promotes healthy eating and sports activities for children aged 4-16, encouraging teachers, parents and communities to promote the idea that sport is fun and healthy eating can be enjoyable.



> www.shapeupeurope.net

Reducing harm caused by alcohol

Harmful alcohol consumption is a very serious concern in the European Union: per capita consumption is double the world average and 55 million adults are estimated to drink at harmful levels. Young Europeans are particularly at risk: the average age for getting drunk for the first time is 14 years and nearly a quarter of 15-16 year-old boys report binge drinking at least three times in the last 30 days.²

Dangers of harmful use of alcohol

Directly responsible for many diseases and health problems such as liver damage, heart disease, mouth and throat cancer, **harmful consumption of alcohol is the third main cause of early death and illness** after tobacco and high blood pressure in the EU.

Alcohol is estimated to be responsible for approximately **195 000 deaths each year** in the EU – not only from cancer and liver cirrhosis, but also from road traffic and other accidents, homicides, suicides and neuropsychotic conditions. More than one death in four in the 15-29 young male group can be attributed to alcohol and 10% in the same female age group.

An EU-wide effort

In October 2006, the European Commission adopted a **strategy to support Member States in reducing alcohol-related harm** with proposals for actions around five main objectives:

- protecting young people, children and the unborn child;
- reducing injuries and deaths from alcohol-related road incidents;
- preventing alcohol-related harm among adults and reducing its negative effects on workplaces;
- raising awareness on the impact on health of harmful alcohol consumption;
- develop a common evidence base.

With this strategy, the EU encourages **cooperation and coordination** between Member States, which are primarily responsible for national policies on alcohol. One area of the strategy is the **promotion of good practices**, including how to better educate young people and parents on the risks of alcohol, effectively enforce minimum age limits for

2. Source: European School Survey project on Alcohol and other Drugs (ESPAD), 2003.



Alcohol consumption

is defined in units (1 unit = 8-9 g of pure alcohol) or drinks (1 drink = 10 g of pure alcohol or more) depending on countries.

Harmful consumption of alcohol:

- Drinking more than
- 40 g of pure alcohol a day for adult men, equivalent to between 4 and 5 glasses (100 ml) of wine;
 - 20 g of pure alcohol a day for adult women, equivalent to between 2 and 3 glasses (100 ml) of wine, except for pregnant women who should not drink at all.

Binge drinking:

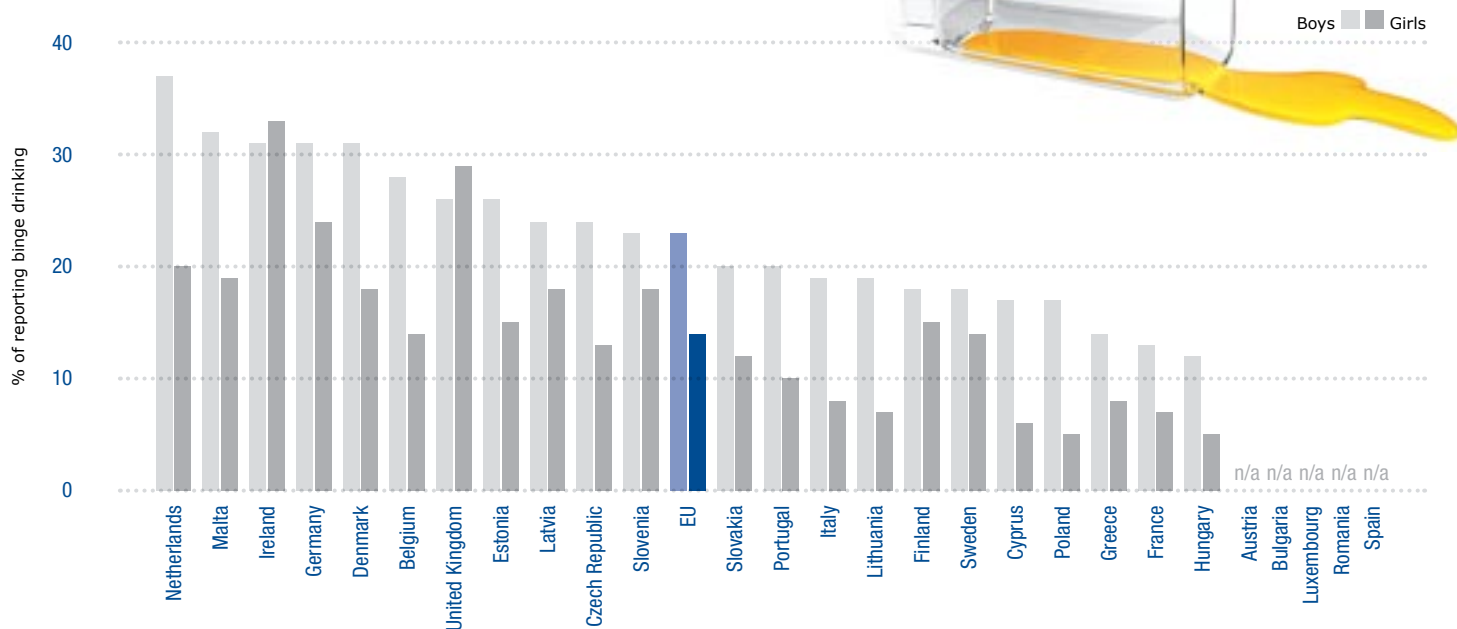
repeated heavy drinking (more than 5 units at a time) with the purpose of getting drunk.

buying alcohol and improve consumer information. The European Commission also works with national authorities, industry and other relevant parties to **prevent the irresponsible marketing** of alcoholic beverages. And, with its **Action Plan on Road Safety**, the EU is supporting initiatives combating drink-driving, especially amongst young drivers.

Binge drinking among boys and girls aged 15-16

3 times or more in the last 30 days

Source: Rand Europe, 2006



Let us talk about alcohol harm

Through its Public Health and Research programmes, the EU finances projects to help reduce alcohol-related health damage, including initiatives to better understand young people's motivations for drinking and to know how to discuss the matter with them. For example, general practitioners could discuss alcohol consumption at the moment of a check-up visit, to educate patients about potential risks and possibly offer short-term assistance. Often, healthcare workers are reluctant to do this, due to lack of time, inadequate training, fear of antagonising patients or because they do not perceive it to be part of their job. To overcome this, professionals from 17 EU countries have joined together to establish a source of information and support for healthcare workers and created a website with guidelines and a training programme.



> www.phepa.net



For **further information** on EU activities relating to **alcohol** visit > http://ec.europa.eu/health/ph_determinants/life_style/alcohol_en.htm or My Lifestyle / Alcohol on the EU Health Portal at > <http://health.europa.eu>

Towards a **tobacco-free** EU

Stopping smoking has a clear and immediate beneficial effect on the health of smokers, even those who smoke heavily. For example, in one year, the risk of a heart attack is halved. Of course it is even better never to start smoking. In 2005, about 68% of Europeans had never smoked or had stopped smoking. The number of smokers has seriously decreased in most EU countries (by nearly 10% within five years). This is linked to the strong public health policies implemented to fight tobacco smoke, including several countries becoming completely smoke-free in their public and work places.

The deadly impact

Smoking is the **single largest cause of avoidable death** in the EU, accounting for about 650 000 deaths each year. Almost half of those dying are people between 35 and 69 years, which is well below the average life expectancy. Long-term smokers have a 50% chance of dying from a tobacco-related disease. It is estimated that 25% of all cancer deaths and 15% of all deaths in the EU could be attributed to smoking. Smoking also affects the health of non-smokers. Passive smoking can cause or aggravate diseases such as asthma, bronchitis and pneumonia in children. For pregnant women, second-hand smoke can impede foetal development, lead to low birth weight or result in a premature birth. It may also slow childhood development and, among newborns, it is associated with increased rates of cot death.

The fight is not over!

Close to **one third of Europeans still smoke** and one in five people aged between 15 and 24 are daily smokers.

The EU has acted assertively in adopting legislation to reduce smoking across Member States. A **ban on tobacco advertising** from the print media, radio and internet came into force in 2005. Tobacco **sponsorship** of cross-border events or sports activities is also prohibited under European law. The **2001 Tobacco Products Directive** sets maximum thresholds for tar, nicotine and carbon monoxide yields and requires clear health warnings on tobacco products.

The EU is also promoting the use of **pictorial warnings** on cigarette packages and has established a photo bank of 42 different images conveying messages on the effects of tobacco on health. These pictorial warnings are starting to appear in Member States.

In 2005, the EU ratified the **Framework Convention on Tobacco Control**, the first ever international treaty on health. It commits countries across the world to act to **reduce the number of deaths and incidence of disease** caused by smoking and contains principles such as protecting citizens from second-hand smoke and stopping



Passive smoking:

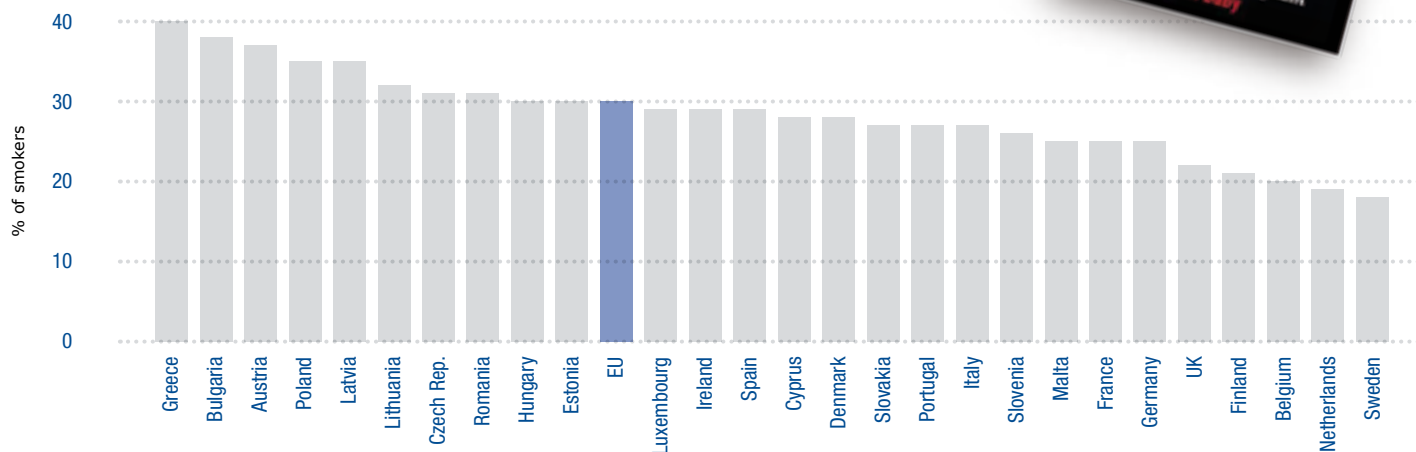
Involuntary exposure to tobacco smoke. The second-hand smoke inhaled by passive smokers is a mixture of smoke exhaled by smokers and smoke directly released from smouldering tobacco. It contains nicotine as well as various carcinogens and toxins.

young people from taking up the habit. The EU is working actively on other policies, such as fighting illicit trade or tobacco taxation, to develop a coherent tobacco control strategy.

The latest development in this strategy concerns the effort to create a smoke-free EU. As **80% of Europeans** would like to see **smoking banned** in public places, the EU is also encouraging Member States to introduce national rules to protect citizens from tobacco smoke.

Percentage of people aged over 15 smoking packed cigarettes

Source: Special Eurobarometer, Attitudes of Europeans towards tobacco, 2006



HELP – for a life without tobacco

The EU is promoting tobacco-free lifestyles among young people with a €72 million campaign that kicked off in March 2005. HELP – for a life without tobacco, runs over a four-year period. It includes TV adverts, mobile advice on tobacco prevention and online information. It is one of the largest international public health campaigns ever set up. In HELP's first 18 months, TV spots were broadcast on more than 80 national channels and achieved more than 1.7 billion contacts within the target group. In parallel, the "HELP" website received more than 1.6 million visits.



> www.help-eu.com



For **further information** on EU activities relating to **tobacco** visit > http://ec.europa.eu/health/ph_determinants/life_style/Tobacco/tobacco_en.htm
 or My Lifestyle / Tobacco on the EU Health Portal at > <http://health.europa.eu>
 Pictorial warnings > http://ec.europa.eu/health/ph_determinants/life_style/Tobacco/ev_20041022_en.htm
 Framework Convention on Tobacco Control > www.who.int/tobacco/framework/en

AIDS is still with us

AIDS presents a dramatic problem, not only in developing countries – particularly those in Africa – but also in the EU and its neighbouring countries. Here, the epidemic is not over but is on the rise again. Every year, there are about 25 000 newly diagnosed cases of HIV; these figures have almost doubled since the late nineties.

Heterosexual transmission dominates

In Europe, sexual transmission of HIV is still the main cause and **heterosexual transmission** is responsible for **more than 50%** of new cases. While some EU citizens may already be taking sensible precautions to reduce the risk of becoming infected, in many instances the emergence and spread of AIDS has **not had an impact** on their lifestyles. **41% of EU citizens are not taking precautions during sexual intercourse.**

A worryingly high percentage of EU citizens are misinformed about HIV/AIDS. For example, almost **four Europeans in ten** tend to believe that HIV could be transmitted by **sitting on a toilet seat** that had been used by an infected person, which is not true.

Information and awareness

The Communication on combating HIV/AIDS within the EU and the neighbouring countries 2006-2009, adopted by the EU in December 2005, encourages the exchange of best practices between national public health authorities and associations. Its **priorities and guiding principles are:**

- to promote **safer sex**;
- to improve **access to HIV testing** and healthcare for all – in particular migrant and excluded populations;
- to support **prevention activities**;
- to **increase the coverage** of risk-reduction programmes;
- to ensure accessible and **affordable healthcare** services for certain target groups;
- to recognise the importance of preventing HIV transmission via **drug use**.

The EU has outlined **best practices** on the prevention and reduction of health-related harm associated with **drug dependence**, aiming to reduce the incidence of drug-related health damage, such as HIV infection.



HIV (Human Immunodeficiency Virus):
Retrovirus that causes AIDS by infecting helper T cells of the immune system.

AIDS (Acquired Immune Deficiency Syndrome):
A serious, often fatal disease of the immune system transmitted through infected blood, semen, vaginal fluid or breast milk.



The Union is also very active in helping to fight HIV/AIDS in developing countries. Between 2003 and 2006, the EU contributed **over €1.2 billion** to the Global Fund to fight AIDS, Tuberculosis and Malaria.

In 2003, the EU contributed to an agreement on heavily discounted (tiered) medicines, helping developing countries **access medical treatments** at the lowest possible costs, while keeping these cut-price products out of the EU, where higher prices are maintained. The EU allocated **€200 million** under the 6th Research Framework Programme to the **European and Developing Countries Clinical Trials Partnership**, a research programme for the development of new medicinal products and vaccines to fight HIV, malaria and tuberculosis in sub-Saharan Africa.



EuroHIV

In order to understand, improve and share data on the evolution of HIV/AIDS, the EU established the European Centre for Epidemiological Monitoring: EuroHIV.

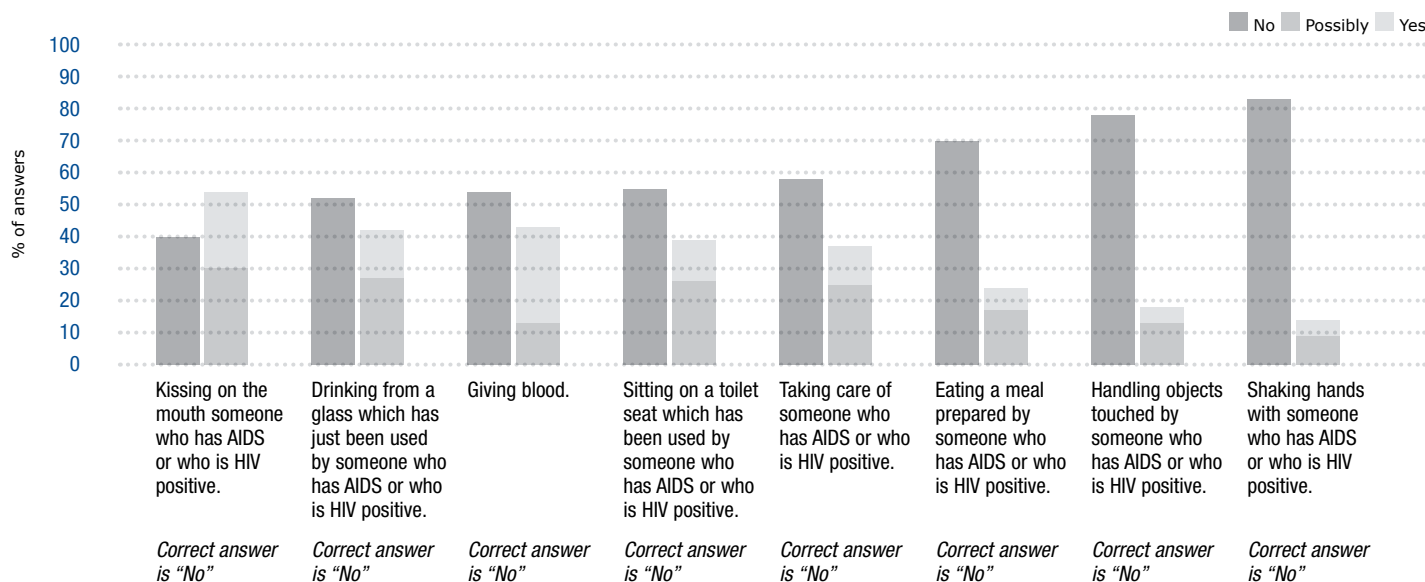
In all 52 countries of the WHO European Region, a single institution in each country now reports national data to EuroHIV. This enables the centre to make international comparisons, assess trends, identify affected populations, predict disease burden and evaluate surveillance methods. EuroHIV also supports national efforts to improve surveillance, and makes data freely and widely available – it publishes half-yearly reports, and its findings are included among the key figures on health published annually by Eurostat.



> www.eurohiv.org

EU citizens' opinion on wrong statements regarding ways of contracting AIDS

Source: Eurobarometer on AIDS Prevention, 2006 (EU 25)



For **further information** on EU activities relating to **AIDS** visit > http://ec.europa.eu/health/ph_threats/com/aids/aids_en.htm or Health Problems / HIV/AIDS on the EU Health Portal at > <http://health.europa.eu>

Safe **blood donations** and **organ transplant**

Common quality and safety rules and procedures from donation to transfusion of blood or transplantation of tissues are vital in ensuring that patients have the same high level of protection across Member States and to guarantee cooperation in case of shortages.

Life-saving not life-threatening

Blood transfusions are used in both medical emergencies and routine surgical procedures. There is a need for a constant supply of blood because it can only be stored for a limited period of time before use. To prevent the transmission of diseases, blood must be **safe** and of **high quality**.

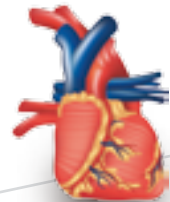
As a biological substance, **blood and its components carry an inherent risk** of causing reactions in patients when they are transfused. Blood may also transmit diseases such as hepatitis and the HIV virus that causes AIDS. To prevent such consequences, careful screening of blood is crucial.

The EU has put **quality and safety standards** in place for the collection, testing and storage of human blood. Obligatory tests need to be carried out before donations are accepted. If there is cause for concern, the EU has established procedures which enable authorities to trace each individual unit of blood or blood component from 'vein to vein'.

In 2006, the EU carried out a survey to check that its recommendations were being implemented, revealing that **safety procedures had improved** across Member States – for example, all EU-15 countries had taken measures to ensure that blood and its components were **fully traceable**.

Tissue and cell transplants without frontiers

Each year, **hundreds of thousands** of patients benefit from a therapeutic treatment based on the use of **tissues and cells** of human origin. These tissues and cells are used not only in reconstructive surgery, such as corneal and hip replacement, but also in the treatment of diseases such as heart diseases, cancer and diabetes and, increasingly, in reproductive medicine. Advances in biotechnology have resulted in the production of tissue-derived products and are opening the door to a promising medical discipline: regenerative medicine.



Tissue:

A functional group of cells.
Includes bones, corneas,
heart valves or bone marrow.
Transplantation of these
tissues and cells can help to
restore an injured hip and
keep a damaged heart beating
or treat diseases such as
cancer and diabetes.

Organ:

Separate part of the body
that performs a specific
function, such as liver,
kidney, skin, heart, lung and
pancreas.



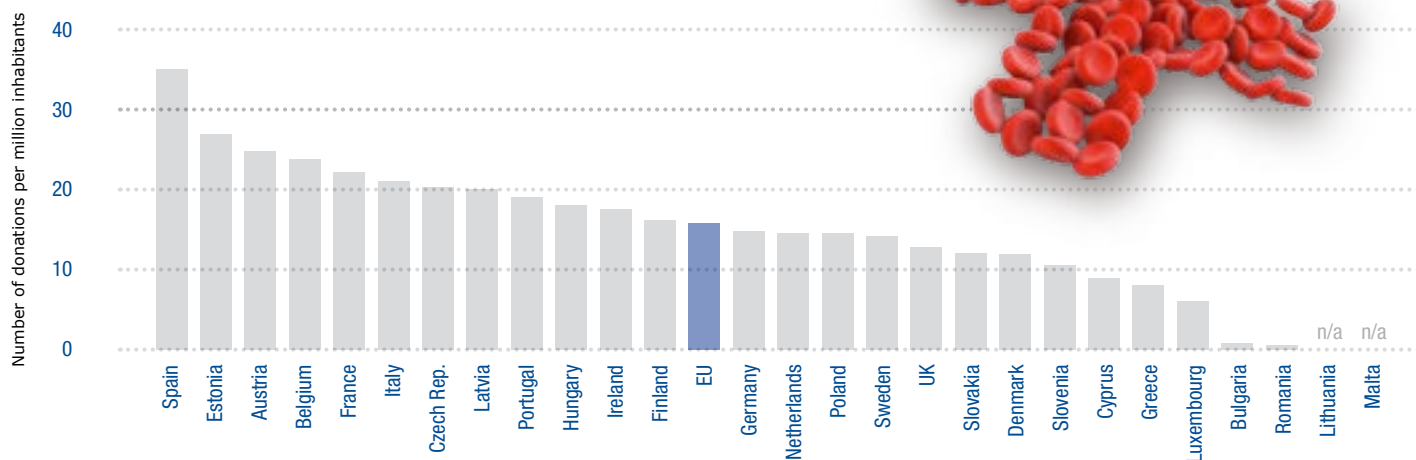
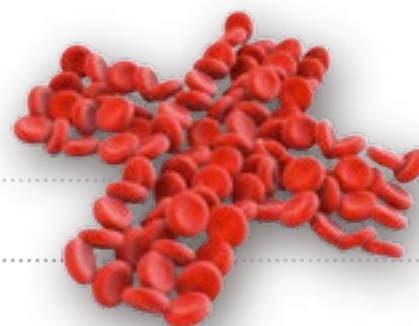
The use of human tissues and cells in therapy also poses the risk of disease transmission to the recipient. This risk could be prevented by establishing basic quality and safety requirements through all steps of the process, from donation to distribution of these substances. The EU has established **principles and common rules** for the safety and quality of these substances in order to ensure a high level of protection of human health.

The gift of life

An organ transplant is the only available life-saving treatment for many patients. With almost **ten people dying every day** in Europe waiting for an organ transplant, and more than **50 000 patients on waiting lists**, demand is much greater than supply and donation rates widely vary between countries. The EU is exploring potential needs for the interchange of organs between countries. It is also working on different initiatives to ensure the quality and safety of human organs used in therapy, to increase donation rates and to avoid organ trafficking.

Organ Donation Rate (2005)

Source: Newsletter of the Council of Europe



For **further information** on EU activities relating to **blood, cells and tissues and organs** visit
 > http://ec.europa.eu/health/ph_threats/human_substance/blood_tissues_organ_en.htm
 or Care for Me / Quality Assurance on the EU Health Portal at > <http://health.europa.eu>

Improving data sharing

To be able to establish an accurate register of data on organ donors and recipients, the EU kick-started the EURO CET initiative in 2005. Funded under the EU's eTEN programme to support electronic networks, it involves 20 partners from 12 Member States. The project collects official and updated figures on the organ, tissue and cell donation and transplantation activities of participating countries. All the statistical data should be available to professionals and the general public via a portal.



> www.eurodonor.org

Rare diseases – together we can fight them

Rare diseases, including those of genetic origin, are life-threatening or chronically debilitating diseases which are so uncommon that special combined efforts are needed to address their effects. Around 6 000-7 000 different rare diseases have already been discovered and, every week, approximately five new diseases are described in medical literature. Between 6% and 8% of the world's population may be suffering from a rare disease. According to ongoing studies, it is estimated that most rare diseases may affect between 1-9 people per 100 000. While these numbers seem small, they translate into a total of between 27 and 36 million Europeans, meaning that it is not unusual to have a rare disease.

Common causes, serious consequences

80% of rare diseases have identified **genetic origins**, involving one or several genes or chromosomal abnormalities. There are also some rare **infectious** diseases, rare cancers, as well as **auto-immune** diseases and very rare **poisonings**. In most cases, signs may be observed at birth or in childhood, but around one third of rare diseases can appear **during adulthood** (see graph).

While rare diseases are considered to have little impact on society as a whole, they pose serious difficulties for sufferers and their families. Many rare diseases are associated with **sensory, motor or mental deficiencies**. Rare diseases can affect life expectancy – and almost **a quarter** are **potentially lethal** at birth or before five years of age. Due to a lack of scientific and medical knowledge, many patients are **not diagnosed**. For those who are, **suitable care** can improve quality of life and increase life expectancy.

Offering encouragement

By supporting research into rare diseases and transmitting the findings, the EU can help to **improve rates of diagnosis**. It can also help in supporting the development of medicines; since 2000, an EU Regulation defines the criteria for a medicine to be considered as an '**orphan drug**' and sets a number of incentives (e.g. 10-year market exclusivity, protocol assistance, access to the Centralised Procedure for Marketing Authorisation) to encourage research, development and marketing of such products. Indeed, the pharmaceutical industry has little interest in developing drugs for which, under normal market conditions, the costs would not be covered by expected sales.

In 2004, the EU established the **Rare Diseases Task Force** to advise and assist in promoting prevention, diagnosis and treatment, and to offer a forum for discussion. This has **45 members**, comprising current and former project leaders of European action and research projects related to rare diseases, and experts from Member States. With its first **Action Programme on Rare Diseases** (1999-2003) and its subsequent **Public Health Programme** (2003-2008), the EU has been continuously supporting initiatives to improve knowledge and access to information on rare diseases.



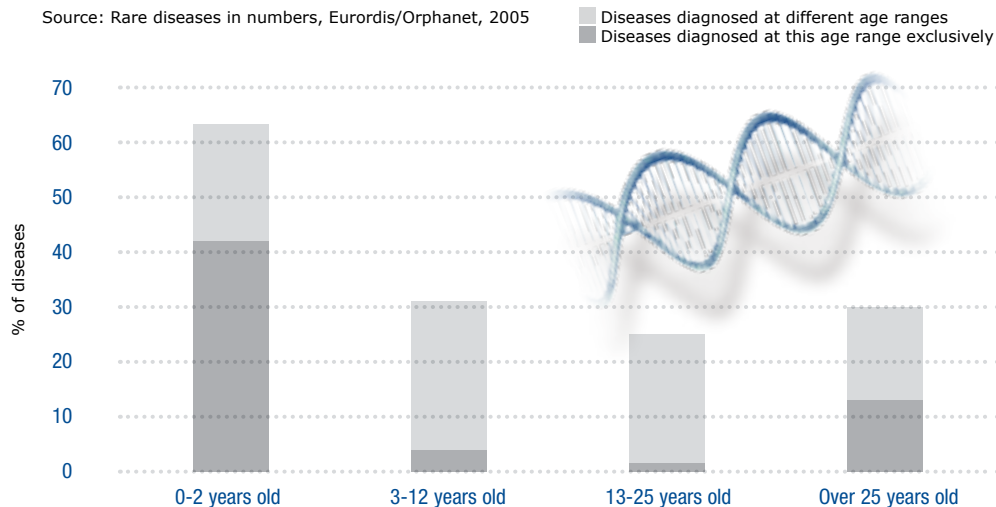
Creating European reference networks for rare diseases

The aim of the European Union when proposing **European reference networks for rare diseases** is to give both health professionals and patients access to high-level expertise in a given field. The idea is that the expertise, rather than the patients, should travel – although patients should also be able to travel to the centres if they need to. This implies that the distance between the patient's home and the centre should not be too great and that the centre be located in an area dependent on the healthcare system of the patient for reimbursement purposes, or in a more distant area but within the framework of an agreement between centres for healthcare delivery. The EU currently **co-finances the setting up of several pilot networks** across Europe.

Age of patient when rare diseases are diagnosed

Sample of 353 rare diseases

Source: Rare diseases in numbers, Eurordis/Orphanet, 2005



N.B.: Figures do not add up to 100% because some diseases are diagnosed at different age ranges.



For **further information** on EU activities relating to **rare diseases** visit > http://ec.europa.eu/health/ph_threats/non_com/rare_diseases_en.htm or Health Problems / Rare diseases on the EU Health Portal at > <http://health.europa.eu> Orphan drugs > http://ec.europa.eu/health/ph_threats/non_com/rare_6_en.htm

Orphanet

Orphanet is a database of rare diseases, established in 1997 by the French Ministry of Health and partly funded by the EU. The database is freely accessible, available in six languages, and contains information on more than 3 600 diseases, an encyclopaedia and a directory of services, such as specialised outpatient clinics, diagnostic laboratories and support groups in Europe. Orphanet has set up the OrphanXchange project to highlight opportunities and facilitate cooperation between academia and industry in the field of rare diseases.

orphanet

> www.orpha.net

EURORDIS

The European Organisation for Rare Diseases (EURORDIS) brings together more than 200 rare disease associations in 16 different countries. The EU has supported some of their projects, such as the Rare Disease Patient Solidarity (RAPSODY) initiative, which looks at the best way to exchange information for patients and their families, compares services across Member States and transmits best practices. EURORDIS carries out a wide range of initiatives including studies on the availability and pricing of orphan drugs, a biobank (collection of DNA, cells and tissues taken from rare-disease patients) and surveys designed to establish the effectiveness of diagnosis of such diseases across Europe.



> www.eurordis.org

Infectious diseases know no boundaries

Together with the development of measures to ease the free circulation of people, the European Union has strengthened its cooperation mechanism to fight infectious diseases. Indeed, certain viruses can spread very rapidly between people, such as influenza viruses or the virus that caused the SARS (Severe Acute Respiratory Syndrome) epidemic in 2003 and 2004, and do not respect national borders. The efficiency of the response will greatly depend on the capacity of public authorities to act quickly and in a consistent manner, from the first signs of an outbreak.

Early warning and response

The first step has been, in 1999, to create a network at Community level to promote cooperation and coordination between the Member States, with a view to improving the prevention and control of communicable diseases in the EU. Later on, in order to ensure a rapid and effective response by the EU to events (including emergencies) related to communicable diseases, the Commission has put in place an **early warning and response system**. This tool, used to ensure rapid exchange of alerts among the Commission, the public health authorities in Member States and the ECDC (see box next page), is a web-based system called EWRS.

In 2005, in the light of past experience (for example, in the case of SARS), the **EU issued a generic preparedness plan** to strengthen the EU's capacity to react to public health emergencies via better coordination and preparedness planning.

Preparing for the next flu pandemic

Experts around the world are warning that the probability of a flu pandemic – i.e. a severe worldwide epidemic caused by a new strain of a human influenza virus – is rising. Worst case scenario predictions suggest that within 2-4 months **up to one third of the population could become ill** and more than 0.3% of these could die. It could cost up to **€180 billion** in lost economic output in the EU.

The European Commission is assisting Member States in strengthening and testing their pandemic influenza preparedness plans and is verifying that the plans include the necessary international coordination arrangements. Regular exercises are carried out. The Commission has also put in place various **communication tools and facilities** in order to coordinate with Member States in case of a crisis.

Close surveillance

Since 1996, the **European Influenza Surveillance Scheme** (EISS), a European surveillance network co-financed by the Commission, has been in action. It intends to reduce the burden of disease associated with influenza in Europe by collecting and exchanging information. EISS publishes a weekly surveillance report on influenza activity in 29 countries, based on data reported by 13 000 physicians and covering around **476 million inhabitants**.

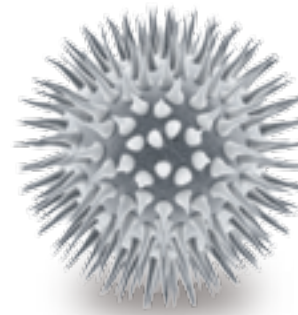


Communicable disease:

Illness caused by micro-organisms and transmitted from an infected person or animal, by direct or indirect contact with them or with their excretions.

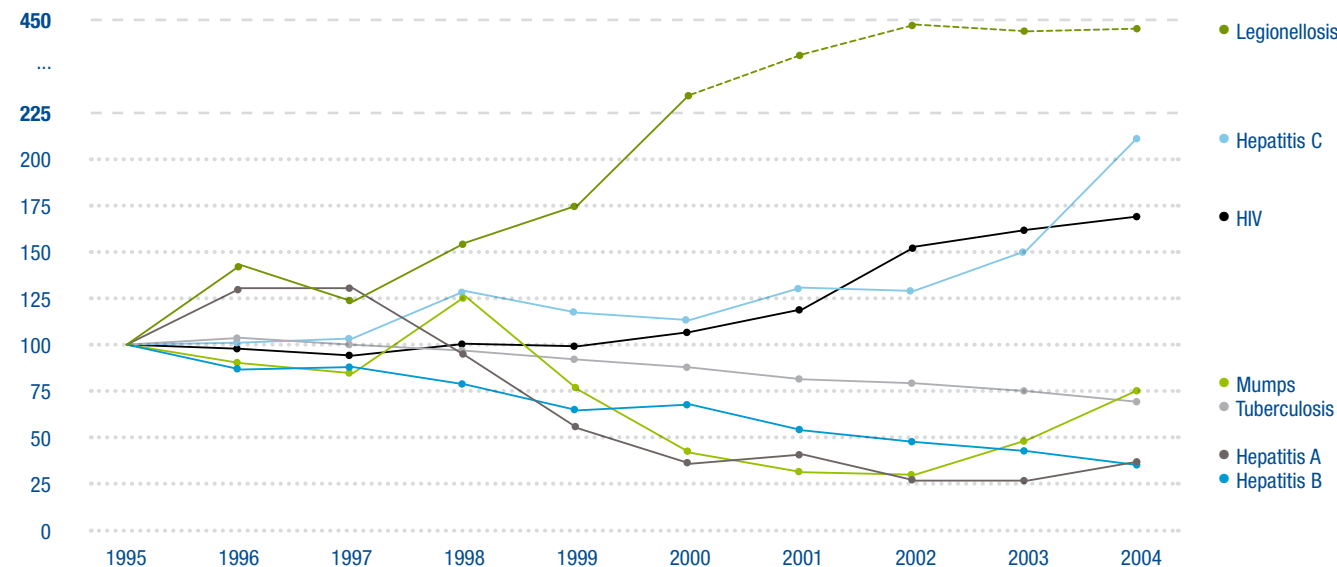
Vaccines: a strong line of defence

The EU is working with Member States and industry to **improve stocks of vaccines and antivirals** and is providing new funding worth €20 million to boost research in this field. Fast-track procedures to authorise and produce future pandemic vaccines have been put in place by the European Agency for the Evaluation of Medicinal Products (EMA). The EU also provided nearly €3.75 million in funding to the **FLUSECURE** project, which started in 2006 to run for three years. It brings together the public and private sectors to develop their capacity for the immediate manufacture of vaccines against a potential flu pandemic.



Comparative trends of incidence of some communicable diseases in the EU (1995-2004)

Index = 100 in 1995 for all diseases.



N.B.: Incidence is measured per 100 000 inhabitants except for HIV (newly diagnosed cases per million inhabitants).



For **further information** on EU activities relating to **disease surveillance and pandemic preparedness** visit > http://ec.europa.eu/health/ph_threats/threats_en.htm or Health Problems / Infectious Diseases on the EU Health Portal at > <http://health.europa.eu>
EISS > www.eiss.org / FLUSECURE > www.flusecure.eu

A dedicated European agency in Stockholm

In May 2005, the EU's European Centre for Disease Prevention and Control (ECDC) became operational, aiming to help strengthen Europe's defences against infectious diseases such as influenza, SARS, tuberculosis and HIV/AIDS. ECDC's mission is to identify, assess and communicate current and emerging threats to human health posed by infectious diseases. In order to achieve this mission, ECDC works in partnership with national health protection bodies across Europe to strengthen and develop continent-wide disease surveillance and early warning systems. In 2006, the Centre had a budget of €16 million and around 100 staff. The Centre's budget will grow to over €50 million by 2010 and its staff to 300. The Centre is located in Stockholm.



> www.ecdc.eu.int

The right to **cross-border care**

All Europeans are entitled to the medical care they need. Having access to high-quality healthcare when and where this is required is their fundamental right. Health and social security systems are primarily the responsibility of Member States, but cooperation between EU countries has been long-established. This ensures that, wherever you travel to within the EU, you can obtain medical treatment and be reimbursed.

One card replaces many forms

To make it easier for EU citizens to receive healthcare in other Member States, in June 2004, the EU launched the **European Health Insurance Card**. This replaced **the previous forms, in particular the well known E 111**. The model for the European Health Insurance Card is identical in all EU countries. Healthcare providers can immediately identify the card, and the person can benefit from a simplified procedure for receiving any medical assistance that might become necessary during a temporary stay.

But it is not only a question of receiving care when becoming ill abroad: in certain cases, patients may be **willing to travel abroad** to get better, faster or cheaper treatments than in their home country. As long as your national healthcare system has given its authorisation, you are free to do this.

Even without authorisation, the European Court of Justice has recognised the right of EU citizens to cross-border care and reimbursement under certain conditions.

Clearer rules for EU citizens and authorities

The EU is working to help shape a **clear, practical framework**, reconciling greater individual choice with the sustainability of health systems overall. One of the main objectives is to achieve **greater legal certainty**, on issues such as:

- terms and conditions for the **authorisation and reimbursement** of cross-border cares;
- provision of **information** to patients on treatments available in other Member States;
- identification of the **health authority** responsible for supervising the medical care and ensuring its **continuity**;
- responsibilities and rights for **compensation** in case things go wrong.



A fundamental right:
Everyone has the right of access to preventive healthcare and the right to benefit from medical treatment under the conditions established by national laws and practice (Art 35 of EU Charter of Fundamental Rights).



Vital cooperation

For certain rare diseases or treatments, collaboration between Member States may be needed. That is why the EU is supporting the development of **Europe-wide networks of centres of reference**, where highly specialised staff and costly high-tech medical equipment can serve several healthcare systems.

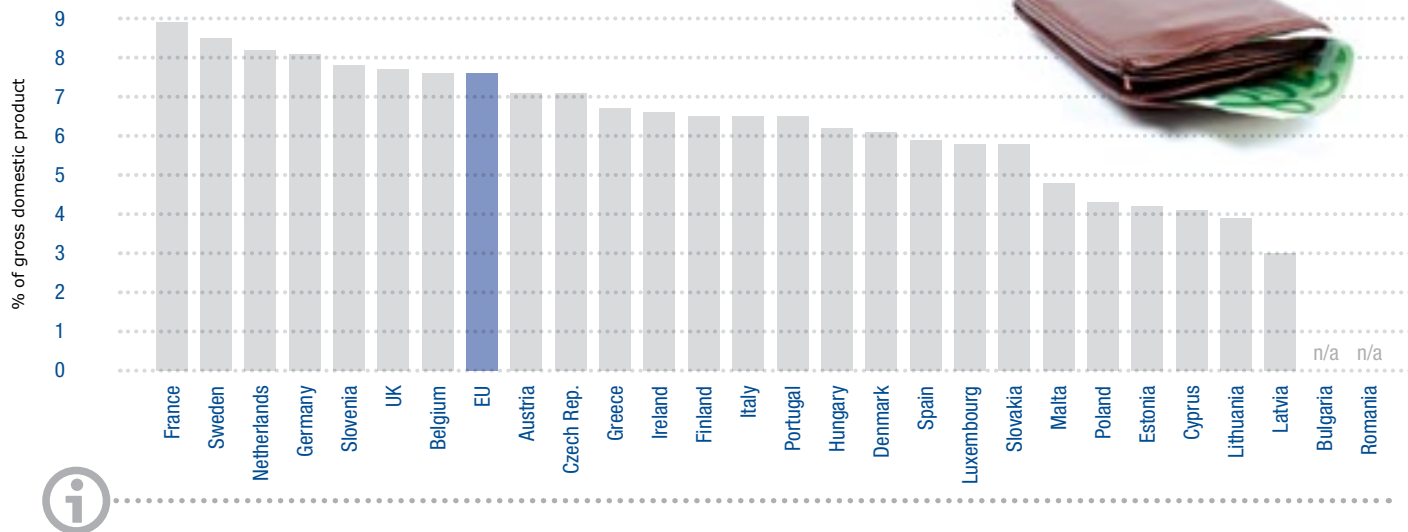
Although healthcare is intended to help patients, sometimes patients suffer harm through errors. The EU is committed to improving cooperation between countries in the field of patient safety, for instance, to ensure that medical treatments are provided on the basis of the best scientific evidence. The EU

supports the development of **Europe-wide cooperation on health technology assessment**, which can help to avoid duplication of resources and could enable the Member States to make best use of new technologies.

Medicines are a special area of **innovation of new technologies**. Today, European patients have access to more medicines and treatments than ever before. However, there are still many diseases and conditions against which treatments do not exist or are insufficient. To pool needs and to enhance the innovation capacity of the European pharmaceutical industry, the Commission has set up a high-level Pharmaceutical Forum, which addresses current challenges in developing new and innovative treatments.

Healthcare expenditure

Eurostat, 2003



For **further information** on EU activities relating to **safety and mobility of patients**

visit > http://ec.europa.eu/health/ph_overview/co_operation/mobility/patient_mobility_en.htm

or Care for Me on the EU Health Portal at > <http://health.europa.eu>

European Health Insurance Card > http://ec.europa.eu/employment_social/social_security_schemes/healthcare/index_en.htm

More freedom to move

To enhance patient mobility by identifying best practices and areas for improvement, the EU is supporting several projects. One of these is Europe for Patients (E4P), which brings together experts from across Member States sharing experience and knowledge on research, health policy and legal issues. The EU also co-finances other research projects in this field such as HealthBasket, Marquis, Euregio or Simpatie-project.

E4P

- > www.iese.edu/en/events/Projects/Health/Home/

HealthBASKET project

- > www.ehma.org/projects/default.asp?NCID=112

Marquis project

- > www.marquis.be

Euregio project

- > www.euregio.nrw.de

Simpatie-project

(Safety Improvement for Patients in Europe)

- > www.simpatie.org

Understanding **more about health**

Gathering and assessing accurate, detailed information on health issues is vital for the EU to effectively design policies and target future actions.

Know more to act better

The EU obtains some of its data on health via reports by **Eurostat** (the European Statistical Office), which contain comparable statistics between countries, such as mortality rates, hospital stays and rates of cancer screening. It also carries out **public opinion surveys** (Eurobarometers) on health-related risks and behaviours, the results of which are made available to the public. Regular reports on health status and on specific health issues are published, as well as a first set of around 400 **health indicators**.

> http://ec.europa.eu/health/ph_information/dissemination/echi/echi_en.htm

The Injury Database (IDB) provides central access to data collected in the Member States under the European Home and Leisure Accident Surveillance System. It contains information on **types and causes** of injuries and provides the basis for **targeted preventative action**.

> <https://webgate.ec.europa.eu/idb>

Another initiative is the **Health in Europe** project which was launched in early 2006. This project involved broadcasting TV and radio documentaries, programmes, and animations focusing on health across Europe, as well as creating an information website.

> http://ec.europa.eu/health/ph_information/dissemination/programme_en.htm

Understanding more about health risks

Identifying health risks is essential for the EU to ensure a high level of health protection for its citizens. Prior to any decision, a thorough risk assessment is carried out on the basis of sound scientific evidence. The EU has set up dedicated agencies, like the European Food Safety Authority, to perform this work and is also assisted by several **committees of independent scientific experts** evaluating potential risks on non-food issues. These committees have delivered opinions on issues such as the potential risks associated with electromagnetic fields, nanotechnologies and indoor air pollution, existing chemical substances, hair dyes and sun beds.



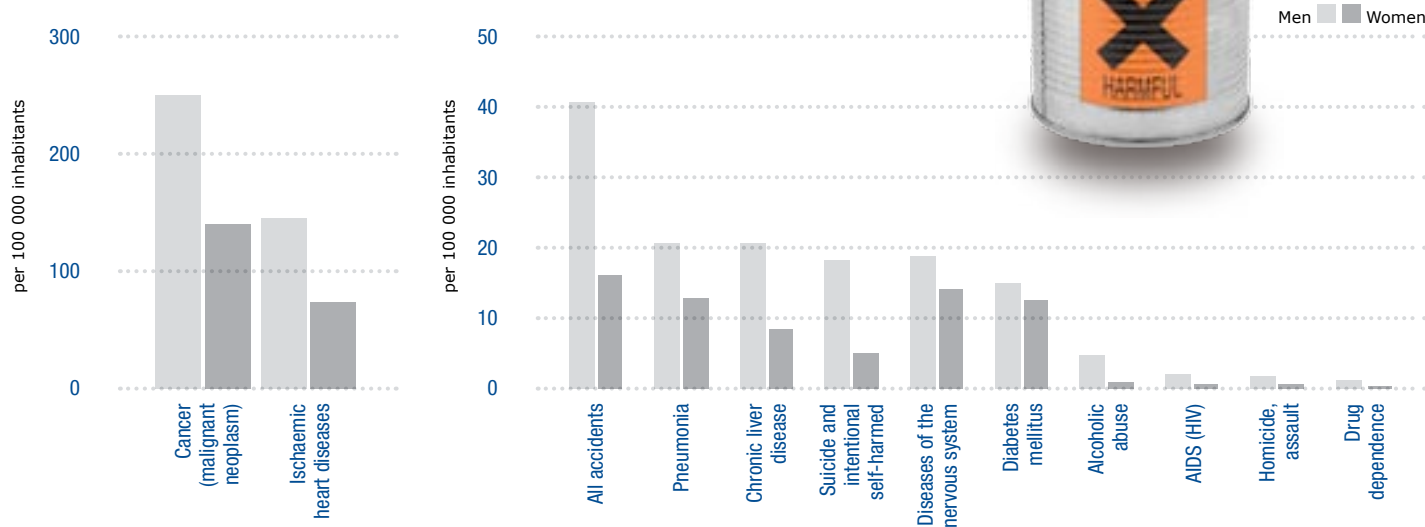
The following committees are active:

- **The Scientific Committee on Consumer Products (SCCP)** deals with safety questions including those on cosmetic products, toys, textiles and clothing;
- **The Scientific Committee on Health and Environmental Risks (SCHER)** handles questions relating to the toxicity and ecotoxicity of chemicals, biochemicals and biological compounds including issues relating to drinking water, indoor air quality and human exposure to mixtures of chemicals;
- **The Scientific Committee on Emerging and Newly Identified Health Risks (SCENIHR)** has a broad mandate to review new and/or complex or multi-disciplinary issues.

Causes of deaths

Standardised death rate, EU-25

Source: Europe in figures, Eurostat yearbook 2006-2007



N.B.: Most causes of death vary depending on people's age and sex. To ensure comparability between countries and over-time a standard European reference population defined by the WHO is used.



EU activities relating to information **collection and dissemination**

visit > http://ec.europa.eu/health/ph_information/information_en.htm

or Health in the EU on the EU Health Portal at > <http://health.europa.eu>

EU non-food Scientific Committees > http://ec.europa.eu/health/ph_risk/committees/committees_en.htm

Health-EU: The Public Health Portal of the European Union

Single access, more information,
healthier choices

The portal is an initiative developed under the European Public Health Programme. It provides a free and easy on-line access to a wide range of reliable information, reports and statistics on 47 health-related issues.

The topics are organised under 6 aspects of citizens' lives:

- > My Health
- > My Lifestyle
- > My Environment
- > Health Problems
- > Care For Me
- > Health in the EU

It has been developed according to the internationally recognised rules on accessibility for disabled and older people and will be made available in 22 official languages of the European Union.



> <http://health.europa.eu>

Further information

If you have questions about Public Health issues:

Consult the **Health-EU Portal** > <http://health.europa.eu>

Consult the **DG SANCO website** > http://ec.europa.eu/health/index_en.htm

Contact the **EUROPE DIRECT** Assistance Service:

See website > <http://ec.europa.eu/europedirect>

Other Useful Addresses:

Executive Agency for Public Health Programme

See website > http://ec.europa.eu/health/ph_programme/agency/agency_en.htm

European Centre for Disease Prevention and Control

See website > <http://ecdc.europa.eu>

EUROSTAT

See website > <http://ec.europa.eu/eurostat>

Directorate-General for the Information Society and Media

See website > http://ec.europa.eu/information_society/qualif/health/index_en.htm

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European Commission

Healthier Together in the European Union

Luxembourg: Office for Official Publications of the European Communities

2007 — 26 pp. — 29.7 x 21.0 cm

ISBN 92-79-04503-2

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