Euro Heart Index

2016
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APPENDIX 2. QUESTIONNAIRE USED IN THE SURVEY FOR THE EURO HEART INDEX 2016 (FH CARE INDICATORS) 69
Mobilising the unexploited potential for better heart care

How far can development of procedures take modern heart care? Quite far, as indicated by the Euro Heart index (EHI) 2016, following up on the situation in 2008. Since then, there has been a general advancement of therapies and procedures, contributing to reducing heart mortality in Europe. What is new is that the success of heart care, prevention and treatment together, has reduced cardiovascular disease from the position of the most prominent cause of death in at least 12 European countries.

What is far from new is the repeated EHI observation that success could be much more common if every country, not only some forerunners, implemented systematic treatment guidelines and protocols to ensure compliance. A number of the EHI indicators point to deviations, anomalies and even black holes in what should be a joint EU/European heart care standard. The 2008 EHI concluded that there was a wide gap between on one hand real-life delivery of care, and on the other the view of the medical profession with regard to compliance to guidelines and best practice. This remains in the EHI 2016, even though the mismatches may have been reduced. The development of quality registries and similar documentation proves to be a strategic investment.

Treatment procedures in acute cardiac care will continue to improve. But that is not enough.

Eight years ago HCP made the conclusion: "There is a “prevention deficit” in most European healthcare systems", pointing to a number of measures to be taken to activate prevention.

Except for pan-European action on smoking, not very much has happened. Prevention remains the big unexploited potential for better heart conditions and survival.

Control of high blood pressure and targeted screening is still rare. Obesity and additional expressions of unhealthy lifestyles are spreading rather than being reduced, sending the signal that government campaigns are not enough to take on a heavy burden related to history, attitudes and wealth. Not much indicates that the European Northwest/Southeast divide in health would be shrinking. It is urgent to advance from policy campaigns to engaging Europeans in taking responsibility for their lifestyle and heart conditions. Yesterday, there was hope for EU initiatives, but the demoralised Brussels of today will hardly be leading the way. Which member state governments will take action?

Johan Hjertqvist
Founder and President
Health Consumer Powerhouse, Ltd.

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1. Summary

1.1 Overview of CVD situation in Europe.

Europe is a continent made up of a variety of societies with different cultures and life styles. The relative contributions of the main risk factors affecting CVD differ in each European country and each society has their own factors that play into the manifestation of a heart disease epidemic. European countries are in different stages of the communicable to non-communicable disease transition. But in most of them, CVD is still the leading cause of death. It causes more than 2 million deaths every year in the region, and therefore are a big threat economically and socially.\(^1\)

For all these reasons, CVD has become a main focus of the European Union and of national health bodies in the last decade. A large number of programmes and initiatives have been funded and implemented all over the region to improve the situation. European and national organisations have been creating guidelines, education, programmes and policy recommendations to promote standards and pathways. In most countries, it is impossible to know how many physicians work according to guidelines. The lack of resources, including doctor training, often limits the capability to work according to them.

In general the European situation has improved since the publication of the first Heart Index in 2008, as the result of a high number of coordinated efforts and measurement at the European, national and regional level. Europe has made progress on lowering heart disease mortality. Comparatively, some countries have done better than others. Beyond the quality of care provided in hospitals, differences in pre-hospital logistics, management and time delays strongly influence patients’ outcomes. Differences in social and economic factors play a crucial role in risk profile, acute coronary care and secondary prevention.\(^2,3,4\)

It is important to remember that CVD can be prevented. Most risk factors associated with CVD are modifiable, including obesity, diabetes, smoking, unhealthy diet, sedentary lifestyle, stress, and excessive alcohol intake. Prevention in the general population is essential to reduce the burden of CVD. Therefore, awareness campaigns and education about healthy life style in the general population and among primary care physicians. As well as, structural regulation measurements (smoke-free environments, limiting marketing of unhealthy food to children, addressing food composition, salt, saturated fat and sugar etc.) are of great relevance. However, because no country faces the exact same risk factors, nor medical or societal conditions, it is impossible to generalize one standard primary prevention approach for all European countries, although broad principles can be established. Monitoring of mortality, morbidity and risk factor prevalence should be robust, population based and well-funded in order to be successful and to reach the right target groups.


\(^2\) Bugiardini, O et al., Exploring In-hospital death from myocardial infarction in Eastern Europe: from the international registry of acute coronary syndromes in transitional countries (ISACS-TC); on the behalf of the working group on Coronary Pathophysiology & Microcirculation of the European Society of Cardiology, Curr. Vasc. Pharmacol. 12 (2014) 903


Additionally, at risk populations need to get regular follow ups for CVD risk factors. Education is needed to empower patients and help them to understand the importance of lifestyle changes, take the suggested medication and when to seek care.

Good **coordination** and **integration** between services and especially between primary and secondary care resulting in reduced waiting time for diagnostic procedures and revascularization treatment. All patients should have timely access to an appropriate range of diagnostic procedures, therapies and long-term follow-up care.

In emergency situations, good coordination and efficient communication after an emergency call with emergency services and ambulances, are essential for timely services to improve outcomes. National and international guidelines recommend that in emergency treatment of patients with STEMI, **primary PCI should be performed within 90 minutes of arrival at the heart attack centre** and within 120 minutes of a patient’s call for professional help (call-to-balloon time, D2B). Most countries, at least those with data available, reach that target. The D2B time has been reduced enormously, in many countries by half, in recent years.

Many patients who suffer myocardial infarction do not know how to act when they have symptoms. Lack of awareness of myocardial infarction increases time from symptom onset to first medical contact. **Local public campaigns** for the general population are needed in order to increase understanding and improve results.

**Enough resources** depending on national situation are required, such as sufficiently trained cardiologists and cardiothoracic surgeons per capita. Priority to fund primary PCI centres with cardiac catheterization labs, with sufficiently **trained** staff, which are easily accessible at all hours (24/7) can have a substantial impact on mortality rates. In general, primary PCI use is increasing very quickly in Europe but huge gaps remain. The number of primary (non-stop) PCI centres is still very uneven between countries. In some countries, and even more in some regions, in Europe it is still difficult to access services 24/7.

### 1.1.1 Secondary prevention

It is still not fully understood that **secondary prevention** is a very important step to improve outcomes and reduce hospital readmission after any ischaemic heart condition. Patients need to get involved in a programme devoted to personalised assessment and modification of risk factors with a purpose-designed exercise programme. Education and support for individual patients, their families and caregivers should be given as well as counselling, behaviour modification strategies and support for self-management. Patients should have regular follow ups with general practitioners (GPs) and specialists. All the above mentioned should be included in post-event rehabilitation. In Europe, access to rehabilitation is quite limited, often because is not or only partially reimbursed. The quality, the length and the content of the programmes available are very diverse.

### 1.1.2 Deployment of pharmaceuticals

There is a large between-country variation of clopidogrel and statin utilization. Both classes of drugs are essential, cheap and generic. However, their use differs widely between European countries. Apparently, there are a number of factors that determine the different utilization of these drugs, such as different national guidelines, reimbursement policies or professional culture. What is food for thought (see Indicators 2.9 and 2.10) is that the deployment rates of these drugs shows less variation between countries if calculated **per capita, without adjustment for CVD prevalence**, i.e. they are prescribed more uniformly **per capita** of the general public than **per capita** for heart patients! The impression is that
doctors are guided more by a common belief on what share of people need these drugs than by really needs them?

1.1.3 CVD registries

The explosion of cardiovascular registries during the past 2 decades has been remarkable. Currently, there are national CVD registries and databases operational in a number of member states. To date, clinical registries of cardiovascular disease have been pre-dominantly established in high income Western countries.

There is still public data missing on important indicators, particularly measuring performance in procedures and outcomes. Even existing registries are not always complete or of optimal quality. Frequently, only patchy sets of data are available. When data exists it is often difficult to access, not only from national registries but also data collections from international organisations. Only in countries like Sweden or the UK where results are regularly published in open sources are the data easy to find.

Compared with other disease areas, data standards and definitions for CVD are better established. Still, important indicators show several “n.a.” (not available) scores due to differences in data standards and methods of collection and recording employed in the different member states, yielding not comparable data (e.g. D2B data or readmission rates).

Some data are collected with slightly different definitions by different organisations, duplicating work for those providing the data. On the other hand, some important data are only recorded on the hospital level.

It is important to measure performances in the region to enable decisions based on robust, global, evidence-based clinical recommendations in order to improve quality of care. For example; in many guidelines, a large proportion of recommended treatments have a level of evidence C, which means that the recommendation is purely based on consensus of the members of the guidelines committee and that reliable data on the recommended diagnostic modalities or treatments are not available in spite of the fact that they are given routinely to many patients.5

While there is a tendency to compare Europe to USA, but it is also vital to understand the situation within Europe, and how individual countries are performing.

1.2 CVD no longer biggest cause of death in 12 European countries

Before the turn of the millennium, it was more or less regarded as axiomatic that CVD was the main cause of death in Europe. Part of this was bad reporting; as death frequently occurs when the heart stops beating, heart failure was often routinely put as cause in death certificates. One such example was Bulgaria, which in the early 2000’s reported CVD as cause of death in 66 % of deaths.

Improvement of cardiac care has significantly changed this situation, as is shown in the Table below⁶.

<table>
<thead>
<tr>
<th>Country</th>
<th>Latest year</th>
<th>Men N of deaths</th>
<th>Year of change</th>
<th>Women N of deaths</th>
<th>Year of change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belgium</td>
<td>2012</td>
<td>15,920</td>
<td>14,299</td>
<td>2010</td>
<td>7613</td>
</tr>
<tr>
<td>Denmark</td>
<td>2012</td>
<td>8226</td>
<td>6442</td>
<td>2010</td>
<td>6654</td>
</tr>
<tr>
<td>France</td>
<td>2011</td>
<td>92,375</td>
<td>64,659</td>
<td>1988</td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td>2012</td>
<td>99,794</td>
<td>99,661</td>
<td>2012</td>
<td></td>
</tr>
<tr>
<td>Israel</td>
<td>2013</td>
<td>5,455</td>
<td>4,819</td>
<td>2009</td>
<td>5,507</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>2013</td>
<td>566</td>
<td>523</td>
<td>2010</td>
<td></td>
</tr>
<tr>
<td>The Netherlands</td>
<td>2013</td>
<td>23,766</td>
<td>18,026</td>
<td>2004</td>
<td></td>
</tr>
<tr>
<td>Norway</td>
<td>2013</td>
<td>5,788</td>
<td>5,630</td>
<td>2013</td>
<td></td>
</tr>
<tr>
<td>Portugal</td>
<td>2013</td>
<td>15,746</td>
<td>13,981</td>
<td>2009</td>
<td></td>
</tr>
<tr>
<td>Slovenia</td>
<td>2010</td>
<td>3,345</td>
<td>3,071</td>
<td>2007</td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td>2013</td>
<td>67,711</td>
<td>53,467</td>
<td>1999</td>
<td></td>
</tr>
<tr>
<td>UK</td>
<td>2013</td>
<td>87,511</td>
<td>79,935</td>
<td>2011</td>
<td></td>
</tr>
</tbody>
</table>

France reached the point, where cancer became a more frequent cause of death than CVD as early as 1988 – that France has a very low CVD rate has been known for 200 years⁷. By 2000, this was achieved also by Spain, with 10 more countries following suit up until 2013.

That this change has to be attributed to improved cardiac care is proven by the WHO⁸. The lifestyle risk factors driving diabetes are largely the same as those driving CVD. An assumption that improved CVD care would not be due to improved healthcare requires the rather drastic conclusion that WHO and world diabetologists are talking through their collective hats!

1.3 What countries provide good CVD care in Europe?

1.3.1 France

France, the winning country has lead the care and treatment of cardiovascular disease with their successful best practice guideline programs. The National Authority for Health has been working with all major stakeholders in focusing on developing and sharing best practices, based on international recommended guidelines. These monitor and record the outcomes of care and treatment from the moment the patient experiences chest pain, the reperfusion treatment to discharge and finally the follow-up appointments of the heart patient.⁹

Success in preventing and treating CVD has led to large decreases in CVD in a number of countries including France. Mortality from CVD has decreased over the past 30 years, being in France 38 % lower than the OECD average, and the lowest in Europe.

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⁷ Blake, S. Clinical and Pathological Reports (monograph), Newry, N. Ireland (1818)
⁹ Cardiovascular Disease and Diabetes: Policies for Better Health and Quality of Care (France). OECD. (2015)
France collects data; France (French Registry on Acute ST-elevation and non-ST-elevation Myocardial Infarction, FAST-MI)\(^{10}\) and monitors performance. Additionally, audits on prevention are regularly performed through CV risk assessments, national surveys, and for some specific diseases through periodic quality controls according to evidence-based care that are conducted by various national health agencies/scientific institutions.

At primary prevention level France continues to promote a healthy lifestyle. It has a whole range of measurement and programs in place at national and/or regional level to keep improving the situation. These projects are conducted and coordinated by numerous stakeholders.

Traditionally, French eating habits did not include nibbling small snacks between meals, but consisted of a light breakfast and two good meals for lunch and dinner. What is surprising is that the French obesity rate (see Indicator 1.1), which was reported as 12\% ten years ago, has risen in the latest WHO data to 23\%, which is higher than the number for Germany!

The close and trusting relationship that general practitioners (GPs), have with their patients is also a rarity among European nations. This allows general practitioners to stimulate primary prevention like lifestyle changes such as smoking cessation or even open conversations to reduce obesity and alcohol consumption. The GPs also play an important role after discharge from hospital, lifestyle risk factor follow ups and medication management\(^{11}\).

Funding is available to reimburse patients and their medication. France is one of those countries with a high non-adherence rate to medication guidelines, in the sense that they seem to be using very large amounts of medicine in relation to CVD prevalence. This is true for most drugs – France has the highest \textit{per capita} consumption of pharmaceuticals of any European country.

\textbf{1.3.2 Norway}

Standing proudly in second place after France and missing the first place only because of a couple of missing data items. In Norway, the mortality rate from cardiovascular disease has decreased over the past 50 years as in most other European countries. The actual mortality rate is 22\% lower than the OECD average\(^{12}\). Nevertheless, cardiovascular diseases are still the main causes of death and a major contributor to chronic disease.

Norway has put significant efforts into health promotion and fighting risk factors of cardiovascular disease. Aggressive introduction of tobacco advertising bans and, more recently, smoking bans by the Norwegian Health Authorities has led to a rapid decline in smoking rates in Norway in the past decade, although smoking rates among women have increased and are now higher than among men. This is likely to be an effect of non-EU member Norway being the only country besides Sweden, where oral moist snuff can be

\(^{10}\) Hanssen M et al., French registry on acute ST-elevation and non ST-elevation myocardial infarction 2010. FAST-MI 2010, Heart 98 (2012) 699–705


\(^{12}\) Cardiovascular Disease and Diabetes: Policies for Better Health and Quality of Care (Norway). OECD.(June 2015).
sold. This is the most likely explanation for these two countries being unique in having fewer male than female smokers.

However, some risk factors are prevalent and increasing, as overweight, prevalence of high cholesterol or blood pressure. Furthermore, the levels of alcohol consumption in Norway have increased by 36% over the past 20 years despite having some of the strictest alcohol regulations and the highest alcohol tax in the OECD13.

Norway is making efforts to promote healthy lifestyles by using all available tools such as regulations, education, incentives, as well as health care programmes and services to work in unison and strengthen their effectiveness. Norway has implemented strategies to promote a healthier diet since the 1970s, and is intensifying its efforts to tackle risk factors of CVD and diabetes through the introduction of nutrition policies in recent years.

All in all, Norwegians are a healthy population and most patients diagnosed with cardiovascular disease are older than the average in Europe.

Norway’s health system prides itself of its good resources and has good capability in primary and secondary care, with waiting list problems as the main drawback.

Until 2012, Norway was the only Nordic country without a national specific National Cardiovascular registry. The registry is national, combined registry (core registry + quality registries), person identifiable and compulsory.

1.3.3 Sweden

Sweden comes in third in the EHI 2016. Even with government initiatives, Sweden struggles with primary prevention of obesity and sedentary lifestyles. A national registry for cardiac care exists to monitor the adherence to recommended international guidelines for myocardial infarction. Since 2009, SWEDHEART audits, lists and follows up every patient that has suffered heart attacks. This information provides live feedbacks on the outcomes and performance of cardiovascular care and treatment in Sweden. A recent report from SWEDHEART stated that in Sweden there is a need to reduce the mortality rate of younger women after a heart attack.

In addition to this, Sweden also has a registry that monitors secondary prevention after heart surgery in the intensive care called SEPHIA. Rehabilitation is available to the patients and reimbursed either by the national health or private insurance. It also has been noted that in Sweden the implementation of the follow up guidelines is not standardised, nor do they emphasise family involvement in the follow-up process.

The strong and lasting Swedish tradition of healthcare quality registries helps to explain its high position in the EHI; just as in other sectors of society, Swedes trust authorities to have access to data about almost anything. Hence, Sweden is one of very few countries to get zero n.a. scores.

Meanwhile, the public health sector continues to encourage lifetime projects that promotes healthier lifestyle. Primary prevention is taught to all students or workers that have contact with health care even in universities. Criticism still exists that there is not sufficient cardiac specialised nurses or dieticians to carry out heart-related primary prevention in non-acute settings. General practitioners of medicine can even prescribe exercises specific to individual patient needs. The follow up on whether the patient carries out the advice is

unclear. There are sufficient Cardiologists available to the needs of the population, who encourage cardiac rehabilitation as well.

It is unusual for Sweden to get as many Green scores for accessibility as it does in the EHI, as there is an attitude problem in Swedish healthcare creating some of the worst waiting time problems anywhere in European healthcare. One reason for this is probably that some EHI wait indicators are measures on process efficiency rather than classical waiting times for an operation etc. “Attitude problem” is because the waiting lists are not linked to lack of resources, but rather to a decades-old culture, where the problem of waiting for healthcare services has become an accepted phenomenon.

1.3.4 Luxembourg

As was observed already in the EHI 2008, cardiac care in particular benefits from good financial resources. The main reason for Luxembourg not finishing higher in the EHI is probably that it is handicapped by “n.a.s” in the score sheet. That in turn is very likely due to the wise realization that it does not make sense for a country of 400 000 people to do all advanced healthcare at home, and Luxembourg does allow its citizens to freely seek care in other (neighbouring) EU countries.

The fact that a significant portion of advanced care for Luxembourgish is performed abroad naturally complicates data acquisition.

1.3.5 Slovenia

After the Groote Schuur hospital in Cape Town, the world’s first heart transplant was performed in Ljubljana. It seems that the strong tradition of excellence in cardiac care still reigns – the 5th position of Slovenia in the EHI is far ahead of any other Eastern European country.

Slovenia, struggling with budget restrictions and limitations in the health care system but has managed very well to keep an effective CV care. Slovenia has negotiated for good prices for medication.

Since 2001, there is a national programme in place that focuses on primary cardiovascular prevention. It aims to educate, monitor and manage the general population at having a healthy lifestyle. These programmes are introduced in school and their messages continue into the workplace of adults.

Slovenia has been able to continue its high quality cardiac rehab programmes. Focus on the patient out of the acute phase of Myocardial Infarct which is a rarity in a country with limited economic means.

2. Areas for improvement: Prevention and more prevention

Cardiovascular disease can be prevented in various ways:

2.1 Primary prevention

Primary prevention consists of interventions to prevent new cases. If successful, it can result in lower health care expenditures and reduced health loss. It is well-documented
that the absence of tobacco smoking, a healthy diet, physical activity and low alcohol consumption are likely to prevent cardiovascular disease, chronic obstructive pulmonary disease (COPD), type 2 diabetes and various cancer types.

There are hundreds of measurements and programmes in place in Europe, to improve and modify population life style. Countries finally realized that the burden of a number of modifiable risk factors that need to be changed in the general population to reduce the risk of non-communicable diseases. Looking at the data collected and being aware that the situation is in general not improving in most countries, it seems that, despite the development of preventive programmes, their implementation may be deficient.

European data on obesity shows a very worrying situation with several countries (almost one third) having more than 25 % of the adult population considered to be obese (BMI >30), and an increasing number of young children becoming either obese or overweight.

Physical exercise habits are changing. Previously, it exercise was part of everyday life. Now, the World Health Organization (WHO) estimates that physical inactivity is associated with 3.2 million deaths worldwide each year\(^\text{14}\). Sedentary life is still very dominant but slowly countries are fostering the practice of physical activity and the reduction of sedentary lifestyle by providing environments conducive to that practice: workplace, school time, transport and travel, etc.

There is still a need for governments to focus on promoting physical activity in a number of settings with more intensity; e.g. at school so kids learn from early ages to move and to have fun through different physical activities. Also, it is important for societies with an ageing population to promote physical activity in day care centres and housing for older people.

There is an increased number of people in the community consuming convenience food, high in fat, salt, sugar and calories. The average sugar consumption is too high in Europe. WHO presented in 2015 a new guideline in which is recommended to adults and children to reduce their daily intake of free sugars to less than 10 % of their total energy intake. Free sugars refer to monosaccharides (such as glucose, fructose) and disaccharides (such as sucrose or table sugar) added to foods and drinks by the manufacturer, cook or consumer, and sugars naturally present in honey, syrups, fruit juices and fruit juice concentrates. “Free sugar“ does not refer to the sugars in fresh fruits and vegetables, and sugars naturally present in milk, because there is no reported evidence of adverse effects of consuming these sugars.

On the other hand the consumption of fresh fruit and vegetables is insufficient (400 grams/per day is recommended by WHO) in almost all countries in Europe. In 15 countries, the consumption is estimated to be below 300 grams per person per day.

There are very different approaches to the problem; the most successful examples in Central and Northern Europe, with more active intervention promoting healthy food intake and promoting activity in kindergarten and schools, among migrant communities or housing for the elderly.

Alcohol consumption has been deeply embedded in European culture for centuries. The current volume of alcohol consumption in the EU has been stable for several years at a high level. Europe is the region with the highest levels of alcohol consumption per person

\(^{14}\) World Health Organization (2011). New physical activity guidance can help reduce risk of breast, colon cancers:
in the world. Patterns of drinking vary, with more irregular heavy drinking in Nordic and CEE countries.

In 2010 a global strategy to reduce the harmful use of alcohol was presented by the WHO, and afterwards the European action plan to reduce the harmful use of alcohol 2012–2020 was launched, endorsed by many countries. It includes a wide range of policies and programmes that are relatively easy and cheap to implement, can reduce the harmful use of alcohol, promote health and well-being, improve productivity, and enhance human, health and social capital across the life course from birth to old age. These are only guides that explain to countries the best ways to fight and improve the situation, but then countries need commitment to reduce alcohol consumption.

Smoking rates in Europe have been steadily reducing since 2003, due to implementation of tight tobacco control laws and tobacco control interventions (publicising the health risks, raise taxes, banning smoking indoors and advertising, and providing support for those trying to quit), but still countries could do more. In most European countries, tobacco is still affordable for most people. Some smokers also get around the taxes by buying counterfeit or smuggled cigarettes; these make up around one tenth of global sales. Furthermore, while many more countries are introducing smoking bans, these can be circumvented: in France and Ireland, people smoke in covered outdoor patio areas. In Greece and Portugal, locals frequently ignore the rules altogether.

In general, large and frequent mass campaigns to raise awareness among the general population, promoting active and healthy life styles, and easy and inexpensive access to healthy food and physical activities would be a good combination.

To improve the situation and change life styles, communities need to adopt integrated radical changes that are not confined to the health sector. Health promotion programs from primary care health workers, community workers, teachers and educators can bring a major societal impact, as because of their regular contact with patients, elderly people, children and all kinds of individuals they have good opportunities to induce healthy habits into the community.

2.2 Secondary prevention

By definition, Secondary prevention consists of tailored long term help to prevent new cardiovascular events or complications in patients with diagnosed CVD. This involves medical care, modification of behavioural risk factors, psychosocial care, education and support for self-management (including adherence to prescribed medicines), which can be delivered in various settings. Rehabilitation programs normally consist of three phases: I) in-patient, II) out-patient, III) long-term intervention. Cardiac rehabilitation improves exercise tolerance, blood lipid levels, sense of general wellbeing, chances of quitting smoking, and survival rates\textsuperscript{15,16}.

\textsuperscript{15} Servey J et al; Cardiac Rehabilitation: Improving Function and Reducing Risk. \textit{Am Fam Physician}. 2016 Jul 1;94(1):37-43.

\textsuperscript{16} Kikkenborg Berg S et al; Comprehensive cardiac rehabilitation improves outcome for patients with implantable cardioverter defibrillator. Findings from the COPE(ICD) randomised clinical trial. European Journal of Cardiovascular Nursing 2015, Vol. 14(1) 34–44.
The cost-effectiveness of cardiac rehabilitation and multidisciplinary management is well described in the literature in other regions of the world, such as Australia\textsuperscript{17,18}, but in Europe more cost-effectiveness evaluations are needed. Large variations between European countries are observed in the provision of services for lifestyle and risk factor management, and also in the use of cardioprotective medications in patients and the provision of cardiac prevention and rehabilitation.

### 2.2.1 Access

In order to implement high quality secondary prevention it is necessary to provide flexible and integrated service options, linking the different rehabilitations needs requested. These need to be tailored to the needs of populations (patient-centered care) and individuals, appropriate to various stages of CVD management (acute, subacute and ongoing care), easy to access, with enough funding and short waiting times. Furthermore, it is essential that countries develop and fund a framework for comprehensive secondary prevention of CVD within primary care, special for long term outpatient prevention (Cardiac rehabilitation, phase III). Supervision of patient adherence to prescribed lifestyle behaviour and constitutes a joint effort of patient, primary care physician and cardiologist.

As described in Euroaspire IV and SURF audits and also looking at the results of the EHI, cardiac rehabilitation and home care services in Europe are underused and not provided in many countries the form of home care. In general, there are poor referral and low participation rates. Wide variations exist between countries in the participation in rehabilitation and in the provision and quality of home care services. Programmes offered are of different length and variable content. The personnel providing home care have a very different range of qualifications.

### 2.2.2 Funding

Secondary prevention of CVD represents a significant proportion of client need and costs. However, current funding for secondary prevention services for CVD and cardiac rehabilitation is fragmented, largely discretionary, and fails to guarantee the continuity of existing services. The resulting uncertainty impedes long-term service planning, prevents the implementation of quality-improvement initiatives, and restricts health professionals’ capacity to provide good clinical services.

### 2.2.3 Data for primary/secondary prevention

When measuring at population level, one main problem with secondary prevention is that many of the preventive measures are common for primary and secondary, and it is very difficult to find separated data that distinguish between the two groups (general population and CVD patients). All indicators selected to separately measure secondary prevention parameters had to be discarded because of the difficulties to collect data.

Fundamental for the process of quality improvement is continuous review of plans and activities, and assessment of the degree of targets are reached. Therefore, development of a nationally agreed minimum data set (including demographics, measures of clinical

\textsuperscript{17} National Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand (Chronic Heart Failure Guidelines Expert Writing Panel). \textit{Guidelines for the prevention, detection and management of chronic heart failure in Australia}, 2006. Melbourne: National Heart Foundation of Australia, 2006.

outcomes and service use) and a system that ensures consistent data collection by all CVD services is recommended. Also, development of national key performance indicators based on realistic procedural and clinical targets. These performance indicators should include measures of referral to secondary prevention services, attendance, retention and completion, and clinical outcomes (e.g. readmission to hospital). Incorporating an automated process in which patients with CVD-related diagnostic codes are identified and referred to cardiac rehabilitation services for follow up within e-Health systems would be highly desirable.
### 3. Results in the Euro Heart Index 2016

#### 1. Prevention

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<td>5</td>
<td>12</td>
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</table>

**Euro Heart Index 2016**
3.1 Total scores and ranking in Euro Heart Index 2016

Graph 3.1 Total scores and country rank in EHI 2016.

As the graph shows, there is some cluster formation in the EHCI ranking; a set of top 7 countries, scoring 808 – 864 points, followed by another set of 7 countries also having good cardiac care, scoring 739 – 767 points. Below the German 739 points, scores start falling away.
**4. Results in “Tetrathlon”**

The Euro Heart Index 2016 is made up of four sub-disciplines. As no country excels across all aspects of measuring a healthcare system, it can therefore be of interest to study how the 30 countries rank in each of the four parts of the “tetrathlon”. The scores within each sub-discipline are summarized in the following table:

<table>
<thead>
<tr>
<th>Sub-discipline</th>
<th>Top country/countries</th>
<th>Top Scores</th>
<th>Maximum score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Prevention</td>
<td>Italy, Luxembourg</td>
<td>240</td>
<td>300</td>
</tr>
<tr>
<td>2. Procedures</td>
<td>Germany, Netherlands</td>
<td>227</td>
<td>250</td>
</tr>
<tr>
<td>3. Access to treatment/care</td>
<td>France, Luxembourg, Netherlands, Norway, Sweden</td>
<td>178</td>
<td>200</td>
</tr>
<tr>
<td>4. Outcomes</td>
<td>Slovenia, Sweden</td>
<td>250</td>
<td>250</td>
</tr>
</tbody>
</table>

France performed good in all sub-disciplines but is best only in access to treatment/care. Seems a fair victory, anyway, for the country with what is by far the lowest CVD mortality in Europe!

There is no country close to the maximum score of 1000. The 2nd and 3rd positions are occupied by two traditional good performers: Sweden and Norway.
5. Production of the EHI 2016

The EHI project is an effort to compile information about CVD care provision in Europe. The EHI project started in January 2016. A total of 30 countries were included in the project, the 28 EU member states plus Switzerland and Norway.

It has been important to have a mix of indicators in different areas; Prevention, Access to services, Service provision and care as well as indicators of “hard facts”-nature showing healthcare quality in Outcomes terms. Compared with other projects there are fewer indicators reflecting topics related with patients information and rights.

Initially, the project also contained some indicators on stroke. A discussion with members of the European Stroke organisation and experts of the panel helped with the decision of concentrate on the present set of indicators.

The high number of data bases collecting indicators related with cardiac care was a nice surprise. However, it was quickly realized that apart from those indicators collected internationally by organisations such as OECD or WHO, and even though the sources of information are growing, the lack of uniformity within Europe and the lack of coordination and sharing made difficult to collect data on a high number of indicators. Therefore, there were indicators of high interest which have proved impossible to be collected.

The project was met with positive interest from national bodies and other health officials and stakeholders around Europe. A large number of professionals were happy to contribute providing indicator data and other information about their own countries. The problem was that several indicators are not being collected by national bodies but by different working groups inside of the National cardio societies. Therefore, the HCP is grateful for the high participation of physicians in this project. Their views and knowledge and data provision have been essential to complete the EHI. The completion of this study would not have been possible without the generous support of authorities and health professionals in many countries. This report has benefitted from the expertise and material received from many health officials, health professionals, and health experts. They spent time to study and find the information the HCP was requesting.

The members of the European Heart Network (EHN) actively supported this project by providing feedback on a number of crucial indicators through filling out an online questionnaire (See Appendix 1). At a late stage, some EHN national organisations had been reviewing the single country score sheet for their countries.

The European Atherosclerosis Society (EAS) and the European FH patient network endorse and actively collaborate and contribute to the Heart Index, primarily by helping with the design of the FH indicators in the project. A number of board members from both organisations assisted us on; indicators selection and definition, to measure FH care situation in Europe. The data on these indicators had been exclusively collected through an e-questionnaire (See appendix 2) that both organisations had been distributing among their members. Three indicators out of the 8 collected through the questionnaire were included in the matrix. The remaining additional information is presented in the discussion in Section 8.5.

To stimulate feedback activities from national bodies and increase understanding of the project, a very high number of National health officials, public health responsible and clinicians in the countries of interest were visited by the EHI team, with very positive results.

In connection with the project a number of countries organised meetings to which all relevant stakeholders were invited. The purpose of the meetings was to discuss data availability and data quality before sending it to the HCP.
One of the aims of this project has been to demonstrate the situation of data availability on the European level. The HCP team spent time discussing the quality and the representativeness of the data sent to us with country representatives and public health experts.

5.1 Indicator areas (sub-disciplines)

The Index is built up by 31 indicators on cardiac care grouped in four sub-disciplines as shown in the Table below:

<table>
<thead>
<tr>
<th>Sub-discipline</th>
<th>Number of indicators</th>
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<tbody>
<tr>
<td>1. Prevention</td>
<td>10</td>
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<tr>
<td>2. Procedures</td>
<td>11</td>
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<tr>
<td>3. Access to treatment/care</td>
<td>6</td>
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<tr>
<td>4. Outcomes</td>
<td>4</td>
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</table>

The expert panel members made a systematic and organized scoring on a long list of very interesting indicators on cardiac care; based on Relevance, Scientific Soundness and Feasibility. This exercise ended up with 44 indicators all considered relevant for the Index.

From those, 12 had to be discarded; some for data availability reasons, some because the definition of the indicator was too unspecific. 4 indicators were related to stroke; as explained above, those were omitted in the index.

One indicator with information on screening of CVD risk factors is presented as additional information in an extra table (See Section 8.1.8).

Additionally, information on 8 indicators on FH care was collected (3 are included in the matrix). These indicators were selected and defined by the board of the EAS and FH patient network, as previously explained. The data was collected exclusively through an online questionnaire provided to members of EAS, and national representatives of the European FH patient network. Only data on 3 of the 8 indicators were included in the matrix, the other data collected is presented and discussed in Section 8.5.

5.2 Scoring in the EHI 2016

The performance of the respective national healthcare systems were graded on a three-grade scale for each indicator, where the grades have the rather obvious meaning of Green = good (☑), Amber = so-so (☒) and red = not-so-good (☐). A Green score earns 3 points, an Amber score or “Not applicable” (n.ap) score 2 points and a Red score or a “not available”, (n.a.) earns 1 point.

Since 2006, the same methodology has been used: For each of the sub-disciplines, the country score is calculated as a percentage of the maximum possible (e.g. for Prevention, the score for a state has been calculated as % of the maximum 3 x 10 = 30).

Thereafter, the sub-discipline scores were multiplied by the weight coefficients given in the following section and added up to make the final country score. These percentages were then rounded to a three-digit integer, so that an “All Green” score on the 31 indicators would yield 1000 points.
5.3 Weight coefficients

The possibility of introducing weight coefficients was discussed already for the EHCI 2005, *i.e.* selecting certain indicator areas (Sub-disciplines) as being more important than others and multiplying their scores by numbers other than 1.

For the EHCI 2006 explicit weight coefficients for the five sub-disciplines were introduced after a careful consideration of which indicators and sub-disciplines should be considered for higher weight. Since then all HCP indices include sub-discipline weight coefficients.

The weights are normally discussed with the members of the expert panel. It is also taken into consideration the number of indicators in each sub-discipline and the quality of the data acquired for each indicator.

Normally, the Outcomes sub-discipline is given the highest weight in HCP Indices. "My chances of getting well", *i.e.* Outcomes, is frequently stated by patient surveys as the most important aspect of a healthcare system. The relative weight for outcomes is 250 points but since there are only 4 indicators in that sub-discipline, a green score contributes 62.5, the highest in the index. Prevention was the discipline with the second highest weight, as it has been commented in the whole report, prevention should be the key stone of cardiovascular care.

In the EHI 2016, the scores for the four sub-disciplines were given the following weights:

<table>
<thead>
<tr>
<th>Sub-discipline</th>
<th>Relative weight (&quot;All Green&quot; score contribution to total maximum score of 1000)</th>
<th>Points for a Green score in each sub-discipline</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prevention</td>
<td>300</td>
<td>30.00</td>
</tr>
<tr>
<td>Procedures</td>
<td>250</td>
<td>22.73</td>
</tr>
<tr>
<td>Access to treatment/care</td>
<td>200</td>
<td>33.33</td>
</tr>
<tr>
<td>Outcomes</td>
<td>250</td>
<td>62.50</td>
</tr>
<tr>
<td><strong>Total sum of weights</strong></td>
<td><strong>1000</strong></td>
<td></td>
</tr>
</tbody>
</table>

Consequently, as the percentages of full scores were added and multiplied by (1000/Total sum of weights), the maximum theoretical score attainable for a national healthcare system in the Index is 1000, and the lowest possible score is 333.

It should be noted that, as there are not many examples of countries that excel in one sub-discipline but do very poorly in others, if at all for data availability problems, the final ranking of countries presented by the EHI 2016 is remarkably stable if the weight coefficients are varied within rather wide limits.

Other sets of scores for Green, Amber and Red, such as 2, 1 and 0 (which would really punish low performers), and also 4, 2 and 1, (which would reward real excellence) have been tried. The final ranking is remarkably stable also during these experiments.

5.4 Regional differences within European states

The HCP is well aware that many European states have very decentralised healthcare systems. Not least for the U.K. it is often argued that “Scotland and Wales have separate NHS services, and should be ranked separately”. The uniformity among different parts of the U.K. is higher than among regions of Spain and Italy, Bundesländer in Germany and possibly even than among counties in tiny 10 million population Sweden.
Grading healthcare systems for European states does present a certain risk of encountering the syndrome of “if you stand with one foot in an ice-bucket and the other on the hot plate, on average you are pretty comfortable”. Italy, having the most dramatic socioeconomic differences inside any European country (GDP/capita of Lombardy being three times that of Calabria) shows this in almost every HCP Euro Index – Green scores in Lombardy and Red scores in Calabria come out as a lot of Yellow scores for Italy. This problem would be quite pronounced if there were an ambition to include the U.S.A. as one country in a Health Consumer Index.

As equity in healthcare has traditionally been high on the agenda in European states, it has been judged that regional differences are small enough to make statements about the national levels of healthcare services relevant and meaningful.

5.5 How to interpret the Index results?

The first and most important consideration on how to treat the Euro Indexes results is: with caution!

Just like any of the Euro Indexes, also the EHI 2016 is an attempt at measuring and ranking the performance of healthcare provision. The results definitely contain information quality problems.

It is important to emphasize that the Euro Indexes, including the Euro Heart Index 2016, displays consumer information, not medically or individual data.

While by no means claiming that the EHI 2016 results are of dissertation quality, the findings should not be dismissed as random findings. The Index is built from the bottom up – this means those countries that are known to have quite similar healthcare systems should be expected not to end up far apart in the ranking.

The Euro Heart Index 2016 is an attempt at measuring and ranking the performance of healthcare provision of the countries included in the study. Most of the data presented has been reviewed more than once not only by HCP staff but by different stakeholders and experts in countries. Additionally, the HCP team received feedback on some indicators through an online questionnaire (See Appendix 1) from national representatives of EHN and physicians, which provided an opportunity to double-check the situation and set a number of questions, in case some of the information collected was incomplete or inconsistent.

The HCP team had been disappointed to find some data, particularly on indicators on Procedures, Access to treatment and especially in Outcomes, quite patchily collected. The HCP finds it far better to present the results available to the public, and to promote constructive discussion rather than staying with the only too common opinion that as long as healthcare information is not a hundred percent complete it should be kept in the closet.

It is important to explain at this point that even though an n.a. always means “not available” in the EHI, the reasons for having an n.a. can have many different reasons. Most frequently, n.a. means that the data is officially not publicly available in the country, e.g. due to poor reporting or lack of registries. It happens that data for an indicator is collected, but somehow the definition of the indicator and therefore data that countries can provide are not compatible with each other or with the main body of data collected for the EHI.

That is the case for the indicator “Readmission rates”, European countries measure and record different time periods for readmissions.

Finally, it is important to mention that the exact position that a country gets in the ranking should not be subject to overly detailed analysis. Small variations in the scoring in any of the indicators may alter the rank. For purely mathematical reasons, this is particularly true for countries in the middle of the ranking (Section 3.1), where Switzerland/Denmark in 8th place and Germany in 14th place are separated by only 28 points. However, it is very relevant if a country is on the top 5 of the ranking, in the middle or at the bottom.
Previous experience from Euro Indexes indicates that consumer ranking by indicators of this nature are looked upon as important tools to reflect healthcare service quality. The HCP hopes that the EHI 2016 results can serve as inspiration for how and where European cardiac care can be improved.

6. Background of the Health Consumer Powerhouse

Since 2004 the HCP has been publishing a wide range of comparative publications on healthcare in various countries. The first Index was the Swedish Health Consumer Index in 2004 (also available in English): by ranking the 21 county councils on 12 basic indicators concerning the design of "systems policy", consumer choice, service level and access to information, benchmarking was introduced as an element in consumer empowerment. In two years’ time this initiative had inspired – or provoked – the Swedish Association of Local Authorities and Regions together with the National Board of Health and Welfare to start a similar ranking, making public comparisons an essential Swedish instrument for change.

For the pan-European indexes or the so-called Euro Indexes developed between 2005 and 2008, HCP aimed to follow the same approach as it did in Sweden, i.e. selecting a number of indicators describing to what extent the national healthcare systems are “user-friendly”, thus providing a basis for comparing different national systems.

Since 2008 the HCP has enlarged the existing benchmarking program considerably (all the noted Indexes are available on the HCP website):

- The first edition of Canada Health Consumer Index was released in September 2008 in co-operation with Frontier Centre for Public Policy, examining healthcare from the perspective of the consumer at the provincial level, and repeated 2009 and 2010.
- In January 2008, the Frontier Centre and HCP released the first Euro-Canada Health Consumer Index, which compared the health care systems in Canada and 29 European countries. The 2009 edition was released in May 2009.
- The Euro Consumer Diabetes Index, launched in September 2008, provided the first ranking of European diabetes healthcare services across five key areas: Information, Consumer Rights and Choice; Generosity, Prevention; Access to Procedures and Outcomes. The updated version of the index, was published in 2014 with a lot more completed information and with a lot of extra material.
- Other Indexes published include the Euro HIV Index 2009, the Euro Headache Index 2012, the Euro Hepatitis Index 2012 and the Euro Pancreatic Cancer Index 2014. The 2013 Euro Vision Scorecard represents a more limited, highly targeted comparison.

Still a somewhat controversial standpoint, HCP advocates that quality comparisons within the field of healthcare is a true win-win situation. For instance, it can help answer questions of the consumers: who will have a better platform for informed choice and action?; to governments, authorities and providers, the sharpened focus on consumer satisfaction and quality outcomes
will support change; and to the media, where HCP offers ranking of clear-cut facts for consumer journalism with some drama into it.

This goes not only for evidence of shortcomings and method flaws but also illustrates the potential for improvement. With such a view the Euro Indexes are designed to become an important benchmark system supporting interactive assessment and improvement.

At one of the presentations/launches of a Euro Index, one of the Ministers of Health, when seeing his country’s preliminary results, claimed: “It’s good to have someone still telling you: you could do better.”

### 6.1 About the authors

**Beatriz Cebolla, Ph.D.,** Project Director for the EHI 2016.

Dr. Cebolla joined Health Consumer Powerhouse the first time in 2007 as project manager for the Diabetes Health Care index, presented in 2008. She was also Project Manager of the Euro HIV Index in 2009, the Euro Hepatitis Index 2012 and the second edition of the Euro Diabetes Index in 2014.

Since 2007, she has been offering her expertise as well as provide advice in diabetes, HIV and hepatitis care in several occasions to different National bodies and stakeholders in different decision making process.

In 2011, she finished her Master in Public Health with a final thesis about quality assurance in Health care.

Before moving into public health in 2007, she spent eight years working as a scientist, in Molecular Biology Research Institutes in Europe (Austria, Germany, Spain,), always in topics related with biomedical aspects.

**Prof. Arne Björnberg, Ph.D.:** Chairman of Health Consumer Powerhouse, Ltd. Prof. Björnberg has previous experience from Research Director positions in Swedish industry. His experience includes having served as CEO of the Swedish National Pharmacy Corporation (“Apoteket AB”), Director of Healthcare & Network Solutions for IBM Europe Middle East & Africa, and CEO of the University Hospital of Northern Sweden (“Norrlands Universitetssjukhus”, Umeå).

Prof. Björnberg was also the project manager for the EHCI 2005 – 2016 projects, the Euro Consumer Heart Index 2008 and numerous other Index projects.

**Ann Yung Phang, RN, B.A.** is an intensive care nurse with over 18 years of critical care experience. She has practised in multi international acute hospital settings, including the London Hammersmith NHS trust and The Great Ormond Street Children’s hospital in the cardiac intensive care unit in London. Later she moved to the USA and worked as a general and cardiac intensive care nurse for children at Lucille Salter Packard Children’s Hospital Stanford in California. After California she moved to Hawaii and practiced critical care nursing there for both adults and children. In between this she has participated in mission trips as a part of a team providing cardiac surgery for children in developing countries. She is still actively working as a critical nurse in the USA.

**Iveta Trojcakova, BSc.** Researcher at Health Consumer Powerhouse since 2016. She graduated in 2015 from the medical University of Pavol Jozef Safarik in Slovakia and followed her studies with a Master degree in Public Health at Southern Denmark University, where she specially focused in Health Economy, Management and Global Health. She is currently finishing her studies and writing a final thesis on HPV prevention strategies in Denmark.
7. Indicator definitions and data sources for the EHI 2016

The aim has been to select a limited number of indicators, within a definite number of evaluation areas, which in combination can present a telling tale of how healthcare is being served by the respective systems.

It is important to notice that data on European level were not available for most of the indicators apart from those included in Prevention and a couple in Outcomes. Most data comes from National Institutions, published reports, articles and national audits. Some data/information was also provided during interviews with national health care officials, public health experts and physicians. The data concerning FH has been collected through an online questionnaire to EAS and FH patient network members. All data has been reviewed by different stakeholders in most countries.

Table 7.1: Indicator definitions and data sources for the EHI 2016.
<table>
<thead>
<tr>
<th>Sub-discipline</th>
<th>Indicator</th>
<th>Explanatory comment</th>
<th>Score 3</th>
<th>Score 2</th>
<th>Score 1</th>
<th>Main Information Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1.2 Prevalence of child obesity</td>
<td>Percentage of children 11 years old who are overweight or obese (WHO child growth curve standards)</td>
<td>&lt; 22%</td>
<td>22 - 25%</td>
<td>&gt; 25%</td>
<td>HBSC-International report 2013/2014</td>
</tr>
<tr>
<td></td>
<td>1.3 Exercise in compulsory school</td>
<td>Total hours of physical activity in up to 10 years of compulsory school</td>
<td>&gt; 700</td>
<td>700 - 600</td>
<td>&lt; 600</td>
<td>Eurydice 2015/2016</td>
</tr>
<tr>
<td></td>
<td>1.4 Consumption of soft drinks</td>
<td>Including juice and nectars, liters per capita, per year</td>
<td>&lt; 100</td>
<td>100 - 120</td>
<td>&gt; 120</td>
<td>UNESA 2014</td>
</tr>
<tr>
<td></td>
<td>1.5 Fresh fruit/vegetable consumption</td>
<td>Availability of fruit and vegetables in grams per capita per day</td>
<td>&gt; 400</td>
<td>400 - 300</td>
<td>&lt; 300</td>
<td>Freshfel, 2013</td>
</tr>
<tr>
<td></td>
<td>1.6 Sugar consumption</td>
<td>Grams per day, per capita (Economic consumption)</td>
<td>Less than 60</td>
<td>60-80</td>
<td>More than 80 grams per day</td>
<td>Euro monitor, 2014</td>
</tr>
<tr>
<td></td>
<td>1.7 Tobacco consumption</td>
<td>Cigarette sales per capita age 15+, (incl. % Counterfeit and Contraband)</td>
<td>&lt; 1100</td>
<td>1100 - 1699</td>
<td>&gt; 1700</td>
<td>KPMG Project Sun 2016</td>
</tr>
<tr>
<td></td>
<td>1.8 Alcohol consumption</td>
<td>Pure alcohol consumption, litres per capita, age 15+, &quot;binge drinking adjusted&quot;</td>
<td>Less than 10 litres</td>
<td>10 to 13 litres</td>
<td>More than 13 litres</td>
<td>WHO HfA July 2016, Special Eurobarometer 331 April 2010</td>
</tr>
<tr>
<td></td>
<td>1.9 Prevalence of raised blood pressure</td>
<td>Prevalence of raised blood pressure (≥140/90) among adults aged ≥25 years (%) (General population)</td>
<td>&lt; 19%</td>
<td>19 - 27 %</td>
<td>&gt; 27 %</td>
<td>WHO (Global health observatory data repository) <a href="http://apps.who.int/gho/data/node.main.2464?lang=en">http://apps.who.int/gho/data/node.main.2464?lang=en</a></td>
</tr>
<tr>
<td></td>
<td>1.10 Familial Hypercholesterolemia (FH) screening</td>
<td>Are family members of patients with FH systematically screened for FH?</td>
<td>Yes, in a systematic way</td>
<td>Yes, in regular practice but not systematic (decision depends upon individual doctor)</td>
<td>No or not for free</td>
<td>Online questionnaire to national members of European Atherosclerosis Society (EAS) and European FH patient network.</td>
</tr>
</tbody>
</table>
## 2. Procedures

### 2.1 Door to balloon delay
STEMI patients (median, minutes)

- Less than 50 minutes
- More than 50 but less than 90 minutes
- > 90 minutes

Data from National registries, national publications. Interviews with health care officials, physicians and public health experts.

### 2.2 Health care personnel certified for CPR
For MI: Is health care and paramedical personnel certified for latest/appropriated CPR (Cardiopulmonary resuscitation)?

- Yes, Statutory for most health care personnel groups
- Yes, by regular practice but not statutory or not only for some health care personnel (e.g. only doctors)
- Yes, in many of the services

Interviews with health care officials, physicians and public health experts.

### 2.3 Pre-hospital thrombolysis
Availability as part of treatment given in ambulances or in primary care settings.

- Yes, widely available
- Yes, but only in specific public places
- No, essentially not or rarely

Interviews with health care officials, physicians and public health experts.

### 2.4 Defibrillators available in public places

- Yes, Widely available
- Yes, but only in specific public places
- No, essentially not or rarely

Interviews with health care officials, physicians and public health experts.

### 2.5 Rehabilitation programme
Composite indicator: Availability of rehabilitation / % of advised patients participating in rehabilitation

- Yes, widely available + more than 50% of patients advised to attend CRP attending
- Yes, in most regions or available for most people + 50 to 20% of patients advised to CRP attending
- No, essentially not or difficult to receive + less than 20% of advised to CRP attending

Euroaspire IV, Bjarnson-Wehrens B et al; 2010, Interviews with health care officials, physicians and public health experts.

### 2.6 Home care available for cardiac patients?
Special cardiac care (Heart failure, endocarditis, Deep vein thrombosis)

- Yes, widely available
- Yes, in most regions or for most patients
- No, essentially not or difficult to receive (e.g. long waiting time…)

Interviews with health care officials, physicians and public health experts.

### 2.7 # of PCI p.m.p.
# of Percutaneous Coronary Interventions (PCI) p.m.p., prevalence adjusted

- > 8000
- 7999 - 4000
- < 4000


### 2.8 PCI/ CABG Ratio of procedures: # of PCI)/ # of Coronary artery bypass (CABG)

- > 5
- 5 to 3.5
- < 3.5

Health at a glance 2015 - © OECD 01-01-2015

### 2.9 Statin deployment
Sales per capita (SU per capita 50+ SDR adjusted)

- > 190
- 190 - 40
- < 40

IMS MIDAS database

### 2.10 Clopidogrel deployment
Sales per capita (SU per capita 50+ SDR adjusted)

- > 103
- 102 - 50
- < 50

IMS MIDAS database
### 2.11 PCSK-9 inhibitor deployment

<table>
<thead>
<tr>
<th>Sales per capita (SU per capita 15+)</th>
<th>&gt; 1.5</th>
<th>1.5-0.5</th>
<th>&lt; 0.5</th>
</tr>
</thead>
<tbody>
<tr>
<td>IMS MIDAS database</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3.1 Waiting time to echocardiography and diagnostics

<table>
<thead>
<tr>
<th>Average waiting time to echocardiography and diagnostics for suspected heart disease; Elective patients</th>
<th>Less than 48 hours</th>
<th>More than 48 hour but less than 4 days</th>
<th>More than 4 days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews with health care officials, physicians and public health experts.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3.2 Waiting time for non-acute revascularization (CABG /PCI)

<table>
<thead>
<tr>
<th>Average waiting time for non-acute revascularization (CABG /PCI) from time of catheterization.</th>
<th>Up to 7 days</th>
<th>8 to 30 days</th>
<th>More than a month</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews with health care officials, physicians and public health experts.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3.3 "Waiting time" for heart transplant

<table>
<thead>
<tr>
<th>Ratio: # of patients on waiting list/# of transplants per year</th>
<th>&lt;1</th>
<th>1 to 3</th>
<th>&gt;3</th>
</tr>
</thead>
</table>

### 3.4 Family support for children with Congenital Heart Disease

<table>
<thead>
<tr>
<th>Free family support available for families with children having congenital heart disease</th>
<th>Yes, essentially available for all families</th>
<th>Only some health facilities or regions offer this service</th>
<th>Typically is not offered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews with health care officials, physicians and public health experts.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3.5 Access to free FH genetic testing?

<table>
<thead>
<tr>
<th>Yes, 100% subsidised (with or without referral)</th>
<th>Partially subsidised</th>
<th>No, only privately paid</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online questionnaire to national members of European Atherosclerosis Society (EAS) and European FH patient network.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 3.6 Access to combination therapy to treat FH

<table>
<thead>
<tr>
<th>Combination therapy (statin plus ezetimibe)</th>
<th>Full reimbursement (or fully subsidised)</th>
<th>Partially reimbursed (or subsidised) (≥75%) reimbursed</th>
<th>No, not reimbursed (or subsidised)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Online questionnaire to national members of European Atherosclerosis Society (EAS) and European FH patient network.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 4.1 30-day case fatality rate after admission for AMI

<table>
<thead>
<tr>
<th>Thirty-day mortality after admission to hospital for AMI based on admission data (2013). Age-sex standardised rate %, patients 45+ SDR, ischaemic heart disease, all ages, per 100 000 (inclination of trend lines for SDR 1997-2013)</th>
<th>Less than 7</th>
<th>7 to 8</th>
<th>More than 8</th>
</tr>
</thead>
</table>

### 4.2 Standardized death rates from CVD

<table>
<thead>
<tr>
<th>Thirty-day mortality after admission to hospital for AMI based on admission data (2013). Age-sex standardised rate %, patients 45+ SDR, ischaemic heart disease, all ages, per 100 000 (inclination of trend lines for SDR 1997-2013)</th>
<th>Less than 7</th>
<th>7 to 8</th>
<th>More than 8</th>
</tr>
</thead>
</table>

### 4.3 Hospital readmission rates for heart failure

<table>
<thead>
<tr>
<th>Thirty-day mortality after admission to hospital for AMI based on admission data (2013). Age-sex standardised rate %, patients 45+ SDR, ischaemic heart disease, all ages, per 100 000 (inclination of trend lines for SDR 1997-2013)</th>
<th>Less than 7</th>
<th>7 to 8</th>
<th>More than 8</th>
</tr>
</thead>
</table>

### 4.4 Surgical mortality for Isolated transposition of the great arteries

<table>
<thead>
<tr>
<th>Hospital mortality rate for Isolated transposition of the great arteries</th>
<th>&lt; 7%</th>
<th>7-14%</th>
<th>More than 14%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews with health care officials, physicians and public health experts, Swedeheart 2015.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
7.1 Additional data gathering – e-questionnaires

Two surveys were designed as part of the data gathering for the EHI:

The first questionnaire (Appendix 1) included a number of the indicators, transformed into multiple choice form, from the Procedures and Access to treatment/care sub-disciplines. The survey was distributed online to be answered by the main stakeholders, and to use the information as additional feed back to the official information collected.

EHN encouraged their National organisations to participate in the survey. A high number of representatives offered their perceptions about the situation through the survey.

In total, 35 answers from 20 different countries were received. This information was only used as feedback, never as primary indicator data.

The second questionnaire (Appendix 2): contains 8 questions related with FH care in Europe. The questions were designed by board members of EAS and the European FH patient network. The survey was distributed exclusively to national members of both organisations. 206 responses from 27 different countries were received. The information on the 3 indicators included in the EHI regarding FH care in Europe was extracted from the analysis of the data collected through the questionnaire.

7.2 Additional data gathering – Single Country Score Sheets

On October 10th, 2016, preliminary score sheets (containing scores for one country only, so called “Single Country Score Sheets”, SCSS) were sent out to Ministries of Health or national agencies of all 30 states giving the opportunity to review the data collected.

Extensive e-mail exchanges, telephone contacts and additional personal visits to ministries/agencies were made during the consecutive two months, until the data from each country was completed to the best of ability of all involved.

In the table below, the countries from which feedback responses were received are shown. In the case of patient organisations, feedback and comments were mostly received through the e-questionnaire.

<table>
<thead>
<tr>
<th>Country</th>
<th>Responded</th>
<th>Country</th>
<th>Responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>✔</td>
<td>Latvia</td>
<td>✔</td>
</tr>
<tr>
<td>Belgium</td>
<td>✔</td>
<td>Lithuania</td>
<td></td>
</tr>
<tr>
<td>Bulgaria</td>
<td>✔</td>
<td>Luxembourg</td>
<td>✔</td>
</tr>
<tr>
<td>Croatia</td>
<td>✔</td>
<td>Malta</td>
<td>✔</td>
</tr>
<tr>
<td>Cyprus</td>
<td>✔</td>
<td>Netherlands</td>
<td>✔</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>✔</td>
<td>Norway</td>
<td></td>
</tr>
<tr>
<td>Denmark</td>
<td>✔</td>
<td>Poland</td>
<td></td>
</tr>
<tr>
<td>Estonia</td>
<td>✔</td>
<td>Portugal</td>
<td>✔</td>
</tr>
<tr>
<td>Finland</td>
<td>✔</td>
<td>Romania</td>
<td>✔</td>
</tr>
<tr>
<td>France</td>
<td></td>
<td>Slovakia</td>
<td></td>
</tr>
<tr>
<td>Germany</td>
<td>✔</td>
<td>Slovenia</td>
<td>✔</td>
</tr>
<tr>
<td>Greece</td>
<td>✔</td>
<td>Spain</td>
<td>✔</td>
</tr>
<tr>
<td>Hungary</td>
<td>✔</td>
<td>Sweden</td>
<td></td>
</tr>
<tr>
<td>Ireland</td>
<td>✔</td>
<td>Switzerland</td>
<td>✔</td>
</tr>
<tr>
<td>Italy</td>
<td>✔</td>
<td>United Kingdom</td>
<td>✔</td>
</tr>
</tbody>
</table>

Table 7.2 Responses from national bodies.
7.3 Threshold value settings

The performance of national healthcare systems was graded on a three-grade scale for each indicator (see more information in section 8.2).

It has not been the ambition to establish a global, scientifically based principle for threshold values to score Green, Amber or Red on the different indicators. Threshold levels have been set after studying the actual parameter value spreads, in order to avoid having indicators showing “all Green” or “totally Red”.

Setting threshold values is typically done by studying a bar graph of country data values on an indicator sorted in ascending order. The usually “S”-shaped curve yielded by that is studied for notches in the curve, which can distinguish clusters of states, and such notches are often taken as cut-off values for scores. A slight preference is also given to threshold values with even numbers.

For each of the four sub-disciplines, the country score was calculated as a percentage of the maximum possible (e.g., for Outcomes, the score for a state has been calculated as percent of the maximum: $4 \times 3 = 12$).

Thereafter, the sub-discipline score percentages were multiplied by the weight coefficients given in Section 5.3 and added to make the total country score. The scores thus obtained were rounded to a three digit integer, giving a score system where a state with “all Green” would receive 1000 points (and “all Red” 333 points).

7.4 CUTS data

Whenever possible, HCP research on data for individual indicators has endeavoured to find a “CUTS” (Comprehensive Uniform Trustworthy Source). If data on the underlying parameter behind an indicator is available for all or most of the 30 states from one single and reasonably reliable source, then there has been a definitive preference to base the scores on the CUTS. As CUTS would be considered WHO databases, OECD Health data, Special Eurobarometers, and scientific papers using well-defined and established methodology.

Apart from the sheer effectiveness of the approach, the basic reason for the concentration on CUTS, when available, is that data collection primarily based on information obtained from 30 national sources, even if those sources are official Ministry of Health or National Health/Statistics agencies, generally yields a high noise level. It is notoriously difficult to obtain precise answers from many sources even when these sources are all answering the same, well-defined question.

7.4.1 The “Rolls-Royce gearbox” factor

Another reason for preferably using CUTS whenever possible is the same reason why Rolls-Royce (in their pre-BMW days) did not build their own gearboxes. The reason was stated as “We simply cannot build a better gearbox than those we can get from outside suppliers, and therefore we do not make them ourselves”. For the small size organisation HCP, this same circumstance would be true for an indicator where a Eurobarometer question, the WHO HfA database, or another CUTS happens to cover an indicator.
7.5 General information on cardiac care.

**Cardiovascular diseases** (CVD) remains the most common cause of morbidity and mortality among high-income countries of the industrialized world, accounting for more than one-third of total deaths. In many countries, CVD still causes more than twice as many deaths as cancer.¹⁹

Globally, an estimated 17.5 million people died from CVD in 2012, representing 31% of all deaths, over 80% of which take place in low-and middle-income countries. Today, CVD is the largest single contributor to global mortality and estimates indicate that nearly 23.6 million people will die from CVD by 2030.²⁰

The percentage of excess premature deaths from CVD ranges from 4% in high-income countries to 42% in low-income countries, leading to growing inequalities in the occurrence and outcome of CVD between countries and populations. Over the past two decades, deaths from CVD have been declining in high-income countries, but have increased at an astonishingly fast rate in low- and middle-income countries (LMIC).²¹

In Europe, CVD remains the main cause of death in most countries but has already been overtaken by cancer in 12 countries cancer, with very significant differences in mortality rates between countries. The differences are greatest between Northern, Southern and Western European countries, and on the other hand Central and Eastern European Countries.¹⁹

Cardiovascular disease includes illnesses that involve the **blood vessels** (veins, arteries and capillaries) or the **heart**. Among the CVD that includes the heart there are; Angina, Arrhythmia, congenital heart disease or heart failure and the among those including blood vessels there are; **Coronary artery disease**, **Peripheral arterial disease** or **Cerebrovascular disease** Atherosclerosis, peripheral venous disease or Stroke.

In some cases cardiovascular disease may be a hereditary condition, or depending on non-modifiable risk factors such as family history, ethnicity or age. In general, CVD is largely preventable and treatable. One of the most important advances in cardiovascular research of the 20th century was the identification of risk factors associated with CVD. This led to treatments being developed, and also control of risk factors which can be modified, as smoking, diabetes, hypertension, abdominal obesity, psychosocial factors, fruit/vegetable consumption, physical activity or alcohol consumption.

There are a number of environmental and societal influences influencing cardiovascular risk factors at population level. In general, CVD is becoming increasingly more common among the poor and more vulnerable populations; unhealthy diet (heavy in fats and high intake in salt and sugar), tobacco use and physical inactivity are the major contributors.²²,²³

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In 2012, CVD was estimated to cost EU economy almost € 196 billion a year. Of the total cost of CVD in the EU, around 54% is due to health care costs, 24% due to productivity losses and 22% due to the informal care of people with CVD.\textsuperscript{24}

To reduce socioeconomic burden caused by CVD and its risk factors, a global response is required, which should include a number of measures and programmes to increase efficiency and effectiveness of cardiac care.

In 2013, two significant milestones were reached for political global response: In May, ministers from 194 WHO member states adopted the Global action plan for the prevention and control of NCDs 2013-2020 at the 66th World Health Assembly.

Two months later, the United Nations (U.N.) Economic and Social Council adopted a resolution requesting that the U.N. secretary general establish an interagency task force on the prevention and control of NCDs. The task force, convened and led by WHO, would help coordinate U.N. organisation activities to implement the initiative. The action plan outlined 9 voluntary global targets to lower the incidence of cardiovascular disease, cancer, diabetes, and chronic respiratory diseases and lower the rate of the premature deaths they cause by 25 % within 12 years. Global status report on non-communicable diseases 2014.

In 2015, countries began to set national targets and measure progress on the 2010 baselines reported in the "Global status report on non-communicable diseases 2014". The UN General Assembly will convene a third high-level meeting on NCDs in 2018 to take stock of national progress in attaining the voluntary global targets by 2025.

Currently, reducing the burden of chronic diseases such as diabetes, cardiovascular disease, cancer and mental disorders is a priority of EU Member States and at the EU Policy level, since they affect 8 out of 10 people aged over 65 in Europe. Approximately 70 – 80 % of health care budgets across the EU are spent on treating chronic diseases. There is a need for knowledge within EU Member States on effective and efficient ways to prevent and manage CVD, stroke and diabetes type-2. A large variety of coordinated efforts between the European Union (EU), national governments, non-profit organisations, private industry, and local communities exist. However, the different goals and interests, the data standardization and data sharing are hindering advances in one straight and unique direction.

8. Content and construction of the EHI 2016

In this chapter is described the main findings in the different sub-disciplines. The description of the individual indicators is found in Section 9.2.

8.1 Sub-discipline: Prevention

CVD remains a leading cause of morbidity and mortality, despite improvements in outcomes. CVD prevention is defined as a coordinated set of actions, at the population level or targeted at an individual, that are aimed at eliminating or minimizing the impact of CVD and their related disabilities. There are a number of risk factors for CVD, including

obesity, high cholesterol, high blood pressure, and physical inactivity, which can prevent the development of these diseases if modified early enough.

Inequalities between countries persist and many risk factors, particularly obesity\(^\text{25}\) and diabetes mellitus (DM)\(^\text{26}\) have been increasing substantially in parts of Europe. If prevention was practised according to guidelines it would markedly reduce the prevalence of CVD. It is thus not only prevailing risk factors that are of concern, but poor implementation of preventive measures as well\(^\text{27,28}\). Prevention should be delivered (i) at the general population level by promoting healthy lifestyle\(^\text{29}\) and (ii) at the individual level, i.e. for people at moderate to high risk of CVD or patients with established CVD, by tackling unhealthy lifestyles (e.g. poor-quality diet, physical inactivity, smoking) and by reducing risk factors. Prevention could be effective: the elimination of health risk behaviours would make it possible to prevent at least 80 % of CVD and also 40 % of cancers\(^\text{30,31}\).

Effective prevention programs must be the number one priority to reduce the burden of CVD in the general population.

### 8.1.1 Obesity

**Obesity** is one of the greatest public health challenges of the 21st century. The proportion of the population who are overweight or obese remains worryingly high for adults and for children and young people. The prevalence has tripled in many countries of the WHO European Region since the 1980’s, and the numbers of those affected continue to rise at an alarming rate. This rise brings a concomitant increase in rates of associated non-communicable diseases. In 2010, it was estimated that around 7 % of national health budgets across the EU are spent on diseases linked to obesity. Substantial indirect costs are also incurred from lost productivity arising from work absenteeism due to health problems and premature death. Recent estimates show that around 2.8 million deaths per year in the EU result from causes associated with overweight and obesity\(^\text{32}\).

A number of programmes are running in various countries to tackle the problem and promote a healthier life style. There is still a long way to go, as almost 2/3 of countries


studied have more than 20 % of the population considered obese (Body Mass Index > 30).

8.1.2 Childhood obesity

Childhood obesity is a multifactorial condition, and is a global epidemic that poses a severe risk to the present and future health of young people. Child obesity has both immediate and long-term effects on health and well-being. Obese youth are more likely to have risk factors for cardiovascular disease, such as high cholesterol or high blood pressure. In a population-based sample of 5 – 17-year-olds, 70 % of obese youth had at least one risk factor for cardiovascular disease. Children and adolescents who are obese are likely to be obese as adults, and are therefore more at risk for adult health problems such as heart disease, type 2 diabetes, stroke, several types of cancer, pulmonary, musculoskeletal and gastrointestinal complications and may have psychosocial consequences such as the development of poor self-esteem, depression and eating disorders.

For children and young people, a healthy diet and a physically active lifestyle can reduce the risk of overweight and obesity in adulthood as well as contributing to healthy growth and development.

There are programmes in several countries to restrict the marketing of unhealthy food aimed at children. However, there is no agreement in Europe on what the definition of unhealthy food is. An objective is to create public awareness about promoting healthy eating in children such as healthier school lunches and no candy or soft drinks vending machines on school grounds.

According to HCP research, more than 22 % of the 11-year-olds are obese in at least half of the countries in Europe, which shows that even though a lot of initiatives, programmes and awareness exist, there is still a long way to go.

8.1.3 Sedentary lifestyle

Sedentary lifestyle is predominant in most of countries even though it is recommended that individuals engage in adequate levels of physical activity throughout their lives. Regular sport practices can be introduced and promoted through schooling years, however physical activity in schools has been reduced in many countries in recent years.

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substituted by other subjects considered of more intellectual value for students and therefore of more interest to the children’s future.

8.1.4 Fruit and vegetable intake

The benefits of consuming the proper amount of vegetables and fruits and their bioactive compounds is well described in literature. However, fruit and vegetable consumption in Europe is still insufficient. The recommended consumption varies from country to country, but as a guide the WHO recommends a minimum of 400 g of fruit and vegetables a day per person (excluding potatoes and other starchy turnips). According to the last publication from Freshfel only 6 countries (Belgium, Greece, Cyprus, Italy, Portugal or Romania) reach this target\(^{40}\).

National interventions and programmes promoting fruit and vegetable intake and healthy life standards have been established worldwide, in Europe mostly in the Central and Northern parts of the continent, where the consumption is lower. It is not clear which benefits that interventions are reaching but in general, citizens in Central and Northern part of Europe are nowadays more aware of the consequences of what they eat through awareness campaigns and education. However, all these messages do not necessary access the least educated and poorest parts of society in which CVD risk factor prevalence is normally higher\(^{41}\).

In the Mediterranean countries eating habits are also changing. Modern life styles are interfering with old healthy eating habits. Citizens are substituting their traditional cuisines for a quick frozen ready-to-eat products accompanied by large amounts of soft drinks. Still the fruit and vegetables intake in those countries is rather high. There is a good chance to stop the tendency on time.

8.1.5 Sugar consumption

Over the past fifty years, the global per capita sugar consumption has increased by over 50%. In Europe, sugar intake in adults ranges from about 7 – 8 % of total energy intake in countries such as Hungary and Norway, to 16 – 17 % in Spain and the United Kingdom. Worryingly, sugar intake is much higher among children, ranging from about 12 % in Denmark, Slovenia and Sweden, to nearly 25 % in Portugal\(^{42}\).

In 2015, WHO published Guidelines on sugar intake for adults and children\(^{43}\) which included an analysis of studies linking sugar intake and body weight. An association was suggested between the reduction of free sugar intake and the reduction of body weight, and similarly, an association between an increased intake of free sugars and a comparable increase in body weight among adults. Studies including children found that children with the highest intake of sugar-sweetened beverages had a greater likelihood of being overweight or obese than children with the lowest intake.

There is increasing concern that intake of added sugars – particularly in the form of sugar-sweetened beverages (Soft drinks) – increases overall energy intake and may reduce the intake of foods containing more nutritionally adequate calories, leading to an unhealthy diet, weight gain and increased risk of non-communicable diseases. Considering

\(^{40}\) Freshfel Fruit and Vegetable Production, Trade, Supply & Consumption monitor in the EU, 2015.


\(^{42}\) \[http://www.who.int/mediacentre/news/releases/2015/sugar-guideline/en/\]

\(^{43}\) \[http://www.who.int/nutrition/publications/guidelines/sugars_intake/en/\]
that global prevalence of overweight and obesity is rising, particularly among children and adolescents, it is imperative that current public health strategies include education about consumption of sugar-sweetened beverages as well as other food containing added sugar, which should be discouraged.

**There is a need to limit the consumption of foods and drinks containing high amounts of sugars (e.g. sugar-sweetened beverages, sugary snacks and candies); and eating fresh fruits and raw vegetables as snacks instead of sugary snacks.**

### 8.1.6 Cigarette smoking

Cigarette smoking increases the risk of coronary heart disease. When it co-acts with other factors, it greatly increases risk. Smoking increases blood pressure, decreases exercise tolerance and increases the tendency for blood to clot. In terms of risk factors, **smoking** remains the major risk factor of concern for all of Europe. Smoking accounts for approximately 20% of all cases of CVD (European Heart Network and European Society of Cardiology, 2012).

Smoking rates remain high throughout Europe, although there has been a decline in all countries in the past years. Substantial inequalities exist in terms of sex, age and education level concerning the proportion of adults who are daily smokers of cigarettes. For example, daily smoking rates among adults vary widely, ranging from 13.1% in Sweden (with less than 10% smokers among men, almost certainly due to the widespread Swedish habit of using oral smokeless tobacco, “snus”) to 38.9% in Greece. Also, considerable differences exist between the Member States with respect to smoking habits.

Several national initiatives are helping to deter people from smoking with varying degrees of success, although it will take more time for improvements in smoking related illnesses to be fully realised.

### 8.1.7 Alcohol

The complex relationship between **alcohol** and the heart is not well understood, mainly because there is no simple association. Moderate drinkers had a 25 to 40 percent reduced risk of heart attack, stroke, peripheral vascular disease, and death from cardiovascular causes compared to non-drinkers. However, high alcohol intake in limited time (“binge drinking”) can cause a weakened heart, known as alcoholic cardiomyopathy, or trigger an irregular heart rate called atrial fibrillation. Rarely, alcohol can lead to an irregular heart rhythm which is sometimes fatal, known as ventricular tachycardia. Drinking in excess also increases the risk of developing other problems, including high blood pressure and stroke.

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People in the European Union consume more alcohol than in other part of the world drinking on average 8.71 litres or around 25 beer-sized glasses of pure alcohol per person, per year. The number of heavy drinkers in some European countries is still very high.

8.1.8 Case finding – Screening for CVD risk factors.

It was of great interest for the EHI to address which risk groups in the respective countries were screened for CVD risk factors (High blood pressure, Overweight and obesity, Smoking, lack of physical activity etc); which are systematically screened following guidelines and which groups are screened depending upon individual doctors (routinely).

What is shown in Table 8.1.8 is a mixture between recommendations and general experience from physicians. Around Europe, there are variations in the target patient groups for CVD risk factor screening. Even in those groups where an S is shown in the table as systematic, it cannot be assured that they are being systematically screened in a whole country or even in a region. Regardless of guidelines it looks like testing of general population or patients for these risk factors is in many cases very dependent on physicians, mainly GP discretion.

The main groups recommended for CVD screening are included in the table (top part).

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There are a number of groups in the population defined as having higher risk of developing CVD. It seems that even when guidelines exist about this issue in most countries, adherence is very different and it is difficult to determine which groups are really systematically checked and which are not. The table shows the main practices.

**Table 8.1.8 Screening of CVD risk factors.** There are a number of groups in the population defined as having higher risk of developing CVD. It seems that even when guidelines exist about this issue in most countries, adherence is very different and it is difficult to determine which groups are really systematically checked and which are not. The table shows the main practices.

### 8.2 Sub-discipline: Procedures

Cardiovascular disease caused by atherosclerosis results in a heart infarct or ischemia. Plaques form by fat, cholesterol and calcium blocks arteries on the surface of the heart leading to injury or death of the heart muscles. A victim of a heart attack will experience chest pain. The gender of the victim will influence how this pain is felt. Men will experience a pain that has been described as an 'elephant sitting on my chest' whereas a woman would have a slight chest discomfort with shortness of breath, feel faint, in addition to extreme fatigue and pain in the jaw, upper, lower back or even upper abdominal pain.
Often, both genders ignore the pre-warning signs like a feeling of ‘impending doom’, tiredness, sweating and a mild chest pain that comes and goes. This confusing array of symptoms adds to the delay of care. The patient is uncertain as to when they should call for help. 

The public needs to be continually educated to the symptoms of a heart attack and instructed on the next step of action when it happens. This could reduce mortality rate from heart attacks as for the arrival of the first responders, a set of guidelines and algorithms will guide them to initiate the correct reperfusion treatment. 

8.2.1 Acute intervention

In a situation where there are no medical personnel onsite An Automated Emergency Defibrillator (AED) can assist a layman through the steps of resuscitation. 

According to the European Resuscitation Council updated guidelines of 2015, the early use of a defibrillator in the first 3 – 5 minutes of a heart attack can increase the survival rate of the victim by 50 – 70 %. Each minute that is lost by not defibrillating the victim results in the reduction of the survival rate by 10 – 12 %. The AED when turned on will sense the cardiac rhythm of the patient and provide an electrical shock if the patient is in ventricular fibrillation or ventricular tachycardia. After the shock the AED will advise the provider to initiate chest compression. In the absence of medical personnel, these automated prompts will assist a witness of a heart attack to provide CPR to the victim. An AED can be used in children from the age of 8. The European Resuscitation Council continues to advise that an AED should be placed in popular public places, planes and even in sections of hospitals where a resuscitation team will take longer to reach. Based on the survey sent out for this index, it has been reported that in Europe AEDs are today widely available in public areas. 

Present data regarding the use and implementation of the AED in Europe is limited to the answers in the questionnaires received. 

The first responder or first medical contact that arrives must, when a heart attack is suspected, in under 10 minutes do a 12 lead electrocardiogram (ECG), assess the patient, and administer nitroglycerine, morphine, oxygen and aspirin. When the ECG has been interpreted and myocardial Infarction is noted, the clock starts ticking. The cardiac catheterisation lab will be contacted of the patient’s emergent arrival. There, reperfusion either by primary percutaneous intervention (PCI) or fibrinolysis (thrombolysis) treatment must occur within a timing called door to balloon time (D2B). The European Society of Cardiology recommends a D2B time of less than 90 – 120 mins from first contact with the medics to the inflation of the catheterisation. Door-to-balloon is a time-quality measurement in emergency cardiac care. Early reperfusion therapy is optimal for salvaging cardiac muscle and improves survival of the patient. D2B times have been improving enormously in all parts of Europe Unfortunately, often national data was not available or measured in different ways. 

It must be noted that in the different EU countries, not all health care personnel including ambulance crew and other paramedical staff are necessarily trained to initiate cardiac resuscitation (CPR) independently. Some countries have a trained doctor as part of the ambulance team. The qualifications and ability of the paramedics that arrives varies greatly even within one single country, which makes quality of the response and the outcomes to be randomly dependent on the quality of each emergency service. Additionally, it is described that in certain countries, there is also a lack of co-operation

between the Emergency service (EMS) team arriving with the receiving Emergency room.\(^{49}\) As can be observed in the EHI most health care personnel including ambulance crew in Europe are statutorily trained. But it can also be seen that for almost half of Europe, this training is not mandatory and sometimes it is limited (mostly economically) to some parts of healthcare staff.

Although PPCI is the treatment of choice, it is often not possible to give it within the required time window in an emergency. In this case, thrombolysis should be considered with the availability of systematic or rescue PCI. In areas, where PCI is not (immediately) available, thrombolysis remains the only treatment option and should be administered as soon as possible, preferably pre-hospital. Half of the countries included in the study widely provide pre-hospital thrombolysis in ambulances or primary care ambulatories.

Extensive research and development has gone into the treatment of heart attacks either by Coronary Artery Bypass Graft (CABG) or Percutaneous Coronary Intervention (PCI). The choice of optimal coronary revascularization method is a vigorously debated question that is of considerable importance to patients, clinicians, regulatory agencies, as well as third-party payers. Guidelines are regularly updated and clarified to adjust for the rapid advances in both fields to produce a high standard of practice and to reduce risks.\(^ {50}\)

PCI is a minimally invasive technique. A CABG is open heart surgery to perform the graft to re-channel coronary arterial flow. CABG come with more risk and intensive care stay in the first few post-surgery days, and higher costs. In general, the decision to perform a CABG depends on the number of vessels blocked in the patient. Due to the highly invasive nature of open heart surgery, there is a longer rehabilitation process needed for the patient to recover and return to their normal activities of daily living.

Apart from the benefits or the practical reasons behind considering one or the other method, countries had been over- or under-performing PCI/CABG for a number of economic reasons. In general, the poorest countries had less capability to perform acute PCI because it requires expensive infrastructure not always available, and also a well-trained team.

There are two indicators in the EHI, 2.7 and 2.8, which try to illustrate the situation in Europe regarding PCI and CABG as procedure practices. In general, the use of PCI has increased everywhere in Europe but there is still large variation among countries, which is weakly GDP-related. To further analyse the situation indicator 2.8 measures the ratio PCI/CABG, on the assumption that the higher the ratio, the more state-of-the-art is cardiac care. The results are rather difficult to analyse but shows interesting differences between countries, for example countries like Latvia or Estonia having almost twice the ratio of notorious “over-spenders” such as the Netherlands or Norway.

### 8.2.2 Rehabilitation

Rehabilitation programmes are divided into 3 phases. They all involve a multidisciplinary team such as physiotherapist, nurses, psychologist, cardiologists and occupational therapists. Focus is given to increasing patients’ physical activities, cessation of smoking, nutritional management, diabetic management, weight management, lipid management, alcohol reduction and psychosocial issues encountered by patient post procedures. Phase 1 occurs directly after surgery in the hospital and involves health education and


intervention in the hospital to prevent weaknesses and complications by early ambulation. Phase 2 occurs in a supervised out-patient setting where the patient is introduced to exercise and reduction of risk factors. Phase 3 is the long-term maintenance and enforcement of what the patient has learnt in phase 2.

Even though rehabilitation reduces patient’s re-admission rates with minimal risks\textsuperscript{51}, it remains an underutilized, cost effective resource in a patient’s recovery process\textsuperscript{52}.

Only countries in the western part of the EU have the economic ability to carry out all 3 phases. Nevertheless, barriers to implementation include gender; less women are referred to the programmes than men, those from the lower social economic groups or ethnic minorities lack the means to adhere to the programmes. Patients themselves may lack the ability to understand the goals of rehabilitation. Other restrictions for participation also include limited patient referral by physicians, logistics coverage by insurance and finally the lack of clear standardized guidelines and legislations between countries on how to implement and who is responsible. The picture in Europe does not look too good regarding rehabilitation, and only few countries provide rehabilitation to most patients who are advised to attend it. Unfortunately, the project does not record information on the quality of those programs, or the outcomes.

Home health care under phase 3 of the rehab includes phone calls from nurse specialists about the patient’s general well-being, drug titration and re-educating patients on adherence to heart friendly life and or remote monitoring. The data shows that only 4 countries provide widely specific cardiac home care for patients with Heart failure, endocarditis or Deep vein thrombosis. Although the European Resuscitation Council acknowledges the benefits of these programmes, it also comments on the lack of qualified staff to perform it. For example, the education levels of the nurses who perform the jobs are markedly different\textsuperscript{53}.

Another factor restricting integrated home health care for patients are the re-imbursement procedures, which vary greatly between the regions in Europe. Like the rehabilitation programme, there is no agreement on who should be involved in implementation, the targets and how costs should be covered\textsuperscript{54}.

8.2.3 Access to medication

Deployment rates of different medication show obvious effects of variation of medical and pharmaceutical professional cultures between European countries. There are a number of countries coming out high in almost any comparison of drug consumption, such as France, Greece, Ireland, Portugal and Ireland.

Indicators 2.9 – 2.11 (see Section 9.2) show the per capita use of statins, anti-platelet medication (clopidogrel) and PCSK-9 inhibitors, statins and clopidogrel being available as inexpensive generic products. The population numbers have been index adjusted for CVD prevalence, regrettably using CVD mortality as a proxy for prevalence, as European data for CVD prevalence could not be found.

\textsuperscript{51} Hasnain M Dolal, Patrick Doherty. Cardiac rehabilitation. Clinical Review. The BMJ. Sept.29 2015

\textsuperscript{52}Mampuya WM. Cardiac rehabilitation past, present and future: an overview. Cardiovasc.Diagn Ther 2012;2(1)38-29.doi:10.3978/j.issn.2223-3652.2012.01.02


There is very large variation in the deployment rates, with a definitive under-use in CEE countries. This was understandable when statins and clopidogrel were still on patent (i.e. expensive), but today should be history.

8.3 Sub-discipline: Access to treatment/care

Very long waiting times also for non-acute patients could have big consequences; as deterioration of the patient, rising cost, loss of income as they wait and of course increased mortality.

Since 1997, the Council of Europe has had a policy aiming to reduce waiting times. Waiting time and waiting list reflects the failure of the health system to adequately meet demand. Reduction in waiting time reflects good service level from health institutions. Long waiting time *increases* cost for the health system, *i.e.* waiting lists are not a way to save money, they *cost* money! The same Council noted that acute illness like heart attacks is prioritized and other surgery like ear, nose, throat, women’s health and eye diseases are pushed aside, being mainly elective. They further recommend that this waiting list for specialist treatment be available to the public to assist them in making a choice of caregiver based on transparency\(^{55}\).

From the data collected for the heart index, it has been noted that in Europe, patients that need access to essential diagnostics and those who are not on the urgent/emergent list struggle with long waiting times. In many countries, data is just not collected, which complicates monitoring of the situation. This can actually be a good sign – that countries such as Belgium and Germany habitually do not produce waiting time statistics, could be for the same type of reason as why Singapore has very few snow-ploughs!

Besides the waiting time for elective surgery and diagnostics, another critical parameter that the matrix measured was the waiting time for a heart transplant. For heart transplant the organ must be obtained from a donor. The policy of presumed consent (opt-out) seems to significantly increase the pool of organ donors. Nevertheless, this is only one factor that promotes a successful transplantation programme. Other important factors to facilitate organ transplantation include a well-coordinated total chain of all the healthcare providers involved, facilities to do the transplants with trained surgeons and intensive care beds, health budget distribution, consent of families and donor registries.

One of the world’s most successful donor countries, Spain (leading Europe for transplants per million population), has programmes in place where there is emphasis on the procurement level placed by physicians and transplant donor co-ordinators at hospital, regional and national level. They focus on identifying and referring specific donor to the programme and promoting the idea of organ donation as part of end-of-life care. Spain also focuses on improving the quality of public information regarding organ donation.

Assumptions are made that a presumed donor system, where citizens are assumed to be willing donors unless they say the opposite, will increase the donation pool and increase donor rates. Studies have shown that the presumed donor system actually increases the donation of organs from deceased donor versus the opt-in system, where consent is needed for a donation. Countries that have an opt-in donor system have higher living donor rates (which is of very marginal, if any, significance for heart donors).\(^{56}\) In those countries, the waiting list of heart transplantation will rely on the consent of the family

\(^{55}\) http://www.coe.int/t/dg3/health/waitinglistreport_en.asp

\(^{56}\) Shepherd,L, O’Carroll,R & Ferguson,E. An international comparison of deceased and living organ donation/transplant rates in opt-in and opt-out system: a panel study. BMC medicine. (2014)
members from donors who are clinically or brain dead. Countries that allow withdrawal of life on the grounds of end-of-life-decision making have lower donation from brain dead donors\textsuperscript{57}.

According to Shepherd (2014), there is a level of mistrust among the public against medical professionals in countries like France with an opt-out system. Organs for donation are public goods but there will be those that suspect that financial incentives are lurking in the background and abuse to the donor will occur. Since 2004, the WHO has adopted a resolution to protect the poorest and most vulnerable groups from transplant tourism and sale and giving attention to human organ and tissue trafficking. The WHO continues to suspect that 10% of organ transplants still fall in this dark category.

8.4 Sub-discipline Outcomes

In general, the situation has improved in recent years. Countries have understood the social and economic burden that CVD represents.

Still cardiovascular disease remains the most common cause of death in Europe and is responsible for 45% of all deaths, equating to 4 million deaths per year. Coronary heart disease is the most common single cause of death, causing 19% of deaths in men and 20% of deaths in women\textsuperscript{58}.

CVD mortality is now falling in most European countries, including Central and Eastern European countries, which saw large increases until the beginning of the 21st century\textsuperscript{59}.

The most recent available data also indicated that there are 13 countries in which cancer is a more common cause of death than CVD in men (Belgium, Denmark, France, Israel, Italy, Luxembourg, the Netherlands, Norway, Portugal, Slovenia, Spain, Switzerland, and the UK).


\textsuperscript{58} WHO Mortality Database.

\textsuperscript{59} European Heart Network; \textit{European Cardiovascular Disease statistics 2012}
Graph 8.4. Standardized death rates from CVD. The length of the bars measure the inclination of the SDR trend line over time (1998-2018), calculated on logarithmic values. Source: WHO HfA, July 2016.

Most countries have shown substantial reductions in hospitalized case fatality rates for acute myocardial infarction (AMI). The collection and collation of quality, comparable, morbidity statistics across Europe would both benefit understanding of CVD within Europe and allow policy makers to target and focus resources within countries and across Europe.

Hospital readmission rates within 30 days after discharge for heart failure is generally considered a good quality measurement, as it requires good coordination of primary and secondary care. A smooth transition to post-event care is vital. Patient education programmes and a cardiac rehab programme for patients preparing to be discharged from hospital can have a dramatic effect on improving outcomes: well-coordinated care, and direct and timely communication with counterpart colleagues in hospital and with the patient on an out-patient basis. Patients and/or their carers should participate in the discharge process and be well informed of their health status and treatment.

Remote cardiac rehabilitation programmes, with their potential utilization of technology and phone calls from trained specialist can monitor patients’ progress closely, not least when there are barriers to physical follow-ups like distance or lack of mobility. The same programme focuses on reducing the factors that lead up to a heart attack. It was quite disappointing to realize the lack of data on this indicator because it is directly linked to other indicators on procedures which could probably describe what the total care picture is like in each of the countries under study.

Additionally, Hospital readmissions receive increasing interest from policy makers because reducing un-necessary readmissions has the potential to simultaneously improve quality and save costs.
8.5 FH care in Europe

Familial hypercholesterolemia (FH) is an inherited, metabolic, autosomal (affecting both sexes the same) dominant disorder. Prevalence of FH has been traditionally estimated as ~1:500, contemporary data suggest an overall frequency of ~1:200 – 300, implying that >30 million individuals could be affected worldwide.\(^{60,61,62}\)

It is characterized by abnormally high total cholesterol (TC) and low-density lipoprotein cholesterol (LDL-C) levels. FH is a common genetic cause of premature coronary heart disease (CHD, i.e. ischaemic heart disease)\(^ {63,64}\). If left untreated, heterozygotic men and women with FH with total cholesterol levels of 8 – 15 mmol/L (310 – 580 mg/dL) typically develop CHD before age 55 and 60, respectively, while homozygotes (having inherited the disposition from both parents) with total cholesterol levels of 12 – 30 mmol/L (460 – 1160 mg/dL) typically develop CHD very early in life and die before age 20 if untreated. However, once diagnosed, heterozygotes can readily be treated with cholesterol lowering medication to attenuate development of atherosclerosis and to prevent CHD\(^ {65}\).

8.5.1 FH case finding

There is a large number of Europeans suffering from FH. Many of them do not know because they are still undiagnosed and therefore left untreated. FH is a disease that is rather easy and cheap to treat.

It is reported that the most cost-effective approach for identification of new FH patients is systematic cascade screening of family members of known index cases.\(^ {66}\) However, identification of new FH subjects is mainly based on clinical random criteria in most countries. In general, opportunistic or targeted systematic screening in primary care, guided by a family history of premature CHD and hypercholesterolemia, or among patients aged 55 – 60 with CHD in hospital settings would improve to find Index cases.

Unfortunately, as can be observed in the table below only two countries (The Netherlands and Norway) in Europe systematically screen family members of FH patients, missing a clear opportunity to improve detection rates and the possibility to reach patients early

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enough to improve outcomes. In the Netherlands, cascade testing in families with a known causative mutation has been carried out very successfully over the last 15 years using trained genetic field workers. In the Netherlands, around 71 % of the estimated population suffering from FH is already detected. This is an exception as in most other European countries, less than 1 % of the estimated number of FH patients have received a diagnosis.

Table 8.5.1.1. This table shows, countries screening performances to family members of FH patients; systematically, by regular practice, not at all or not for free.

Further than that and as it could be observed in Fig 8.5.1.2, only 6 countries out of 30 do provide patients with 100 % subsidised genetic testing, the lack of which prevents patients from getting tested and thus improve detection rates.

Fig 8.5.1.2. This table shows if genetic testing for FH is subsidised; Green represent that genetic testing is 100 % subsidised with or without referral, Yellow represents partially subsidised and Red means that FH genetic testing is accessible only if privately paid.

8.5.2 Access to FH care

FH is a chronic disease and it is of vital importance for good outcomes to teach patients and their families how to manage their disease. It is recommended that all patients and their families undergo intensive education targeting lifestyle management, including on smoking cessation, diet, and physical activity. It is essential to avoid overweight, so, for example, a certified dietician/nutritionist should support implementation of a healthy diet with the involvement of the whole family. Finally, cholesterol-lowering drugs should be initiated immediately at diagnosis in adults and strongly considered starting at age 8–10 in childhood, along with lifestyle management.

When, despite use of the highest doses of potent statins, patients with FH do not achieve the LDL cholesterol target with monotherapy alone it is recommended to begin so called combination therapy (statins plus ezetimibe) with a great potential to decrease LDL cholesterol, few side effects and high compliance.

For all chronic diseases like FH, it is important that treatments are affordable for patients so they are able to follow the recommended medication to manage their disease.

It can be observed in Figure 8.5.2 that only approximately one third of countries included in the index offer free access (unrestricted) to combination (statin plus...

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67 Nordestgaard B et al; Familial hypercholesterolaemia is underdiagnosed and undertreated in the general population: guidance for clinicians to prevent coronary heart disease; Eur Heart J. 2013 Dec;34(45):3478-90a.

ezetimibe) therapy for FH patients. In most other countries, combination therapy is only partially reimbursed, meaning that the therapy is less generously subsidized than the typical prescription medication. This could represent for some individuals a rather high amount of out-of-pocket money that some patients or families cannot afford, reducing the access to the right treatment.

Fig 8.5.2: Shows subsidized/reimbursement of combination therapy (statin plus ezetimibe). Green represents cost of the drugs fully covert. Yellow means combination therapy is partially reimbursed (or subsidized) (≥75%), red means combination therapy is not reimbursed (or subsidized).

8.5.3 Other FH treatments: PCSK9 inhibitors

Although current LDL-C lowering therapies, most notably statins, represent the cornerstone of drug management of hypercholesterolemia, a substantial proportion of high-risk patients fail to achieve guideline-recommended plasma LDL-C goals. FH is either insufficiently treated or treated late and, even with current best therapies (high-dose statins and cholesterol absorption inhibitors), only ~20% of individuals attain guideline-recommended LDL-C goals.

Therefore, new treatment strategies are required. PCSK9-targeted therapy is therefore an interesting proposition that may vastly improve the management of patients at high to very high cardiovascular risk. The access to this drug for patients is still restricted in Europe and needs to be paid privately in most cases, as it can be observed in fig 8.5.3 only one country The Netherlands subsidizes PCSK9 inhibitor for FH patients when prescribed.

Fig 8.5.3. Shows subsidies or reimbursement of PCSK9 inhibitors for FH patients. Green means subsidized for any patient group, Yellow subsidized for some patient groups, R indicates represents that they are not subsidized.

The market approval of PCSK9 inhibitors was given in Europe only early 2016. However, as can be observed in Indicator 2.11 (Section 9.2.2.11) there are already big differences in the use of these drugs. At the moment and due to the high prices of these drugs, the use is still very limited, and in most countries administrated to patients only in very specific cases.

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selected cases, where other drugs like statins were not sufficiently effective or poorly tolerated.

The manufacturers have not yet generated and submitted data to show that the drugs improve outcomes of cardiovascular disease; it is assumed that lowering LDL-particle concentrations would reduce cardiac event rates, as has occurred in all statin clinical trials, pending ongoing further clinical trials of PCSK9 inhibitors. 73,74

The Netherlands and Norway are the countries where most FH patients are identified. The Netherlands is the only country where PCSK-9 is fully reimbursed. However, it is not the country where the drug is most used (see 9.2.2.11). Luxembourg, Greece, France or Portugal are the countries were PCSK9 inhibitors have the highest per capita sales in Europe, probably being bought by patients privately.

8.5.4 Awareness

To overcome the existing gaps in care and reduce the preventable global burden of disease arising from FH, major efforts are needed to institute early detection and effective treatment. Central to these efforts is increasing awareness, dissemination of information and promotion of education among healthcare providers, policy makers and patients. To start with community awareness, as well as campaigns and training activities for health care workers, particularly working in primary care, could provide quick tangible improvements in the number of people diagnosed, would improve treatment and therefore outcomes. Most activities or campaigns done in Europe regarding FH awareness in the last two years were supported in by private funding and most times directly depending on National medical societies (See fig 8.5.4).

Fig 8.5.4. This table shows whether there have been any activities or campaigns during the last two years to increase awareness with public funding, or if any activity has been exclusively supported privately, either by the pharmaceutical industry or organized by a National society.

8.5.5 Guidelines

A great number of guidelines have been issued in recent years on these issues. In October 2016, new guidelines for the Management of Dyslipidaemias were published with the support of ESC/EAS.75

In general, guidelines provide additional tools for healthcare professionals to promote up-to-date intervention strategies and integrate these strategies into national or regional prevention frameworks and to translate them into locally delivered healthcare services, in line with the recommendations of the World Health Organisation (WHO) Global Status

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74 Doggrell SA, Lynch KA. Is there enough evidence with evolocumab and alirocumab (antibodies to proprotein convertase substilisin-kexin type, PCSK9) on cardiovascular outcomes to use them widely?. Expert Opinion on Biological Therapy. (2015).

As it can be observed in fig 8.5.5, most European countries do not have any official recommendations or guidelines implemented regarding treatment of FH. Good registries with good data acquisition would also help to understand the burden of the disease and to find the right strategies to tackle the problem.

Fig 8.5.5. This table shows, if any official recommendations or guidelines, approved by the government, are in place in the countries regarding treatment and/or screening of FH. Green means yes and red no.

As a final conclusion, FH represents a major global health problem because it is common, widely under-diagnosed, undertreated and as a result often fatal. The consequences of FH in the form of premature atherosclerosis and cardiovascular events are potentially preventable but require effective initiatives and policies to reduce the current burden of disease.

9. How the Euro Heart Index 2016 was built

9.1 Production phases

The Index does not take into account whether a national healthcare system is publicly or privately funded and/or operated. The purpose is health consumer empowerment, not the promotion of political ideology. Aiming for dialogue and co-operation, the ambition of the HCP is to be looked upon as a partner in developing healthcare around Europe.

The EHI 2016 was constructed under the following project plan.

9.1.1 Phase 1

1. Selection of a number of experts to be part of the expert panel and set up the first meeting.

The composition of the Expert panel can be found in Section 10.

2. Start-up meeting with the Expert Reference Panel - Mapping of existing data

- The major area of activity was to evaluate to what extent relevant information is available and accessible for the selected countries. The European diabetes care situation was studied to evaluate which indicators from the previous index could still be interesting to use. The basic methods were:
  - Web search, journal search
  - Relevant byelaws and policy documents
  - Actual outcome data in relation to policies

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3. Pre-design a number of interesting indicators and possible sub-disciplines for the project which were discussed during the first expert panel meeting.

9.1.2 Phase 2

1. **Indicator scoring.** During the first expert panel meeting a large number of indicators were selected as being relevant to be included in the project. This “long-list” included more than 50 indicators. The experts then performed an indicator scoring in an organized and systematic manner to shorten the list and select the indicators most relevant for the project. The research team started working with 44 indicators.

2. **Data collection to assemble presently available information to be included in the EHI 2016.**
   - Identification of vital areas where additional information needed to be assembled.
   - Collection of raw data for these areas.

3. **Surveys to relevant stakeholders.** An online questionnaire was developed and opened on January 15th. The closing date was August 20th. The survey was mentioned and introduced to physicians and other stakeholders through the HCP website and Facebook. Particular individuals were directly contacted by HCP researchers. In addition, EHN encouraged their members to answer the questionnaire.

   In total, 35 answers from 20 different countries were received. This information was only used as feedback, never as primary indicator data.

   The second questionnaire (See Appendix 2): contains 8 questions related with FH care in Europe. The questions were designed by board members of EAS and the European FH patient network. The survey was distributed exclusively to national members of both organisations. 206 answers were received from 27 different countries. The information on the 3 indicators in the matrix regarding FH care in Europe was extracted from the analysis of the data collected through the questionnaire.

4. **A round of personal visits by HCP researchers** to Health Ministries and/or State Agencies for supervision and/or Quality Assurance of Healthcare Services.

5. **Regular contacts with the Expert Reference Panel** mainly to discuss the indicators, the criteria to score them, and the data acquisition problems. Finally, there was a second meeting on September 26, 2016, at which each of the indicators was discussed in detail, including those that could not be included in the Index due to lack of data. Also,
the discrepancies between data from different sources were analyzed. Sub-discipline relative weights were also discussed and set.

**9.1.2.1 "Single Country Score Sheets” send-out.**

On October 10th, 2016, all 30 states received their respective preliminary score sheets (with no reference to other states’ scores) as an e-mail send-out asking for updates/corrections by November 1st. The send-out was made to contacts at ministries/state agencies as advised by states during the contact efforts and to all EHN members. Corrective feedback from states was accepted up until November 22nd, by which time replies had been received from countries denoted in section Additional data gathering – feedback from National Ministries/Agencies for more information on national feedback.

**9.1.3 Phase 3**

Project presentation and reports

- A report describing the results and principles of how the EHI 2016 was constructed.
- Presentation of EHI 2016 on December 7th at an online webinar with panel discussion.
- On-line launch on [www.healthpowerhouse.com](http://www.healthpowerhouse.com).

**9.2 Content of indicators in the EHI 2016**

The research team of the Euro Heart Index 2016 collected data on the 31 healthcare performance indicators selected for the final EHI version. Additionally, one table containing information on screening of CVD risk factors for risk groups is included in section 8.1.8, as a part of the discussion. Also in section 8.5, a description on FH care in Europe, including different tables and figures containing additional data collected on this issue but not included in the matrix.

**9.2.1 Prevention**

While some risk factors contributing to the development of CVD are beyond person's control as age or family history, there are also a number of modifiable risk factors, the control and modification of them and the adoption of a healthy lifestyle, reduce or delay the development of CVD and help to improve overall quality of life.

The right selection of data for this sub-discipline has been difficult to achieve. There are many different set of data on most of the prevention indicators that we were looking for, they are measuring the basically the same topics in different way but this time we wanted to present something closer to what may happen in reality, closer and more understandable for the patient but that still allows us to compare performances. Our aim was to try to show the most real and fair picture we could.

**9.2.1.1 Prevalence of obesity in adults**

Age-standardized prevalence of obesity (Percentage of total population with BMI≥30 kg/m²) in people aged 18 years and over, estimates (%). We decided to use this data collection because most consulted experts agreed, that the number presented here even
thought they are estimations, could be the closest to the real situation. Due to HCP methodology to score performances, we could not used data sets like OECD data, in which measure data and reported are collected together, for the simple reason that those countries with measure data (always higher than reported) would be unfairly punished.

**Source:** WHO Global health observatory 2014

### 9.2.1.2 Prevalence of child obesity

Percentage of children 11 years old who are overweight or obese (WHO child growth curve standards). Childhood obesity has reached epidemic proportions. Many of these children have risk factors for later disease, including cardiovascular disease.

**Source:** HBSC-International report 2013/2014

### 9.2.1.3 Exercise in compulsory school

Total hours of physical activity in up to 10 years of compulsory school. Physical exercise is beneficial to reduce risk for illness for a vast spectrum of diseases. There is statistics on parameters such as “number of hours of jogging or similar per person per week” for many countries. However, the radio noise level of this data is quite high. Also, this is a parameter which is very difficult for any decision makers to change for a significant part of a population within a reasonable time frame. Therefore, the physical exercise parameter chosen for the EHCI 2015 is “number of hours of physical exercise in compulsory school” (counting a maximum of 10 school years), according to nationally set standards. This is a parameter that e.g. a government has the power to change. Some countries get a Yellow score for not having a set national standard for number of hours.

**Source:** Eurydice 2015/2016
9.2.1.4 Consumption of soft drinks

Consumption of soft drinks including Juice and nectars (liters per capita). UNESDA membership comprises national associations and company members. UNESDA company members are soft drinks producers, bottlers and distributors operating across more than five EU markets. The data represents sale numbers.

Source: Union of European Soft Drinks Associations (UNESDA) 2014

9.2.1.5 Fresh fruit/vegetable consumption

Consumption of fruit and vegetables in grams/per capita/per day.

Data from the annual consumption monitor published by the European Fresh Product Association (Freshfel). Although a significant number of national reports and studies on consumption of fruits and vegetables are available in the various EU Member States (often in different formats), consolidated information on fresh produce consumption at the European level remains scarce. After analyzing different sets of data it was agreed that this could best describe the situation.

Source: Freshfel (data 2013)

9.2.1.6 Sugar consumption

Grams per day, per capita (Economic consumption).

Data from Euro monitor, a market research firm, which collects sales data on a number of packaged products and analyses the total amount of sugar that those products contain. These measurements are closer to the daily sugar consumption that any other data that could be collected.

Source: Euro monitor 2014

9.2.1.7 Tobacco consumption

Cigarette sales per capita age 15+ (incl. Counterfeit and Contraband, not including duty free, which probably underestimates the consumption of countries such as Norway and the UK.)

Sources: KPMG Project Sun 2016

9.2.1.8 Alcohol consumption

Unlike cigarette smoking, alcohol as a risk factor is not always harmful. It has been shown in numerous studies that a modest alcohol intake (the equivalent of one glass of wine per day for women, and 1 –2 glasses per day for men) reduces the risk of death from CVD enough to result in a lower mortality than for total abstainers. For example; persons with Higher LDL (“Bad cholesterol”) by drinking in moderation can raise HDL, or “good” cholesterol. Alcohol can act as an anticoagulant, making the blood less sticky and less likely to clot and also, alcohol may also reduce inflammation, which plays a role in heart attacks and strokes. On the other hand, drinking vast quantities of alcohol on single occasions (“binge drinking”) is a known risk factor for CVD, and also for some cancer forms. This seems particularly true for binge drinking involving hard liquor consumption.
For these reasons, this indicator is based on “hard liquor consumption (litres of pure alcohol), binge drinking adjusted”. The adjustment is made by multiplying the nominal consumption by \((1 + \text{percentage of population having had } \geq 5 \text{ drinks on their latest drinking occasion})\).

**Sources:** WHO HfA September 2016, Special Eurobarometer 331, April 2010 (for binge drinking habits). National reports. CUTS data.

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### 9.2.1.9 Prevalence of raised blood pressure

Prevalence of raised blood pressure (SBP≥140 OR DBP≥90) among adults aged ≥25 years (%) (General population) High blood pressure is a major risk factor for CVD and stroke.

**Source:** WHO (Global health observatory data repository, 2014).

### 1.10 Familial Hypercholesterolemia (FH) screening

Are family members of patients with FH systematically screened for FH?

**Source:** Online questionnaire to national members of European Atherosclerosis Society (EAS) and European FH patient network.

### 9.2.2 Procedures.

The provision of CVD services is complex. Care is provided by a wide range of professionals, including general practitioners (GPs) and other physicians and paramedic staff. The achievement of good outcomes for people suffering from any cardiovascular disease is dependent on the provision of well-organised and coordinated services which draw on the knowledge and skills of health and social care professionals working across primary and secondary care.
9.2.2.1 *Door to balloon delay for STEMI patients (median, minutes)*

Door to balloon time (D2B), the time from the arrival of an STEMI patient at a hospital to the time of PCI. Refers to the time a patient arrives at a PCI centre to the time of PCI treatment. This therefore assesses how quickly the PCI unit can perform primary PCI.

National and international guidelines recommend that in the emergency treatment of patients with STEMI, **primary PCI should be performed within 90 minutes of arrival at the heart attack centre (door-to-balloon time)** and within 120 minutes of a patient’s call for professional help (call-to-balloon time).

**Source:** Data from National registries, national publications, interviews with health care officials, physicians and public health experts.

9.2.2.2 *Health care and paramedical personnel certified for CPR*

For MI: Is health care and paramedical personnel certified for latest/appropriated CPR (Cardiopulmonary resuscitation)?

A **paramedic** is a healthcare professional, predominantly in the pre-hospital and out-of-hospital environment, and working mainly as part of emergency medical services (EMS), such as on an ambulance. Their role and knowledge it is of extrem relevance. This indicator try to find out if most health care personnel groups, get statutory and regularly certified for CPR, or if there are only some groups as doctors or nurses getting this certification, or if the updating on this kind of certifications is unsystematic depending on random variables.

**Sources:** Interviews with health care officials, national physicians and public health experts.

9.2.2.3 *Pre-hospital Thrombolysis*

The aim of this indicator is to collect information on the availability of thrombolysis, as part of treatment given in ambulances or in primary care settings. The importance of reducing time to thrombolysis in the treatment of STEMI is known, with the greatest benefits gained when reperfusion is closest to first medical contact. The ambulance or the primary care setting service is often this contact, and is uniquely placed to administer pre-hospital thrombolysis with cardiology support.

There are countries like Malta or Cyprus which because of geographical size of the country do not really need to have special ambulances providing pre-hospital thrombolysis. Therefore they all received **n.ap.** (not applicable).

**Sources:** Interviews with health care officials, national physicians and public health experts.

9.2.2.4 *Emergency defibrillators available in public places*

Are there automated emergency defibrillators **widely available** in public places (such as shopping centres, airports, offices, government buildings, schools, health & sports clubs, transportation centres, day care centres, and casinos)? Early defibrillation is a critical
component in treating sudden cardiac arrest. Availability in public places is important for rapid access.

**Sources:** Interviews with health care officials, national physicians and public health experts.

### 9.2.2.5 Rehabilitation programme

Combine indicator: % of advised patients participating in rehabilitation/ Access to rehabilitation program (waiting list, partially paid). It is defined as structured short-term programs for delivering personal assessment and modification of risk factors, purpose-designed exercise programs, health education, counselling, behaviour modification strategies and support for self-management. This type of care is normally provided during the initial period after hospitalisation.

Despite the clear benefits of participation in cardiac rehabilitation, improving outcomes and decreasing short terms readmission rates. Rehab following a cardiac event remains underutilized. Question: is it easy for those patients advised to access rehabilitation after a cardiac event or if otherwise there is something that prevent patients from access, like a long waiting list or having to pay a lot out of pocket. As this data is informative but perhaps subjective, data on how many of the patients advised to attend rehabilitation actually have attended was also reviewed.

**Sources:** Euroaspira IV, Bjarnson-Wehrens B et al; 2010, Interviews with health care officials, physicians and public health experts.

### 9.2.2.6 Home care available for cardiac patients?

Special cardiac care (Heart failure, endocarditis, Deep vein thrombosis). Patients with heart failure (HF) need long-term and complex care delivered by healthcare professionals in primary and secondary care. Better integrated care is warranted in this population and specialised care can save costs and improve the quality of care. However, only a few European countries have implemented specialised home care and offer this to a larger number of patients.

**Sources:** Interviews with health care officials, national physicians and public health experts.

### 9.2.2.7 Number of PCI p.m.p:

Frequency of PCI in +50 population. Total number of PCI per (+50) million population.

**Source:** Health at a glance 2015 - © OECD 01-01-2015

### 9.2.2.8 PCI/ CABG

Ratio of procedures: number of Percutaneous Coronary Intervention (PCI)/ Coronary artery bypass (CABG). The higher the ratio, the more state-of-the-art cardiac care.

**Source:** Health at a glance 2015 - © OECD 01-01-2015
9.2.2.9 Statin deployment

On drug consumption indicators (2.9 – 2.11), for copyright reasons the graphs show only relative sales (no values on the Y-axis).

Sales per capita (SU per capita 50+ SDR adjusted). Statins, which have been on the market for almost 30 years, are the primary therapy used to prevent cardiovascular events. They lower LDL-C levels by inhibiting the enzyme HMG-CoA reductase, which has a vital role in the production of cholesterol in the liver. Statins typically reduce LDL-C levels by 30 – 40% and are directly associated with reducing the risk of heart attack and stroke. The EHI is using actual sales data.

It is interesting to note that the straight per capita use, when NOT corrected for CVD prevalence, is more even across Europe than the prevalence-adjusted! There are (at least) two possible explanations for this:

i) Active use of these essential drugs brings down CVD mortality, resulting in higher per capita numbers in the prevalence-adjusted data.

ii) The medical profession is more affected by “kitchen wisdom” popular belief about which share of the population should receive these drugs, than governed by guidelines.

Source: IMS MIDAS database, 12 months ending June 2016.

Graph 9.2.2.9a. Deployment of Statins, as International Units of lipid control medication (ATC C10A sales) per capita 50+ (Prevalence adjusted). Sources: IMS Health MIDAS database.
Graph 9.2.2.9b. Deployment of Statins, as International Units of lipid control medication (ATC C10A sales) per capita 50+ (NOT prevalence adjusted). Sources: IMS Health MIDAS database.

9.2.2.10 Clopidogrel deployment

Sales per capita (SU per capita 50+ SDR adjusted). Clopidogrel helps to prevent platelets in your blood from sticking together and forming a blood clot. Unwanted blood clots can occur with certain heart or blood vessel conditions. Clopidogrel is used to prevent blood clots after a recent heart attack or stroke, and in people with certain disorders of the heart or blood vessels. The EHI is using actual sales data.

Source: IMS MIDAS database, 12 months ending June 2016.
Graph 9.2.2.10. Anti-platelet medication use, expressed as International Units (ATC B1C sales) per capita 50+ (Prevalence adjusted). Sources: IMS Health MIDAS database.

9.2.2.11 PCSK-9 inhibitor deployment

Sales per capita (SU per capita 15+). This protein plays a major regulatory role in cholesterol homeostasis, mainly by reducing LDLR levels on the plasma membrane. Reduced LDLR levels result in decreased metabolism of LDL-particles, which could lead to hypercholesterolemia. We are using sales data as an approximation to PCSK-9 inhibitor consumption. Because of their recent market approval and the prices, the consumption of PCSK-9 inhibitors is presently limited in the whole of Europe.

Source: IMS MIDAS database

Graph 9.2.2.11. PCSK9 inhibitor deployment; expressed as International Units of PCSK9 inhibitor per capita + 15. Sources: IMS Health MIDAS database (sales, July 2015 – June 2016).
9.2.3 Access to treatment/care
People with cardiovascular disease or who are at high cardiovascular risk (due to the presence of one or more risk factors such as hypertension, diabetes, hyperlipidaemia or already established disease) need early detection and management using counselling and medicines, as appropriate.

9.2.3.1 Waiting time to echocardiography and diagnostics.
Average waiting time to echocardiography and diagnostics for suspected heart disease; Elective patients.
Sources: Interviews with health care officials, physicians and public health experts.

9.2.3.2 Waiting time for non-acute revascularization (CABG /PCI).
Average waiting time for non-acute revascularization (CABG /PCI), from time of catheterization.
Sources: Interviews with health care officials, physicians and public health experts.

9.2.3.3 "Waiting time" for heart transplant
Ratio: Number of patients on waiting list/ Number of transplants per year
Sources: Council of Europe Newsletter Transplant 21/Sept 2016

9.2.3.4 Support for families with children with congenital Heart Disease (CHD).
Free family support available for families with children having congenital heart disease. CHD describes a number of different problems affecting the heart. It is the most common type of birth defect and is responsible for more deaths in the first year of life than any other birth defect. Congenital heart disease can present in new-born infants or older children in a variety of different ways. Parents and families need support not only from friends and families but from the health system to understand the situation and be able to face and manage the situation. Mainly in topics related with parents' psychological health, family life, parenting challenges, and family-focused interventions.
Unfortunately, the data only covers the provision of services, not the quality.
Sources: Interviews with health care officials, national physicians and public health experts.

9.2.3.5 Access to free FH genetic testing
A genetic test can tell which altered gene, and which type of FH, a patient has. It can help doctors to ensure the right treatment for FH and can also help find other family
members who have the same condition. Additionally, it is described that cascade screening to family members of FH patients is cost-effective.

Genetic testing can be expensive. Therefore the indicator is based on information on what is the situation regarding reimbursement or subsided genetic testing.

**Sources:** Online questionnaire to national members of European Atherosclerosis Society (EAS) and European FH patient network.

### 9.2.3.6 Combination therapy (statin plus ezetimibe) to treat FH reimbursed or subsidised

When despite use of the highest doses of potent Statins, patients with FH do not achieve the LDL cholesterol target with monotherapy alone, the so-called combination therapy (Statins plus ezetimibe) is recommended, with a great potential to decrease LDL cholesterol, few side effects and high compliance. This indicator measures the reimbursement/subsidy situations across Europe.

**Sources:** Online questionnaire to national members of European Atherosclerosis Society (EAS) and European FH patient network.

### 9.2.4 Outcomes

#### 9.2.4.1 30-day case fatality rate after admission for AMI

Thirty-day mortality after admission to hospital for AMI (based on admission data). Age-sex standardised rate %, patients 45+.

**Source:** OECD Health Statistics 2015, [http://dx.doi.org/10.1787/health-data-en](http://dx.doi.org/10.1787/health-data-en) and interviews with health care officials, physicians and public health experts.

#### 9.2.4.2 Standardized death rates from CVD

Data availability on the Acute Heart Infarct (AMI) in-hospital case fatality indicator is shockingly fragmented and incoherent over Europe. For this reason, that indicator has been replaced since the EHCI 2014 by the indicator “Inclination of the long-Time trend line for ischaemic heart disease Standardized Death Rates”. This is based on the assumption that modern healthcare is the dominating reason for the decrease of cardiac deaths. That lifestyle changes are not the major factor is supported by the discussion on the Diabetes Epidemic. Diabetes shares most of the risk factors with CVD, and with the exception of smoking rates slowly decreasing, other risk factors such as obesity, drinking and sedentary lifestyle are on the increase.

The actual indicator data is the steepness of the long time trend line inclination. This calculation has been done on the logarithmic values of the SDR numbers to compensate for the fact that *e.g.* France starts the comparison at an SDR around one 6th of some CEE countries (see graph Section 8.4).

**Sources:** WHO HfA, July 2016 and Interviews with health care officials, physicians and public health experts.
9.2.4.3 Hospital readmission rates for heart failure

30 days after discharge, all-cause, latest data published. Thirty-day readmission rates are a key performance metric for acute care and long-term care hospitals.

**Sources:** Interviews with health care officials, physicians and public health experts, diabetes registries.

9.2.4.4 Surgical mortality for Isolated transposition of the great arteries (TGA) < 7%.

Hospital mortality rate for Isolated transposition of the great arteries.

**TGA** is the most common cyanotic congenital cardiac anomaly with cyanosis in the first 24 hours of life. It accounts for up to 7% of all congenital cardiac anomalies.

**Sources:** Interviews with health care officials, physicians and public health experts.

10. External Expert Reference Panel

As is the standard working mode for all HCP Indexes, an external Expert Reference Panel was recruited. The panel met for two 6-hour sittings during the course of the project. The following persons have taken part in the Expert Reference Panel work for EHI 2016:

<table>
<thead>
<tr>
<th>Name</th>
<th>Affiliation</th>
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<tbody>
<tr>
<td>Norbert Bachl, Prof.</td>
<td>Centre for Sport Science, Sport medicine and performance Physiology. Sport University, Vienna. Austria</td>
</tr>
<tr>
<td>Carlos Brotons, Dr.</td>
<td>Sardenya Primary Health Care Centre. Biomedical Research Institute Sant Pau. Barcelona. Spain.</td>
</tr>
<tr>
<td>Zlatko Fras, Prof.</td>
<td>Division of Internal Medicine, University Medical Centre Ljubljana, Slovenia</td>
</tr>
<tr>
<td>Dan Gaita Prof.</td>
<td>University of Medicine &amp; Pharmacy &quot;Victor Babes&quot;, Timisoara, Romania</td>
</tr>
<tr>
<td>Ian Graham, Prof.</td>
<td>Trinity College, Dublin. Secretary/Treasurer, European Society of Cardiology.</td>
</tr>
<tr>
<td>Ulrich Keil. Prof.</td>
<td>Institute of Epidemiology and Social Medicine, University of Münster. Germany</td>
</tr>
<tr>
<td>Chistos Lionis, Prof.</td>
<td>Clinic of Social and Family Medicine, Faculty of Medicine, University of Crete, Heraklion, Crete, Greece</td>
</tr>
<tr>
<td>Francesca Pluchinotta, Dr.</td>
<td>Dpt of Paediatric Cardiology and Adult Congenital Heart Disease - IRCCS Policlinico San Donato. Italy</td>
</tr>
<tr>
<td>Giacomo Pongiglione, Prof.</td>
<td>Formal Director, Department of Paediatric Cardiology and Cardiac Surgery. Ospedale Pediatrico Bambino Gesù. Roma. Italy</td>
</tr>
<tr>
<td>Eva Swahn, Prof.</td>
<td>Department of Cardiology and Department of Medical and Health Sciences, Linköping University, Linköping, Sweden</td>
</tr>
</tbody>
</table>
The Expert Reference Panel for a HCP Index has two core tasks:

a) To assist in the design and selection of sub-disciplines and indicators. This is obviously of vital importance for an Index. They also assist with the criteria selection to evaluate the data collected.

b) To review the final results of research undertaken by HCP researchers before the final scores are set and also to set the relative weights of each sub-discipline depending on the relevance of the indicators for the disease and also on the quality and the availability of the data collected. If the information obtained seems to clash too violently with the many decades of healthcare experience represented by the panel members, this has been taken as a strong signal to do an extra review of the results.

The HCP wishes to extend its sincere thanks to the members of the panel for their fundamentally important contribution to the Index work, and for very valuable discussions during the course of the project.

11. References

11.1 Main sources

The main sources of input for the various indicators are given in Table 7.1 above. For all indicators, this information has been supplemented by interviews and discussions with healthcare officials in both the public and private sectors.
Appendix 1. Questionnaire used in the survey for the Euro Heart Index 2016.

1. Initially, could you please indicate in which European country you are based?

2. Which is your area of expertise?
   - Clinician
   - Nurse
   - Public Health Expert
   - Academic/researcher
   - Patient Organisation representative
   - Accompanying person
   - Press
   - Other
   Other (please specify)

3. Is screening of CV risk factors recommended (systematic and subsidised) for the following groups? (Please indicate in the table below all that apply). R for routinely done (but not systematic)/ S for systematic.

<table>
<thead>
<tr>
<th>Risk Factor</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history of (CVD, premature coronary heart disease (CHD), sudden death, arrhythmia.....)</td>
<td></td>
</tr>
<tr>
<td>Specific age groups in general population (e.g +65)</td>
<td></td>
</tr>
<tr>
<td>Patients with diabetes</td>
<td></td>
</tr>
<tr>
<td>Patients with depression</td>
<td></td>
</tr>
<tr>
<td>Pre-diabetes patients(IFG and IGT)</td>
<td></td>
</tr>
<tr>
<td>High blood pressure patients</td>
<td></td>
</tr>
<tr>
<td>People with BMI &gt; 30</td>
<td></td>
</tr>
<tr>
<td>Patients with high level of LDL cholesterol</td>
<td></td>
</tr>
<tr>
<td>Obese children (BMI/waist circ)</td>
<td></td>
</tr>
<tr>
<td>Neonates, infants and children (for congenital heart disease)</td>
<td></td>
</tr>
<tr>
<td>Patients with Dyslipidemia (e.g Familial hypercholesterolemia (FH))</td>
<td></td>
</tr>
</tbody>
</table>
4. Is health care personnel certified for latest/appropriated CPR (Cardiopulmonary resuscitation)?
   - yes, statutory
   - Yes, by regular practice but not statutory
   - Very unsystematic
   - I do not know

5. Is pre-hospital thrombolysis available as part of treatment given in ambulances or in primary care settings?
   - Yes, widely available in the country
   - Yes, in many of the services
   - No, essentially not
   - I do not know

6. In your country, are automated emergency defibrillators available in public places (such as shopping centres, airports, offices, government buildings, schools, health & sports clubs, transportation centres, daycare centres, and casinos)?
   - Yes, Widely available
   - Yes, but only in specific public places
   - No, essentially not or rarely
   - I do not know

7. Is home care for cardiac patients available in your country?
   - Yes, widely available in the country
   - Yes, in most regions or available for most of the people in need
   - No, essentially not or difficult to receive (e.g long waiting time...)
   - I do not know

8. Is support for families with children having congenital heart disease freely available in your country? (e.g General counselling, psychology, genetic consultation...)
   - Yes, essentially available for all families
   - Only some health facilities or regions offer this service.
   - Typically is not offered
9. Typically, how long is the waiting time to echocardiography and diagnostics for suspected heart disease?

- Less than 48 hours
- More than 48 hours but less than 4 days
- More than 4 days
- I do not know

10. Typically, how long is the waiting time for non-acute coronary revascularization procedures from time of catheterization?

- 3 to 7 days
- 8 to 30 days
- More than a month
- I do not know

11. Are comprehensive post cardiac event rehabilitation programmes available in your country?

- Yes, widely available in the country
- Yes, in most regions or available for most people in need
- No, essentially not or difficult to receive (e.g. long waiting times......)
- I do not know
Appendix 2. Questionnaire used in the survey for the Euro Heart Index 2016 (FH care Indicators).

1. Initially, could you please indicate in which European country you are based?

2. Which is your area of expertise?
   - Clinician
   - Nurse
   - Public Health Expert
   - Academic/researcher
   - Patient Organisation representative
   - Accompanying person
   - Press
   - Other
   Other (please specify)

3. Over the last two-year period, have any activities or campaigns been taking place to increase awareness among: (Please select all that apply)

<table>
<thead>
<tr>
<th></th>
<th>Private funding</th>
<th>Public funding</th>
</tr>
</thead>
<tbody>
<tr>
<td>General population</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cardiovascular specialists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care physicians</td>
<td></td>
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<tr>
<td>Paediatricians</td>
<td></td>
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</tbody>
</table>

4. In your country, are family members of patients with FH systematically screened for FH?
   - a) Yes, in a systematic way
   - b) Yes, in regular practice but not systematic (decision depends upon individual doctor)
   - c) No or not for free
   - d) I do not know

5. In your country, are there currently any official recommendations or guidelines in place that are approved by the government regarding treatment and/or screening of FH?
6. Assuming that around 0.2-0.5% of the population has FH, what is the estimated percentage of patients detected and treated in your country?

7. In your country, are there specialised clinics for screening and treatment of FH (Lipid clinics)?
   - a) Yes, widely available for people in need
   - b) Yes, but not enough (long waiting times)
   - c) No, not available in my country
   - d) I do not know
   - Other (please specify)

8. Is the combination therapy to treat FH (statin plus ezetimibe) currently reimbursed or subsidised in your country?
   - a) Full reimbursement (or fully subsidised)
   - b) Partially reimbursed (or subsidised) (≥75%) reimbursed
   - c) No, not reimbursed (or subsidised)
   - d) I do not know
   - Other (please specify)

9. Is genetic testing subsidised?
   - a) Yes, 100% subsidised (with or without referral)
   - b) Partially subsidised
   - c) No, only privately paid
   - Other (please specify)

10. In your country, is treatment with PCSK9 inhibitors subsidised (reimbursed)?... (Please select all that apply)
    - For any FH patient groups
    - For some FH patients
    - Other (please specify)