Health Consumer Powerhouse

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Report

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Killing neglect

Diabetes is growing around Europe, with a significant predicted increase during the next generation. Diabetes is a disease more and more people live with for many years. Diabetes increases the risk to get a heart complication, renal dysfunction, become blind or loose a limb. Obesity and smoking increase the risk of diabetes. The costs to individuals and society are huge. A long list of troublesome effects cold be drafted.

Taking into regard the often serious, even fatal, consequences it seems reasonable that ambitious and efficient diabetes care would be given a high priority in every country in Europe. But sadly this is far from the case!

This first ever comparison of how the European national healthcare systems perform from the diabetic point of view offers a rather shocking picture:

- In many countries there is a blatant risk that the lack of systematic prevention will not detect and stop your diabetes in time. In every second country there are no regular check-ups of blood sugar (or the government cannot really tell what the situation is!)
- There is a huge diabetic population neither diagnosed nor properly treated. Because of this, renal complications seem to be a significant problem in half of the measured countries. Due to neglect the damage grows much worse than with adequate disease management.
- The severe lack of diabetes data hinders awareness of the problem and efficient treatment.

It is time for a systematic re-shaping of European diabetes care, or the growing numbers of senior Europeans will meet a dire future.

Our reality check-up indicates that this should be done as a start:

- The key to success in diabetes management is easy access to competent primary healthcare combined with quality patient information. Give priority to such reforms!
- Much more should be done to keep death rates down through simple lifestyle-oriented preventive measures such as assistance with smoking cessation!
- Provide diabetes patients with access to modern medical devices and medication to control their disease and facilitate quality of life!

Good diabetes care is mainly not a matter of GDP but of culture and organisation.

To motivate and involve the patients is a daily struggle. That is why user-friendly public benchmarks are of such importance. To make individuals understand that there are huge variations in diabetes care builds a demand for quality.

Since 2004 we have contributed to the improvement of healthcare by ranking performance in 30 countries. HCP Indexes provide reality check-ups to governments, benchmarks to care providers and empowerment to care consumers. The 2008 Euro Consumer Diabetes Index is our 16th Index.

Johan Hjertqvist

President
Health Consumer Powerhouse
Stockholm/Brussels/Winnipeg

1. Index champions and key outcomes

Denmark (837 points out of 1000) emerges as the winner of the Euro Consumer Diabetes Index 2008. Denmark performs better than their neighbours in central and northern Europe. In spite of spending less money per capita on healthcare than other central and northern European countries, Denmark provides very well organized diabetes management with enough diabetes professionals and great access to services. Denmark's strategy meets the healthcare needs of the country.

UK (836 points) very closely follows Denmark with respect to good diabetes management. Only one point separates the two countries. The UK provides many very well trained diabetes nurses, diabetes multidisciplinary working groups and great access to services. Although the UK does not provide enough foot specialists, it still offers services for diabetes patients that are better than most European countries, resulting in the best outcomes in Europe. The UK, however, could improve how it distributes information: patient education for diabetics is scarce.

Runners-up are France (814) and the Netherlands (813), both with very good diabetes care. France is stronger in Prevention and The Netherlands performs well on the use of modern therapeutic procedures. Belgium (803) makes it to the 5th position by a strong performance on Prevention and Procedures with a good screening program.

Behind the five leaders, come a number of very competent healthcare systems: Norway (781 points), Italy (752). Germany (751), Ireland and Switzerland all scored above 720 points.

What characterizes the best diabetes care?

The countries that do perform well are those who predominantly treat diabetes early in the healthcare chain, *i.e.* in primary care. This is not surprising, as diabetes is a well-understood disease, and benefits dramatically from early diagnosis and intervention. Therefore routine screening for diabetes – of the type easily offered by GPs and nurse practitioners in a primary care setting – represents an effective management tool.

Financial strength seems to be helpful but not essential for providing good diabetes care. For example, Denmark and UK, both winners of this Index, spend about the average amount of money on health care expenses and Lithuania (696) or Latvia (683) provide better diabetes healthcare than countries spending three times more money on healthcare.

Need for improvement!

All European countries, especially eastern European countries, need to improve their diabetes care.

More and better staff need to be trained and recruited. Furthermore, healthcare systems need to adhere to guidelines for specific therapies, provide better access to screening and surgery, and establish more preventive work to curb the rising incidence levels of diabetes.

If healthcare officials and politicians would "borrow" successful ideas from their EU colleagues, the diabetes care of national health systems could move closer to the theoretical top score of 1000.

As more data becomes available, subsequent versions of the Euro Consumer Diabetes Index will in all likelihood have a modified set of indicators.

1.1 General observations

This study shows considerable variation in approaches taken by EU member states, approaches that still need to be refined if we want good diabetes care across Europe. Most countries could improve their Prevention strategies. This would require long-term commitment and could result in very substantial reductions of the numbers of diabetics in Europe. Patient education needs to be more efficient, intensive, and focus on follow-up. This means dedicating more time and personnel to the patients and letting nurses play a more important role. In addition, healthcare providers and educators need to provide the general public with more and better information about diabetes and its risk factors. This would help not only to improve prevention but to avoid daily life discrimination against diabetics as has been reported in some EU countries.

Waiting times, still an issue, are not reflected by any indicator, as it has proved very difficult to find waiting time data specifically attributable to diabetes care. Patients from several countries (*e.g.* Ireland and Spain) constantly complain about waiting times (sometimes up to a year) for check-ups, surgeries, or any other kind of appointment. "You can get many devices to control your diabetes but to learn how to use them can take up to six months". Waiting times seems an obvious indicator to include in later editions of the Euro Consumer Diabetes Index.

Many patients with diabetes cannot or do not follow recommended therapies because these are too expensive. This is surprisingly a reality for most of diabetics with foot ulcers or any other minor foot complications that require specially adapted shoes and insoles in order to prevent more serious foot complications or even amputations.

The EU only addresses these healthcare issues in a very limited way. Information to patients on where to seek diabetes care, based on which clinic has the best results, is still a European disaster area. It is a continued source of wonder why this should be so much more difficult to provide in Europe than on the other side of the Atlantic. Finally, it is very important to emphasize the necessity of quality data acquisition, especially in eastern European countries. That is why the ambitious project Tele Diab in the Black Sea region is of great importance and inspiration to others.

1.2 Areas for diabetes care improvement

1. More emphasis on prevention programmes could reduce the number of diabetics and also the frequency of diabetes complications.
2. The number of trained and qualified staff should be increased especially in eastern European countries. Some countries are already making an effort in this issue; training courses for nurses and doctors to become specialist in diabetes have recently started. The CEE states face an additional problem because there is a loss of

healthcare professionals moving to the west for higher salaries, which makes it difficult to improve conditions. Moreover, the few specialists are often concentrated in the big cities, leaving the countryside neglected.

3. There are three areas with a general lack of trained professionals:
    - Specialists in diabetes foot care. Very important in foot complications prevention and care.
    - Medical experts in diabetes eye care. Very important in eye complications prevention and care.
    - Diabetes nurse practitioners. Very important in diabetes management and patient education.
4. There are many barriers and lack of smooth procedures to make it easier for patients who choose to be treated outside their national borders. Many national officials say that their citizens hardly ever take advantage of going abroad, and would prefer to be treated at home since diabetes is a chronic disease requiring continuous care.
5. The prevalence of obesity and the number of smokers is still very high in Europe. It is important to notice that obesity and smoking are two of the main risk factors not only for diabetes, but also for cardiovascular diseases; it seems incredible that at least one-third of the population still smokes and almost 20% of the population is obese. Surprisingly, a low percentage of smokers are supported by healthcare services to stop smoking, when that should be considered a high priority.

2. Diabetes – a growing threat to health

Diabetes mellitus (DM) is the most common metabolic disease worldwide and the number of newly diagnosed cases is rising globally. DM is strongly associated with a number of devastating chronic late complications, including retinopathy (function loss in the retina of the eye), nephropathy (kidney failure), and neuropathy (circulation complications in small blood vessels), as well as cardiovascular disease (circulation complications in large blood vessels).

In the next 20 years, the number of cases of diabetes is expected to increase by 71% worldwide: by 21% in the European Region (World Health Organisation), and by 16% across the European Union (IDF Atlas). The prevalence and complications can be reduced through early and appropriate intervention.

Diabetes mellitus is a chronic disease, characterised by too high levels of blood sugar (hyperglycaemia), resulting from defects in insulin secretion, insulin action or both. The two most important forms are Type 1 (immune mediated diabetes mellitus) and Type 2 (insulin resistance mediated diabetes mellitus), both included in our study since they represent the majority of the diabetic population.

Immune mediated or Type 1 diabetes – a destruction of the β cells in the pancreas that is usually diagnosed in childhood or early teens – often leads to an absolute deficiency of

insulin production. For this form of diabetes, insulin injection therapy is the only adequate therapy.

Type 2 diabetes, characterised initially by insulin resistance with a relative insulin deficiency, may become a predominantly secretory defect of the pancreatic β cells. Clinical symptoms may not always be present at onset and in some cases the diagnosis will only be made at the discovery of late complications. Overweight/obesity, a major risk factor for Type 2 diabetes, causes insulin resistance, leading eventually to Type 2 diabetes. With age, the risk of hyperglycaemia increases. Diet and/or physical exercise will modify insulin resistance, improving insulin sensitivity, normalising blood glucose. If no normalisation of blood glucose levels is obtained through weight loss (dieting), oral medication to lower blood sugar levels will be introduced. If this therapy fails to normalise blood glucose values, insulin treatment will be started.

Impaired glucose tolerance or impaired fasting plasma glucose (IGT/IFG) refers to a metabolic state that is somewhere between the normal state and the diabetic one. This population is at increased risk to develop diabetes mellitus and cardiovascular disease although it does not fulfil the diagnostic criteria of diabetes mellitus.

Damaging effects

Although risk factors for the development of Type 1 and Type 2 diabetes are different, long-term complications (macro and/or micro angiopathy – destroyed function in large and small blood vessels) present a major risk to both groups. Longitudinal studies clearly demonstrate the relationship between diabetes and ischemic heart disease, stroke, gangrene, and lower limb amputation.

On the rise

The global prevalence of diabetes mellitus is increasing and estimated to rise from 135 million in 1995 to 300 million by 2025. These estimates include both diagnosed and an estimate of undiagnosed cases of diabetes. Sedentary life style, changed eating habits, environmental factors, and genetic predisposition are all considered potential risk factors for Type 2 diabetes. Progression of overweight and obesity in younger age groups (WHO estimate over 22 million children < 5 yrs are overweight) is a major contributor as well.

Can be prevented

In the intermediate phase (IFP, IGT), Type 2 diabetes can be prevented. At different levels, intervention programs can change progression and outcome in a positive way. Lifestyle changes in persons at risk can be effective. Early diagnosis and intensive treatment of the persons who have the disease will lead to a reduced prevalence of complications and improve long-term prognosis.

This report is intended to present a snapshot of the actual picture of the diabetes situation in the EU; however, the lack of comparable indicators available for monitoring the

different aspects/presence of diabetes and its morbidity still presents some problems (See 8.2).

3. Background

The Health Consumer Powerhouse (HCP) promotes plans and actions related to consumer healthcare in Europe. Tomorrow's health consumer will not accept any traditional borders. To become a powerful actor, building the necessary reform pressure from below, the consumer will need access to knowledge to compare health policies, consumer services, and quality outcomes. HCP wants to add to this development.

Since 2004, the HCP has published the Swedish Health Consumer Index (www.vardkonsumentindex.se, also in an English translation). By ranking the 21 county councils using 12 basic indicators concerning the design of "systems policy", consumer choice, service level, and access to information, we introduced benchmarks so consumers can evaluate healthcare options.

For the pan-European generalist indexes in 2005 – 2008, HCP has followed the same approach, selecting a number of indicators describing to what extent the national healthcare systems are "user-friendly", providing a basis for comparing different national systems. The HCP is now benchmarking healthcare in 30 countries.

HCP advocates that quality comparisons within the field of healthcare are a true win-win situation: the consumer can use the information to make an informed choice and governments, authorities, and providers can use the information to improve consumer satisfaction and quality outcomes. With such a view, the Euro Consumer Diabetes Index 2008 is designed to become an important benchmark system that supports interactive assessment and improvement.

3.1 About the authors

Project Management for the Euro Consumer Diabetes Index 2008 was executed by **Beatriz Cebolla, Ph.D**.

After graduating in biochemistry, Dr. Cebolla has worked as a researcher for the last ten years and has been attached to various institutions relevant to the healthcare field. She completed her Ph.D. at the Biomedical Research Institute (IIB/CSIC) in Madrid and continued with a postdoctoral fellowship at the Institute for Molecular Pathology (IMP) in Vienna in Dr. Meinrad Busslinger's laboratory.
She has carried out several collaborations with other scientist groups working on cancer and diabetes and is currently studying a Master in International Public Health.

Arne Björnberg, Ph.D., Vice President Production, R&D for the HCP.

Dr. Björnberg has previous experience from Research Director positions in Swedish industry. His experience includes serving 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).

Dr. Björnberg is also the project manager for the Euro Health Consumer Index 2005 – 2008 projects.

4. Results of the Euro Consumer Diabetes Index 2008

Euro Consumer Diabetes Index 2008

Sub-discipline	Indicator	Austria	Belgium	Bulgaria	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia
Information, consumer rights, choice	Diabetes registry?	◑	◑	◑	○	○	●	◑	○	○	◑	○	◑	○	○	●
	Quality information about Diabetes care providers	◑	◑	○	○	○	●	○	◑	◑	◑	○	○	◑	◑	○
	Right to choose among providers, domestic	●	◑	●	◑	◑	●	●	○	●	◑	●	●	●	●	●
	Right to choose among providers, EU	○	○	○	○	○	●	○	◑	○	○	○	○	◑	◑	○
	Patient organisation participation in HC decisions	◑	◑	◑	○	◑	◑	●	◑	◑	◑	◑	◑	◑	●	◑
	Subdiscipline weighted score	133	120	120	80	93	187	133	107	120	120	107	120	133	147	133
Generosity	Co-payment for diabetes drugs (including self-	○	●	○	●	◑	●	●	●	●	●	◑	●	●	●	◑
	Is foot care for diabetics provided	●	●	◑	○	●	●	◑	◑	●	●	●	●	◑	○	●
	Specially adapted shoes for diabetics	◑	◑	○	○	◑	●	◑	◑	●	●	○	◑	●	◑	◑
	Subdiscipline weighted score	100	133	67	83	117	150	117	117	150	150	100	133	133	100	117
Prevention	Obesity	○	◑	○	◑	○	●	●	○	●	○	○	◑	●	◑	◑
	Physical activity in schools	●	◑	○	◑	◑	◑	◑	◑	●	●	◑	●	○	●	○
	Moderate Physical activity	◑	◑	●	◑	◑	◑	●	◑	○	◑	◑	◑	○	○	●
	Smoking cessation assistance	◑	●	○	◑	○	●	◑	●	◑	◑	○	○	◑	◑	○
	Hypertension (high blood pressure)	◑	●	◑	◑	◑	●	◑	◑	◑	○	◑	○	○	◑	○
	Blood pressure check up?	●	●	●	●	●	●	●	●	●	●	●	●	●	●	●
	Cholesterol check up?	●	●	○	●	○	○	◑	◑	●	◑	●	◑	◑	●	◑
	Blood sugar check up? (+45)	●	●	○	n.a.	n.a.	○	○	○	●	◑	◑	n.a.	◑	◑	○
	Subdiscipline weighted score	211	233	144	189	144	200	200	178	222	178	178	167	167	200	156
Access to procedures	Eye check-up	●	●	n.a.	○	●	◑	○	◑	●	●	◑	●	●	●	◑
	Microalbuminuria control (kidney function)	●	●	n.a.	○	◑	●	○	●	●	●	●	◑	●	●	n.a.
	HbA1c control (long-term blood sugar level)	●	●	n.a.	●	●	●	◑	●	●	●	●	●	●	●	●
	Foot examinations	◑	●	n.a.	○	◑	●	○	◑	●	●	○	n.a.	●	○	◑
	Diabetic foot a recognized sub-speciality?	◑	●	○	○	○	●	○	●	◑	●	○	○	◑	◑	◑
	Diabetes nurse practitioners	●	●	○	○	◑	◑	◑	◑	◑	◑	○	◑	◑	◑	◑
	Subdiscipline weighted score	222	250	83	111	181	222	111	208	222	236	153	167	222	194	167
Outcomes	Death by Diabetes	○	◑	◑	○	◑	◑	◑	●	◑	◑	●	◑	◑	◑	●
	Renal failure prevalence	○	◑	n.a.	n.a.	n.a.	◑	○	○	●	○	◑	n.a.	n.a.	●	●
	Foot amputation incidence	○	n.a.	n.a.	n.a.	◑	◑	◑	○	◑	○	n.a.	n.a.	n.a.	◑	○
	% of patients with HbA1c > 7%	○	○	n.a.	○	◑	○	○	●	◑	◑	●	◑	●	●	●
	Subdiscipline weighted score	44	67	56	44	78	78	67	89	100	67	100	67	78	111	111
	Total score	711	803	470	508	613	837	628	698	814	751	637	653	733	752	683
	Rank	12	5	29	28	23	1	22	14	3	8	21	19	9	7	16

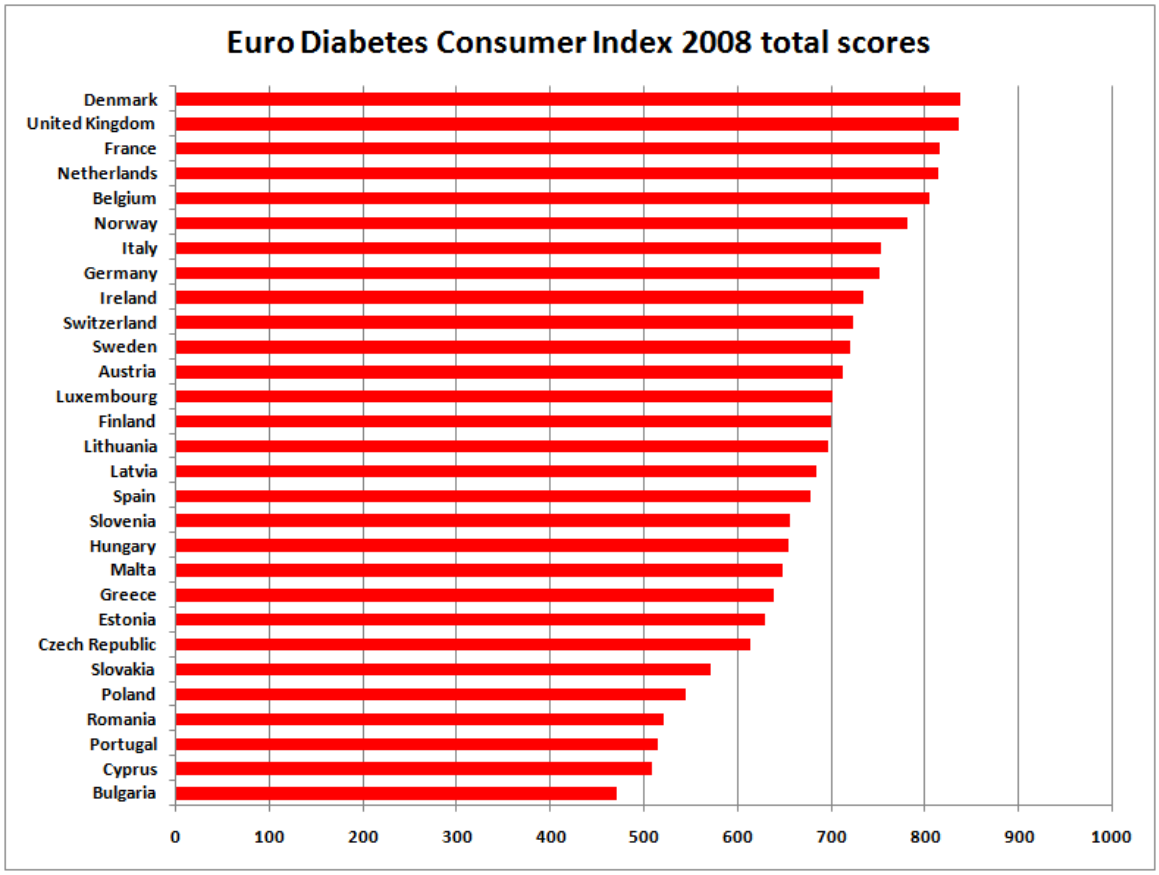
Euro Consumer Diabetes Index 2008

Sub-discipline	Indicator	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom
Information, consumer rights, choice	Diabetes registry?	●	○	◑	◑	◑	○	○	○	●	◑	◑	●	○	●
	Quality information about Diabetes care providers	◑	◑	○	●	○	◑	○	○	○	○	○	◑	◑	◑
	Right to choose among providers, domestic	●	●	●	◑	●	○	○	●	●	●	○	◑	●	●
	Right to choose among providers, EU	○	●	○	◑	◑	○	○	○	○	◑	○	◑	◑	○
	Patient organisation participation in HC decisions	●	○	◑	◑	◑	○	◑	○	○	◑	◑	◑	◑	◑
	Subdiscipline weighted score	160	133	120	147	133	80	80	93	120	133	93	147	133	147
Generosity	Co-payment for diabetes drugs (including self-	●	●	●	●	●	○	●	◑	●	●	○	●	●	●
	Is foot care for diabetics provided	●	○	●	○	●	○	●	●	●	●	◑	●	●	●
	Specially adapted shoes for diabetics	●	◑	◑	●	◑	○	○	○	◑	●	◑	○	●	●
	Subdiscipline weighted score	150	100	133	117	133	50	117	100	133	150	83	117	150	150
Prevention	Obesity	◑	◑	○	●	●	◑	◑	●	◑	○	◑	●	◑	○
	Physical activity in schools	◑	◑	○	○	◑	◑	○	○	◑	●	○	○	◑	●
	Moderate Physical activity	◑	◑	○	●	n.a.	◑	○	◑	●	●	○	○	n.a.	○
	Smoking cessation assistance	○	◑	◑	○	●	○	◑	○	○	○	◑	◑	◑	●
	Hypertension (high blood pressure)	○	●	n.a.	◑	○	◑	◑	◑	○	◑	●	◑	●	○
	Blood pressure check up?	●	●	●	●	●	●	●	●	●	●	●	●	●	●
	Cholesterol check up?	○	●	◑	○	◑	◑	●	○	●	◑	●	○	○	○
	Blood sugar check up? (+45)	◑	●	●	◑	◑	◑	n.a.	○	n.a.	○	●	○	○	○
	Subdiscipline weighted score	156	222	156	178	189	178	167	156	178	178	200	156	167	156
Access to procedures	Eye check-up	◑	●	n.a.	●	●	●	n.a.	n.a.	○	◑	●	◑	◑	●
	Microalbuminuria control (kidney function)	n.a.	n.a.	●	●	●	◑	n.a.	n.a.	n.a.	n.a.	●	◑	●	●
	HbA1c control (long-term blood sugar level)	◑	●	●	●	●	●	n.a.	n.a.	n.a.	●	●	●	●	●
	Foot examinations	◑	◑	◑	●	●	●	n.a.	n.a.	n.a.	○	●	●	◑	●
	Diabetic foot a recognized sub-speciality?	◑	○	●	●	●	○	○	○	○	◑	◑	●	◑	●
	Diabetes nurse practitioners	◑	◑	◑	●	◑	○	○	○	○	○	◑	●	◑	●
	Subdiscipline weighted score	153	167	194	250	236	181	83	83	83	139	222	222	194	250
Outcomes	Death by Diabetes	●	●	○	◑	●	◑	○	●	◑	○	◑	◑	◑	●
	Renal failure prevalence	n.a.	n.a.	○	●	●	○	n.a.	●	○	◑	●	◑	n.a.	●
	Foot amputation incidence	◑	◑	n.a.	●	○	○	●	n.a.	○	n.a.	○	n.a.	●	●
	% of patients with HbA1c > 7%	○	n.a.	n.a.	●	○	○	n.a.	n.a.	n.a.	○	○	◑	n.a.	●
	Subdiscipline weighted score	78	78	44	122	89	56	67	89	56	56	78	78	78	133
	Total score	696	700	648	813	781	544	513	521	570	656	677	719	722	836
	Rank	15	13	20	4	6	25	27	26	24	18	17	11	10	2

4.1 Results summary: what country provides the best diabetes care?

Denmark is the winner of the Euro Consumer Diabetes Index 2008, scoring 837 points out of a maximum of 1000 points. This country performs extremely well in every sub-discipline except Prevention and Outcomes where there is more room for improvement. The U.K. is in a very close second position with 836 points. The U.K. seems to have a good structure to provide efficient access, furthermore provide their patients with enough subsidy to follow the recommend procedures. Probably more podiatrists are needed, but compared with other countries, the number per patient is still rather high and they are well trained. UK have the best outcomes in Europe, if we would give outcomes the same weight as other previous indexes, UK would be the absolute winner of the diabetes Index.

Neither Denmark nor the UK have the highest spend per capita in healthcare; in fact, both are average, spending the same amount of money as countries such as Finland or Greece, countries that perform considerably worse. The financial issues seem not to be essential to having good diabetes care.



France (814) and Netherlands (813) are difficult to separate; it should be noticed that any subtle change in a single score would modify the internal order of these two countries. The analysis of the data suggests that even with almost the same score these two countries have a very different organization and performance. France is one of the few countries with a good prevention strategy, but also performance rather good in access to procedures. French are doing a big effort to become better and better in diabetes care. On the other hand, Netherlands has the best Access to procedures performance and one of the

best diabetes care management in Europe, with a strong structure of diabetes care. In addition, some pilot projects in primary care are taking place to improve the participation of GP and nurses in diabetes care in prevention and information.

Finally, the last country in the top five is Belgium (803 points). It seems that Belgium share the best from its neighbours: being the best in Prevention and as good as Netherlands in Access to Procedures. However, Belgium scores surprisingly bad in Outcomes, a score probably due to deficient quality data acquisition. Probably in the near future Belgium could climb positions in the futures edition of the Index when the current national data collection projects take effect.

5. What do the Diabetes Index 2008 results reveal?

5.1 Sub-discipline: Information, consumer rights, choice

There is no debate that a good national diabetes registry provides essential information about indicators such as diabetes prevalence rate. Accurate data is extremely difficult to find in Europe. Only few countries, such as Denmark and the UK, have good national registries. Also, several countries, such as Spain do have regional registries, but most countries – such as Belgium and the Czech Republic – only have registries including diabetes Type I for patients younger than 18 years old. Many critics complain about how difficult it is to continue registries because of the lack of economic support.

It is essentially impossible to get any type of official data on the quality of diabetes healthcare in most European countries. It seems that citizens mainly need to rely on word-of-mouth information with respect to finding good diabetes healthcare. In many instances, they simply trust the fact that diabetes care is provided at the same standard in any clinic or rely on the opinion and referrals made by their GPs or specialists (which might be just fine, if the GP is experienced and knowledgeable). Denmark and the Netherlands provide their citizens with latest quality information: Where are the good diabetes clinics or experts and what is the number of patients with complications? However, sometimes this information is difficult to find.

In many countries, the EU healthcare consumer has the right to choose among providers of healthcare anywhere in their country. The exceptions to this are Finland, Poland, Portugal, and Spain, where patients are assigned to a specific district GP or specialist. In terms of choosing healthcare providers across borders, there are many barriers and no smooth mechanisms have been put in place to make it easier for patients who choose to be treated outside their national borders. Many national officials say that their citizens hardly ever take advantage of going abroad and would prefer to be treated at home since diabetes is a chronic disease requiring permanent care. If Europeans feel that the cross-border option is not offered despite the decisions of the European Court of Justice, it is hardly surprising. Many countries also choose not to inform citizens that they could be treated in other EU countries.

This needs to be improved:

There should be a general effort to develop good diabetes registries all over Europe to simplify the analysis of the real situation of the different healthcare systems, allowing healthcare providers to concentrate their efforts wherever needed to improve quality and transparency. Furthermore, national healthcare systems should make quality information of their diabetes healthcare providers transparent. Consumers/patients should have the right to choose where to go for diabetes treatment on the basis of publicly available quality information. Also, users should have the choice of cross-border care and get it without facing barriers and time-constraints. This would be important in countries with long waiting lists or that lack some specialists.

5.2 Subdiscipline: Generosity

Typically, the EU provides special status for diabetics in terms of co-payments for drugs and devices (especially insulin or derivates and self-monitoring devices). Because diabetes is very expensive for patients, they need governmental economic support. This issue is particularly relevant in families with sick children. It is alarming to hear that even in France parents deny having diabetic children for the fear of discrimination when it comes to bank credits or applying for a job.

Several eastern European countries do not provide enough economic support for diabetic patients. It is generally accepted that intensive therapy is highly recommended and several studies support this theory. However, in countries such as Bulgaria, Romania, Estonia and Poland patients are not able to follow the intensive therapy because of the costs they have to pay out-of-pocket.

The problem in Poland goes a bit further being the only country in Europe where insulin analogues are not included in the subsidized medication list.

Diabetes podiatric care is not always provided by specialists; in many cases endocrinologists or nurses must voluntarily learn to take care of the patients. Podiatric education should be encouraged as well as a definition of podiatry. Further investigation is needed, as the term “diabetes podiatrist” has different meanings in various countries.

There is a general problem in the provision of special shoes and insoles for diabetics even in countries spending significant amount of money in health care such as Norway, Finland, and Luxembourg. Typically, subsidies are provided for one pair of shoes per year, a subsidy that is not enough in many cases, especially for child diabetics or the purchase of seasonal footwear. Additionally, these subsidies apply only after having had surgery, not as part of preventive care.

This needs to be improved:

In terms of generosity to diabetes foot healthcare, European healthcare services need to provide better services by increasing the number of diabetes podiatrists and including them in multidisciplinary teams. Since foot complications often result in a significant amount of psycho-emotional problems for the patient, education, emotional support, and access to special shoes should be available, especially as it has been demonstrated that the use of these shoes prevents further complications including amputations.

5.3 Subdiscipline: Prevention

No single country achieved a perfect score. According to the data, only a few countries systematically tackled prevention/screening of diabetes. In Austria, Belgium, France, Luxembourg and Spain screening of blood pressure, cholesterol, and blood sugar is routine.

Surprisingly, a low percentage of smokers are supported by healthcare services to stop smoking. Countries where this number is high: United Kingdom, Ireland, Malta and Norway.

The amount of time devoted to physical activities in compulsory schools, where it is believed that a person would pick up good fitness habits, is not as high as expected. France leads Europe on this parameter. However, it seems that encouraging sports in schools does not necessarily mean promotion of sport in daily life. In France and Italy, schools require students to participate for many hours although they do not necessarily agree that they participate in regular exercise.

The prevalence of obesity and the number of smokers is still very high in Europe, especially in Bulgaria, Estonia, Germany, Greece, Hungary, Latvia, Malta and Poland. It is important to notice that obesity and smoking are two of the main risk factors not only for diabetes, but also for cardiovascular diseases; it seems incredible that at least one-third of the population still smokes and almost 20% of the population is obese.

This needs to be improved:

It seems there is still a lot for national governments to do in terms of prevention of diabetes: from screening their population and follow the trends to encouraging their citizens to actively engage on a regular basis in pursuing physical activities, to developing proper eating habits and support those who decide to quit smoking. In terms of smoking restrictions, it seems that all countries to some degree have engaged in increasing taxes on tobacco, restrict smoking in public places, are prohibiting tobacco advertisement etc., but still this field remains a challenge for many countries. Furthermore governments can do more to prevent diabetes, such as screening their population regularly. 95% of the people answering our survey comment that they found out about their diabetes by coincidence!

5.4 Subdiscipline: Access to procedures

This field was probably the most difficult to follow-up on in many countries as data was not readily available and collection methods have influenced the outcome of the indicator. Since eye, foot, HbA1c, and microalbuminuria are supposed to be measured at least once a year, this indicator should be 100% for all ages. Some guidelines recommend measuring these parameters more often.

The data acquisition about screening is not regular and the quality is generally low. All the experts consulted agreed that there is a recoding problem in many countries, a problem that means reality is not reflected in the data. For this reason, opinions expressed by the patients through the Patient View survey are important. Some official data said that only 50% of people get this or that screening, but when out of 200 responses 95%

admit that they had had at least one check per year; the patients' responses have been given precedence over the scoring. In many cases, patients and statistics do agree.

There were many countries that could not provide data – Bulgaria, Portugal, Romania, Ireland, and Slovakia. Officially, Ireland could not provide data, but 250 Irish patients answered the Patient View survey and 95% confirmed they had received check ups at least once a year.

Patients should have regular access to routine podiatric care, but the reality of most healthcare systems is that podiatry resources are limited. There is a lack of diabetes foot clinics or units, and in many diabetes multidisciplinary teams there is no diabetes podiatrist although there is increasing evidence that treatment of active diabetes foot problems carried out by multidisciplinary foot care teams reduce amputations.

The indicator about nurse practitioners was very difficult to find because there is no clear idea about the differences between diabetes nurse practitioner, diabetes nurse, and diabetes educator. Health authorities are not always aware of what is what, so this question creates a lot of confusion.

Only a few countries–Austria, Belgium, Netherlands, Sweden, and U.K.– were found to have nurse practitioners. Most other countries have diabetes nurses (as speciality), and some other countries concentrated to eastern Europe usually only have a few of them. The reasons are that the training programmes to become a diabetes nurse are rather new but also due to the fact that nurses are emigrating to the west for higher salaries.

This needs to be improved:

If every country should have 100% of patients screened annually, the result is very disappointing, particularly concerning eye and foot check-ups. It seems there is still a lot to do, especially in the CEE. Some doctors commented that they have to persuade their patients to take part in the screening process, more importantly so if they live in the countryside where this care is not provided. The quality and the lack of data should also be taken into account.

Efficient use of resources dictates that routine podiatric care should be directed towards patients in greatest need. Unfortunately, this is often not the case, with needy patients being denied timely access to podiatry and foot care because clinics are overbooked with patients with less severe conditions.

In central and northern Europe diabetes practitioners are playing an increasingly important role in diabetes teams and in diabetes management and education. We believe these professionals should be more and more involved in coming years as key players in diabetes care.

5.5 Sub-discipline: Outcomes

Data gathering and scoring has been extremely difficult as many countries were not able to report data (n.a.) or data was not comparable. Two indicators considered very important were dropped out because there was no data available in most countries. These were Annual Incidence of Myocardial Infarction and Retinopathy Incidence among Diabetics (or percent of patients suffering new blindness).

The death rates due to diabetes as a primary cause of death **underestimates** the number of deaths by diabetes; however, five countries – Austria, Cyprus, Malta, Portugal, and Slovenia – report a rate of 20 deaths by diabetes per 100 000 deaths.

Almost half of the EU member states could not report any data about foot amputation because they did not know the number of diabetics they have in their country. That is, they could not provide the rate, or they did not know how many amputees were also diabetics.

Most guidelines recommend HbA1c should be < 7%. From the states reporting data, there are ten countries (Austria, Belgium, Cyprus, Denmark, Estonia, Lithuania, Norway, Poland, Slovenia, and Spain) that have more than 50% of patients above 7. However, some of them explain that many of the patients included in these 50% stay between 7 and 7.5. Once more the remarkable lack of data and its quality was a problem.

This need to be improved:

Diabetes is considered a global problem in Europe and an effort in recoding outcome values should be done. Otherwise, there is no transparency of what happens in each country and what countries are in need of most help. It is almost unbelievable that the U.K. is the only country able to report data for all the Index indicators – "Pearson's law" (saying that measuring and reporting in itself does raise performance) could explain why the U.K. is the single country scoring "All Green" on the Outcomes indicators.

5.6 Results in "Pentathlon" – sub-discipline winners

The Euro Consumer Diabetes Index is made up of five sub-disciplines. As no country excels across all aspects of measuring, it is of interest to study how the 29 countries rank in each of the five parts of the "pentathlon". The scores within each sub-discipline are summarized in the following table:

Sub-discipline	Austria	Belgium	Bulgaria	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom
Information, consumer rights, choice	133	120	120	80	93	187	133	107	120	120	107	120	133	147	133	160	133	120	147	133	80	80	93	120	133	93	147	133	147
Generosity	100	133	67	83	117	150	117	117	150	150	100	133	133	100	117	150	100	133	117	133	50	117	100	133	150	83	117	150	150
Prevention	211	233	144	189	144	200	200	178	222	178	178	167	167	200	156	156	222	156	178	189	178	167	156	178	178	200	156	167	156
Access to procedures	222	250	83	111	181	222	111	208	222	236	153	167	222	194	167	153	167	194	250	236	181	83	83	83	139	222	222	194	250
Outcomes	44	67	56	44	78	78	67	89	100	67	100	67	78	111	111	78	78	44	122	89	56	67	89	56	56	78	78	78	133
	711	803	470	508	613	837	628	698	814	751	637	653	733	752	683	696	700	648	813	781	544	513	521	570	656	677	719	722	836
	12	5	29	28	23	1	22	14	3	8	21	19	9	7	16	15	13	20	4	6	25	27	26	24	18	17	11	10	2

The three sub-disciplines carrying the highest weight coefficients are **Information, consumer rights and choice, Prevention and Access to procedures**.

Denmark scored highest in two of them. As in the Euro Health Consumer Index 2007 and the Euro Consumer Heart Index 2008, Denmark is top in the **Information, consumer rights and choice** discipline. It is well known for their excellent diabetes registry, considered the best in Europe in terms of quality. Denmark is also well known their freedom to choose among health care providers.

More than one country score maximum in **Generosity**; Denmark, France, Germany, Lithuania, Switzerland and the UK.

The performance of Belgium on **prevention** largely explains why that country makes its way into the top five. France is also scoring very high in prevention, as was also found in the Euro Consumer Heart Index. Regular check-ups for the general population is widely accessible not only in these two (France and Belgium) but also in Austria, Luxemburg and Spain.

Belgium, Netherlands and the UK are the only countries that obtain the highest score in **Access to procedures** with a good Access to doctors and some of the best foot care in Europe. The UK is the only European country getting a maximum score in **Outcome**s. It has been able to provide data to all the indicators and has good results on diabetes care.

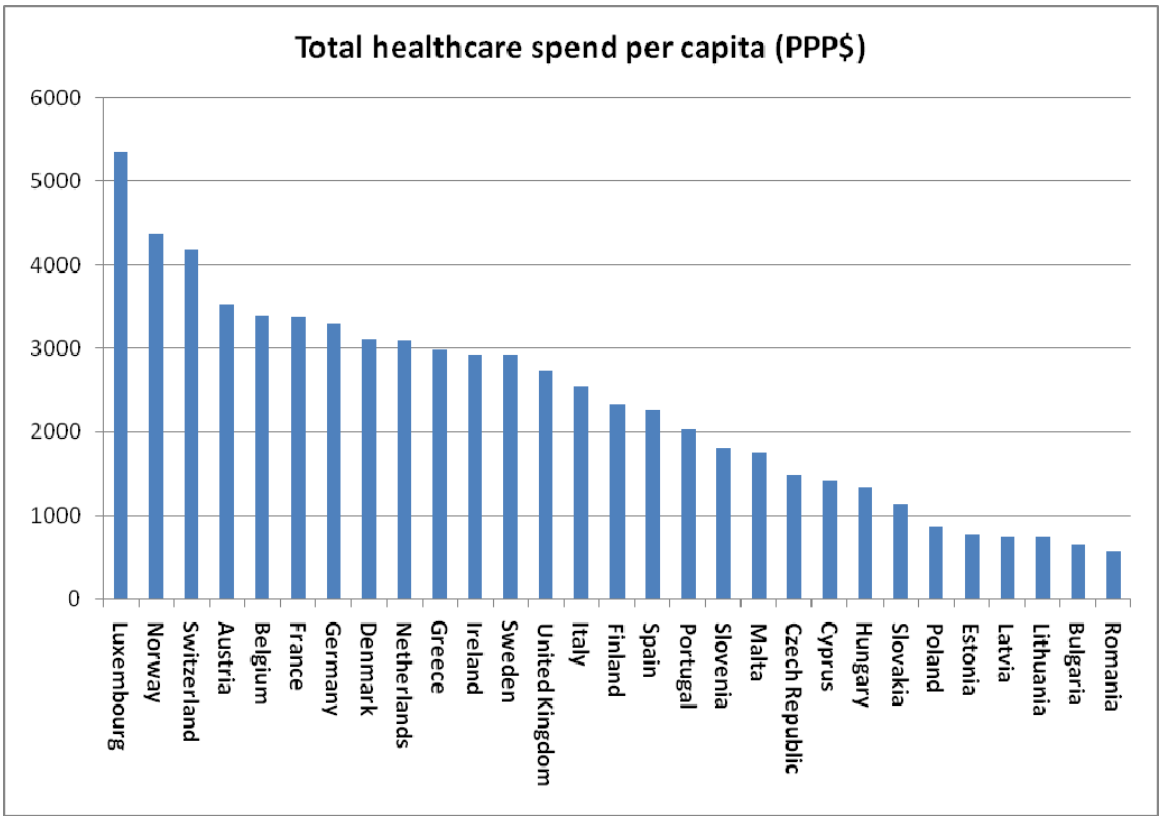
6. Bang-For-the-Buck adjusted scores

With all 29 EU member states included in previous projects, it becomes apparent that the Index tries to compare states with very different financial resources. The annual healthcare spending, in PPP-adjusted (Purchasing Power Parity) US dollars, varies from around $600 in Bulgaria and Romania to $4000 – 5000 in Norway, Switzerland, and Luxembourg. Continental western Europe and Nordic countries generally fall between $2700 and 3200. As a separate exercise, the Diabetes Index 2008 has added a value for money-adjusted score: the Bang-For-the-Buck adjusted score, or "BFB Score".

6.1 BFB adjustment methodology

It is not obvious how to do such an adjustment. If scores would be adjusted in full proportion to healthcare spend per capita, the effect would simply be to elevate all less affluent states to the top of the scoring sheet. This, however, would be decidedly unfair to the financially stronger states. Even if healthcare spending is PPP adjusted, it is obvious that also PPP dollars go a lot further to purchase healthcare services in member states, where the monthly salary of a nurse is € 200, than in states where nurse's salaries exceed € 3500. For this reason, the PPP adjusted scores have been calculated as follows:

Healthcare spends per capita in PPP dollars have been taken from the WHO HfA database (November 2007; latest available numbers, most frequently 2005) as illustrated in the graph below*):



*) For Bulgaria and Romania, the WHO HfA database (November 2007) actually seems to contain errors for the healthcare spend; it gives $214 and $314, respectively, which are unreasonably low numbers. The

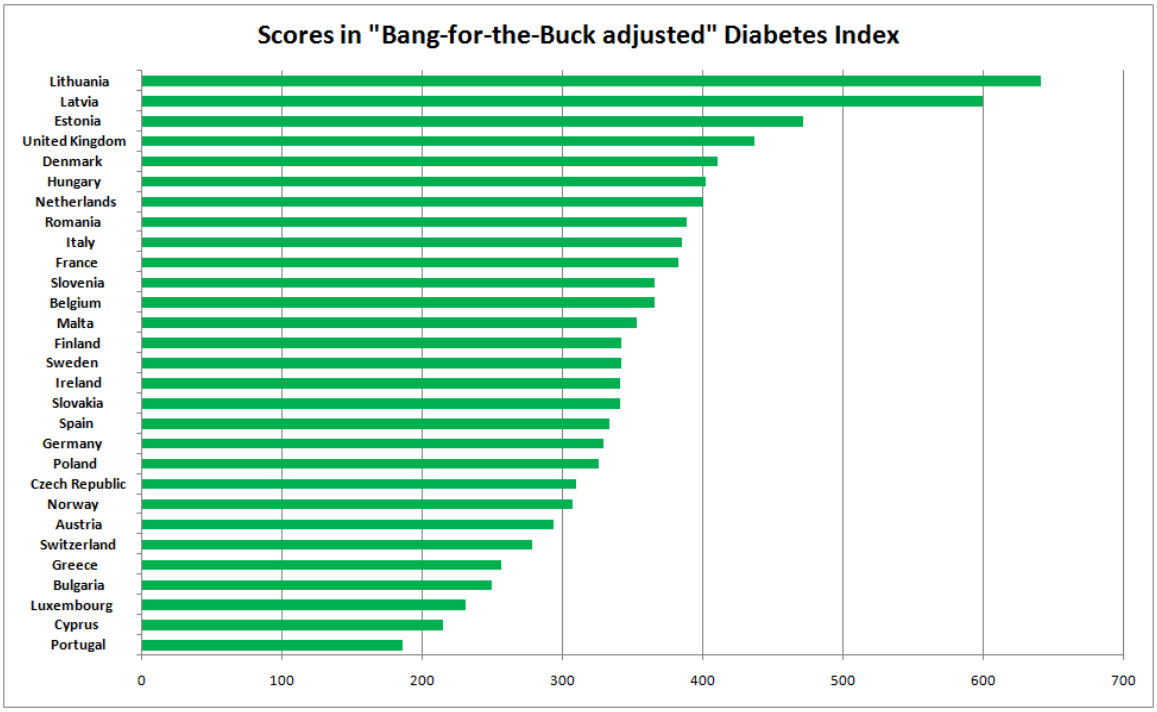
European Observatory HiT report (http://www.euro.who.int/Document/E90023brief.pdf) on Bulgaria quotes the WHO, giving the number $648, also confirming the fact that this is slightly higher than the Romanian figure. The number for Romania was taken from a report from the Romanian MoH (http://www.euro.who.int/document/MPS/ROM_MPSEURO_countryprofiles.pdf), also quoting the WHO.

For each country *the square root* of the healthcare spend has been calculated. The reason for this is that domestically produced healthcare services are cheaper roughly in proportion to the healthcare money spent.

In the basic Diabetes Index, the minimum score is 333 and the maximum 1000. For the Bang-For-the-Buck exercise, it is necessary for a value-for-money adjustment to subtract the 333 "free" bottom points from each national score, or the B-F-B adjustment will only have the effect of catapulting the less affluent countries to the top of the list. The (Diabetes Index scores -333) have been divided by the square root of healthcare spend. The number thus obtained has been multiplied by the arithmetic mean of all 29 square roots (creating the effect that scores are normalized back to the same numerical value *range* as the original scores).

6.2 Results in the BFB Score sheet

The outcome of the BFB exercise is shown in the graphic below. Even with the square root exercise described in the previous section, the effect is to dramatically elevate many less affluent nations in the scoring sheet.



The BFB scores, naturally, are to be regarded as somewhat of an academic exercise. Not least the method of adjusting to the square root of healthcare spent certainly lacks scientific support. After the research work, however, it does seem that certainly the

supreme winner in the BFB score, Lithuania, is doing very well within their financial capacity. The same could be said about Latvia and Estonia.

What the authors find interesting is to see which countries top the list in the BFB Scores, and which countries do reasonably well in the original scores. Examples of such countries are the U.K., Denmark, the Netherlands, and France.

7. How to interpret the Index results?

The first and most important consideration on how to treat the results is with great care and restrictions against drastic conclusions.

The Euro Consumer Diabetes Index 2008 is an attempt at measuring and ranking the performance of diabetes care provision from a consumer viewpoint. The results definitely contain information quality problems. There is a shortage of pan-European, uniform set procedures for data gathering.

But again, the HCP finds it far better to present the results 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. Again, it is important to stress that the Index displays consumer information, not medically or individually sensitive data.

While by no means claiming that the Diabetes Index 2008 results are dissertation quality, the findings should not be dismissed as random findings. On the contrary, previous experience from the general Euro Health Consumer Indexes reflects that consumer ranking by similar indicators is looked upon as an important tool to display healthcare service quality. The HCP hopes that the Diabetes Index 2008 results can serve as inspiration for how and where European Diabetes care can be improved.

8. Poor European data availability on diabetes care

8.1 General

There is one predominant feature that characterizes European public healthcare (and other welfare states): there is an abundance of statistics on input of resources, but a traditional scarcity of data on quantitative or qualitative *output*.

Organisations like the WHO and OECD are publishing easily accessible and frequently updated statistics on topics several topics such as

- the number of doctors/nurses per capita,
- hospital beds per capita,
- share of patients receiving certain treatments,
- number of consultations per capita,
- number of MR units per million of population,

- health expenditure by sources of funds, and
- drug sales in doses and monetary value (endless tables).

Systems with a history of funding structures based on grant schemes and global budgeting often exhibit a management culture where monitoring and follow-up is more or less entirely focused on input factors. Such factors can be staff numbers, costs of all kinds (though not usually put in relation to output factors), and other factors of the nature illustrated by the above bullet list.

Healthcare systems operating more on an industrial basis have a natural inclination to focus monitoring on *output*, and much more naturally relate measurements of costs to output factors in order to measure productivity, cost-effectiveness, and quality.

8.2 Many promises, less action

In October 1989, European nations agreed unanimously on general goals for people with diabetes; this happened in St. Vincent in Italy. About 15 working groups were set up and about 40 diabetes national plans were formulated. By 1999, however, there had been more words than action by government health departments. The nations of Europe again agreed unanimously to set and meet goals and targets and high standards of care. Every good quality improvement system consists of various interrelated activities:

a) Identification and selection of areas needing improvement, and problem definition;

b) Setting or selecting guidelines, criteria or targets for good quality care (by consensus development, evidence-based setting of guidelines, local arrangements on care provision, identifying good practices, benchmarking, etc.);

c) Data collection on, and assessment of, actual quality of care (measuring actual care, determining variation, evaluating whether quality criteria have been met, etc.); and

d) Performing change (by quality improvement strategies or programs or by solving problems, evaluation of progress).

A collaborative action called Diabcare was initiated (after the St Vincent declaration) to improve quality of care. On a voluntary basis, patient data was collected in primary and secondary care. This allowed comparison between health care, outcome, and the effect of interventions. The project had several limitations. It did not succeed as much as expected, but was very helpful as a pilot project.

From 2000 until 2002, a project called European Diabetes Indicator project (**EUDIP**) was carried out. The aim of the project was the "establishment of indicators monitoring diabetes and its morbidity" on a national level. A set of indicators was conducted and tested for feasibility.

After completion of EUDIP, a new consortium was formed to collect indicators in the EU. The European Core Indicators for Diabetes Mellitus project (**EUCID**) set up a stable organization to collect and analyse data on health status and care delivery for diabetes mellitus in the EU countries and the future member states in order to promote the

planning for a good diabetes health status and diabetes care organization in the different countries (EUCID).

The vast amount of data that was collected for the EUCID project is not equally distributed over all the countries. Some countries had almost all the indicators available, while others only had a few available. Some have national databases, while others have more or less representative regional data. This shows that the availability of diabetes-related information is not as standardized as we would wish it to be. For this reason, the data provided by IDF in their Diabetes Atlas consists of estimates. It is obvious that the number of indicators available varies considerably amongst the countries.

It is very disappointing to hear health officials say they do not know the diabetes prevalence in their countries. They have an estimated number of people living with diabetes and further estimated number of undiagnosed patients. Furthermore, the estimated cost of diabetes in several European countries is also unknown.

In general, data on screening or outcomes are not available. Data related with retinopathy (proliferative retinopathy; eye complications) is not available for most countries even though it is considered an important indicator by most guidelines, as it is urgent for this patient to receive laser treatment.

Nevertheless, data collected by EUCID project has been the best quality data found from the countries participating in the project. Their indicator definition has been very useful for finding comparable data. The HCP would like to thank several members of the EUCID project for very good cooperation and suggestions, corrections, and comments.

Not too long ago a new consortium was formed called EUBIROD. Building upon the collaboration between the projects BIRO and EUCID the aim is to establish a permanent and sustainable **European Diabetes register**. The Health Consumer Powerhouse wishes the best of success to this consortium in this project.

9. Methodology: The Development of the Diabetes Index

The Euro Consumer Diabetes Index 2008 is based on the methodology developed during the work on the first three editions of the generalist Euro Health Consumer Index (EHCI). Therefore, the development history of that Index will be described below.

9.1 Previous Euro Health Consumer Indexes

9.1.1 Scope and content of the Euro Health Consumer Index 2005

Countries included in the EHCI 2005 were Belgium, Estonia, France, Germany, Hungary, Italy, the Netherlands, Poland, Spain, Sweden, the United Kingdom, and, for comparison, Switzerland. To include all 25 member states right from the start would have been a very difficult task, particularly as many memberships were recent and would present dramatic

methodological and statistic difficulties. The EHCI 2005 sought a representative sample of large and small and long-standing and recent EU membership states. One important conclusion from the work on EHCI 2005 was that it is indeed possible to construct and obtain data for an index comparing and ranking national healthcare systems seen from the consumer/patient's viewpoint.

9.1.2 Scope and content of EHCI 2006 – 2007

The EHCI 2006 included all the 25 EU member states of that time and Switzerland using essentially the same methodology as in 2005. The number of indicators was also increased from 20 in the EHCI 2005 to 28 in the 2006 issue. The number of sub-disciplines was kept at five. The "Customer Friendliness" sub-discipline was merged into "Patient Rights and Information". The new subdiscipline "Generosity" (What is included in the public healthcare offering?) was introduced because many observers, not the least healthcare politicians in countries having pronounced waiting-time problems, noted that absence of waiting-times could be a result of "meanness". That is, national healthcare systems often restrict who gets certain operations so they appear to have less waiting list problems.

To achieve a higher level of reliability of information, one essential work ingredient has been to establish a net of contacts directly with national healthcare authorities in a systematic way. The weaknesses in European healthcare statistics described in previous EHCI reports can only be offset by in-depth discussions with key personnel at a national healthcare authority level. This is true also for the Euro Consumer Diabetes Index 2008.

9.1.3 Euro Consumer Heart Index 2008

The first disease area-specific European HCP Index was the Euro Consumer Heart Index, published on July 3, 2008. It was deemed important to have a mix of indicators in different fields; areas of service attitude and customer orientation as well as indicators of a "hard facts" nature showing healthcare quality in outcome terms. It was also decided to search for indicators on actual results in the form of outcomes and also indicators depicting procedures, such as "needle time" (time between patient arrival to an A&E department and thrombolytic injection), percentage of heart patients thrombolysed or given PCI, etcetera.

Unlike previous HCP Indexes, the Heart Index contained indicators measuring public health status, such as total heart disease mortality. Also, under the Prevention sub-discipline, the Heart Index went outside the scope of healthcare services by including factors such as smoking and diet. Such indicators tend to be primarily dependent on lifestyle or environmental factors rather than healthcare system performance, as general lifestyle factors are governed by so many other aspects of life.

9.2 Euro Consumer Diabetes Index 2008

The Diabetes Index is a compromise between which indicators were judged to be most significant for providing information about the different national healthcare systems from

a user's/consumer's viewpoint and the availability of data for these indicators. Therefore, it has been important to have a mix of indicators in different fields. Service attitude and customer orientation as well as "hard fact" indicators help show healthcare quality in outcome terms. It was also decided to use indicators depicting procedures – such as "percent of patients getting annual eye, foot, HbA1c, and microalbuminuria check-ups" – as these have been recommended in several guidelines as a way to prevent diabetes complications. It was also decided to include an indicator that shows whether diabetes nurse practitioners are available. Several publications show the key role that these professionals play in chronic disease management and preventive services within institutional settings as well as in their patient's homes.

Under the Prevention sub-discipline, the Diabetes Index goes outside the scope of healthcare services, as we did already in the Heart Index, by including factors such as smoking and physical activity in the general population. Such indicators primarily reflect lifestyle or environmental factors rather than healthcare system performance, as general lifestyle factors are influenced by many other aspects of life. However, promoting smoking cessation and increased physical activity can reduce diabetes. Therefore, they are included as indicators that an identifiable group of people (such as a national government) could possibly do something about, using a strategy such as "the national guideline for minimum amount of hours of physical exercise in statutory school".

9.2.1 Sub-disciplines chosen for the Diabetes Index 2008

Experience from the three consecutive annual Euro Health Consumer Index editions, and from the Euro Consumer Heart Index, has been evaluated and applied when designing the Diabetes Index. After thorough discussions at several meetings with an expert reference panel, it was decided to divide the Diabetes Index into five subdisciplines:

Sub-discipline	**Number of indicators**
Information, consumer rights, choice	5
Generosity	3
Prevention	8
Access to procedures	6
Outcomes	4

The weight of a sub-discipline is entirely independent of the number of indicators under each sub-discipline: the weight is given only by the applied weight coefficient. However, the effect of having a high number of indicators in a sub-discipline does reduce the relative weight of each single indicator in the final total score (see Table in Section 9.2.4).

9.2.2 Scoring in the Diabetes Index 2008

The performance of national healthcare systems was graded on a three-grade scale for each indicator, where the grades have the rather obvious meaning of green = good (i),

amber = so-so (l), and red = not-so-good (h). A green score earns 3 points, an amber score 2 points, and a red score (or a "not available") 1 point.

For each of the five sub-disciplines, the country score was calculated as a percentage of the maximum possible (e.g., for prevention, the score for a state has been calculated as percent of the maximum: 8 x 3 = 24).

Thereafter, the sub-discipline scores were multiplied by the weight coefficients given in the following section and added to make the total country score. The scores thus obtained were multiplied by (1000/the sum of weights; see Section 5.2.1) and 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).

One (minor) reason for this somewhat complex scoring methodology has been driven by the "competition" element of the Heart Index, reducing the likelihood of two or more states ending up in a tied position. The "Eurovision Song Contest" method, for example, changed the score in the same direction after four countries tied for first place in 1969.

9.2.3 Threshold value settings

There has not been an 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". For example, for diabetes podiatrists or nurses, it is clear that the need for such services is not saturated anywhere in Europe; however, some countries have a lot more diabetes podiatrists or nurses than others and the service is better organized. These countries received a green score.

Setting threshold values for indicators where the data are numerical values is typically done by studying a bar graph of country data values on an indicator sorted in ascending order. This approach usually produces a S-shaped curve that is studied for notches in the curve, which can distinguish clusters of states. These notches are often taken as cut-off values for scores. A slight preference is also given to threshold values with even numbers. An example of this is the "Exercise in compulsory school" indicator, where the cut-offs for green and amber were set at 800 and 500 although a mathematical algorithm searching for "notches" in the S-curve might have found the notches at slightly different numbers.

Finally, the HCP is a value-driven organisation. We believe in Patient/Consumer Empowerment, an approach that places highest importance on quantitative and qualitative healthcare services. As is illustrated by the "Quality information about diabetes care providers" indicator, this sometimes leads to the inclusion of indicators where only few countries, theoretically none, score green (in this case, only Denmark and the Netherlands do).

9.2.4 Weight coefficients

The weighting mechanism used to determine the relative weights of the sub-disciplines was originally introduced for the HCP Euro Health Consumer Index 2006. Explicit weight coefficients for the five sub-disciplines were introduced after a careful

consideration and discussion with the expert reference panel on which sub-disciplines should be considered for higher weight. In the Diabetes Index, the Prevention sub-discipline was the main candidate for a high weight coefficient based mainly on the discussion with the expert reference panel and the large number of publications that addressed prevention and screening of the general population (both included under discipline "Prevention") as the two main strategies that reduce diabetes prevalence in Europe. Thereafter, access to procedures was chosen as the second most important sub-discipline. Then the third most important category was consider to be Information, patient rights and choice, essential for diabetes patients to manage their sickness the best way possible. This is closely follow by generosity very important in the case of diabetes (specially diabetes type I) because the constant necessity of using drugs and devices for its proper care.

The research team and expert reference panel (especially the experts in data acquisition) agreed that Outcomes should be a sub-discipline carrying a high weight. After evaluating the data available and the quality of it, it was decided to reduce the weight of the Outcomes sub-discipline. For example, it would be perfect to have an indicator reflecting death by diabetes not only as a primary (initial) cause of death but as a contributing (secondary) cause. Furthermore, we used number of diabetics among the total renal failure prevalence being, this data could be depended or influence by the number of diabetics in the country, which is of course sub-optimal. It would be more significant to gather data (not available for most of the countries) about dialysis or transplantation among the diabetes population. Out of all the indicator candidates on the "long list" at the early stages of the project, only half can be presented because of poor data availability. Here, as for the whole of the Index, input on how to improve methodology is welcomed.

In the Diabetes Index 2008, the scores for the five sub-disciplines were given the following weights:

Sub-discipline	Relative weight	"All Green" contribution to max score of 1000	Points for a Green score in each sub-discipline
Information, consumer rights, choice	200	200	40
Generosity	150	150	50
Prevention	267	267	33,37
Access to procedures	250	250	41,6
Outcomes	133	133	33,25
Total sum of weights	**1000**	**1000**	

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, as there are not many examples of countries that excel in one sub-discipline but do very poorly in others, that the final ranking of countries presented by the Diabetes Index 2008 is remarkably stable if the weight coefficients are varied within reasonable limits. The four countries making up the top group in the Index results remain the same also if weights are varied within quite wide limits. It is, of course, possible to create subtle differences in the internal order of countries placed close together (see Section 6.1) by changing the weights, but such subtle differences should not be the basis for any detailed conclusions.

The project has been testing 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). The final ranking is remarkably stable also during these experiments. In addition, it would probably be grossly unfair to countries scoring red to give that score the numerical value of 0. In 2008, the standards of diabetes care in Europe, also in states scoring low in the Index, are not so low that a score of 0 would be appropriate.

9.2.5 Regional differences within European states

The Health Consumer Powerhouse 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 HNS services, and should be ranked separately". Indeed, we have been using data from the English (Scotland and Wales not included) Quality and Outcomes Framework (QOF) that operates in Primary Care for General Practitioners. That is, numbers quoted for the U.K. are sometimes the numbers for England only. The uniformity among different parts of the U.K. is probably higher than among regions of Spain, Italy, and Germany; also, as there are more than 50 million English and only a few

million Scottish and Welsh, numbers for Scotland or Wales would have to be very different indeed to make significant impact.

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 relevant and meaningful statements about the national levels of healthcare services.

9.3 "CUTS" data sources

Whenever possible, 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 29 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 EUCID data, 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 29 national sources, even if those sources are official Ministry of Health or National Health/Statistics agencies, generally has high noise levels. It is notoriously difficult to obtain precise answers from many sources even when these sources are all answering the same question. For example, it has been difficult to find answers to indicators like "Do you have nurse practitioners in your country?" or "Is diabetes foot (podiatrist) a recognized sub-speciality in your country?". The reason is very simple: the definition of what is a diabetes nurse or a diabetes podiatrist and the amount of education and training required to qualify are different in every country. It has to be emphasized that also when a CUTS for an indicator has been identified, the data are still checked through procedures described in section 5.4.2, as there have frequently been occasions where national sources or scientific papers have been able to supply more recent and/or higher precision data.

9.3.1 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 organization 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.

9.4 Indicator definitions and data sources for the Euro Consumer Diabetes Index 2008

A more extensive description of the precise questions behind the indicators is found in section 9.6.

Sub-discipline	Indicator	Explanatory comment	● Score 3	◑ Score 2	○ Score 1	Main Information Sources
Information, consumer rights, choice	Diabetes registry?		Yes, national registry	Yes, regional registries or any register with any limitations (Only type I)	No, diabetes registry	Interviews with national diabetes experts and health care officials
	Quality information about Diabetes care providers (hospitals/clinics)?		Yes,easily and permanently available (www or publication) and it includes statistics on the results of these providers of care	Intermittently available and/or non-offical source or hard to get	No	Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008
	Right to choose among providers, domestic	Can patients freely choose a diabetes clinic anywhere in the country?	Yes	Yes, severely limited	No, you "get sent" to a certain care provider	Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008
	Right to choose among providers, EU	Can patients freely choose a diabetes clinic in another country?	Yes	Yes, with pre-approval, but usually no problem	Yes, with pre-approval, but usually problems or time delays	Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008
	Patient organisation participation in HC decisions	Do pat. org:s have formal right to participate in HC decision making?	Yes, statutory	Yes, by common practice in advisory capacity	No, not compulsory or generally done in practice	Interviews patients associations and health care officials
Generosity	Co-payment for diabetes drugs (including self-diagnosis materials?	Do patients get these on the same terms as other prescription drugs?	Special status	small reduction for diabetic or only in some drugs or devices	Same subsidy rules as all other Rx drugs or not enough	IDF Atlas, Interviews with national diabetes experts and health care officials
	Is foot care for diabetics provided	On the same terms as medical care?	Provided on the same terms as nurses or doctors	Provided on the same terms as nurses or doctors but small fee or with some special requirement not essential for other specialties	Only private	Interviews foot diabetes experts and health care officials
	Specially adapted shoes for diabetics	Does healthcare system provide specially adapted shoes for diabetics?	Yes	Yes but not enough or only partially subsidised (restricted)	No, those would be a matter of private consumption	Interviews foot diabetes experts and health care officials

Sub-discipline	Indicator	Explanatory comment	● Score 3	◑ Score 2	○ Score 1	Main Information Sources
Prevention	Obesity	% of population with BMI >30 in general population	< 11 %	11.1 - 16 %	> 16 %	The SuRF Report 2 (2005) WHO
	Physical activity in schools	Total hours of compulsory physical activity in statutory school	> 800	799 - 500	< 500	www.eurydice.org
	Moderate Physical activity	Time average (minutes) per week	>400	400-200	< 200	Special Eurobarometer on Health and food, Nov- Dec 2005
	Smoking prevalence	Adults both sexes 15+	< 20 %	20-30 %	>30 %	Smokers in the population WHO HfA database nov 2007
	Hypertension; mean systolic pressure in the population	Mean systolic blood pressure in population	< 125	125 - 129	>129	WHOSIS 2002
	Blood pressure check up?	What % of patients get annual check up? General population	>40 %	40-30 %	< 30 %	Eurobarometer 2006
	Cholesterol check up?	What % of patients get annual check up? General population	>40 %	40-30 %	< 30 %	Eurobarometer 2006
	Blood sugar check up?	What % of patients get annual check up? General population (45+)	>40 %	40-30 %	< 30 %	Interviews with national diabetes experts, health care officials and Patient Survey commissioned by HCP From Patient View 2008
Access to procedures	Eye check-up	What % of patients get annual Eye check-up?	>75 %	75-50 %	< 50 %	EUCID, Interviews with national diabetes experts or health care officials and Patient Survey commissioned by HCP from Patient View 2008
	Microalbuminuria control	What % of patients get annual Microalbuminuria check?	>75 %	75-50 %	< 50 %	EUCID, Interviews with national diabetes experts or health care officials and Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008
	HbA1c control	What % of patients get annual HbA1c check?	>75 %	75-50 %	< 50 %	EUCID, Interviews with national diabetes experts or health care officials and Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008
	Foot examinations	What % of patients get annual foot examination?	>75 %	75-50 %	< 50 %	EUCID, Interviews with national diabetes experts or health care officials and Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008
	Diabetic foot a recognized sub-speciality?		Yes, widely available	Yes, limited availability	Very limited or essentially not	Interviews foot diabetes experts and health care officials
	Diabetes nurse practitioners	Do you have diabetes nurse practicioners?	Yes, wildely available in the country	Available in some hospitals or clinics or only as nurse speciality	No or not enough (very few)	FEND, and National Nurses associations
Outcomes	Death by Diabetes	Standarized death rate per 100 000 persons.Adjusted to a standard age distribution. Primary cause of death only (hypoglycemia, ketoacidosis...)	< 10	10,1-20	> 20	EUROSTAT 2007
	Renal failure prevalence	Prevalence per million population by cause renal failure (diabetics) age unadjusted	< 14	14-20	> 20	Era-EDTA (annual report 2006)
	Foot amputation incidence	Annual incidence of major amputation (major=above ankle) per 100.000 diabetic population	< 150	150-300	> 300	EUCID, Interviews with national diabetes experts and health care officials
	% of patients with HbA1c > 7%	Percentage of total diabetic population with HbA1C above 7	< 50 %	50-60 %	>60 %	EUCID, Interviews with national diabetes experts and health care officials

Table 9.4: Indicator definitions and data sources for the Euro Consumer Diabetes Index 2008

9.4.1 Additional data gathering/evaluation - survey

In addition to public sources, as has been the practice for all editions of the generalist Euro Health Consumer Index and later also Euro heart Consumer Index, an e-mail survey to Patient organisations was commissioned from Patient View (Woodhouse Place, Upper Woodhouse, Knighton, Powys, LD7 1NG, Wales, Tel: 0044-(0)1547-520-965; info@patient-view.com).

For the Diabetes Index 2008, the survey covered information, consumer rights, and choice indicators, all Access to procedures indicators (with the exception of podiatrist as speciality and nurse practitioner) and prevention indicators related to screening. A total of 834 responses were obtained on this survey. The results of the survey have been used mainly to assess the "real situation" regarding some of the indicators. On no indicator the survey has been awarded CUTS status.

9.4.2 Additional data gathering – feedback from National Ministries /Agencies and particularly national Diabetes experts

In the first half of July 2008, the individual country preliminary score sheets were sent out to several parties where contact has been established such as the respective Ministries of Health and /or national agencies and especially diabetes experts and their respective professional associations of all 29 countries, giving the opportunity to supply more recent data and/or higher quality data than what is available in the public domain.

Gathering data took place primarily throughout March, April, and May 2008 in personal meetings, telephone meetings, and extensive e-mail exchanges with officials at national Ministries of Health and/or health agencies and diabetes experts. Feedback responses were provided by the countries presented in the table below. The table shows which countries returned an actual updated score sheet with comments. In addition to these score sheets, feedback was provided in several ways, both written and oral, from 25 of the countries.

Country	Responded in forms of feedback on the preliminary score sheet in 2008	Country	Responded in forms of feedback on the preliminary score sheet in 2008
Austria	√	Lithuania	√
Belgium	√	Luxembourg	√
Bulgaria	√	Malta	√
Cyprus		Netherlands	√
Czech Republic	√	Norway	
Denmark		Poland	√
Estonia	√	Portugal	√
Finland	√	Romania	√
France	√	Slovakia	√
Germany		Slovenia	√
Greece	√	Spain	√
Hungary	√	Sweden	√
Ireland	√	Switzerland	√
Italy	√	United Kingdom	√
Latvia	√		

Corrections were accepted only in the form of actual data, evidence, or background information and not by merely changing a score. Surprisingly, honesty often prevailed and scores were sometimes revised downwards after reconsideration of the scores on the individual country's preliminary score sheets.

9.5 Symmetry of in-data

It is important to note that there is absolutely no symmetry in the data used for the scores in the Diabetes Index. The project has consistently been using "latest available" statistics. As an example, this means that the Diabetes Index compares the WHO's Health for All data from 1997 from one country with 2006 data from other countries. In accordance with the HCP mission to drive active quantitative and qualitative monitoring of healthcare services, this is in the HCP Index projects and is considered a problem in countries not monitoring/reporting rather than a HCP problem.

For many indicators, perhaps most notably the "Foot amputation rate", in the Euro Consumer Diabetes Index, data from several sources have been piled on top of each other in order to obtain what could be considered the least inaccurate picture of the real situation. HCP has also allowed itself to test official policy decisions in a patient survey and by interviews with healthcare officials. In some cases, where real life practice does not seem to coincide with official policy decisions, scores have been modified accordingly.

9.6 Content of indicators in the Diabetes Index 2008

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

After the first meeting with the Expert Reference Panel (December 2008), further discussions with diabetes quality data acquisition experts and exploratory research on data availability on a number of aspects of diabetes care, the abovementioned five sub-disciplines (Section 4.1), were selected to describe important aspects of diabetes care. In the following, each indicator, with the actual indicator question asked, is briefly described.

On indicators where scores are based on a CUTS (Comprehensive Uniform Trustworthy Source), this is noted under each indicator bullet. The HCP survey commissioned from Patient View is not awarded CUTS status.

"Interviews with national Diabetes Experts and healthcare officials" normally means that HCP staff had been paying personal visits to Ministries of Health and/or National Health Agencies, National Statistical Agencies, and individual diabetes experts. The usual meeting form has been a two-hour sitting with groups of 2 -10 people. In some cases, these contacts have been conducted over the telephone. These meetings have also served as preparation for the "preliminary score sheet send out" (Section 8.3.3).

9.6.1 Indicators for information, consumer rights, choice

- *Diabetes registry*. National Diabetes Registers (NDRs) help provide effective diabetes care by monitoring delivery of services and outcomes outlined in the targets of the St. Vincent Declaration. It was found that very few countries have developed NDRs. The data comes from interviews with national diabetes experts and health care officials. Non-CUTS data.
- *Is Quality information about Diabetes care providers* readily available to the public? That is, is such data on outcomes accessible on the Internet or in widely spread publications? The data has been obtained from the Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008 and from interviews with health officials. Non-CUTS data.
- *Right to choose domestic healthcare providers* (Do patients have a free choice of which hospital or clinic they want to go to after referral from their primary care doctor?). Patients should have the possibility to choose the providers in his or her country. The data was acquired from interviews with health officials and the Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008. Non-CUTS data
- *Right to choose among providers across borders in the EU?* Patients should have the right to choose healthcare providers in neighboring countries, as was recently confirmed by the European Commission. For chronic diseases, this is not the optimal option because constant care is required and patients usually prefer to be treated at home. However, to have an option is always positive. The data was acquired from interviews with health officials and Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008. Non-CUTS data
- *Patient participation in Health Care decisions*. As representatives of the patients, healthcare providers should help patients voice their opinions and experiences before considering any new strategy or decision. The data comes from interviews with patients' associations and healthcare officials. Non-CUTS data.

9.6.2 Indicators for Generosity

- *Co-payment for diabetes drugs and devices*: In diabetes (Type 1 or Type 2), strict metabolic control means better outcomes, and a reduced risk of complications that usually shorten lifespan. It is beneficial to maintain optimal blood sugar levels, whether it is done through lifestyle choices (diet, exercise, etc.) or through medication. To treat diabetes requires several drugs and devices. All patients should be given the possibility to have the best treatment independent of their income. This is why experts want an indicator that reflects how countries support patient expenses. Data was acquired from interviews with health officials and patients' associations. Non-CUTS data.
- *Is podiatric care for diabetics provided on the same terms as other medical care*?

  As global incidence of diabetes has increased, disabling complications, including diabetic foot, have increased. Lower extremity ulcers (leg and foot ulcers) are a common problem among patients with diabetes. Leg ulcers can be caused by

venous and/or arterial insufficiency; foot ulcers are an especially serious complication of diabetes. Research has shown that approximately 4% to 10% of people with diabetes suffer from chronic ulcerations. The prevalence of ulcers varies markedly between countries due to differences in socioeconomic conditions, standards of foot care, and quality of footwear. It has been proven that a coordinated approach to foot health can prevent up to 50% of these problems.

It seems there is a lot to be done on this front. Because the goals in all the countries are far from being reached, we have concentrated our efforts to find information on access to diabetes foot care.

On this indicator, it was not asked who was providing foot care (endocrinologist, podiatrist, nurse, etc.), but who was paying for it and the terms of subsidy for this type of care**.** Data was collected from interviews with health officials, diabetes foot experts (DFSG and International working group on the diabetic foot), and patients associations. Non-CUTS data.

- *Does the healthcare system provide specially adapted shoes for diabetics?* Governments should provide enough subsidy to patients so they can buy special shoes that prevent severe foot complications. Data was collected from interviews with health officials, diabetes foot experts (DFSG and International working group on the diabetic foot), and patients associations. Non-CUTS data.

9.6.3 Indicators for Prevention

When discussing prevention of risk factors for diabetes mellitus, the subtypes –Type 1 and Type 2 diabetes – have to be separated. The indicators selected in this section are mainly related with diabetes Type 2.

Prevention not only means the prevention of the sickness but also the prevention of later complications. Therefore, in the expert reference panel discussions, it was agreed that the main factors affecting risk for Diabetes disease are obesity, smoking, physical activity or inactivity, hypertension, and nutritional habits (apart from hereditary factors). Indicator design reflects circumstances that an identifiable group of people could influence/change rather than just reflecting "global" public health parameters.

- *Is there a National Diabetes screening programme*?

  Early diagnosis of diabetes will reduce complications and improve long-term prognosis. After hearing that "formal screening programmes are in place in most countries", the challenge became apparent: How to find an indicator that is not just a plan or policy, as HCP indexes do not award scores for good intentions? To do so, this indicator was split into three indicators.

  The data for the first two indicators come from the Special Eurobarometer on Health, September 2007. Equivalent data were reported by the Swiss Bundesamt für Statistik (CUTS data).

  - The percent of positive responses to the question "Have you had your blood pressure checked in the past 12 months?"

  - The percent of positive responses to the question "Have you had a cholesterol check in the past 12 months?"
  - The percent of positive responses to the question "Have you had a blood sugar check in the past 12 months?" (only persons older than 45).Data obtained from interviews with national diabetes experts and health care officials and compared with the data from a Patient Survey commissioned by Health Consumer Powerhouse From Patient View 2008. Non-CUTS data.

- *Obesity/overweight* is a major risk factor for Type 2 diabetes. It causes insulin resistance, which will lead eventually to Type 2 diabetes. In people with diabetes, obesity increases the risk for macro and micro vascular complications. We have chosen an indicator for obesity, reflecting the percentage of persons in a population with a Body Mass Index (BMI) > 30% (cut off point based on recent WHO recommendation). Data from the WHO SuRF Report 2 (2005). CUTS data.
- *Moderate Physical Activity*. The data of this indicator comes from the special Eurobarometer on Health and Food, Nov-Dec 2005. This indicator is important as sedentary lifestyle contributes to the development of Type 2 diabetes, partly through increased risk for obesity. It is important to note that this indicator depends very much on life habits, habits that can be changed. It is the result of the combination of two questions: "How many days did you do moderate physical activity in the past 7 days"? and "How many minutes on average do you do moderate physical activity"? CUTS data.
- *Exercise in compulsory school.* To prevent obesity and promote a healthy life, governments should require exercise in the schools. This is why we selected this indicator: "The total number of compulsory physical exercise in statutory school". Data was collected from a report on the topic from www.eurydice.org , "The Information Network on Education in Europe". CUTS data.
- *Smoking cessation assistance*. Data from Special Eurobarometer on Health, September 2007. "What percentage of smokers having tried to quit, have responded that they did so with the assistance from healthcare services." CUTS data.
- *Hypertension or the mean systolic pressure in population.* It is an independent risk factor for the development of diabetes complications. It would have been preferable to have the indicator "prevalence of blood pressure above 140/90", but such data were found only for five large western European states (plus the U.S. and Canada) and for Portugal. Data from WHOSIS. CUTS data.

9.6.4 Indicators on Access to procedures

Access to procedures indicators provide information on the frequency with which a certain test (lab/clinical examination, etc.) is being performed and will be an indicator on the quality of the process during care provided to diabetics.

Intensive treatment and early intervention have been demonstrated to improve long-term prognosis. Based on this, internationally accepted guidelines have been introduced. These practices may prevent deterioration and further progression of late complications.

- *What percent of diabetics get annual check-up?* The percentage of persons with diabetes having access to different examinations (eyes, Microalbuminuria, HbA1c, and foot examination) within the last 12 months is a process indicator that provides information on the frequency of control. The best data comes from an EUCID report and additional data from interviews with national diabetes experts or health care officials and the patient survey commissioned by Health Consumer Powerhouse from Patient View 2008. Non-CUTS data.
  - **Foot**: Foot problems in diabetic patients are very difficult to treat. Therefore, visual recognition of early clinical signs is a vital component of early diagnosis and start of treatment. It is recommended that annual screenings be performed to avoid complications.
  - **Eye**: After 20 years of diabetes, almost all persons with Type 1 and > 60% of the persons with Type 2 diabetes suffer from diabetic retinopathy to some degree. Early diagnosis followed by an optimatization of metabolic control can stop progression and in some situations prevent blindness.
  - **HbA1c**: This indicator is important because glucose binds to HbA1c and is only released very slowly; therefore, HbA1c represents the average blood glucose level over the previous four weeks. It is a more stable of the degree of diabetes than isolated blood sugar determinations. The test gives a good estimate of how well diabetes has been managed for the previous two or three months.
  - **Microalbuminuria:** Presence of microalbuminuria has been identified as a risk factor for the development of renal and vascular complications. When it is detected, adequate therapeutic action can delay and/or stop progression towards further kidney failure or hypertension.

Good procedures directly depends on good access to high qualify professionals:

- *Is diabetic foot a recognized sub-speciality?* What percent of diabetes multidisciplinary groups have diabetes foot specialists or how many foot centres have diabetes specialists? This information, however, was unavailable and an approximation was chosen. Data was collected from interviews with health officials, diabetes foot experts (DFSG and International working group on the diabetic foot), and patients' associations. Non-CUTS data.
- *Are there diabetes nurse practitioners?* Nurse practitioners are registered nurses who have completed additional education and clinical training so that they may diagnose and treat many common and chronic illnesses, focusing on health promotion and disease prevention activities, including patient education and counselling. In general, NPs have either a certificate or a master's degree in NP, work in collaboration with a physician, and can prescribe medications. Their role has been demonstrated to be essential in improving the quality of care provided to

people with diabetes. The information has been collected by talking with nurse associations all over Europe. Non-CUTS data.

9.6.5 Indicators on Outcomes

Treatment and management of chronic illness is an increasing concern as both costs of medical care rise and the number of persons with chronic illnesses grows. A better understanding is needed of the effectiveness and costs of interventions designed to improve patient control over chronic conditions.

- *Death rates from Diabetes* (only as a primary cause of death only (hypoglycemia, ketoacidosis, etc.). Causes of Death data refer to the underlying cause that is "the disease or injury which initiated the train of morbid events leading directly to death, or the circumstances of the accident or violence which produced the fatal injury". However, many diabetes patients die of cardiovascular disease (CVD); in these cases, cardiovascular disease is usually recorded as the primary cause of death. Therefore, the actual number of deaths for which diabetes was a contributing factor is underestimated. Data was obtained from EUROSTAT 2007. CUTS data.
- Renal failure; delay and/or prevention of progressive nephropathy is possible with intensive treatment and normal blood pressure. If no action is taken, micro vascular lesions in the kidneys will lead to renal compromises. First signals are the detection of microalbuminuria, followed by an increase in creatinine levels. Progression ultimately will lead to **renal failure** necessitating renal replacement therapy. This indicator refers to prevalence per million by cause of renal failure (diabetics) and is age unadjusted. It refers to the percent of persons reported suffering renal failure and diabetes. Data was obtained from Era-EDTA database (Annual report 2006). CUTS data.
- *Foot amputation incidence:* The incidence of major limb amputation in a diabetic population is an outcome of macrovascular disease – a serious diabetes complication. Data was obtained from EUCID and interviews with national diabetes experts and health care officials. Non-CUTS data.
- *Percent of patients with HbA1c > 7%:* Reaching optimal blood glucose in diabetes is important for optimisation of the risk of microvascular complications. In many guidelines, instead of 7% the goal is set to 6.5, 7.5, or even 8%. For this reason, data acquisition is not always standard among the countries. Data was obtained from EUCID and interviews with national diabetes experts and health care officials. Non-CUTS data.

9.7 This is how the Diabetes Index 2008 was built

9.7.1 Strategy

In April 2004 the HCP first launched the Swedish Health Consumer Index (www.vardkonsumentindex.se, also in a translation to English). By ranking the 21 county councils (the regional parliaments responsible for funding, purchasing and generally also providing healthcare) using 12 basic indicators concerning the design of "systems policy", consumer choice, service level, and access to information, we introduced benchmarking as an element in consumer empowerment.

There is a pronounced need for improvement. The very strong media impact of the Index all over Sweden confirmed that the image of healthcare is rapidly moving from rationed public goods into consumer-related services measurable by common quality perspectives,

For the Euro Health Consumer Indexes and for the Diabetes Index, the Health Consumer Powerhouse has been aiming to follow basically the same approach, *i.e.,* selecting a number of indicators that describe to what extent the national healthcare systems are "user-friendly", thus providing a basis for comparing different national systems.

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 HCP is to be looked upon as a partner in developing healthcare around Europe.

9.8 Production phases

The Diabetes Index 2008 was constructed under the following project plan.

9.8.1 Phase 1

Start-up meeting with the Expert Reference Panel (2007-12-18)

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 basic methods were:

- Web search,
- Telephone and e-mail interviews with key individuals, and
- Personal visits when required.

Web search:
a) Relevant byelaws and policy documents
b) Actual outcome data in relation to policies

Information providers:

a) National and regional Health Authorities

b) Institutions (EHMA, Cochrane Institute, Picker Institute, University of York Health Economics, others)

c) Private enterprise (IMS Health, pharmaceutical industry, others)

Interviews (to evaluate findings from earlier sources, particularly to verify the real outcomes of policy decisions):
a) Phone and e-mail

b) Personal visits to key information providers

9.8.2 Phase 2

- Data collection to assemble presently available information to be included in the Diabetes Index 2008.
- Identification of vital areas where additional information needed to be assembled was performed.
- Collection of raw data for these areas
- A round of personal visits by the researchers to Health Ministries and/or State Agencies for supervision and/or Quality Assurance of Healthcare Services.
- We kept regular contact with the Expert Reference Panel mainly to discuss the indicators, the criteria to define them, and the data acquisition problems. Finally, we had a second meeting on June 27 in which we talked in detail about each of the indicators, including the ones that could not be included in the Index due to lack of data. Also, the discrepancies between data from different sources were analyzed.

9.8.3 Phase 3

9.8.3.1 Consulting European patient advocates and citizens through HCP survey performed by external research facility (Patient View, U.K.).

The Diabetes Index survey contained the questions mentioned in Section 4.4.1 and is also found in Appendix 1 of this report. The survey was posted on the Internet in mid-March in English, German, French, Spanish, Swedish, and Greek. The closing date should have been May 29, but this was extended to June 20; 833 responses were submitted, but there were only 15 countries represented by more than 10 responses. This means that the survey essentially has not been used as stand-alone data for any indicator.

9.8.3.2 "Score update sheet" send-out.

On July 7, 2008, all 29 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 July 17. The send-out was made to contacts at ministries/state agencies as advised by states during the contact efforts of the spring of 2008. Two reminders were also sent out.

Corrective feedback from states was accepted up until September 1st, by which time replies had been received as listed in section 5.5.2 above.

9.8.4 Phase 4

Project presentation and reports

- A report describing the principles of how the Diabetes Index 2008 was constructed.
- Presentation of Diabetes Index 2008 at various events on 2008-09-30 in Brussels and other venues in the following months.
- On-line launch on www.healthpowerhouse.com .

9.9 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 Panel Members having been sent the Index working material in advance. The following persons have taken part in the Expert Reference Panel Work:

Name	**Affiliation**
Prof. Christos Barsocas	MITERA Pediatric hospital, Athens, Greece
Inge Duimel., PhD.	Hausarzversorgung Heuvelland (RHZ), The Netherlands
Dr. Gabriel Gímenez Pérez	Diabetes, Endocrinology and Nutrition Unit, Department of medicine. Granollers General Hospital, Barcelona, Spain.
Prof. Simon Pruna	Institute of Diabetes "N. Paulescu", Romania
Dr. Tarvo Rajasalu	Department of Internal Medicine, University of Tartu, Estonia
Prof. Urban Rosenqvist	Department of Public Health and Caring, University of Uppsala, Sweden
Dr. Eric Senneville	Diabetic Foot Clinic, Dron Hospital, France
Dr. Fred Storms	Dutch Institute for health care improvement, CBO, The Netherlands
Prof.MuDr. Jan Vavrinec	Klinika detí a dorostu 3. lékatské fakulty UK a FN Královské Vinohrady, Prague, Czech Republic.

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, if the ambition is to be able to say that a state scoring well can truly be considered to have good, consumer-friendly healthcare services.

B. To review the final results of research undertaken by HCP researchers before the final scores are set. If the information obtained seems to clash too violently with the many decades of cardiac care 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.

10.FAQs

What is the Euro Consumer Diabetes Index?

The Euro Consumer Diabetes Index measures the performance of countries on differing aspects of delivery of diabetes care. The information is presented as a series of easy to understand rankings, designed to empower consumers of healthcare services in obtaining the best outcomes form their cardiac care. It is produced by the Health Consumer Powerhouse (HCP), which also produces the Euro Health Consumer Index. The HCP believes that increasing transparency in healthcare systems can only benefit consumers, and that revealing differing levels of performance can help healthcare delivery to improve overall.

Who will use the Diabetes Index?

The main audiences for the Diabetes Index are those involved in healthcare policy formation: civil servants, clinicians, and, of course, journalists. The ultimate goal is to reach the consumer directly via, for example, media coverage of the Index findings.

Will consumers be able to understand this information easily?

Yes. Healthcare consumers have a clear interest in knowing more so they can make the best possible decision. For professional services, which can be complex to explain, there is always a risk of over simplification. The HCP already has experience in communicating complex information on health in a concise way, clearly illustrating the good and the bad. We work hard to ensure our information is as accessible and consumer-friendly as possible while ensuring we do not ‘dumb down’.

The European Commission has also declared that transparency and competition are essential in making European healthcare more efficient. Improved insight into to the standards of our European neighbours will support patient mobility within the EU.

What kind of impact will the Diabetes Index have?

The HCP expects governments to look into the findings, draw conclusions, and take appropriate action to remedy the problems in their healthcare systems, as they have with

our existing indexes. We have created a set of recommendations for each country; these can be found on www.healthpowerhouse.com.

Can all countries really afford to follow your recommendations?

It is not as simple as making blanket recommendations – on some levels there are common failings across many healthcare systems, such as lack of information. On other levels, it could be inexpensive steps such as increasing transparency in the system.

Is it really possible to measure and compare healthcare in this way?

Absolutely. You can measure and compare in many ways; the HCP feels this approach has several advantages:

- Focuses on those measures which impact the ability of the consumers to best use the available healthcare services;
- Focuses on such aspects of healthcare delivery, which the medical profession, administrators, and/or regional or national politicians could actually do something about if they want to; and
- Highlights the differences between countries, helping consumers understand where they could and should reasonably expect more from their providers.

A recent report[1] from the Canadian Institute for Health Information and Statistics Canada describes the important issues for measuring and comparing healthcare systems.

Does the WHO or the EU not already provide this kind of data?

Our information is complementary to the existing WHO and EU data; they provide statistical information on overall public health which we use, but the Heart Index also needs qualitative date to focus on providing consumer information. The comparative analyses we provide is not delivered by other institutions.

Is this really research?

It is compiled consumer information. It is not clinical research and is not to be looked upon as research in the true academic sense.

How reliable is the Diabetes Index data? Some of it seems dated, and there appears to be a number of 'gaps'.

[1] Canadian Institute for Health Information, *Making Sense of Health Rankings,* (Ottawa, Ont.: CIHI, 2008).

We bring data together from public sources and our own investigations and research. This is consumer information, and our philosophy is that providing data – even where seemingly inconsistent – is better than saying nothing at all.

The data is as reliable as it has been possible to make them and is always based upon "latest available". Healthcare data can be inconsistent, difficult to access, and frequently outdated. For one country, the latest data may be quite recent; for another one, several years old. The HCP has a system to assess and validate all data, which includes collecting feedback from national authorities on the preliminary findings of the Index research. Ministries of Health or state agencies are given the opportunity to correct/update/validate the results. We have also commissioned a survey with patients. Highlighting this data quality issue is one benefit of the Index exercise; it is a challenge to European governments and institutions, not an Index weakness.

How were the indicators and weighting selected, and why?

The indicators were developed through dialogue between the HCP, the Expert Reference Panel, and numerous stakeholders. They were chosen to provide the best overall indication of outcomes in diabetes disease.

How were the indicators selected?

A limited number of indicators were chosen within closely defined evaluation areas. Taken together they can present a telling tale of how well – or badly – the consumer is being served by their respective healthcare systems.

Why is Denmark the winner?

Denmark is the best in two out of most important disciplines for HCP. A combination of fantastic performance in information /rights and access, very high generosity, plus very effective diabetics screening programs makes Denmark the best. Denmark presents very complete, high quality diabetes care.

Is it really useful to provide overall measurements when many European systems are increasingly decentralised/regionalised?

There still are national common streaks also in decentralised healthcare systems, which definitely justify comparing healthcare delivery on national level.

Who is behind the Diabetes Index?

The Index was initiated by, and is produced by, the Health Consumer Powerhouse, which holds the copyright to the **Euro Consumer Diabetes Index**. The HCP is a private healthcare analyst and information provider and is registered in Sweden.

Who supports the Diabetes Index?

This work has been undertaken via an unrestricted grant from Pfizer, Inc.

11. References

11.1 Main sources

The main sources of input for the various indicators are given in Table 5.4 above. For all indicators, this information has been supplemented by interviews and discussions with healthcare officials in both the public and private sectors and by data from national registries and communication from national Ministries of Health, state agencies, and local endocrinology societies, associations, and /or Diabetes experts.

11.2 Useful links

Web search exercises have yielded useful complementary information from. Below is a list of some these sources.

Links to trans-national data

A DIRECT-TO-PATIENT INFORMATION TOOL ON: "DIABETES"	http://ec.europa.eu/health/ph_overview/other_policies/pharmaceutical/docs/diabetes_package_en.pdf
Black Sea Telediab	http://www.telemed.ro/BSTD/BSTD_Broch.pdf
Diabcare	http://www.ehto.org/aim/volume2/diabcare.html
Diabetes foot study group	http://www.dfsg.org/
Diabetes: The Policy puzzle	http://www.idf.org/webdata/docs/idf-europe/DiabetesReport2005.pdf
EUCID	http://www.eucid.eu/eucid/home.do
EUDIP	http://ec.europa.eu/health/ph_projects/2000/monitoring/fp_monitoring_2000_frep_11_en.pdf
EUROASPIRE III	http://www.escardio.org/knowledge/ehs/survey/scheduled-surveys/Euroaspire_III.htm
EUROBIROD	http://www.biro-project.eu/documents/downloa

	ds/Brochure2007.pdf
Eurodiale	http://81.241.226.158/eurodiale/(2jtxb0uus4jne3555aroc0mi)/main.aspx?page=general.html
European comparison on cost of diabetes and % of total health care budget	http://ec.europa.eu/health/ph_information/dissemination/diseases/diabet8.pdf
European Nurses Organization	http://www.nurses.info/organizations_europe.htm
European Observatory	http://www.euro.who.int/observatory
European Renal association	http://www.era-edta-reg.org/index.jsp?p=annrep
Federation of European nurse in diabetes	http://www.fend.org/
Health in the European Union Fieldwork Nov - Dec 2005 (Publication November 2006)	http://ec.europa.eu/health/ph_publication/eb_food_en.pdf
Health in the European Union Fieldwork October - November 2006 (Publication September 2007)	http://ec.europa.eu/health/ph_publication/eb_health_en.pdf
International working group on diabetes foot	http://www.iwgdf.org/
Mortality (SDR) per 100,000 for diabetes (ICD-10 code E10-E14) for all ages, male, female and total, in Iceland, Norway, Switzerland and the EU-27, 2004 (source: Eurostat, 2007)	http://www.euphix.org/object_document/o4616n27165.html
OECD Health Policy & Data Department	http://www.oecd.org/department/0,2688,en_2649_33929_1_1_1_1_1,00.html
Patient View	http://www.patient-view.com/hscnetwork.htm
Screening for diabetes retinopathy	http://www.drscreening2005.org.uk/amsterdam2008.html
The B.I.R.O Project	http://www.biro-project.eu/results.htm
The diabetic foot: a global view	http://www3.interscience.wiley.com/journal/74000078/abstract?CRETRY=1&SRETRY=0
The Public Health Portal of the European Union	http://ec.europa.eu/health-eu/index_en.htm
WHO “Health for All” database	http://www.euro.who.int/hfadb
WHO HfA Mortality database	http://www.who.int/healthinfo/statistics/mortdata/en/
World Health Statistics 2008	http://ww.who.int/whosis

Links to national data

Austria	ÖSTERREICHISCHEN DIABETES GESELLSCHAFT	www.oedg.org
Austria	Qualitätsmanagement und Gesundheitssystemforschung Bundesministerium für Gesundheit, Familie und Jugend	http://www.bmgfj.gv.at
Austria	Forum Qualitätssicherung in der Diabetologie Österreich (FQSD-Ö)	http://www.fqsd.at
Belgium	Belgian diabetes registry	http://www.bdronline.be/langN.htm
Belgium	Enquête de Santé par Interview Belgique 2004	http://www.iph.fgov.be/EPIDEMIO/epifr/crospfr/hisfr/his04fr/hisfr.pdf
Belgium	Initiative pour la Promotion de la Qualité et Epidémiologie dans les cliniques multidisciplinaires du pied Diabétique.	http://www.iph.fgov.be/EPIDEMIO/epifr/iked/ikedpied0506fr.pdf
Belgium	Cost and resource utilization for prevention and treatment of foot lesions in a diabetic foot clinic in Belgium	http://linkinghub.elsevier.com/retrieve/pii/S0168822700001571
Czech Republic	Detailed view on diabetes (patients, treatment) can be taken from the monothematic publication Care of Diabetics 2006	http://www.uzis.cz/download_file.php?file=3163
Czech Republic	Czech Health Statistics Yearbook 2006	http://www.uzis.cz/download_file.php?file=3210
Denmark	Diabetesforeningen	www.diabetes.dk
Denmark	Sundhedskvalitet	www.sundhedskvalitet.dk
Estonia		
Finland	Diabeteksen ehkäisyn ja hoidon kehittämisohjelma (DEHKO 2000-2010)	www.diabetes.fi
Germany	Gesundheitsberichterstattung des Bundes	www.gbe-bund.de
Greece	Foot amputation rates	http://www.ncbi.nlm.nih.gov/pubmed/18413176?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum
Hungary	Diabetes Hungary	http://www.diabetesvoice.org/files/attachments/article_251_en.pdf
Hungary	Primary care diabetes in Hungary	http://linkinghub.elsevier.com/retrieve/pii/S17519918070007

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Italy	Italian standards for Diabetes Mellitus 2007	http://www.siditalia.it/documenti/AMD-SID_Italian%20standards%20for%20diabetes%20mellitus%20%202007.pdf
Italy	Risultati nazionali dello studio QUADRI (QUalità dell'Assistenza alle persone Diabetiche nelle Regioni Italiane)	http://dspace.iss.it/dspace/bitstream/2198/-26340/1/1123-3117_2007_I_07_10.pdf
Latvia	Health Compulsory Insurance State Agency (HCISA) – supervisory state authority of Ministry of Health	http://www.voava.gov.lv/eng/
Lithuania	Lithuanian Health Information Centre	http://www.lsic.lt/html/en/lhic.htm
Luxembourg	Proposition d'un mode de surveillance du diabète au Luxembourg : Analyse de deux modèles de recueil de données	www.crp-sante.lu
Netherlands	Health Council	http://www.gr.nl/zoek.php?Keywords=diabetes&Zoeken=Search
Norway	National Diabetes Strategy. 2006-2010	http://www.regjeringen.no/Upload/HOD/Vedlegg/Engelsk/Diabetes.pdf
Norway	Diabetes foot study in Norway	file:///C:/Documents%20and%20Settings/Betriz/Escritorio/papers%20interesants/foot%20care%20Norway.htm
Spain	National strategy diabetes	http://www.msc.es/organizacion/sns/planCalidadSNS/pdf/excelencia/cuidadospaliativos-diabetes/DIABETES/estrategia_diabetes_sistema_nacional_salud.pdf
Switzerland	Bundesamt für Statistik	http://www.bfs.admin.ch/bfs/portal/de/index/themen/14/22/lexi.topic.1.html
Switzerland	Bundesamt für Statistik	http://www.bfs.admin.ch/bfs/portal/de/index/themen/14/22/publ.html?publicationID=1951
Switzerland	Bundesamt für Statistik	http://www.bfs.admin.ch/bfs/portal/de/index/themen/14/02/01/key/01.html
UK	Prevalence and QOF page on our website	http://www.diabetes.org.uk/Professionals/Information_resources/Reports/Diabetes-

		prevalence-2007/
UK	Diabetes in the UK 2004	http://www.diabetes.org.uk/Professionals/Information_resources/Reports/Diabetes_in_the_UK_2004/
UK	Quality & Outcomes Framework results	http://www.ic.nhs.uk/our-services/improving-patient-care/the-quality-and-outcomes-framework-qof-2006/07/qof-2006-07-data-tables
UK	Healthcare Commission Survey	http://www.healthcarecommission.org.uk/nationalfindings/surveys/patientsandthepublic/patientsurveyresults/diabetes.cfm
UK	National Diabetes Audit	http://www.ic.nhs.uk/our-services/improving-patient-care/national-clinical-audit-support-programme-ncasp/audit-reports/diabetes

Appendix 1. Questionnaire used in the survey commissioned from Patient View for the Euro Consumer Diabetes Index 2008.

The compiler of the annual EuroHealth Consumer Index, the Brussels and Stockholm-based HEALTH CONSUMER POWERHOUSE (HCP), has now started looking at how well each country in Europe treats individual diseases.

One of the first such medical conditions to be examined by HCP is diabetes.

The questionnaire below allows you to contribute your views to HCP's forthcoming Euro Consumer Diabetes Index 2008. The questionnaire has only ten questions, followed by some very brief profiling questions. Filling it in should take no more than about 5 (or, at most, 10) minutes.

The survey is being conducted online on this specialist survey site, so allowing all responses to be completely ANONYMOUS. No IP addresses or email details can reach the survey managers (unless you choose to mention such information in the survey). If, however, you would like to be sent the weblink to the completed Euro Consumer Diabetes Index 2008 when it is published in September 2008, you can specify your CONTACT DETAILS at the end of the questionnaire.

The survey will close on Monday, 28th May 2008 (but we would welcome your input earlier than that, as your opinions can help to quickly establish some trends). The survey is being administered by PatientView (a UK-based publishing and research organisation) on behalf of Health Consumer Powerhouse, and is being supported by an unrestricted grant from Pfizer.

Should you have any questions regarding this survey, please do not hesitate to contact the survey administrator (name and contact details given).

1. When did you first discover that you had diabetes? *[Please specify only one option]*

- In the last year.
- 1 to 2 years ago.
- 2 to 5 years ago.
- 5 to 10 years ago.
- More than 10 years ago.
- I do not know.

2. How did you first find out that you had diabetes? *[Please specify only one option]*

- I was feeling unwell, and I sought medical advice.
- After my parents took me to the doctor, when I was a child.
- After a routine, regular check up by the GP/nurse.
- After a hospital check up, following a visit to the Accident & Emergency department.
- After a hospital check up before an operation.
- After a routine test at my sports/health club.
- After a routine test at my workplace.
- After a routine test when I applied for private medical/life insurance.

3. Before you were diagnosed with diabetes, how often did you get the following checked by a doctor/nurse?

a. Your blood sugar level *[Please specify only one option]*

- ■ At least twice a year.
- ■ Once a year.
- ■ Less often than once a year.
- ■ Never, to my knowledge.
- ■ I do not know.

b. Your blood pressure *[Please specify only one option]*

- ■ At least twice a year.
- ■ Once a year.
- ■ Less often than once a year.
- ■ Never, to my knowledge.
- ■ I do not know.

c. Your blood lipid level *[Please specify only one option]*

- ■ At least twice a year.
- ■ Once a year.
- ■ Less often than once a year.
- ■ Never, to my knowledge.
- ■ I do not know.

4. Is high-quality information about the providers of diabetes care (hospitals/clinics) easily available to you?

In this survey, "high-quality information" means up-to-date information on the performance of your hospital/clinic (especially how good or bad they are at treating diabetes). *[Please specify only one option]*

- ■ Yes, with statistics on treatment results..
- ■ It is available, but hard to get.
- ■ No information is available.
- ■ I do not know.

5. Is high-quality information about diabetes medicines and diabetes medical devices easily available from any of the following sources?

The information can be either in print, on the Internet, or by word of mouth, but please only specify an option **if the information comes from within your own country**. *[You may specify more than one option if you wish]*

- ■ Doctors and other health professionals.
- ■ Industry (pharmaceutical and medical device companies).

- Insurers.
- The media (including the medical press).
- National or local government.
- Patient/consumer organisations.
- Pharmacists.
- Regulators of medicines and devices.
- Schools.
- Supermarkets, health clubs, and travel companies.
- Universities and researchers.
- I do not know.

6. Do you take lipid-lowering medication (statins)? *[Please specify only one option]*

- Yes (though I have not had a heart problem).
- Yes (I have had a heart problem).
- No, because I would have to pay it myself.
- No.

7. Are you suffering from any diabetes complications? *[You may specify more than one option if you wish]*

- Yes, serious complications.
- Yes, minor complications.
- No.

8. Do you get checked for:

a. Eye conditions? *[Please specify only one option]*

- More than once a year.
- Once a year.
- Less than once a year.
- I do not get checked for this.

b. Kidney (microalbumin test)? *[Please specify only one option]*

- More than once a year.
- Once a year.
- Less than once a year.
- I do not get checked for this.

c. Foot examination? *[Please specify only one option]*

- ■ More than once a year.
- ■ Once a year.
- ■ Less than once a year.
- ■ I do not get checked for this.

d. HbA1c test (of average blood sugar level)? *[Please specify only one option]*

- ■ More than once a year.
- ■ Once a year.
- ■ Less than once a year.
- ■ I do not get checked for this.

9. Given your own treatment thus far, how good do you think your country's healthcare system is at treating/caring for people with diabetes? *[Please specify only one option]*

- ■ Excellent.
- ■ Good.
- ■ Fair.
- ■ Poor.

10. Which of the following do you regard as the single-most important change to your country's healthcare services that could help people with diabetes. *[Please specify only one option]*

- ■ More doctors and nurses skilled and expert in diabetes treatment/care.
- ■ Better information about the correct treatment/care/support.
- ■ Better support, so that people with diabetes can lead a more normal, independent life.
- ■ Policies that ensure that people with diabetes get the correct treatment/care/support.
- ■ Training in communication skills for doctors and nurses, so that they are better at listening to patients.
- ■ Reductions in bureaucracy and barriers, to make it easier for patients with diabetes to receive medical care.