



Health Consumer Powerhouse



**Euro Diabetes Index**

**2014**



**Health Consumer Powerhouse**

**Euro Diabetes Index  
2014**

**Report**

Beatriz Cebolla Garrofé, PhD

Arne Björnberg, PhD

Ann Yung Phang, RN, BA

[info@healthpowerhouse.com](mailto:info@healthpowerhouse.com)

Health Consumer Powerhouse Ltd.

2014-09-17

*Number of pages: 72*

This report may be freely quoted, referring to the source.

© Health Consumer Powerhouse Ltd., 2014.

ISBN 978-91-980687-4-0

# Contents

<b>NO DATA, NO CURE</b> .....	<b>5</b>
<b>1. SUMMARY</b> .....	<b>6</b>
1.2 CHARACTERISTICS OF GOOD DIABETES CARE .....	6
1.3 TOP PERFORMERS IN THE INDEX. WHAT ARE THEY DOING WELL? .....	8
<b>2. AREAS FOR IMPROVEMENT</b> .....	<b>12</b>
2.1 PREVENTION .....	13
2.2 ACCESS TO TESTING .....	14
2.3 ACCESS TO CARE AND TREATMENT.....	14
2.4 REGISTRY DATA: EUROPEAN DIABETES REGISTER.....	16
<b>3. RESULTS IN EURO DIABETES INDEX 2014</b> .....	<b>17</b>
3.1 TOTAL SCORES AND RANKING IN EURO DIABETES INDEX 2014 .....	19
3.2 RESULTS IN “HEXATHLON” .....	20
<b>4. BACKGROUND</b> .....	<b>21</b>
4.1 GENERAL INFORMATION ON DIABETES .....	21
4.2 BACKGROUND OF THE HEALTH CONSUMER POWERHOUSE .....	22
4.3 INDEX SCOPE .....	23
4.4 ABOUT THE AUTHORS .....	23
<b>5. HOW TO INTERPRET THE INDEX RESULTS?</b> .....	<b>24</b>
<b>6. EURO DIABETES CARE INDEX 2014</b> .....	<b>25</b>
6.1 INDICATOR AREAS (SUB-DISCIPLINES) .....	26
6.2 SCORING IN THE EDI 2014 .....	26
6.3 WEIGHT COEFFICIENTS .....	26
6.4 REGIONAL DIFFERENCES WITHIN EUROPEAN STATES .....	27
6.5 INDICATOR DEFINITIONS AND DATA SOURCES FOR THE EDI 2014.....	28
6.6 ADDITIONAL DATA GATHERING – E-QUESTIONNAIRE.....	32
6.7 ADDITIONAL DATA GATHERING – SINGLE COUNTRY SCORE SHEETS.....	32
6.8 THRESHOLD VALUE SETTINGS .....	33
6.9 CUTS DATA .....	33
<b>7. CONTENT AND CONSTRUCTION OF THE EDI 2014</b> .....	<b>34</b>
7.1 SUB-DISCIPLINE: PREVENTION .....	34
7.2 SUB-DISCIPLINE: CASE FINDING .....	36
7.3 SUB-DISCIPLINE: RANGE AND REACH OF SERVICES .....	39
7.4 SUB-DISCIPLINE: ACCESS TO TREATMENT/CARE .....	47
7.5 SUB-DISCIPLINE: PROCEDURES .....	51
7.6 SUB-DISCIPLINE OUTCOMES .....	52
<b>8. HOW THE EURO DIABETES INDEX 2014 WAS BUILT</b> .....	<b>52</b>
8.1 PRODUCTION PHASES.....	52
8.2 CONTENT OF INDICATORS IN THE EDI 2014 .....	54
<b>9. EXTERNAL EXPERT REFERENCE PANEL</b> .....	<b>62</b>
<b>10. LITERATURE REFERENCES</b> .....	<b>63</b>
<b>APPENDIX 1. QUESTIONNAIRE USED IN THE SURVEY FOR THE EURO DIABETES INDEX 2014</b> .....	<b>66</b>

## No data, no cure

When HCP published the inaugural Euro Diabetes Index 2008, the foreword had the headline “Killing neglect”. This somewhat pessimistic conclusion was that many European diabetics had to suffer or even die due to lack of efficient registering and monitoring of diabetes. The lack of systematic knowledge was a killer.

Six years later, when we repeat this unique exercise, what is the impression? A mixed picture:

The upside is that in spite of a continuous growth of diabetes prevalence, less people die. A comparison between the 2008 and 2014 Indices suggests that prevention and screening has improved. Today, the blood-sugar level of diabetics is monitored and controlled in far more countries, an essential way to avoid complications. The awareness of the relation between life-style, manifest through diet and obesity, and diabetes has become stronger. Patient management by devices for self-monitoring and medication is spreading, a most important step to empower individuals. Patient education is improving.

At the same time, the downside is evident: Still, a very high number of Europeans with diabetes are undiagnosed. Early detection of the disease significantly improves the chances of a complication-free future, with preserved quality of life. Detection and the following treatment is a matter of knowledge how to drive the care process. As long as important data is not systematically reported and transformed into methodology, diabetes care will remain inefficient and, at worst, haphazard.

Forming an evidence-based diabetes care system is what separates the leading Index performers from the rest. Only seven out of 30 countries have established a national diabetes registry. Half of European countries cannot provide reasonably good data of procedure indicators. Such gaps no doubt mean a huge risk of undetected, undertreated and maltreated cases.

It can be said “No data, no cure”. Good diabetes care requires an integrated healthcare system, making many professionals and functions work together. There are good examples among the top performers. The systems approach will become more and more necessary to handle complex diseases such as cancer, Alzheimer, mental disorders *etc.* Such systems are found mainly among more affluent countries. Probably money is not the key factor, but rather openness and transparency. If all players understand and respect the power of information they dare report also negative findings. The prestige of individuals and groups is not allowed to sabotage the learning process and mutual trust exists. Daily gathering and reporting of data is kept up for a higher purpose. This is a matter of democracy in the best sense. Every health care system must accept this reality to keep improving.

European diabetes care can and must deal with these challenges. Monitoring strong and weak aspects is key. Health Consumer Powerhouse is proud to contribute once again to the improved understanding of European diabetes care.

Stockholm, September 4, 2014

Johan Hjertqvist  
HCP Founder & President

## 1. Summary

### 1.1 What country provides good Diabetes Care?

The term *diabetes mellitus* includes several different metabolic disorders that all, if left untreated, result in abnormally high concentrations of a sugar called glucose in the blood. The EDI project included diabetes mellitus type 1 which occurs, with an onset frequently under age 20, when the pancreas no longer produces sufficient amounts of the hormone insulin due to the destruction of the insulin-producing beta cells of the pancreas. Diabetes mellitus type 2 ("old age diabetes"), results from *insulin resistance* and typically has an onset after age 50. The pancreas of a person with type 2 diabetes may still be producing normal or even abnormally large amounts of insulin.

Diabetes is a chronic disease; there are many characteristics common for both disease types; diabetes type 1 need to be treated by insulin and patients with type 2 are normally first treated by modifying their lifestyle, such as weight loss and exercising then with oral medication but in a later stage many of them might need to combine oral medication with insulin or just insulin alone to treat their diabetes.

Diabetes mellitus type 1 cannot be prevented. Type 1 diabetes is the result of an autoimmune process with very sudden onset. Only some people with a genetic predisposition to type 1 diabetes actually end up getting it. It may present at any age, but most typically in early life with a peak around the time of puberty. Patients need insulin therapy to survive. The increasing incidence of type 1 diabetes suggests an environmental contribution, but the role of specific factors such as viruses remains controversial. Type 1 diabetes has historically been most prevalent in populations of European origin, but is becoming more frequent in other ethnic groups. Within Europe the highest rates of childhood diabetes are found in Scandinavia and north-western Europe.

Both patient groups need similar approaches to manage and treat their disease once it is diagnosed.

Good diabetes care provision requires a number of well-implemented and coordinated programmes and actions from the health care sector and the entire society to reduce the burden of the epidemic.

In Europe there is still a very high number of undiagnosed patients. It is necessary to *detect patients* early enough to be able to treat and care for them. The earlier the diagnosis the better the options are for treatment and the possibility to prevent secondary complications.

Improving secondary outcomes makes it cost-effective to treat diabetes. Hospital stays are shortened and patients' quality of life improves. Secondary prevention begins at the first appointment with a primary care physician and carries on to the involvement of other specialists and health care professionals throughout the lifespan of this disease.

### 1.2 Characteristics of good diabetes care

There are a number of things that describe a good diabetes care system.

- A **Transparent Healthcare** system which shares information on best practice between health care providers. Their success rate is reflected by reduction in the secondary complications.
- Using a **National Standard of Diabetes care plan** agreed on by patients, health care professionals and government.
- Primary care doctors are key players to increase the number of patients detected.
- Qualified professionals like **Diabetes specialist nurses and dieticians** to optimise the process and management of the disease according to best practice plans.

- GP's, nurses and other health care providers on the primary care level need to be **well trained** and up to date with the latest treatment plan for Diabetes.
- The collaboration of a **multidisciplinary specialist teams** to care and manage diabetes and its complications.
- **Patient centred health care**, which means that care is provided with respect and sensitivity to the individual's specific needs, expectations and values, and that these are taken into account in clinical decisions.
- Patient and families need to **have access to a fully subsidised structured good quality education**. Patient education must actively empower the patient to manage his or her own disease. It must include immediate care givers of the patient community so that the patient will receive continuous psychosocial support. The goal of this education is to show people with diabetes how they can maintain well-functioning self-care with good control of risk factors for ill health, while maintaining good quality of life. In many countries, culturally adapted education programmes focussing on specific minority groups would need to be developed.
- **Timely health care** means that no patient should have to wait an unreasonable period of time for the treatment, care or help he or she needs. NB! Running a healthcare system *without* waiting times is *less costly* than having waiting times!
- **Treatment adherence** depends on good awareness of the patient to understand and accept the relevancy of good disease management. Routine visits to physicians (including nurses) as well as permanent regular contacts and feedbacks are necessary to control and review the process of the disease and make quick changes to optimize results, such as insulin dose adjustments. Insufficient counselling has been identified as the most important reason for non-compliance to diabetes-related care.
- **Access to adequate subsidized/reimbursed treatment and devices** to manage diabetes: devices like insulin pumps, continuous glucose monitoring sensors and glucose test strips.
- **Regular check-ups** to reduce secondary complications. In order to produce the best outcome in a diabetic patient's life, yearly checks of lipids, microalbuminuria, HbA1c level and feet are needed. A biennial eye exam is recommended to monitor for Diabetes retinopathy.
- **A national registry** is important to combine the efforts of a multidisciplinary team tackling diabetes. It provides long-term collection of data that will allow for comparison and sharing of information for best practice among health care providers and patients. It can centralise information and standardise a diabetes treatment plan between countries. The present data on reports in Europe is fragmented by regions, unreliable and undervalued.

<http://www.cardiosource.org/News-Media/Media-Center/News-Releases/2014/06/Diabetes-Registry-PR.aspx>

[http://ec.europa.eu/health/highlights/2012/13/short\\_content\\_en.htm](http://ec.europa.eu/health/highlights/2012/13/short_content_en.htm)

Apart from all this, there is the need of efficient prevention programs to reduce the burden in all countries from diabetes type 2 caused by increase of obesity and sedentary life style. Patients themselves need to be part of the planning process of these programmes.

## 1.3 Top performers in the Index. What are they doing well?

### 1.3.1 Sweden

The Diabetes Index 2014 shows Sweden (936 points out of a maximum possible of 1000; the highest score ever observed in a HCP Index) as the country with the best diabetes care delivery in Europe.

The secret of Swedish high performance is probably “The art of knowing what you are doing”. It is the only country out of 30 countries assessed that could provide data on all 28 indicators.

Sweden has a National diabetes registry (NDR) initiated already in 1996 by the Swedish Society of Diabetology. National guidelines for diabetes care were established in parallel in the same year and are intermittently reviewed. Data on quality indicators is also being collected. Continuous quality assessment of diabetes care is done in Sweden to provide local centres with data regarding the quality indicators of diabetes care, and also making a comparison possible with the national or regional data.<sup>1</sup>

But not only data availability brought Sweden to the top. Sweden has **strong health care structure to manage and treat diabetes**. In almost all diabetes clinics, there are specialized physicians and nurses actively involved. They are supported by other experts of different specialities forming multidisciplinary teams. However, this level is not consistent throughout the very decentralized Swedish healthcare system. Some county councils and some municipalities fall short.

Sweden’s trained diabetes nurses not only have specific university education in diabetes care, but also need an educational background such as university competence in adult learning approaches.

Regular follow-ups on patients with Type 1 and Type 2 diabetes are carried out annually on foot status, lipid levels, HbA1c level, microalbuminuria and eye examinations.

Health care providers are expected to follow a strict national standard guideline on the treatment of diabetes. Thus a majority of the Swedish patients reach their targeted goals of HbA1c < 7%. Blood cholesterol and blood pressure are frequently within the target range as well. The incidence of foot amputations is lower in Sweden compared with other countries.<sup>2</sup>

Diabetics in Sweden receive 100% subsidy for prescribed medications and monitoring equipment prescribed for diabetes<sup>3</sup>. The average rate of subsidy on other prescription drugs in Sweden is ~75%.

### 1.3.2 The Netherlands

Second in the ranking is The Netherlands at 922 points. There is no doubt that diabetes care in The Netherlands is of very high quality. Famous for having the best multidisciplinary team approach and coordinated efforts to deal with diabetes.

Primary care physicians follow the national standard so strictly that new ideas not accepted in the standard is shunned. To make diabetes care cost effective, General Physician assistants handle most of the patient traffic for diabetes. The system is effective but some have questioned the quality.

---

<sup>1</sup> SOFFIA GUDBJORNSDOTTIR et al; 2003

<sup>2</sup> Quality and efficiency of diabetes care in Sweden. National performance assessment, 2011.

<sup>3</sup> Law on Pharmacy Benefits (2002), §18, p.3.

The strict national diabetes care standard ensures that patients will receive a correct diagnosis, treatments and follow up plans. The Dutch diabetes care standard agrees with the indicators in this index and includes smoking cessation, blood pressure measurements, annual BMI measurements and quarterly visits to the doctors.

Criticism remains that the outcomes measured by the Dutch diabetes management programme are utilitarian, and there is no data on short-term Outcomes such as the number of foot amputations or even heart attacks. Significant evidence gaps in basic statistics and in treatment evidence suggest insufficient supporting incentives for critical research.<sup>4</sup>

In 2007, a bundle payment for diabetes was initiated. This led to the formation of diabetes care groups in 2010. Type 2 diabetic patients are treated in the primary care groups. Diabetic patients with more complex co-morbidities are treated in secondary care. Care in- and outside hospital is completely separated. A patient is in one system or the other. If a patient is referred to hospital the fee for the GP stops. At best, an internist/endocrinologist is attached to a primary care group for consulting.<sup>5</sup>

This change in the health care delivery system gave funding for primary care physicians to hire specialist nurses for their practice, and outcomes in general were improved. Optometrists could now do more eye examinations previously performed only by ophthalmologists. Patients are given a fixed amount of re-imburement for their medicine and the care group will cover the extra cost. This shifting of health care cost to the provider ensures that only guideline recommended medication is prescribed for the patient<sup>6</sup>.

### 1.3.3 Denmark

Third in rank is Denmark with 863. The general consensus is that diabetes care in Denmark is very high on the political agenda.

Denmark with its impressive ***quality monitoring and improvement initiatives*** has extensive databases on the processes and outcomes of care. A strong agenda exists to strengthen its information infrastructure; it can also boast many local clinical guidelines, national guidelines and standards developed as part of disease management programmes and pathways.

Denmark has a National Registry which monitors 96% of the incidence and prevalence of diagnosed diabetes in the Danish population, with three linked nationwide medical databases which include diabetes data from primary and secondary health care, and they are:

- The Danish National Patient Register, which records in- and out-patients with a diagnosis of diabetes.
- The Danish National Health Service Register which records care and services provided by primary and secondary care physicians. It also records glucose measurements and chiropody services performed.

---

<sup>4</sup> Dutch Diabetes manager programme; European healthcare innovation Leadership Network, Type 2 diabetes working group. 2011.

<sup>5</sup> Marjo JE Campmans-Kuijpers et al; 2013

<sup>6</sup> Struijs *et al*/Three years of bundled payment for diabetes care in the Netherlands, 2012.  
[www.ncbi.nlm.nih.gov/pubmed/22323174](http://www.ncbi.nlm.nih.gov/pubmed/22323174); [www.ncbi.nlm.nih.gov/pmc/articles/PMC3886599/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3886599/)

- The Danish National Prescription Registry which collects info on all antidiabetic drugs prescribed by in house physicians or General physicians and dispensed by the Danish pharmacies.<sup>7</sup>

In 2011, the software Sentinel Data Capture (SDC) was launched in Denmark. The system collects data from Danish general physicians' office in regards to the quality of care for a diabetic patient receives. It is accessible only by the physician and the patient. This programme then collects data annually on 10 key values (blood pressure, lipids, HbA1c, frequency of exercise, smoking status, BMI and waist circumference) to give a visual comparison against the patients targeted goals.. This programme has been so successful that it has been expanded to include other chronic diseases. The data collected by the Sentinel Data Capture is then used for peer review and results can be compared with the municipalities, regional or even the national average, in order to benchmark practices to improve outcomes and implementing cost effective measures.<sup>8</sup>

[www.dak-e.dk/flx/en/general-practice/sentinel-data-capture/](http://www.dak-e.dk/flx/en/general-practice/sentinel-data-capture/)

Novo Nordisk plays a big part in the treatment and care of diabetes in Denmark. They have created foundations to support the research of diabetes, diabetes centre and public awareness of diabetes.

Denmark has universal healthcare for its citizens that provides access to primary and secondary care with partial reimbursement for prescribed medications. The first access into the health care system is via the general practitioner *only*, unless the patient has a condition justifying the attention of a hospital A&E department.

Access to some devices may be quite limited, Very few people with diabetes in Denmark get continuous glucose monitors (CGMs). The same goes for insulin pumps. A few people can get sensors for a limited period of time if they have large variations in blood glucose levels.

One important issues for patients with diabetes in Demark is improvement in psychosocial support. The access to psychologists or group sessions is very limited and most people in need end up paying out-of-pocket.

### 1.3.4 UK

Fourth in rank is the UK with 812 points.

The United Kingdom *in lieu* of a national registry has a National Diabetes Audit for England and Wales and a Scottish Diabetes Survey. Their data is annually updated with open access for the public. Whereas Northern Ireland have yet to develop a national registry. A Separate audit of paediatric diabetes is done for England and Wales by the Royal College of paediatric and child health. These audits collect information on the outcomes of diabetes care based on the national standard framework (NSF) and the management of diabetes based on the national institute for Health and Clinical Excellence (NICE). [www.rcpch.ac.uk/child-health/standards-care/clinical-audit-and-quality-improvement/national-paediatric-diabetes-au-1](http://www.rcpch.ac.uk/child-health/standards-care/clinical-audit-and-quality-improvement/national-paediatric-diabetes-au-1)

The National Institute for Health and Clinical Excellence (NICE) has designed clear pathway guidelines for the management of Type 1, Type 2 and gestational diabetes mellitus. It gives clear instructions on prevention and management of diabetes. Those are regularly updated and reviewed. They include innovative and new ideas to treat both Type 1 and Type 2 diabetes.

---

<sup>7</sup> Thomsen et al; 2012

<sup>8</sup> Improving the quality of diabetes care in Denmark; Sentinel data capture. 2012

[www.nice.org.uk/Guidance/Conditions-and-diseases/Diabetes-and-other-endocrinal--nutritional-and-metabolic-conditions/Diabetes](http://www.nice.org.uk/Guidance/Conditions-and-diseases/Diabetes-and-other-endocrinal--nutritional-and-metabolic-conditions/Diabetes)

The government in the UK is very aware of the burden of diabetes on society. They have implemented national policies to reduce obesity and improve diet as well as helping young children to get a healthy start at life. Reality, unfortunately, has been proving resilient – the UK still has rather severe obesity and dietary habit problems. NHS England itself has established action plans for diabetes to integrate their systems for better management of type 2 diabetes in primary care settings on top of the guidelines provided by NICE.

[www.nao.org.uk/wp-content/uploads/2012/06/1213192es.pdf](http://www.nao.org.uk/wp-content/uploads/2012/06/1213192es.pdf)

[www.england.nhs.uk/2014/01/10/tackling-diabetes-2014/](http://www.england.nhs.uk/2014/01/10/tackling-diabetes-2014/)

[www.england.nhs.uk/ourwork/qual-clin-lead/action-for-diabetes/](http://www.england.nhs.uk/ourwork/qual-clin-lead/action-for-diabetes/)

[www.england.nhs.uk/wp-content/uploads/2014/01/act-for-diabetes-31-01.pdf](http://www.england.nhs.uk/wp-content/uploads/2014/01/act-for-diabetes-31-01.pdf)

Additional organisations like National Cardiovascular Intelligence Network (NCVIN) and National Diabetes Information Service (NDIS) have been created to further provide data, tools and information for health care providers to improve services.

However there are great variations of outcomes and services between the 4 nations of the UK, and also between regions of England. Even within the small counties in England, health care will vary. Some Diabetes patients are not even receiving the basic care recommended by NICE. Despite these variations, recent reports have shown that the 4 nations are closing their performance gaps.

<http://rcnpublishing.com/doi/abs/10.7748/phc2012.07.22.6.4.p8805>

[www.rightcare.nhs.uk/index.php/atlas/diabetes](http://www.rightcare.nhs.uk/index.php/atlas/diabetes)

<https://docs.google.com/a/healthpowerhouse.com/file/d/0B8ePB71diJorc2ISVmFibEVIVGM/edit?pli=1>

[www.nuffieldtrust.org.uk/our-work/projects/funding-and-performance-health-care-systems-four-countries-uk](http://www.nuffieldtrust.org.uk/our-work/projects/funding-and-performance-health-care-systems-four-countries-uk)

[www.diabetes.org.uk/documents/reports/state-of-the-nation-2012.pdf](http://www.diabetes.org.uk/documents/reports/state-of-the-nation-2012.pdf)

[www.pulsetoday.co.uk/clinical/therapy-areas/diabetes/huge-variation-in-quality-of-diabetes-care-audit-finds/20004921.article#.VANU\\_GSSwu8](http://www.pulsetoday.co.uk/clinical/therapy-areas/diabetes/huge-variation-in-quality-of-diabetes-care-audit-finds/20004921.article#.VANU_GSSwu8)

[www.diabetes.org.uk/Professionals/Service-improvement/National-Diabetes-Audit/NDA-reports/](http://www.diabetes.org.uk/Professionals/Service-improvement/National-Diabetes-Audit/NDA-reports/)

[www.rightcare.nhs.uk/index.php/atlas/diabetes](http://www.rightcare.nhs.uk/index.php/atlas/diabetes)

### 1.3.5 Switzerland

5<sup>th</sup> in the ranking is Switzerland with 799 points.

Switzerland with its model example of a universal health system just made it into the top 5 of the country ranking, narrowly beating Slovenia. All Swiss citizens must purchase compulsory health insurance and pay a high deductible and co-payment of 10% with a limit set by the federal government. The insurer covers all extra costs. The insurance plan premium cost the same for all patients regardless of their health status. This cost will vary between the different 26 cantons

in Switzerland. Health care in Switzerland is highly decentralised; this means that there is no equal quality of services provided in hospitals controlled by the different cantons.<sup>9</sup>

There is no doubt that Switzerland has good quality healthcare and that its citizens benefit from a high quality of life. Patients are free to visit a GP of their choice and also to seek specialist consultations without referral from a primary care doctor. Diabetes patients in Switzerland have the necessary equipment to monitor and control their diabetes. In January of 2013 Switzerland implemented a new national strategy called 'Health 2020' to improve the prevention and screening of non-communicable diseases.<sup>10</sup>

Even with all these benefits, experts have noted that it has been difficult to collect epidemiological and statistical data on health in Switzerland. The routine care required for diabetes management is regularly performed. However other screening for co-morbidities of like foot ulcers, diabetes retinopathy and kidney functions are severely lacking for such a reputable health system. There are gaps in some of the indicators for Switzerland. This is mainly due to the lack of uniformity data collection from the various cantons in a very decentralised system, or that the data available comes from a small study group of patients. This lack of data limits comparison of systems and promoting best practices in the country.<sup>1112</sup>

[www.itup.org/Reports/Fresh%20Thinking/Switzerland.pdf](http://www.itup.org/Reports/Fresh%20Thinking/Switzerland.pdf)

Experts agree that Switzerland has much room to improve on the quality of care and disease management for Diabetes. It has been recommended that Switzerland create databases and regular surveys of the various cantons to modify the health inequalities that exist. Coordination between the federal and health levels needs to be strengthened and the Swiss e-Health strategy implemented.<sup>1314</sup>

[www.e-health-suisse.ch/index.html?lang=en](http://www.e-health-suisse.ch/index.html?lang=en)

## 2. Areas for improvement

The overall impression is that diabetes care has improved over the years. Some countries have extremely good quality services and care delivery. In general, countries are aware of the necessity of implementing measurements to tackle the problem, particularly because of the burden of increasing diabetes prevalence and the cost that this disease represents.

It is important to note that *in spite of increasing diabetes incidence*, the death rates from diabetes has been steadily *decreasing* in almost all countries, also right through the "financial crisis" (see Table 2.1)!

---

<sup>9</sup> Claire Daley and James Gubb; 2013

<sup>10</sup> Thomson L; 2013

<sup>11</sup> Peytremann-Bridevaux et al; 2013

<sup>12</sup> *Switzerland: Health Care Systems in Transition*, The European Observatory on Health Care Systems, 2000

<sup>13</sup> OECD/WHO (2011), *OECD Reviews of Health Systems: Switzerland 2011*, OECD Publishing.

<http://dx.doi.org/10.1787/9789264120914-en>

<sup>14</sup> Lovis C et al; 2012

SDR, diabetes, all ages, per 100 000		
Source: WHO HfA April 2014		
	2006, or 6 years previously	2012/latest available
Austria	28.01	18.62
Belgium	10.13	8.33
Bulgaria	18.72	13.17
Croatia	17.27	18.44
Cyprus	38.99	33.01
Czech Republic	10.68	14.25
Denmark	16.82	15.40
Estonia	12.80	8.13
Finland	7.02	5.57
France	11.24	9.12
Germany	15.07	13.82
Greece	7.22	5.58
Hungary	21.93	18.42
Ireland	11.07	9.52
Italy	17.50	15.76
Latvia	8.86	14.17
Lithuania	8.13	6.21
Luxembourg	9.05	7.63
Malta	24.30	6.97
Netherlands	16.56	10.31
Norway	10.71	9.11
Poland	13.12	12.95
Portugal	25.70	22.31
Romania	8.41	8.66
Slovakia	13.00	10.28
Slovenia	23.09	7.75
Spain	13.82	10.99
Sweden	12.08	10.75
Switzerland	12.44	8.71
United Kingdom	7.36	5.86
EU	13.63	11.61

**Table 2.1** SDR (all ages) from diabetes 2012 and six years earlier. Source: WHO HfA database, April 2014.

In the mid-1980's, a country such as Malta had a 3-digit SDR from diabetes!

## 2.1 Prevention

European data on obesity shows a very worrying situation with several countries having more than 25 % of the adult population considered to be obese (BMI >30). Additionally, there is an increased number of children of early age becoming either obese or overweight.

Looking into the data collected it seems clear that in general, countries are far from having efficient prevention or healthier life promotion programs even when it has been demonstrated that these are cost-effective.

Physical exercise is a changing concept. Previously, it was integrated with everyday life, and there was almost no option for being sedentary. Today, green areas, playgrounds, parks, bike pathways

and areas that allow all kind of activities are more and more frequent to find, even in poor suburbs.

Still, governments should focus on promoting physical activity in a number of settings; *e.g.* at school so kids learn from early ages to move and to have fun through different physical activities. Also important, as age is a marked risk factor for developing type 2 diabetes, for societies with an aging population to promote physical activity in day care center and elderly care homes.

There is an increased number of people consuming cheap food, high in fat, salt and calories. Consumption of fruit and vegetables is insufficient almost in all countries in Europe, with the possible exception of Greece and a few other Mediterranean countries.

There are very different approaches to the problem, on one hand, in the central and north part of Europe, with more active intervention promoting healthy food intake in kindergarten and schools, among migrant communities or housing for the elderly.

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

Health promotion from primary care health workers, community workers, teachers and educators can bring a major impact into society because of their regular contact with patients, elderly people, children and all kinds of individuals. They have good opportunity to induce healthy habits into the community.

## 2.2 Access to testing

Healthcare workers in primary care need to be aware and trained to understand the importance of diabetes early detection. General practitioners and nurses are essential key players for improving case finding.

**Case finding and Screening should be done in a more systematic way for risk populations to reduce undiagnosed patients.** There is a need in Europe of clear definition of risk groups to be tested, and for GP's to understand who should be tested. At the moment screening seems very much dependent on physicians' discretion.

The general public should be more aware about the diabetes problem, and the main risk factors from diabetes and other chronically diseases. Mass campaigns, schools or work could be used as good points to improve knowledge among general public.

It also seems obvious that for good coverage of screening, people need a mild form of prompting such as an invitation letter. Countries such as Germany, with very easily accessible screening but no active invitation system, have less good coverage than some traditional "waiting list" territories, where patients are actively invited to screening.

## 2.3 Access to care and Treatment

As a chronic disease, diabetes patients need good access to care and treatment to reduce the burden of secondary complication and also to improve their quality of life.

**Access to patient education:** Diabetes patients need to take many decisions per day regarding self-management of their own disease. It is very important to empower these patients to be able to take informed decisions. Therefore, continuous high-quality patient education is important. It was disappointing to see that patient education is a lottery in most of countries. To receive good education depends very much where patients get treated.

**Treatment adherence:** Lack of patient adherence to medication regimens is a significant problem in the management of diabetes. There are several publications describing better adherence to be associated with improved glycaemic control and decreased health care resource utilization. Unfortunately, adherence is found to be poor especially in primary care. Provision of information about the treatment, a regular contact with a health care worker and an increased number of follow ups with patients and families, would reduce the problem<sup>15,16,17</sup>.

In general, patients treated in primary care are those with worse outcomes. This underlines the necessity of primary care doctors and nurses as well as other health care workers in primary care to get proper **training** to monitor diabetes, to educate patients etc.

**Access to medical devices to manage diabetes.** Frequent self-monitoring of blood glucose is necessary to achieve tight glycaemic control in patients with diabetes mellitus, particularly for those requiring insulin therapy<sup>18</sup>. The situation in Europe is quite alarming on this point. If systems do not provide enough help for these patients to properly manage their disease, outcomes will improve much more slowly.

Access to test strips for glucose level monitoring is essential for patients on insulin, both type 1 and type 2. Almost half of countries *do not* reimburse for sufficient test strips to help insulin-dependent patients to monitor their blood glucose so that insulin doses can be adjusted. This means that in most cases, patients have to pay privately or be monitoring their blood glucose less frequently, risking episodes of hyper- or hypoglycaemia.

The use of **Insulin pumps** for diabetes type 1 patients remains currently limited in many European countries, and well behind that in the United States. The main reason is the late approval of cost coverage by most national healthcare insurance systems, and the number of trained physicians to introduce the use of pump therapy to the patients. Nevertheless, pump use is increasing, particularly in paediatric age populations during recent years, following evidence-based demonstrations of the benefits of pump therapy for these patients leading to an international consensus on pump indications and practice<sup>19,20</sup>.

**Continuous Glucose Monitoring (CGM) systems** for type 1 diabetes is a methodology that could represent great improvement for patients, but it remains very limited. The use of CGM is not common practice and its reimbursement status is a point of debate in many countries<sup>21,22</sup>.

In general for the community, the benefits and the limitations of using CGM are still not clear. Many health officials have been expressing their interest in the technology and they were welcoming new advances. Hopefully, many more patients can benefit from this technology over the coming years.

**Special footwear is provided** almost everywhere, but with restrictions. Most countries provide one pair of shoes per year per patient, and for any extra pair is need strong co-payments or total pay. In case of children that is particularly too little.

**Drug consumption:** Formal reimbursement regulations give the impression that access to diabetes drugs in Europe is very similar everywhere. Actual prevalence-adjusted numbers on

---

<sup>15</sup> Alan M. Delamater; 2007

<sup>16</sup> Anderson RM *et al*; 2002

<sup>17</sup> Anderson BJ *et al*; 2002

<sup>18</sup> Farmer *et al.*, 2007 and Klonoff, 2007.

<sup>19</sup> Renard E; 2010

<sup>20</sup> Hammond, P; 2013

<sup>21</sup> [Cochrane Database Syst Rev](#). 2012 Jan 18;1:CD008101. doi: 10.1002/14651858

<sup>22</sup> [Langendam M](#) *et al*, 2012.

deployment of some of these drugs show that obviously the use of these medicaments differ very much among countries without any medical explanation. Eventually it could be worth a stronger recommendation within national guidelines. To standardize process and enable comparison of long-term outcome studies from different countries it could be suggested European guidelines to homogenize the national procedures. *E.g.*, metformin is regarded as a cost-efficient first-line medication to treat type 2 diabetes. However, in some countries it is under-prescribed. This phenomenon shows no obvious correlation with monetary factors.

**Coordination of care;** A good illustration is provided by comparing care delivery of Ireland (20<sup>th</sup> in the EDI) and the UK (4<sup>th</sup>). In Ireland, care is delivered in a variety of ways to patients with diabetes including traditional mixed care, hospital-led care, shared care arrangements and primary care-led management. At GP level, care is often ad-hoc reflected by the absence of patient registries, irregular review and the lack of guideline use among GP's<sup>23</sup>. Access to essential support is variable and inconsistent with multiple providers of services, often influenced by whether a patient is attending the public or private health system. In England and Wales, diabetes care delivery is supported by an infrastructure including a dedicated policy framework, screening programmes, robust IT systems in general practice and a financial incentive structure to promote quality assurance as well as an annual audit that measures the effectiveness of diabetes healthcare against NICE Clinical Guidelines and NICE Quality Standards.

## 2.4 Registry data: European diabetes register

In general, good availability of quality data is rare in Europe. Data is often not collected nationally, but rather only in some hospital or region. In addition to this problem, there are limitations in the comparability of some of the data collected. Data on process and outcomes indicators often comes from large national projects or studies. Frequently, data is collected only intermittently and not necessarily representing the whole country.

A number of countries recognized the importance of measure performance and they have established a diabetes National registry, the latest being Norway.

Some years ago there was a good initiative, which unfortunately seems to have ended up in someone's drawer. It was called the EUBIROD. In the pilot phase, information on a large number of indicators would be collected using uniform definitions in single institutions in a rather large number of countries. After some years and a significant amount of European money invested in the project the data never saw the light for political reasons. A good example to illustrate what happened is the project in Cyprus; In this project there was one hospital participating from Cyprus. When that started back in 2007 as a partner of the BIRO project, the first part of the EUBIROD, the Ministry announced that the particular method of data collection they were using, if proven to be successful will be used by all who look after people with diabetes on the island. The process and outcomes indicators in that hospital had been improving year per year until today and it is the only data available in the whole island. Unfortunately, there is no active firm policy and strategic plan in place for diabetes in the ministry. With each new government that comes and goes and depending on the personal interests and disciplines of the people in charge at any given time, projects that have started and proven to be successful may be allowed to fall by the wayside.

---

<sup>23</sup> Mc Hugh S et al; 2011

### 3. Results in Euro Diabetes Index 2014

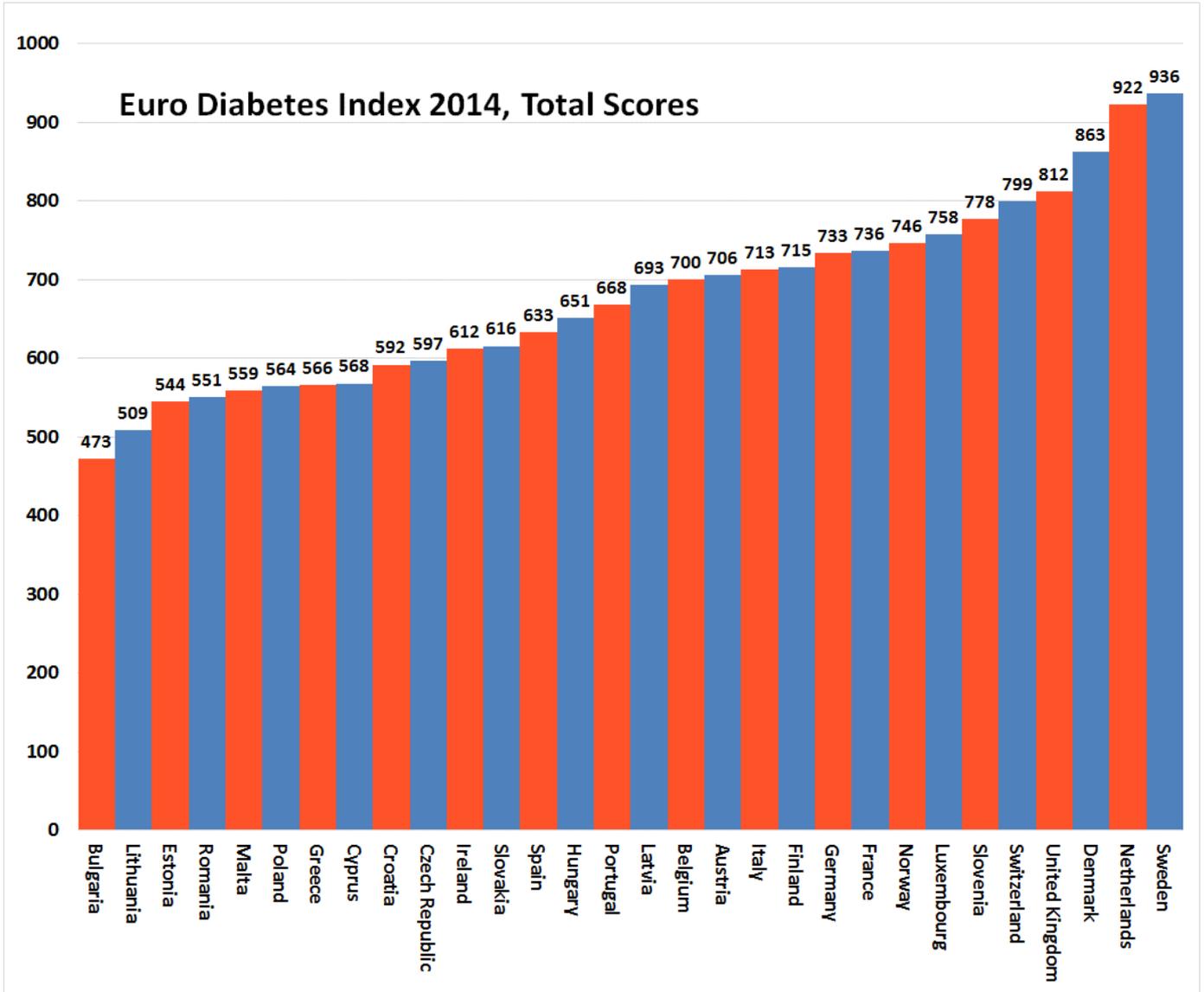
## Euro Diabetes Index 2014

Sub-discipline	Indicator	Austria	Belgium	Bulgaria	Croatia	Cyprus	Czech Republic	Denmark	Estonia	Finland	France	Germany	Greece	Hungary	Ireland	Italy
1. Prevention	1.1 Prevalence of obesity in adults	👍	👍	👍	👍	👎	👎	👍	👍	👍	👍	👍	👍	👎	👎	👍
	1.2 Exercise in compulsory school	👍	👍	👎	👎	👎	👎	👍	👎	👎	👍	👍	👎	👎	👎	👎
	1.3 Bicycle usage	👍	👍	👎	n.a.	👎	👍	👍	👎	👎	👍	👍	👎	👎	👎	👎
	1.4 Consumption of soft drinks	👎	👎	👍	n.a.	👍	👎	👍	👍	👍	👍	👎	👍	👍	👍	👍
	1.5 Fruit/vegetable consumption	👍	👍	👎	👍	👍	👎	👍	👎	👎	👍	👎	👍	👍	👍	👍
	1.6 Raised blood pressure among adults	👍	👍	👎	👎	👍	👎	👍	👎	👎	👍	👍	👍	👎	👍	👍
	<b>Subdiscipline weighted score</b>	<b>126</b>	<b>126</b>	<b>78</b>	<b>78</b>	<b>107</b>	<b>68</b>	<b>146</b>	<b>88</b>	<b>107</b>	<b>146</b>	<b>107</b>	<b>136</b>	<b>126</b>	<b>88</b>	<b>146</b>
2. Case finding	2.1 Diabetes registry	👎	👎	👎	👍	👎	👍	👍	👎	👍	👍	👍	👎	👍	👍	👍
	2.2 Screening for gestational diabetes	👍	👍	👎	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	<b>Subdiscipline weighted score</b>	<b>33</b>	<b>33</b>	<b>17</b>	<b>50</b>	<b>25</b>	<b>42</b>	<b>50</b>	<b>33</b>	<b>42</b>	<b>42</b>	<b>42</b>	<b>33</b>	<b>50</b>	<b>33</b>	<b>42</b>
3. Range and reach of services	3.1 Special footwear	👍	👍	👎	👍	👎	👍	👍	👎	👍	👍	👍	👍	👍	👎	👍
	3.2 Podiatric care	👍	👍	👎	👎	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	3.3 Eye care	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	3.4 Metformin deployment	👎	👍	👍	👍	n.a.	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	<b>Subdiscipline weighted score</b>	<b>146</b>	<b>160</b>	<b>102</b>	<b>117</b>	<b>117</b>	<b>160</b>	<b>146</b>	<b>131</b>	<b>160</b>	<b>146</b>	<b>131</b>	<b>117</b>	<b>146</b>	<b>117</b>	<b>146</b>
4. Access to treatment/care	4.1 Insulin pump therapy for DM T1	👍	👍	👎	👎	👎	👍	👍	👎	👍	👍	👍	👍	👍	👍	👍
	4.2 CGM (Continuous glucose monitoring)	👍	👎	👎	👍	👍	👍	👍	👍	👍	👎	👍	👎	👎	👍	👍
	4.3 Test strips for people on Insulin DM1	👍	👍	👎	👍	👍	👎	👍	👎	👍	👍	👍	👍	👍	👍	👍
	4.4 Test strips for people on Insulin DM2	👍	👍	👎	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	4.5 Access to patient education	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍
	<b>Subdiscipline weighted score</b>	<b>173</b>	<b>147</b>	<b>80</b>	<b>120</b>	<b>147</b>	<b>120</b>	<b>173</b>	<b>107</b>	<b>187</b>	<b>160</b>	<b>187</b>	<b>120</b>	<b>120</b>	<b>187</b>	<b>133</b>
5. Procedures	5.1 Annual HbA1c test	n.a.	👍	n.a.	👍	n.a.	n.a.	👍	n.a.	👍	👍	👍	n.a.	👍	n.a.	👍
	5.2 Annual foot examination	n.a.	n.a.	n.a.	👎	n.a.	n.a.	👍	n.a.	n.a.	👍	👍	n.a.	👍	n.a.	👎
	5.3 Annual microalbuminuria check	n.a.	👎	n.a.	👎	n.a.	n.a.	👍	n.a.	n.a.	👎	👍	n.a.	👎	n.a.	👎
	5.4 Annual blood lipid levels test	n.a.	👍	n.a.	👍	n.a.	n.a.	👍	n.a.	n.a.	👍	👍	n.a.	👍	n.a.	👍
	5.5 Biennial eye examination	n.a.	n.a.	n.a.	👎	n.a.	n.a.	👍	n.a.	n.a.	👍	👎	n.a.	👍	n.a.	👎
	5.6 Waiting time for eye operation	👍	👍	👍	👎	👍	👍	👍	👍	👍	👎	👍	👍	n.a.	👍	👍
	5.7 Waiting time for patient education	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	👍	n.a.	👎	👍
	<b>Subdiscipline weighted score</b>	<b>144</b>	<b>170</b>	<b>144</b>	<b>144</b>	<b>131</b>	<b>144</b>	<b>275</b>	<b>144</b>	<b>157</b>	<b>170</b>	<b>183</b>	<b>118</b>	<b>157</b>	<b>105</b>	<b>183</b>
6. Outcomes	6.1 Incidence of renal replacement therapy	👎	👎	n.a.	👎	n.a.	n.a.	👍	n.a.	👍	👎	n.a.	👎	n.a.	n.a.	n.a.
	6.2 Foot amputation incidence	👎	👎	n.a.	👎	n.a.	👎	n.a.	n.a.	👎	👍	n.a.	n.a.	👎	👍	👍
	6.3 % of patients with HbA1c > 7%	👍	👍	👍	👍	n.a.	n.a.	👍	n.a.	👍	👍	👍	n.a.	👍	👍	👎
	6.4 Recorded prevalence of blindness among diabetics	👍	n.a.	n.a.	👍	n.a.	👍	n.a.	n.a.	n.a.	n.a.	👍	n.a.	n.a.	👍	n.a.
	<b>Subdiscipline weighted score</b>	<b>83</b>	<b>63</b>	<b>52</b>	<b>83</b>	<b>42</b>	<b>63</b>	<b>73</b>	<b>42</b>	<b>63</b>	<b>73</b>	<b>83</b>	<b>42</b>	<b>52</b>	<b>83</b>	<b>63</b>
<b>Total score</b>	<b>706</b>	<b>700</b>	<b>473</b>	<b>592</b>	<b>568</b>	<b>597</b>	<b>863</b>	<b>544</b>	<b>715</b>	<b>736</b>	<b>733</b>	<b>566</b>	<b>651</b>	<b>612</b>	<b>713</b>	
<b>Rank</b>	<b>13</b>	<b>14</b>	<b>30</b>	<b>22</b>	<b>23</b>	<b>21</b>	<b>3</b>	<b>28</b>	<b>11</b>	<b>9</b>	<b>10</b>	<b>24</b>	<b>17</b>	<b>20</b>	<b>12</b>	

# Euro Diabetes Index 2014

Sub-discipline	Indicator	Latvia	Lithuania	Luxembourg	Malta	Netherlands	Norway	Poland	Portugal	Romania	Slovakia	Slovenia	Spain	Sweden	Switzerland	United Kingdom	
1. Prevention	1.1 Prevalence of obesity in adults																
	1.2 Exercise in compulsory school																
	1.3 Bicycle usage						n.a.								n.a.		
	1.4 Consumption of soft drinks			n.a.	n.a.		n.a.									n.a.	
	1.5 Fruit/vegetable consumption																
	1.6 Raised blood pressure among adults																
	<b>Subdiscipline weighted score</b>	97	78	117	88	126	97	97	136	107	78	107	97	136	126	107	
2. Case finding	2.1 Diabetes registry																
	2.2 Screening for gestational diabetes																
	<b>Subdiscipline weighted score</b>	42	33	42	25	42	50	42	42	25	42	42	42	50	42	42	
3. Range and reach of services	3.1 Special footwear																
	3.2 Podiatric care																
	3.3 Eye care																
	3.4 Metformin deployment				n.a.												
	<b>Subdiscipline weighted score</b>	131	131	146	131	175	146	146	117	117	146	131	131	160	146	160	
4. Access to treatment/care	4.1 Insulin pump therapy for DM T1																
	4.2 CGM (Continuous glucose monitoring)																
	4.3 Test strips for people on Insulin DM1																
	4.4 Test strips for people on Insulin DM2																
	4.5 Access to patient education																
	<b>Subdiscipline weighted score</b>	120	107	200	80	200	187	120	107	80	133	173	120	200	200	160	
5. Procedures	5.1 Annual HbA1c test		n.a.				n.a.	n.a.			n.a.						
	5.2 Annual foot examination		n.a.	n.a.				n.a.			n.a.		n.a.				
	5.3 Annual microalbuminuria check		n.a.		n.a.			n.a.			n.a.						
	5.4 Annual blood lipid levels test		n.a.					n.a.			n.a.						
	5.5 Biennial eye examination		n.a.		n.a.			n.a.	n.a.		n.a.		n.a.				
	5.6 Waiting time for eye operation															n.a.	
	5.7 Waiting time for patient education																
	<b>Subdiscipline weighted score</b>	210	118	170	183	275	183	118	183	170	144	262	170	275	223	249	
6. Outcomes	6.1 Incidence of renal replacement therapy		n.a.	n.a.	n.a.			n.a.	n.a.	n.a.	n.a.				n.a.		
	6.2 Foot amputation incidence		n.a.			n.a.	n.a.	n.a.			n.a.				n.a.		
	6.3 % of patients with HbA1c > 7%		n.a.					n.a.				n.a.					
	6.4 Recorded prevalence of blindness among diabetics	n.a.	n.a.	n.a.	n.a.		n.a.	n.a.	n.a.	n.a.		n.a.	n.a.		n.a.	n.a.	
	<b>Subdiscipline weighted score</b>	94	42	83	52	104	83	42	83	52	73	63	73	115	63	94	
<b>Total score</b>		693	509	758	559	922	746	564	668	551	616	778	633	936	799	812	
<b>Rank</b>		15	29	7	26	2	8	25	16	27	19	6	18	1	5	4	

### 3.1 Total scores and ranking in Euro Diabetes Index 2014



**Graph 3.1** Total scores and country ranks in EDI 2014.

### 3.2 Results in “Hexathlon”

The EDI 2014 is made up of six sub-disciplines. As no country excels across all aspects of measuring a healthcare system, it can therefore be of interest to study how the 30 countries rank in each of the five parts of the “hexathlon”. The scores within each sub-discipline are summarized in the following table:

Sub-discipline	Austria	Belgium	Bulgaria	Croatia	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
<b>1. Prevention</b>	126	126	78	78	107	68	146	88	107	146	107	136	126	88	146	97	78	117	88	126	97	97	136	107	78	107	97	136	126	107
<b>2. Case finding</b>	33	33	17	50	25	42	50	33	42	42	42	33	50	33	42	42	33	42	25	42	50	42	42	25	42	42	42	50	42	42
<b>3. Range and reach of services</b>	146	160	102	117	117	160	146	131	160	146	131	117	146	117	146	131	131	146	131	175	146	146	117	117	146	131	131	160	146	160
<b>4. Access to treatment/care</b>	173	147	80	120	147	120	173	107	187	160	187	120	120	187	133	120	107	200	80	200	187	120	107	80	133	173	120	200	200	160
<b>5. Procedures</b>	144	170	144	144	131	144	275	144	157	170	183	118	157	105	183	210	118	170	183	275	183	118	183	170	144	262	170	275	223	249
<b>6. Outcomes</b>	83	63	52	83	42	63	73	42	63	73	83	42	52	83	63	94	42	83	52	104	83	42	83	52	73	63	73	115	63	94
<b>Total score</b>	706	700	473	592	568	597	863	544	715	736	733	566	651	612	713	693	509	758	559	922	746	564	668	551	616	778	633	936	799	812
<b>Rank</b>	13	14	30	22	23	21	3	28	11	9	10	24	17	20	12	15	29	7	26	2	8	25	16	27	19	6	18	1	5	4

As the table indicates, the total top position of the Swedish healthcare system is to a great extent “We know what we are doing”. Sweden is the only country not having a “not available” on any indicator, presumably thanks to having had a National Diabetes Registry for almost 20 years. The “traditional” two top countries in HCP Indices The Netherlands and Denmark end up 2<sup>nd</sup> and 3<sup>rd</sup>.

936 is the highest score observed in any HCP Index. Also the NL score of 922 is higher than any previously seen.

Sub-discipline	Top country/countries	Top Scores	Maximum score
<b>1. Prevention</b>	Denmark, France, Italy	146	175
<b>2. Case finding</b>	Croatia, Denmark, Hungary, Norway, Sweden	50	50
<b>3. Range and reach of services</b>	Netherlands	175	175
<b>4. Access</b>	Luxembourg, Netherlands, Sweden, Switzerland	200	200
<b>5. Procedures</b>	Sweden	275	275
<b>6. Outcomes</b>	Sweden	115	125

## 4. Background

### 4.1 General information on Diabetes

The European Diabetes Leadership Forum in Copenhagen conducted by The OECD on 2013 declared diabetes to be not just a chronic disease but an epidemic.

In 2013, The IDF diabetes Atlas, 6<sup>th</sup> edition, stated that 382 million people in the world are living with diabetes. 46% out of those patients are undiagnosed.

Undiagnosed diabetes can lead to long-term health damage. There are 56.3 Million people with diabetes in Europe alone, with a projected increase of 22% to 68.9 million in 2035. Europe also has the highest prevalence and high incidence of newly diagnosed children with Type 1 Diabetes<sup>24</sup>.

Diabetes is a chronic disease that occurs when the pancreas does not produce sufficient insulin or when the body does not use insulin efficiently for its needs. The hormone insulin is required to control blood glucose, which circulates in cells and gives us energy. Blood glucose must always be at equilibrium to the needs of the body. High blood sugar (Hyperglycaemia) is the result of uncontrolled Diabetes. Over time, this hyperglycaemic state along with increased lipid levels and raised blood pressure will eventually lead to heart disease, kidney failure, blindness, diabetic foot, nerve damages, strokes and eventually early death. 50% of all diabetics have heart disease and nerve damage. 10% of them have problems with their vision and finally 10 – 20 % have kidney disease<sup>25</sup>. 28% of mortality in Europe for people less than 60 years old is a result of uncontrolled Diabetes.

There are three common forms of Diabetes. Type 1, is when the pancreas produces no insulin. Type 2, the most common form, is when the body uses the insulin inefficiently (insulin resistance) or there is a reduction in the production of insulin. Third, Gestational Diabetes that occurs in pregnant women in the later stages of pregnancy as the pregnancy hormones increases insulin resistance leading to hyperglycaemia. 2 – 6 % of pregnant women in Europe will develop gestational diabetes. Uncontrolled gestational diabetes results in oversize babies who can complicate the birthing process and potentially lead to Type 2 diabetes in mother and child later in life.

Diabetes has a large economic burden on society. It costs Europe EUR 100 – 150 billion annually to manage and treat diabetes. The true cost of diabetes is unknown, as productivity loss is also not precisely calculated. However, there are wide variations between the regions of Europe on diabetes spending. People who are at a social and economic disadvantage are most affected by diabetes. There is also the psychosocial affect that diabetes has on its victims. 37% of diabetic patients express that they feel emotionally distressed and 17% also complain of depression and discrimination caused by this diagnosis. Diabetes and other chronic diseases combined are the cause of 86% of deaths in Europe.

Complications from diabetes are rising as health systems struggle to cope with this epidemic. Diabetic ketoacidosis incidences are increasing in children who suffer from Type 1 diabetes and blindness is increasing among Type 2 diabetics. All these are preventable by patient awareness and active screening to lower prevalence rates. Hypoglycaemia, when blood sugars are low, occurs when patients have injected too much insulin. This is also a complication of diabetes which is underreported. The use of insulin pumps and continuous glucose monitoring can reduce the risk of these incidences.

Diabetes and other chronic diseases share the same risk factors: high blood pressure, obesity, low consumption of fruits and vegetable, smoking, alcohol intake, elevated cholesterol and a

---

<sup>24</sup> Diabetes Atlas 6th edition; 2013

<sup>25</sup> Diabetes leadership forum 2014

sedentary lifestyle. These risk factors are all modifiable. Other risk factors like age, and ethnicity cannot be changed. One factor that affects Europe specifically with regard to diabetes is its aging factor. As the population ages the number of people at risk for diabetes also increases.

At the 2011 United Nations Political declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases, governments agree to reduce risk factors and create health-promoting environment, strengthen national policies and health care systems. There was a compromise to give priority to detection, monitoring, diagnosis prevention and control of chronic disease, which includes diabetes.

[http://www.un.org/ga/search/view\\_doc.asp?symbol=A/66/L.1](http://www.un.org/ga/search/view_doc.asp?symbol=A/66/L.1)

In March 2012 the EU parliament agreed on a targeted EU strategy on diabetes prevention, diagnosis, management, education and research, and on EU governments to develop and implement national programmes. Since then, there is still a struggle to implement a standard of practice at national and regional levels in the EU.

At the last European Diabetes Leadership forum in Brussels 2014, strategies to achieve proper diabetes care and management were suggested. The meeting agreed on a health care system that involves multidisciplinary teams, not only patient centered but also focussing on secondary prevention of complications of diabetes. Patients themselves must lead the way to combat diabetes by being proactive. Countries need to provide diabetic patients with education as awareness can improve diabetes outcomes. It was suggested that patient organisations should be involved when policies are created to assist in better outcomes for patients. EU countries themselves need to unify the implementation of their plan at regional and national level. Finally, a re-emphasis towards transparent cooperation in sharing of information across borders so that together Europe can learn what works best in combating this diabetes epidemic.

## 4.2 Background of the Health Consumer Powerhouse

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

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

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

- The first edition of Canada Health Consumer Index was released in September 2008 in co-operation with Frontier Centre for Public Policy, examining healthcare from the perspective of the consumer at the provincial level, and repeated 2009 and 2010.
- In January 2008, the Frontier Centre and HCP released the first Euro-Canada Health Consumer Index, which compared the health care systems in Canada and 29 European countries. The 2009 edition was released in May 2009.
- The Euro Consumer Heart Index, launched in July 2008, compares 29 European cardiovascular healthcare systems on five sub-disciplines, covering 28 performance indicators.

- The Euro Consumer Diabetes Index, launched in September 2008, provided the first ranking of European diabetes healthcare services across five key areas: Information, Consumer Rights and Choice; Generosity, Prevention; Access to Procedures and Outcomes.
- Other Indexes published include the Euro HIV Index 2009, the Euro Headache Index 2012, the Euro Hepatitis Index 2012 and the Euro Pancreatic Cancer Index 2014. The 2013 Euro Vision Scorecard represents a more limited, highly targeted comparison.
- The most recent edition of the Euro Health Consumer Index (2013) covers 48 healthcare performance indicators for 35 countries.

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

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

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

### 4.3 Index scope

The aim has been to select a limited number of indicators, grouped in sub-disciplines, which in combination can present a tale of how healthcare is being served by the respective national systems.

### 4.4 About the authors

Project Director for the EDI 2014 was executed by **Beatriz Cebolla, Ph.D.**

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

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

During 2013, she participated as a consultant in two key initiatives; the Blue Print project run by the European Liver Patient Association (ELPA) and World Hepatitis Alliance (WHA) to create a website where any country can design their own viral hepatitis National strategy. The second initiative studied the barriers encountered for hepatitis treatment in Europe, the results of which are about to be submitted to a peer-reviewed journal.

Previously she was working as a researcher (Molecular Biology) for more than 10 years in research Institutes, among them Institute for Molecular Pathology (IMP) in Vienna and the Biomedical Research Institute in Madrid (IIB/CSIC) where she finished her PhD in Biomedicine in 2004.

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

Dr. Björnberg was also the project manager for the EHCI 2005 – 2013 projects, the Euro Consumer Heart Index 2008 and numerous other Index projects.

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

## 5. How to interpret the Index results?

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

Just like any of the Euro Indexes, also the EDI 2014 is an attempt at measuring and ranking the performance of healthcare 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. The European Commission attempts to introduce common, measurable health indicators have made very little impact.

It is important to emphasize that the Euro Indexes, including the Euro Diabetes Index 2014, displays consumer information, not medically or individually sensitive data.

While by no means claiming that the EDI 2014 results are dissertation quality, the findings should not be dismissed as random findings. The Index is built from bottom up – this means those countries that are known to have quite similar healthcare systems should be expected not to end up far apart in the ranking.

The Euro Diabetes Index 2014 is an attempt at measuring and ranking the performance of healthcare provision of the countries included in the study. Most of the data presented has been reviewed more than once not only by HCP staff but by different stakeholders in countries. Additionally, the HCP team received feedback through an online questionnaire (see Appendix 1) from patient organization representatives and physicians, which provided an opportunity to double-check the situation and set a number of questions, in case some of the information collected was incomplete or inconsistent.

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

Finally, it is important to mention that the positions that a country get inside the ranking should not be taken as something very accurate. Small variations in the scoring in any of the indicators

may alter the ranking. It is very relevant though if a country is on the top 5 of the ranking in the middle or at the bottom.

Previous experience from Euro Indexes indicates that consumer ranking by indicators of this nature are looked upon as important tools to reflect healthcare service quality. The HCP hopes that the EDI 2014 results can serve as inspiration for how and where European diabetes care can be improved.

## **6. Euro Diabetes care Index 2014**

The EDI project is an effort to compile information about diabetes healthcare provision in Europe. The EDI project started in September 2013. The 28 EU member states plus Switzerland and Norway have been included in the EDI, a total of 30 countries.

It has been deemed important to have a mix of indicators in areas of service attitude and customer orientation as well as indicators of a "hard facts"-nature showing healthcare quality in Outcomes terms.

**There is a number of indicators of high interest** which have proved impossible or very difficult to score. Some results of the research on those indicators are presented in a number of tables as additional information (pp 39 - 47).

From the beginning, the project was met with clear interest from National bodies and other health officials and stakeholders. A high number were happy to contribute providing indicator data and other information about their own countries. The existence of a number of parallel ("competing") projects sometimes affected their time availability. To make it easier and increase their understanding of the project a very high number of National health officials, public health responsible and clinicians in the countries of interest were visited by the EDI team, with very positive results.

In relation with the project, a number of countries organized meetings to which all relevant stakeholders were invited. Their idea was to discuss the data availability and data quality before sending it to the HCP.

It important to mention the valuable contribution of National bodies and other health officials. They expended time to study and find the information the HCP was requesting.

The completion of this study would not have been possible without the generous support of the authorities in many countries. This report has benefitted from the expertise and material received from many health officials, health professionals, and health experts.

**It is also important to mention the high participation of physicians in this project.** Their views have been essential to distinguish between what is described through protocols, guidelines or policies, and what happens in reality in day-to-day practice.

**IDF Europe (International Diabetes Federation, European Region) has supported this project.** The actual contribution to the EDI project was limited. A high number of patient organization representatives contributed giving their feedbacks on the indicators, filling out the online questionnaire.

The HCP received data from different sources, from Denmark and Sweden direct from the National diabetes registry. A number of countries sent data from a compilation from sources such as Regional registries, diabetes disease management programs, National Audits as the one in the UK and a high number of various studies. The HCP also received a large number of estimations of varying degrees of accuracy. Such data was not used for scoring indicators, but is still interesting information. (See page 52)

One of the aims of this project was to demonstrate the situation of data availability on the European level. The HCP team spent time discussing the quality and the representativeness of the data sent to us with country representatives and public health experts.

## 6.1 Indicator areas (sub-disciplines)

The Index is built up by 28 indicators grouped in six sub-disciplines as shown in the next table:

Sub-discipline	Number of indicator
1. Prevention	6
2. Case finding/Screening	2
3. Range and reach of services	4
4. Access to treatment/care	5
5. Procedures	7
6. Outcomes	4

**The expert panel members made a systematic and organized scoring on a long list of very interesting indicators** based on Relevance, Scientific Soundness and Feasibility. This exercise ended up with 37 indicators all considered relevant for the Index. From those 6 had to be discarded for data availability reasons or for not being able to decide what should be fair criteria for a Green/Yellow/Red score setting. 3 indicators are presented as additional information in extra tables, giving a total of 28 indicators in the EDI.

## 6.2 Scoring in the EDI 2014

The performance of the respective national healthcare systems were graded on a three-grade scale for each indicator, where the grades have the rather obvious meaning of Green = good (👍), Amber = so-so (👉) and red = not-so-good (👎). A Green score earns 3 points, an Amber score 2 points and a Red score (or a "not available", **n.a.**) earns 1 point.

Since 2006, the same methodology has been used: For each of the sub-disciplines, the country score is calculated as a percentage of the maximum possible (*e.g.* for Prevention, the score for a state has been calculated as % of the maximum  $3 \times 6 = 18$ ).

Thereafter, the sub-discipline scores were multiplied by the weight coefficients given in the following section and added up to make the final country score. These percentages were then rounded to a three digit integer, so that an "All Green" score on the 28 indicators would yield 1000 points.

## 6.3 Weight coefficients

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

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

Normally, the Outcomes sub-discipline is given the highest weight in HCP Indices. Just as in the Diabetes Index 2008, data availability on this sub-discipline did not justify that higher weight. For

the EDI 2014, range and reach of services, access to treatment/care as well as procedures were decided as the main candidates for higher weight coefficients based mainly on discussions with the expert panels. Also, the number of indicators in each sub-discipline was taken into account and the quality of the data acquired for each indicator. In the EDI 2014, the scores for the six sub-disciplines were given the following weights:

<b>Sub-discipline</b>	<b>Relative weight ("All Green" score contribution to total maximum score of 1000)</b>	<b>Points for a Green score in each sub-discipline</b>
Prevention	175	29
Case finding/Screening	50	25
Range and reach of services	175	43.75
Access to treatment/care	200	40
Procedures	275	39.3
Outcomes	125	31.5
<b>Total sum of weights</b>	<b>1000</b>	

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

It should be noted that, as there are not many examples of countries that excel in one sub-discipline but do very poorly in others, if at all for data availability problems, the final ranking of countries presented by the EDI 2014 is remarkably stable if the weight coefficients are varied within rather wide limits.

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

## 6.4 Regional differences within European states

The HCP is well aware that many European states have very decentralised healthcare systems. Not least for the U.K. it is often argued that "Scotland and Wales have separate NHS services, and should be ranked separately". The uniformity among different parts of the U.K. is higher than among regions of Spain and Italy, Bundesländer in Germany and possibly even than among counties in tiny 9½ million population Sweden.

Grading healthcare systems for European states does present a certain risk of encountering the syndrome of "if you stand with one foot in an ice-bucket and the other on the hot plate, on average you are pretty comfortable". This problem would be quite pronounced if there were an ambition to include the U.S.A. as one country in a Health Consumer Index.

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

## 6.5 Indicator definitions and data sources for the EDI 2014

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

It is important to notice that data on European level was not available for most of the indicators apart from a few from a number included in Prevention. Most data is coming from National Institutions, referring national data, and also from interviews with National health care officials, public health experts and physicians. The data has been reviewed by different stakeholders in most countries.

**Table 6.5:** Indicator definitions and data sources for the EDI 2014

Sub-discipline	Indicator	Comment	Score 3 👍	Score 2 👉	Score 3 👎	Main sources
1. Prevention	1.1 Prevalence of obesity in adults	Percentage of total population with BMI≥30 kg/m <sup>2</sup>	< 20%	20 - 22%	> 22%	WHO World Health Statistics 2013
	1.2 Exercise in compulsory school	Total hours of physical activity in up to 10 years of compulsory school	> 700	700 - 600	< 600	Eurydice 2013
	1.3 Bicycle usage	% of population using cycling as main mode of transport	>10%	10% - 5%	< 5%	Eurobarometer 312, "Future of transport" 2011
	1.4 Consumption of soft drinks	Including juice and nectars, liters per capita	< 100	100 - 120	> 120	UNESDA 2012
	1.5 Fruit/vegetable consumption	Fruit and vegetables kg per capita per year	> 250	250 - 200	< 200	WHO HfA July 2013
	1.6 Raised blood pressure among adults	Prevalence of raised blood pressure among adults aged ≥25 years (%)	< 25%	25 - 35 %	> 35 %	WHO World Health Statistics 2013
2. Case finding	2.1 Diabetes registry	Registering both type 1 and Type 2 diabetes, regularly updated	Yes, national	Yes, regional/ Only national Type I or Type II	Only in some hospitals or None	Interviews with health care officials, national physicians and public health experts.
	2.2 Screening for gestational diabetes		Universal and free screening	Screening is done routinely on risk group patients only (Free screening)/ Only partially subsidized/ low accessibility	Not routinely at all or must be paid by the patient (Private testing)	Interviews with health care officials, national physicians and public health experts, data from Gestational Diabetes Mellitus Prevention (DALI) research programme.

<b>3. Range and reach of services</b>	<b>3.1 Special footwear</b>		At least two pairs/year free of charge	Less than two pairs/year, or limited by significant patient co-payment/Only to selected groups of patients with special conditions	Only if privately paid	Interviews with health care officials, physicians and public health experts.
	<b>3.2 Podiatric care</b>		Yes, on the same economic terms as a normal doctor's appointment	Yes, with a lower subsidy (higher co-payment) as for a typical doctor appointment/ Same subsidy as other doctors but very limited in number	Only if privately paid	Interviews with health care officials, physicians and public health experts.
	<b>3.3 Eye care</b>		Yes, on the same economic terms as a normal doctor's appointment	Yes, with a lower subsidy (higher co-payment) than for a typical doctor appointment/ Same subsidy as other doctors but very limited in number or access	Only if privately paid	Interviews with health care officials, physicians and public health experts.
	<b>3.4 Metformin deployment</b>	IMS Standard Units per diabetic person	>400	399 - 250	< 250	IMS Health MIDAS, diabetes prevalence from IDF
<b>4. Access to treatment/care</b>	<b>4.1 Insulin pump therapy for DM T1</b>	Penetration rates of continuous subcutaneous insulin infusion (CSII) therapy in patients with diabetes type 1	> 15 %	15 - 5 %	< 5 %	Renard; 2010, The UK insulin pump audit (ABCD, 2012), Hammond p; 2013) and Interviews with health care officials, physicians and public health experts.
	<b>4.2 CGM (Continuous glucose monitoring)</b>	For diabetes type 1	Yes, subsidised for all patients if prescribed, no medical restriction.	Subsidised if prescribed but only for some specific patients (e.g. pregnant patients, only those treated in reference centers) or CGM is only partially subsidised	No, CGM for DM type 1 is not subsidised.	Heinemann I et al; 2012, De Vries H; 2012, Interviews with health care officials, physicians and public health experts.
	<b>4.3 Test strips for people on Insulin DM T1</b>	Free access to test strips to proper manage diabetes (Type 1)	Free access to at least 3-4 strips per day (1095-1460 per year)	Only partially subsidised, or limited number of strips are subsidised: Anything below free access to 3-4 strips per day (1095-1460 per year)	Not subsidised at all or only for some specific populations of type 1 / Very limited in number of strips meaning high risk for patients	Interviews with health care officials, physicians and public health experts, Access to quality medicines and Medical devices for diabetes care in Europe (International Diabetes Federation, 2014)

	<b>4.4 Test strips for people on Insulin DM T2</b>	Free access to test strips to proper manage diabetes (Type 2)	Free access to at least 1 strip per day (365 per year)	Only partially subsidised or only a number of strips are subsidised: Anything below 1 strip per day (365 per year)	Very limited in number of strips meaning high risk for patients/ No possibility for a Type 2 patient to access more strips in case of acute disease or limitation significantly below 1095 strips per year if being treated with multiple insulin injections	Interviews with health care officials, physicians and public health experts.
	<b>4.5 Access to patient education</b>	Access to structured patient education: Do all patients have access to PE or is it limited?	All patients (equal)	Limited: only patients treated by multidisciplinary diabetes groups; or only in some geographies	Typically not/ It is not free	Interviews with health care officials, physicians and public health experts. Results from DAWN2 project.
<b>5. Procedures</b>	<b>5.1 Annual HbA1c test</b>	% of patients receiving annual HbA1c test	> 75 %	75 - 50 %	< 50 %	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.
	<b>5.2 Annual foot examination</b>	% of patients receiving annual foot examination	> 75 %	75 - 50 %	< 50 %	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.
	<b>5.3 Annual microalbuminuria check</b>	% of patients receiving annual Microalbuminuria check? (or protein test to measure kidney function)	> 75 %	75 - 50 %	< 50 %	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.
	<b>5.4 Annual blood lipid levels test</b>	% of patients having lipid levels tested annually	> 75 %	75 - 50 %	< 50 %	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.
	<b>5.5 Biennial eye examination</b>	% of patients receiving biennial (dilated) eye examination?	> 75 %	75 - 50 %	< 50 %	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.

	<b>5.6 Waiting time for eye operation</b>	Typical waiting time for eye laser procedure or surgery	Less than three months	3 - 6 months	More than 6 months	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.
	<b>5.7 Mean waiting time for patient education</b>	Mean waiting time for patient education	Less than three months	3 - 6 months	More than 6 months	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.
<b>6. Outcomes</b>	<b>6.1 Incidence rate of renal replacement therapy</b>	Incidence rate PmP for RRT (renal replacement therapy), cause of renal failure being diabetes (2011)	< 25	25-30	> 30	Era-EDTA
	<b>6.2 Foot amputation incidence</b>	Annual incidence of amputation (major + minor amputations) per 100.000 diabetic population.	< 150	150-300	> 300	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.
	<b>6.3 % of patients with HbA1c &gt; 7%</b>	Diabetes type 1 and diabetes Type 2 (latest available period)	< 50 %	50-60%	> 60 %	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.
	<b>6.4 Recorded prevalence of blindness among diabetics</b>		Data available		Data not available	National registries, regional registries, National audits, diabetes management programs, other national regional programs, publication on national/relevant studies.

## 6.6 Additional data gathering – e-questionnaire

A survey to be answered by the main stakeholders and use the information as an additional feed back to the official information collected was designed as part of the data gathering for the EDI. The questionnaire included a number of the indicators, transformed into a multiple choice form (See Appendix 1.). The questionnaire was distributed to a long list of contacts including many different stakeholders but mainly patient organizations and National societies.

IDF encouraged their National organizations to participate in the survey and as reflected in Table 6.7 a high number of patient organization representatives offered their perceptions through the survey.

In total, 37 answers from 18 different countries were received. This information was only used as feedback, never as primary indicator data.

## 6.7 Additional data gathering – Single Country Score Sheets

On May 20<sup>th</sup>, 2014, preliminary score sheets (containing scores for one country only, so called "Single Country Score Sheets", SCSS) were sent out to Ministries of Health or national agencies of all 30 states giving the opportunity to review the data collected.

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

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

Country	Responded in 2014	Patient Organizations responded in 2014
Austria	✓	✓
Belgium	✓	✓
Bulgaria	✓	
Croatia	✓	✓
Cyprus	✓	
Czech Republic		✓
Denmark	✓	
Estonia		✓
Finland	✓	
France	✓	
Germany	✓	
Greece	✓	✓
Hungary		
Ireland	✓	✓
Italy	✓	
Latvia	✓	✓
Lithuania	✓	
Luxembourg	✓	✓
Malta	✓	
Netherlands	✓	

Country	Responded in 2014	Patient Organizations responded in 2014
Norway		
Poland	✓	✓
Portugal	✓	✓
Romania	✓	✓
Slovakia	✓	✓
Slovenia	✓	✓
Spain	✓	✓
Sweden		
Switzerland	✓	✓
United Kingdom	✓	

**Table 6.7** Responses from national bodies and patient organisations.

## 6.8 Threshold value settings

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

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

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

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

Thereafter, the sub-discipline score percentages were multiplied by the [weight coefficients](#) given in section 6.3 and added to make the total country score. The scores thus obtained were rounded to a three digit integer, giving a score system where a state with “all Green” would receive 1000 points (and “all Red” 333 points).

## 6.9 CUTS data

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 30 states from one single and reasonably reliable source, then there has been a definitive preference to base the scores on the CUTS. As CUTS would be considered WHO databases, OECD Health data, Special Eurobarometers, and scientific papers using well-defined and established methodology.

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

obtain precise answers from many sources even when these sources are all answering the same, well-defined question.

As an example, the indicator “long list” originally had an indicator asking for Incidence of myocardial infarction in diabetics (Total including type 1 and type 2 patients). Some of the data received data obviously from the values had to be *prevalence* (however that is defined) of MI. The HCP also received data only for Type 2 and data measuring MI, angina, and revascularization coronaries together.

### 6.9.1 The “Rolls-Royce gearbox” factor

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

## 7. Content and construction of the EDI 2014

In this chapter is described the main findings in the different sub-disciplines. The description of the individual indicators is found in chapter 8.12.

### 7.1 Sub-discipline: Prevention

Diabetes type 2 and other chronic diseases can be prevented or delayed. There are a number of risk factors for type 2 diabetes, including obesity, high cholesterol, high blood pressure, and physical inactivity, which can prevent the development of these diseases if modified early enough.

Effective prevention programs must be the number one priority to reduce the burden of diabetes type 2 in the general population. In order for a prevention programme to succeed, family members of patients must be involved in the programme.

Patient centered teaching should be a cornerstone of Diabetes prevention. Aging is also a risk factor for Diabetes but since this cannot be influenced, the modification of diet and lifestyle must be emphasized repeatedly to curb diabetes<sup>26</sup>.

**Obesity** is one of the greatest public health challenges of the 21st century. The prevalence has tripled in many countries of the WHO European Region since the 1980's, and the numbers of those affected continue to rise at an alarming rate. A number of all kind of programmes are running in various countries to tackle the problem and promote a healthier life style. There is still a long way to go, as almost 2/3 of countries studied have more than 20 % of the population considered obese (Body Mass Index > 30).

There is a crisis of obesity in children. It must be emphasized that obese children will be or are presently suffering from chronic diseases like diabetes. Research has shown that

---

<sup>26</sup> [www.diapedia.org/management](http://www.diapedia.org/management)

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

Today, sedentary life style is predominant in most of countries even though it is recommended that individuals engage in adequate levels of physical activity throughout their lives. A combination of resistance and aerobic exercises can decrease a diabetic patient's HbA1c by 0.6%. The same benefits can be seen in lowered blood pressure among hypertensives<sup>27</sup>.

Regular sport practices can be introduced and promoted through schooling years, However physical activity in schools has been reduced in many countries in recent years, substituted by other subjects considered of more intellectual value for students and therefore of more interest to the children's future.

### **Low consumption of fruits and vegetables:**

Fruits and vegetables consumption in Europe is still insufficient. The WHO recommends >400 g of fruits and vegetables a day. This goal has been hard to reach. Fibre from fruits and vegetables reduces the flood of insulin into the body on the consumption of carbohydrate. Fruits and vegetables also have a low glycaemic index, meaning that when eaten also reduce the level of glucose in the body compared with other foodstuffs.<sup>28</sup>

Interventions and programmes promoting fruit and vegetable intake and healthy life standards are running in many countries, special in the central and Northern parts of Europe. At least some parts of the population in those countries are nowadays more aware of the repercussion of what they eat through awareness campaigns and education. However, all these messages do not necessarily access the poorest parts of the society in which diabetes prevalence is normally higher<sup>29</sup>.

It should also be noted that low income alone does not necessarily limit the individual's ability to purchase healthy food. Their choice is affected also by the taste of the food<sup>30</sup>. Instead, there is a need to alter consumer behaviour to promote consumption of fruit and vegetables. Short persistent messages should be used to change the public mindset. There are hints that more focus should be given to vegetables consumption versus fruit because of the higher fructose content.

[http://www.eufic.org/page/en/show/latest-science-news/page/LS/ftid/Are\\_worldwide\\_efforts\\_to\\_promote\\_fruit\\_and\\_vegetable\\_consumption\\_effective\\_enough/](http://www.eufic.org/page/en/show/latest-science-news/page/LS/ftid/Are_worldwide_efforts_to_promote_fruit_and_vegetable_consumption_effective_enough/)

---

<sup>27</sup> Avery L et al; 2012

<sup>28</sup> Bazzano I (WHO); 2005

<sup>29</sup> Mackenbach JP. Health inequalities: Europe in profile. 2006. Available from: [http://ec.europa.eu/health/ph\\_determinants/socio\\_economics/documents/ev\\_060302\\_rd06\\_en.pdf](http://ec.europa.eu/health/ph_determinants/socio_economics/documents/ev_060302_rd06_en.pdf) (accessed 2012-03-06).

<sup>30</sup> Cheng et al; 2012

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

## 7.2 Sub-discipline: Case finding

### National registries / data collection limited in Europe

National registries are the only way for a country to measure a disease problem and plan the management of disease control. In Europe, there are only 7 National registries: Croatia, Denmark, Hungary, Latvia, Norway, Sweden and the UK.

**Denmark** has excellent data collection for diabetes, with a very good National diabetes registry established in 2006. The registry is a source of demographic information for the diabetes population in itself, and also a source of linkable information for studies of diabetes as outcome and as determinant.

In parallel a Sentinel Data Capture tool was established in 2011. On a weekly basis, quality data is made readily available for GPs to benchmark against practices achieving better results and to learn from them in order to deliver better value.

**Sweden:** The Swedish National Diabetes Register (NDR) was initiated in 1996. National guidelines for diabetes care were established at the same time, and quality indicators. The NDR was started as a tool for local quality control and benchmarking against the national treatment aims, based on several large randomized intervention trials in both type 1 and type 2 diabetic patients.

**England, Wales and Scotland** have the National Diabetes Audit which creates a registry of (nearly) everyone with diagnosed diabetes. It is possible to link together the records for successive audit cohorts to track individuals over a number of years. Any registry data would be taken from or repeated in primary and secondary care records. The audit extracts the data from these systems to reduce the burden of data collection. It is called an 'audit' rather than a registry because of the source of the funding and the fact that its primary purpose is to monitor the care services provided.

**Italy** has measured both process and outcome indicators since approximately 2004, showing improvements in both measurement and laboratory outcomes, as well as increases in complication rates. In 2004, the Italian Association of Diabetologists (AMD) realized the importance of measuring and sharing quality-of-care data to reduce the burden of diabetes and began collecting diabetes quality indicators from all diabetes outpatient clinics. The initiative now involves 250 diabetes clinics throughout Italy, covering a total of over 400,000 people with type 1 or type 2 diabetes (The total number of diabetics in Italy is approximately 2½ million). This approach represents a key feature of the continuous quality-improvement effort implemented in Italy.

**Latvia** produces annually a publication called "*Cukura diabetes*" which includes Statistical data on the number of patients by region, age, gender, type of diabetes, type of treatment, complications of diabetes and clinical findings.

**Screening diabetes.**

It was of great interest for the EDI to address which risk groups in the respective countries were routinely screened for type 2 diabetes. There are some variations in the target patient groups and basis risk factors for routine diabetes testing (Table 8.2.1). What is shown in the table is a mixture between recommendations and general practice from physicians. It is not known if those groups are really systematically screened, in a whole country or even in a region. Regardless of guidelines it looks like testing of patients for diabetes is very dependent on GP discretion.

The main groups recommended for diabetes testing are included in the table.

Diabetes Screening															
Countries	Specific age groups in General population	Classic: polyuria, polydipsia, weight loss;	People with BMI > 30	Large waist circumference	A family history of the disease	Insulin resistance or conditions associated with insulin resistance: High blood pressure, High Lipid profile, Acanthosis nigricans, Polycystic ovary syndrome.	Pre-diabetes patients	History of CVD	Previous test for IGT	Birth of a baby ≥9 lbs	Having had gestational diabetes while pregnant	Members of specific migrant communities	Specific ethnics groups	HIV positive patients	Hepatitis C patient or liver damage
Austria		x	x		x	x	x	x	x	x				x	x
Belgium	x	x	x		x	x	x	x	x	x					
Bulgaria	x	x	x	x	x	x	x	x	x	x				x	x
Croatia	X		x		x		x		x	x					
Cyprus															
Cz	X (>40)	x	x			x	x			x					
Denmark		x	x	x	x	x	x	x	x	x					
Estonia															
Finland															
France	X	x			x	x	x		x	x					
Germany	X (>35)	x	x	x	x	x	x	x	x	x					
Greece															
Hungary															
Ireland		x	x		x	x	x	x	x	x	x	x	x		
Italy	x		x		x	x	x	x		x			x		
Latvia		x			x	x			x	x					
Lithuania	x	x	x	x	x	x	x	x	x	x					
Luxembourg	x		x		x	x			x	x					
Malta										X					
Netherlands															
Norway															
Poland	x	x	x	x	x	x	x	x	x	x					
Portugal			x	x	x										
Romania	X (>40)	x	x	x		x	x	x		x					
Slovakia	x	x	x		x										
Slovenia	x	x	x	x	x	x	x	x	x	x				x	x
Spain															
Sweden															
Switzerland		x				x	x		x						
UK															

**Table 7.2.1** Case finding in population at risk: There are a number of groups in the population defined as having higher risk of being exposed to develop diabetes. It seems that even when guidelines exist about this issue in most countries, performance is very different and it is difficult to determine which groups are really systematically checked and which are not. The table shows the main practices.

**Screening practices for gestational diabetes** are inconsistent across Europe and even within countries. Practices range from systematic screening of all pregnant women as in Austria, Belgium, Germany, Denmark etc, to testing on a case-by-case basis according to clinician or patient decisions or by risk factors as in Ireland or Cyprus. Where systematic screening is in place, variations exist in protocols followed, risk factors considered, and diagnostic tests and threshold values used.<sup>31</sup>

There was one indicator that was discharged because it was difficult to score. Countries were asked about any *specific screening activities for the early identification of diabetes risk factors routinely use by health care professionals*. The responses were of very different nature but in general a high number of countries use individual diabetes risk score (FINDRISK). This is already validated for a high number of countries. Recommendations to primary health care physicians have been established to maximize its use. Its impact and whether it is systematically used is difficult to estimate.

### 7.3 Sub-discipline: Range and reach of services

This sub-discipline address the policies of physician access; in particular podiatric and eye doctors. However, it has been difficult to assess if the number of doctors available is sufficient in a country, length of time required for an appointment or whether the physician provides adequate diabetes care.

In a large number of countries access to an eye doctor seems similar as assessing any other specialist.

Podiatric care remains limited and a number of countries such as Bulgaria and Croatia only provide foot care on private basis. Still the situation has improved since the previous Diabetes Index in 2008.

#### **Footwear for diabetics:**

All experts agree that the number of special footwear for diabetics in order to provide adequate care and prevention of diabetes foot should be decided on an individual basis. In particular, the different needs between an adult and a child. A growing child's foot requires new special footwear more often than an adult. However, it seems there is frequently a restriction in most European countries in Europe that one annual pair of shoes should be sufficient. In some countries, significant patient co-payments are applied. This situation may prevent patients from proper management and care of foot ulcers.

#### **Access to diabetes medication/Medication adherence**

Because many patients with diabetes have two or more co-morbidities, they often require multiple medication. The prevalence of medication non-adherence is high among patients with chronic conditions, such as diabetes, and non-adherence is associated with public health issues and higher health care costs. One reason for non-adherence is the cost of medications. EDI wanted to review the accessibility and the barriers patients face to access diabetes treatment.

---

<sup>31</sup> Buckley et al; 2011

As it has been reported that patients may have to wait to get an appointment with their specialist or travel long distances for a visit, it was parallel recorded at the same time whether GPs are allow to prescribe some of these drugs, to make them more easily accessible.

As can be seen in the tables below in general it seems drugs are available in EDI countries. In the cases of gliptins, GLP-1RA and intermediate/long-acting insulins they are subsidised/reimbursed almost everywhere. Access to Proliferative Retinopathy medication (anti-VEGF) is more limited. Most countries do not subsidise/reimburse it but it is registered for sale everywhere. Knowing this, it was disappointing to see the sales numbers per country for these drugs and realizing how differently these drugs are being used. (Section 7.3.1)

Gliptins					
Countries	Available	100 % subsidised (free of charge)	Subsidised same as typical prescription drugs	Subsidised less than typical prescription drugs or not at all	Can these drugs be prescribed by the GP?
Austria	x	x			x
Belgium	x	Restrictions	x		x
Bulgaria	x	x			
Croatia	x	x			x
Cyprus	x	Only in public sector			Only in public sector
Czech Republic	x		x		
Denmark	x	x			
Estonia	x			x	x
Finland					
France	x				
Germany	x	x			x
Greece	x	x			x
Hungary					
Ireland	x	x			x
Italy	x	x			x
Latvia	x	x			x
Lithuania	x	x			x
Luxembourg	x	x			x
Malta	x			x	x
Netherlands					
Norway					
Poland	x			x	
Portugal	x				x
Romania	x	x			
Slovakia	x		x		
Slovenia	Limited	x			
Spain					
Sweden	x	Restrictions			x
Switzerland	x		x		
UK					

GLP-1RA					
Countries	Available	100 % subsidised (free of charge)	Subsidised same as typical prescription drugs	Subsidised less than typical prescription drugs or not at all	Can these drugs be prescribed by the GP?
Austria	x	In specific individual cases	x		
Belgium	x	Restrictions	x		x
Bulgaria	x	x			
Croatia	x	x			
Cyprus	x (only in private sector)			x (Paid by patient)	
Czech Republic	x		x		
Denmark	x	x			
Estonia	x			x	x
Finland					
France	x				
Germany	x	x			x
Greece	x	x			x
Hungary					
Ireland	x	x			
Italy	x	x			x
Latvia	x			x	
Lithuania	x	x			x
Luxembourg	x	x			x
Malta	x			x	x
Netherlands					
Norway					
Poland	x			x	
Portugal	x				x
Romania	x	x			
Slovakia	x		x		
Slovenia	Limited	x			
Spain					
Sweden	x	x			x
Switzerland	x		x		
UK					

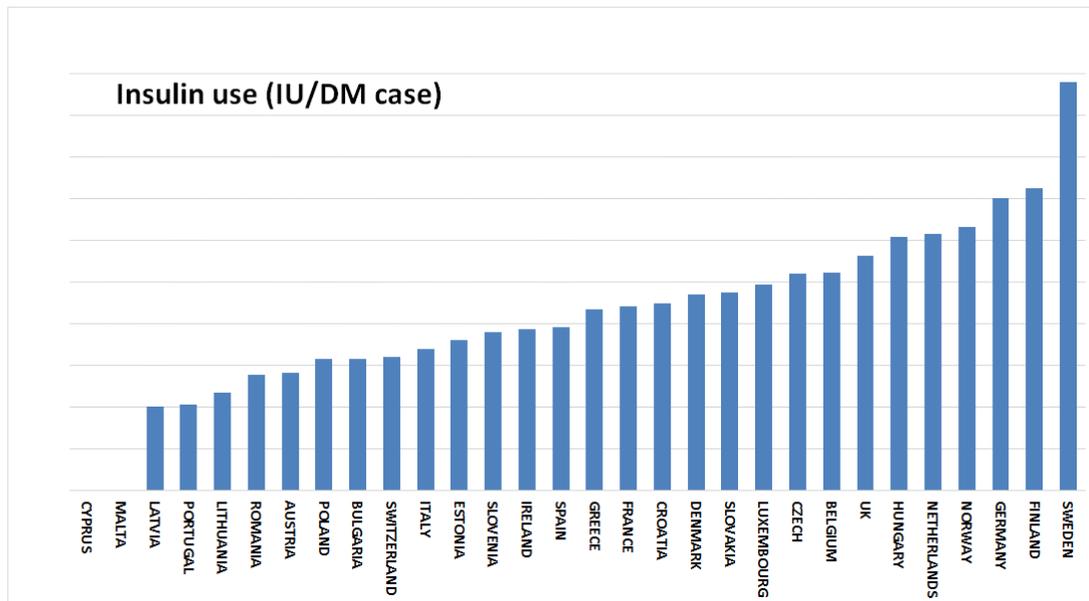
Intermediate/long acting insulins (type 1)					
Countries	Available	100 % subsidised (free of charge)	Subsidised same as typical prescription drugs	Subsidised less than typical prescription drugs or not at all	Can these drugs be prescribed by the GP?
Austria	x	x			x
Belgium	x	Restrictions	x		x
Bulgaria	x	x			
Croatia	x	x			
Cyprus	X (Private and public)	x			x
Czech Republic	x	x			
Denmark	x	x			
Estonia	x			x	x
Finland					
France	x	x			x
Germany	x	x			x
Greece	x	x			x
Hungary					
Ireland	x	x			
Italy	x	x			x
Latvia	x	x			x
Lithuania	x	x			x
Luxembourg	x	x			x
Malta	x	x			x
Netherlands					
Norway					
Poland	x			x	x
Portugal	x				x
Romania	x	x			
Slovakia	x	x			
Slovenia	x	x			x
Spain					
Sweden	x	x			x
Switzerland	x		x		
UK					

### 7.3.1 Deployment of other diabetes drugs

Using the same sources as for the metformin deployment indicator (see Indicator 3.4), the Index study also looked at deployment rates of insulin and gliptins. Gliptins are effective at lowering blood glucose; diabetes is a progressive condition. After a while, a single medicine will not be enough to control blood glucose levels. It could be months or

years before this happens — but once it does, another kind of diabetes medicine will need to be added to metformin (and/or a sulfonylurea) to control blood sugar. Gliptins are not taken on their own, but can be added to metformin, a sulfonylurea, or a glitazone. The first gliptin came on the market in 2006.

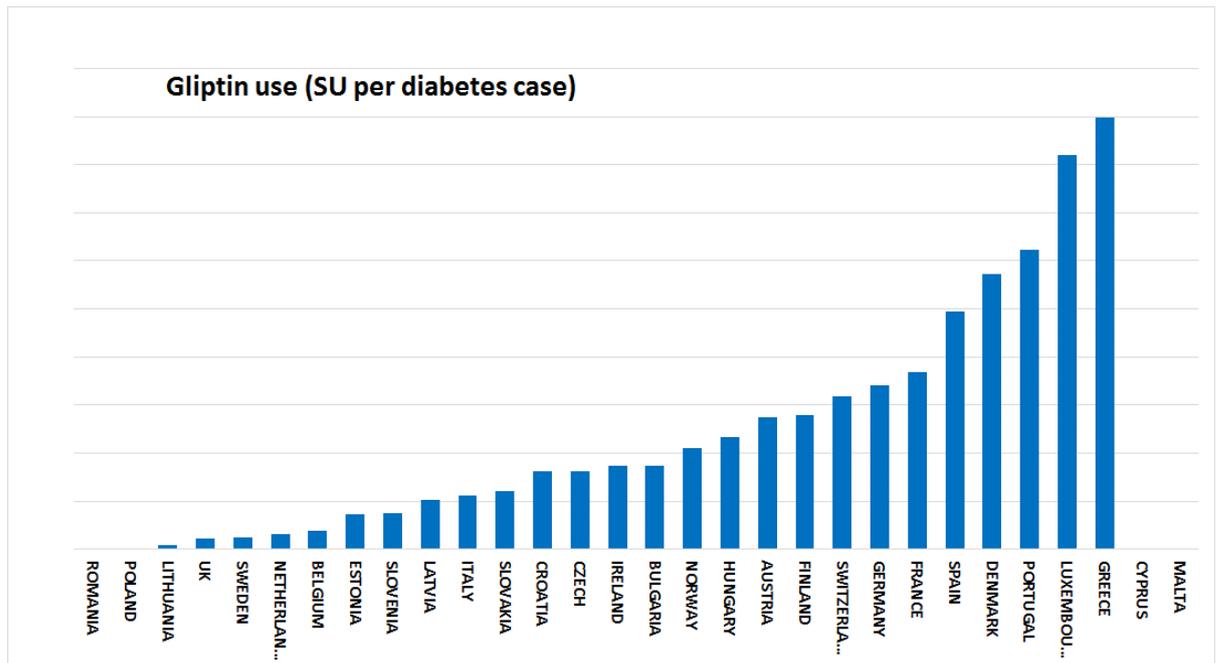
Rather surprisingly, the study found relative differences in insulin *per capita* use which were as big as for metformin (see graph below):



**Graph 7.3.1a.** Insulin use expressed as International Units of insulin divided by the number of diabetics in the country. Sources: IMS Health MIDAS database (insulin sales), IDF Atlas 6<sup>th</sup> ed. (# of diabetics).

The equivalent study for the more “modern” supplement, gliptin drugs, shows among other things that high metformin- and insulin-use healthcare systems, such as Sweden and the UK, are quite restrictive with the use of gliptins:

As there was no general agreement in the Expert Panel as to whether a high or low use of insulin or gliptins is clearly beneficial, they do not appear as scored indicators in the EDI 2014.



**Graph 7.3.1b.** Gliptin use expressed as Standard Units divided by the number of diabetics in the country. Sources: IMS Health MIDAS database (insulin sales), IDF Atlas 6<sup>th</sup> ed. (# of diabetics).

## Proliferative Rethinopathy medication (antiVEGF)

Countries	Available	100 % subsidised (free of charge)	Subsidised same as typical prescription drugs	Subsidised less than typical prescription drugs or not at all
Austria	x	x		
Belgium	x		x	
Bulgaria	Only partially			x
Croatia	x	x		
Cyprus	x	x (Public)		x (Private)
Czech Republic	x		x	
Denmark	x	x		
Estonia	x			x
Finland				
France	x			
Germany	x	x		
Greece	x	x		
Hungary				
Ireland	x			x
Italy	x	x		
Latvia	x			x
Lithuania	x			x
Luxembourg	x	x		
Malta	x	x		
Netherlands				
Norway				
Poland	x	x		
Portugal	x			x
Romania	x			x
Slovakia	x			x
Slovenia	Restricted	x		
Spain				
Sweden	x		x	x
Switzerland	x		x	
UK				

## 7.4 Sub-discipline: Access to treatment/care

There is a high number of people in Europe who do not have access to the care they need: There is unequal access to care; care provided is of different quality even within a country or a region depending on if patients are being treated by a multidisciplinary team, in primary care or by a diabetologist.

Experts and organizations all agree that in order to improve outcomes, treatment for diabetes should include a multidisciplinary team using multi-factorial treatment strategies and focusing on the patient as an individual.

In general, there is a lack of well trained professionals in primary care such as GPs, nurses, educators etc. In CEE countries there is a limited number of qualified physicians which creates limits in the availability to tackle diabetes.

### Access to patient education

Diabetes has no cure and therefore, good access for patients to treatment and care is extremely important to limit complications and improve quality of lives for those persons suffering from the disease and their families.

Once diabetes is detected, patients and families should be provided with structured and easy-to-access education to increase patients' understanding of diabetes, the best way to manage it and to understand how to deal with it in the most effective way. Good understanding of the disease can prevent or at least delay complications and reduce the number and duration of hospitalisations, which in turn can improve quality of life and glucose control.

Across Europe there are many different varieties of education programs, it seems education is rather random depending on where the patient happens to seek care.

In a number of countries such as Denmark, Germany, Ireland, Luxembourg, Netherlands, Norway, Slovakia, Switzerland and Sweden education is provided to all Type 1 & 2 patients in primary care practice and/or hospitals.

In the UK, there are the DAFNE programme for type 1 Diabetes Patients and the DESMOND for type 2 diabetes. These teach patients what to eat and how much insulin to use. Both programmes are to encourage self-management for diabetic patients. In France, SOPHIA is a patient-centered diabetes management programme of co-operation with healthcare professionals to lower health expenditure and improve the quality of life for diabetic patients.

[www.dafne.uk.com/What\\_is\\_DAFNE\\_-I293.html](http://www.dafne.uk.com/What_is_DAFNE_-I293.html)

[www.desmond-project.org.uk/whatisthedesmondprogramme-271.html](http://www.desmond-project.org.uk/whatisthedesmondprogramme-271.html)

In most other countries, education programmes are offered only for diabetic patients being treated by a multi-disciplinary teams, in academic teaching hospitals or other institutions. In many countries, patient organizations or individual physicians try to compensate for this lack of patient education.

The composition of programmes varies by centre, region and country although all usually include the following: general diabetes information, diet and exercise, glucose monitoring, hypoglycemia identification and treatment, insulin delivery (when applicable), complications and their prevention.

The way the education is structured also influences its success rate. In order for education programmes to be successful they need to extend over a longer a period of time with follow ups<sup>32</sup>.

### **Patient monitoring**

Type 1 patients are seen mostly by an endocrinologist or diabetologist, while Type 2 patients irrespective of medication requirements are seen either a GP or endocrinologist with similar frequency. To prevent or delay the development of complications from type 1 or type 2 diabetes, patients need to take a proactive role in the management of their health care. This includes making regular visits to the primary care physician and other professionals. There is a number of parameter that needs to be regular review. The EDI team collected information on the access to some of those regular follow-ups in a high number of countries asking if they are being subsidised/reimbursed by the system, if they are available and offered on an annual basis, in the table below:

---

<sup>32</sup> Khunti et al; 2012

Availability/Subsidised						
Countries	Annual Lipid testing	Annual Micro- and macroalbuminuria test	Body weight and/or waist circumference	Annual healthy lifestyle adaptation (Dietary advice, evaluation of quality of life, physical activity, smoking)	Annual Adjustments of the existing treatment regimen	Psychosocial care
Austria	👉	👉	👉	👉	👉	👉
Belgium	👉	👉	👉	👉	👉	👉
Bulgaria	👉	👉	👉	👉	👉	👉
Croatia	👉	👉	👉	👉	👉	👉
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	👉	👉	👉	👉	👉	👉
UK						

Psychological issues are increasingly recognized to be of high importance in diabetes management. Understanding the psychosocial barriers facing individuals and their families and being able to provide the tools to support them to overcome those barriers is an essential part of diabetes care. The lack of psychosocial support for diabetic patients limits their ability to manage their disease efficiently. Healthcare professionals have expressed that due to the lack of extra training, they are not confident to discuss the emotional issues of diabetes with their patient. Access to psychological care is reduced and most of the time only accessible if privately paid.

[www.dawnstudy.com/dawn2/dawn-2-study-results.asp](http://www.dawnstudy.com/dawn2/dawn-2-study-results.asp)

### **7.4.1 Access to devices to properly manage diabetes**

#### **Insulin pumps**

Insulin pumps have created great expectations among many research groups. However, their use remains rather limited. Prescription of insulin pumps has been permanently excluded by certain number of doctors as a possible therapy. A number of countries reported the low used of insulin pumps related with the low number of healthcare professionals qualified to train people with Type 1 diabetes to use a pump, with the lack of diabetes specialist nurses (DSNs) a particular problem. Physicians are still the main driving force of healthcare delivery in most European countries, including education to treatment use. Diabetes educators, as a specific entity of healthcare givers, are still lacking in many countries in Europe. This means that a huge amount of time must be dedicated by European physicians to the teaching and follow-up of diabetes patients treated by pumps. Enrollment of new patients may be dramatically slowed by the limited time that can be available for this task.

#### **Continuous Glucose Monitoring**

Continuous glucose monitoring (CGM) "reads" patients' glucose levels throughout the day and night. It gives a picture of the patterns of blood glucose highs and lows after eating different foods, activity and insulin, and allows patients to gain better control. In many countries there is no clear consensus about the clinical indications for CGM in actual clinical practice. In principle, CGM is an innovative technology intended to benefit a large group of patients with diabetes but it is unfortunately still not widely reimbursed in Europe.

#### **Test strips for people on insulin**

Self-monitoring of blood glucose is an essential tool for diabetes management. Self-monitoring gives regular feedback for patients about their blood glucose status, but decisions on both the method and frequency of testing need to be made on an individual basis. Monitoring is only useful if it is used to inform decisions (insulin dosage). Access to test strips for a patient should be made according to the personal situation of everyone. EDI found a number of countries with severe limitations on free access the minimal number of strips for a satisfactory management of diabetes on either type 1 diabetes or type 2. It is well describe in the literature that proper diabetes management is very cost effective.

There were 3 indicators that were discarded in this sub-discipline because they were impossible to quantify to compare care provision among the countries, or data was not recorded almost anywhere:

- Children access to diabetes specialist
- What is the mean waiting time for an appointment with a diabetes specialist?
- What percentage of DM T1 are followed by a diabetologist?

### 7.5 Sub-discipline: Procedures

A number of tests are recommended for monitoring diabetic patients: annual checks on HbA1c, foot examination, microalbuminuria, blood lipids and biennial eye test.

In practice, the percentage and frequency of patients tested does not always reflect the guidelines. Clinically, all the monitoring processes recorded in the EDI research should occur at least annually in all patients with diabetes except eye test that it is recommended biennially, if there is no indication of any complication. However, as can be seen in the data collected, there is evidence that this is not occurring.

Apart from this, the sub-discipline faces a big problem with the lack of measured data and the excess of estimations (= "educated guesses" by healthcare professionals), as can be seen in the next two tables:

Excluding estimations:

Euro Diabetes Index 2014		Austria	Belgium	Bulgaria	Croatia	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
5. Procedures	5.1 Annual HbA1c test	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
	5.2 Annual foot examination	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
	5.3 Annual microalbuminuria check	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
	5.4 Annual blood lipid levels test	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
	5.5 Biennial eye examination	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
	5.6 Waiting time for eye operation	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
	5.7 Mean waiting time for patient education	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.
Subdiscipline weighted score		144	170	144	144	131	144	275	144	157	170	183	118	157	105	183	210	118	170	183	275	183	118	183	170	144	262	170	275	223	249

Including estimations:

Euro Diabetes Index 2014		Austria	Belgium	Bulgaria	Croatia	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
5. Procedures	5.1 Annual HbA1c test	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
	5.2 Annual foot examination	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
	5.3 Annual microalbuminuria check	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
	5.4 Annual blood lipid levels test	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
	5.5 Biennial eye examination	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	n.a.	
Subdiscipline weighted score		183	118	170	92	170	183	196	183	196	131	131	196	131	157	118	144	183	92	105	196	105	105	170	92	196	183	118	196	144	196

For an unknown reason, data not recorded often has the tendency to be overrated in the eyes of experts that it is in reality once it is recorded.

## 7.6 Sub-discipline Outcomes

Comprehensive outcomes data is vital in order to understand where deviations from optimal diabetes practice and patient care may occur, including regional variations. Unfortunately for diabetes care, outcomes data is limited in most countries. Although regular monitoring and evaluation is recommended in all EU countries, it is unclear how often monitoring occurs and what outcomes are achieved. For example, only 8 countries were able to provide data on prevalence of blindness among diabetes.

Apart from the lack of data the results are not all positive. There is a need to improve results almost everywhere in Europe.

At the beginning the indicator on foot amputation was thought to collect data on incidence of major foot amputations. However, in Europe most countries do not distinguish between major and minor amputations. Therefore, what is presented is incidence of foot (major+minor) amputation. It is worrying to see that only 3 countries score green in this indicator.

The indicator **incidence of myocardial infarction in diabetic population** was discarded because it was difficult for countries to report incidence.

## 8. How the Euro Diabetes Index 2014 was built

### 8.1 Production phases

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

The EDI 2014 was constructed under the following project plan.

#### 8.1.1 Phase 1

**1. Selection of a number of experts to be part of the expert panel and set up the first meeting.** The composition of the Expert panel can be found in section [9.3](#).

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

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

- National and regional Health Authorities
- Institutions (EHMA, ECDC, CDC, OECD and others)
- Private enterprise (IMS Health, pharmaceutical industry, others)
- **Personal visits when required.**
- 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

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

#### **8.1.2 Phase 2**

**1. Indicator scoring.** During the first expert panel meeting a large number of indicators were selected as being relevant to be included in the project. This “long-list” included more than 50 indicators. The experts then performed an indicator scoring in an organized and systematic manner to shorten the list and select the indicators most relevant for the project. The research team started working with 37 indicators.

#### **2. Data collection to assemble presently available information to be included in the EDI 2014.**

- Identification of vital areas where additional information needed to be assembled was performed.
- Collection of raw data for these areas.

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

33 responses from 16 different countries were received, mostly from patient organization representatives.

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

**5. Regular contacts with the Expert Reference Panel** mainly to discuss the indicators, the criteria to score them, and the data acquisition problems. Finally, there was a second meeting on July 4<sup>th</sup>, 2014, at which each of the indicators was discussed in detail, including those that could not be included in the Index due to lack of data. Also, the discrepancies between data from different sources were analyzed. Sub-discipline relative weights were also discussed and set.

### **8.1.2.1 "Single Country Score Sheets" send-out.**

On May 20<sup>th</sup>, 2014, all 30 states received their respective preliminary score sheets (with no reference to other states' scores) as an e-mail send-out asking for updates/corrections by July 20<sup>th</sup>. The send-out was made to contacts at ministries/state agencies as advised by states during the contact efforts prior to May 2014 and to all IDF members. Corrective feedback from states was accepted up until August 20<sup>th</sup>, by which time replies had been received from countries denoted in section [Additional data gathering – feedback from National Ministries/Agencies](#) for more information on national feedback.

### **8.1.3 Phase 3**

Project presentation and reports

- A report describing the results and principles of how the EDI 2014 was constructed.
- Presentation of EDI 2014 at a seminar and web conference in Vienna on September 17<sup>th</sup>.
- On-line launch on [www.healthpowerhouse.com](http://www.healthpowerhouse.com) .

## **8.2 Content of indicators in the EDI 2014**

The research team of the Euro diabetes Index 2014 collected data on 28 healthcare performance indicators, structured in a framework of six sub-disciplines. The indicators come numbered in the report, to provide more reader friendliness and clarity.

At the starting point, the "long list" of indicators had more than 50 indicators of interest. After scoring, 37 were retained. From those, 6 were discarded mainly because of lack of data or comparability problems between countries. There are 3 indicators presented in tables, as additional information (See 39-47), leaving 28 indicators in the EDI.

### **8.2.1 Prevention**

Diabetes mellitus is one of the most common chronic disorders, affecting people of all age groups.

While some things that contribute to the development of diabetes are beyond a person's control, there are also a number of modifiable risk factors. By making healthy changes in these areas, people can reduce their risks or delay the development of diabetes (and other chronic diseases) and improve their overall quality of life.

The overall prevalence of Type 2 diabetes in the population can be reduced by preventing obesity in the general population and promoting a healthy and balance diet and physical activity.

**1.1 Prevalence of obesity in adults:** This is a major risk factor for Type 2 diabetes. **Percentage of total population with BMI  $\geq 30$  kg/m<sup>2</sup>.** Data based on both sexes.

Source: WHO Health Statistics 2013

### **1.2 Exercise in compulsory school: *Total hours of physical activity in up to 10 years of compulsory school.***

Sedentary lifestyle contributes to developing Type 2 diabetes, partly through increased risk for obesity. To prevent obesity and promote healthy life governments should and can increase exercise in schools.

Source: Eurydice 2012/13

### **1.3 Bicycle usage: *Cycling as main mode of transport, % of population.***

Along with overweight/obesity, physical inactivity ranks among the top modifiable risk factors for pre-diabetes and Type 2 diabetes.

After a number of mail exchanges and conversation over the phone with the European Cyclist Federation (ECF) it was decided that the best indicator to measure bicycle usage in Europe was data published in Eurobarometer 312, 2011.

**Source:** Eurobarometer 312 (Future of transport), 2011.

### **1.4 Consumption of soft drinks: *Consumption of soft drinks including Juice and nectars (litres per capita).***

Consumption of sugar-sweetened beverages has been shown to be associated with Type 2 diabetes incidence.

**Source:** Union of European Soft Drinks Associations (UNESDA) 2012

**1.5 Fruit/vegetable consumption:** Evidence shows that people who have diets high in vegetables and fruit have a lower risk of developing certain health conditions, such as coronary heart disease, stroke, cancer and Type 2 diabetes.

#### ***Average amount of fruits and vegetables consumed per person per year (in kg)***

**Source:** WHO HfA July 2013

**1.6 Elevated blood pressure among adults aged  $\geq 25$  years:** In addition to causing damage to the cardiovascular system, untreated high blood pressure has been linked to development of diabetes. ***Prevalence of elevated blood pressure among adults aged  $\geq 25$  years (%)***

**Source:** WHO World Health Statistics 2013

## **8.2.2 Case finding**

Active programmes to identify people with Type 2 diabetes early enough to promote appropriate diabetes care and treatment should be established. Those at increased risk of Type 2 diabetes should be targeted as part of systematic case finding and annual health checks. The objectives of such initiatives are to reduce the numbers of people with undiagnosed diabetes, the burden of complications at diagnosis and the impact on the person with diabetes.

## 2.1 Diabetes registry:

It is essential to promote evidence-based development of diabetes care by offering up-to-date information about changes in treatment of glycaemia and other risk factors, as well as diabetic complications, and also to support improvement in quality of care provided by participating units at hospitals and primary care clinics. The overall objective is to reduce morbidity and mortality, as well as to maximise the cost-effectiveness of diabetes care.

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

## 2.2 Screening for gestational diabetes: What is the coverage of screening programs for gestational diabetes?

All pregnant women **should be offered a screening test for gestational diabetes.**

Gestational diabetes is a specific type of diabetes that can develop late in pregnancy (usually after the 24<sup>th</sup> week). Women who develop this complication do not have diabetes before becoming pregnant. Gestational diabetes is detected by using an oral glucose tolerance test (OGTT), usually at 24-28 weeks. For an OGTT, a blood sample is tested, before the patient is given a glucose drink. Another sample of blood will then be taken two hours later to see how the body is dealing with the glucose. Most women who have *gestational diabetes* give *birth* to healthy *babies*, but the *child* is at higher *risk* for developing Type 2 diabetes later in life.

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

## 8.2.3 Range and reach of services.

The provision of diabetes services is complex. Care is provided by a wide range of professionals, including general practitioners (GPs) and other primary healthcare professionals and specialist diabetes teams, as well as people with diabetes and their carers. The achievement of good outcomes for people with diabetes is dependent on the provision of well-organised and coordinated diabetes services which draw on the knowledge and skills of health and social care professionals working across primary and secondary care.

**3.1 Special footwear provided:** Ensuring correctly fitting footwear is very important for people who suffer with diabetes because of poorly fitting shoes. Too loose or too tight can cause rubbing, leading to ulcers and further complications if not prevented. Many people with diabetes experience numbness and loss of sensation in their feet. Thus, it becomes even more critical that they wear correctly fitting shoes to ensure that ulcers do not develop.

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

Indicators **3.2** and **3.3** measure whether access to these specialists is on the same economic terms as services from any other doctor. Unfortunately, it was impossible to measure if a country has enough professionals or how well trained doctors are.

### **3.2 Podiatric care: Is podiatric care for diabetics provided on the same terms as medical care?**

Podiatry (foot care) for people with diabetes is one of the most overlooked aspects of diabetes management. Higher levels of blood glucose can damage the nerve endings in many areas of the body and organs, which is why tight blood glucose control is an essential aspect of diabetes care. Good (subsidised) accessibility to podiatric care is essential to properly manage the disease.

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

### **3.3 Eye care: Is eye care for diabetics provided on the same terms as medical care?**

Patients with diabetes are at an increased risk of developing eye diseases that can lead to vision loss such as diabetic retinopathy, cataracts and glaucoma. Diabetes is the leading cause of blindness in Europe. Diabetic-related eye problems develop from high blood sugar levels, which can cause damage to blood vessels in the eye. Over 40 percent of diabetic patients will develop some form of eye disease during their lifetime. The risk of developing eye problems can be reduced through regular eye exams. Therefore, easy cheap access to specialist is important.

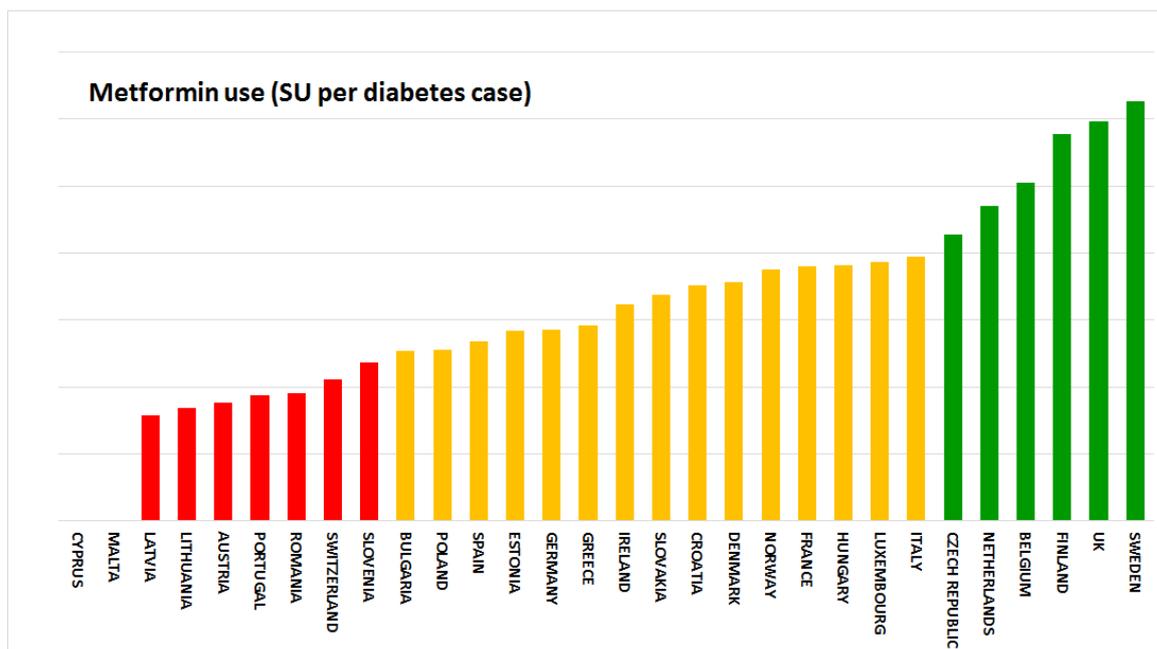
**Sources:** Interviews with health care officials, national physicians and public health experts.

### **3.4 Metformin deployment**

Metformin is an oral anti-diabetic drug in the biguanide class. It is the first-line drug of choice for the treatment of Type 2 diabetes, particularly in overweight and obese people and those with normal kidney function.

The scoring was calculated as the ratio between "drug sales expressed in Standard Units (*i.e.* volume, not monetary value) divided by the number of diabetes cases" in each country.

As metformin should be the first-line drug of choice, the Expert Panel were united in the opinion that generous deployment deserved a Green score. The European situation is shown in the graph below. As the graph shows, there is a 4-fold difference in the *per capita* deployment, although metformin is an inexpensive drug.



**Source:** Sales data on metformin was acquired from IMS Health (MIDAS database). Data on number of diabetics per country was taken from the IDF Diabetes atlas 6th edition, 2013. For reasons concerning intellectual property, the HCP cannot publish numbers on the Y-axis of these graphs. However, the Y-axis does start at Zero in all drug use graphs.

### 8.2.4 Access to treatment/care

There is NO cure for diabetes. Diabetes is a chronic disease. The aim of treating diabetes is to help people with the condition, control their blood glucose levels and minimise the risk of developing future complications.

For a chronic condition, patients (and their families) need to be educated and trained to be able to participate and manage the best way possible in their own disease. Countries need to be able to empower patients.

There are 5 indicators in this sub-discipline:

#### 4.1 Insulin pump therapy for DM T1: *Penetration rates of continuous subcutaneous insulin infusion (CSII) therapy in patients with type 1 diabetes mellitus (T1DM) in European countries.*

Insulin pump therapy is an increasingly popular method of insulin replacement therapy. Because the insulin delivery from insulin pumps can more closely mimic what the body does naturally, patients can improve their blood sugar control. With that control comes improved quality of life.

**Sources:** Renard; 2010, the UK insulin pump audit (ABCD, 2012), Hammond p; 2013) and Interviews with health care officials, physicians and public health experts.

#### 4.2 CGM (Continuous glucose monitoring) for DM T1: *Is CGM (Continuous glucose monitoring) for DM T1 refunded, if yes with which medical restrictions?*

CGM is a way to measure glucose levels throughout the day and night. A tiny electrode called a glucose sensor is inserted under the skin to measure glucose levels in tissue fluid. It is connected to a transmitter that sends the information via wireless radio frequency to a monitoring and display device. Different evaluations point the benefits and success in the outcomes of using CGM in the right patients. Using CGM devices enables people who have achieved excellent control (with HbA1c levels below 7 percent) to continue to tightly manage their diabetes while cutting down on the frequency of hypoglycaemia. The refund concerns the sensors, which are a consumable.

**Sources:** Heinemann I et al; 2012, De Vries H; 2012. Interviews with health care officials, physicians and public health experts.

#### **4.3 and 4.4 Test strips for people on Insulin DM T1 and DMT2: *Free access to test strips to properly manage diabetes (Type 1 and Type 2).***

Blood glucose test strips (diabetes test strips) are one of the components of a diabetes monitoring system. It is the cornerstone of self-care for diabetes. A small amount of blood is applied on the test strip, and glucose concentration is determined. The numbers revealed by strips can dictate what the patient can eat, how much exercise to do, how much insulin is needed, or how much trouble the patient could be in during a low.

**Type 1:** Anything below free access to 3-4 strips per day (1095-1460 per year) scores Yellow. This number should be allowed to be increased if glycaemic control worsens, to prevent hyperglycaemic episodes. Also in case of evaluating a change or intensification of insulin treatment. If the limitation is significantly below this figure or limited to specific populations of type 1, the score is Red.

**Type 2:** Anything below 1 strip per day (365 per year) would score Yellow. If the limitation is significantly below this figure or limited to specific populations of Type 2, it would score Red. Again if there is no possibility for a Type 2 patient to access more strips in case of acute disease, or there is a limitation significantly below 1095 strips per year if being treated with multiple insulin injections, the score is Red.

**Sources:** Interviews with health care officials, physicians and public health experts, Access to quality medicines and Medical devices for diabetes care in Europe (International Diabetes Federation, 2014)

**4.5 Access to free structured patient education: Do all patients have access to Patient education or is it limited?** Diabetes is a chronic and progressive disorder which impacts upon almost every aspect of life. People living with diabetes have a crucial role in managing their own condition on a day-to-day basis, so supporting self-care should be central to any diabetes service. The aim of patient education is for people with diabetes to improve their knowledge, skills and confidence, enabling them to take increasing control of their own condition and integrate effective self-management into their daily lives.

Mechanisms for ensuring that all people with newly diagnosed diabetes receive initial and ongoing education about diabetes and its management should be agreed. Structured patient education should be made available **to all people** with diabetes at the time of initial diagnosis and should then be available as required on an ongoing basis.

**Source:** Interviews with health care officials, physicians and public health experts. Results from DAWN2 project.

### 8.2.5 Procedures

Meticulous metabolic control can prevent or delay the onset of the complications of diabetes. The impact of these complications can be greatly reduced if they are detected early and appropriately managed.

#### 5.1 Annual HbA1c test. % of diabetics who received annual HbA1c test.

HbA1c (“long-term blood glucose”) testing provides clinicians with a reliable indication that therapy is working appropriately and the risk of long-term complications, particularly microvascular complications is reduced (Saudek & Brick 2009). The test does not show the highs and lows that regular self-testing shows and therefore does not replace it, but is an added tool, in giving the overall picture of blood glucose management. Tight glycemic control reduces the risk of development and progression of organ complications in people with both type 1 and Type 2 diabetes.

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

#### 5.2 Annual foot examination. % of diabetics who received annual foot examination.

People who have diabetes are vulnerable to nerve and vascular damage that can result in loss of protective sensation in the feet, poor circulation, and poor healing of foot ulcers. All of these conditions contribute to the high amputation rate in people with diabetes. The absence of nerve and vascular symptoms, however, does not mean that patients’ feet are not at risk. Risk of ulceration cannot be assessed without careful examination of the patients’ bare feet. Early identification of foot problems and early intervention to prevent problems from worsening can avert many amputations. Good foot care, therefore, is an essential part of diabetes management. It is recommended annual screenings to avoid complications.

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

#### 5.3 Annual microalbuminuria follow up. % of diabetics who received annual foot examination.

Presence of microalbuminuria (“egg white in the bloodstream”) 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.

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

#### **5.4 % of patients getting lipid levels measured annually.**

Heart attacks and strokes are the leading causes of death for people with diabetes. Research indicates that high levels of lipids, also known as blood fats (including cholesterol), increase the risk of heart disease.

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

#### **5.5 % of diabetics who receive biennial eye examination.**

After 20 years of diabetes almost all persons with type 1 diabetes and more than 60 % of Type 2 diabetics suffer from diabetic retinopathy to some degree. Early diagnosis followed by an optimisation of metabolic control can stop progression and in some situations prevent blindness. There are two major types of retinopathy: non-proliferative and proliferative (less common). People who keep their blood sugar levels closer to normal are less likely to have retinopathy or to have milder forms.

The retina can be badly damaged before noticing any change in vision. Most people with non-proliferative retinopathy have no symptoms. Even with proliferative retinopathy, the more dangerous form, people sometimes have no symptoms until it is too late to treat them. For this reason, eyes must be examined regularly by an eye care professional.

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

#### **5.6 Typical waiting time for eye laser procedure or surgery.**

**Source:** Interviews with health care officials, physicians and public health experts, national waiting time statistics.

#### **5.7 Mean waiting time for patient education.**

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

### **8.2.6 Outcomes**

Due to the lack of data related with outcomes indicators, only four out of the six initial indicators survived in this sub-discipline. To increase the possibilities of collecting data, the study team asked about two or three indicators in similar subjects:

Incidence of Myocardial event and also incidence of Myocardial infarction, Incidence of foot amputation in diabetics (major amputation) and also major + minor amputations. Prevalence of ESRF (End Stage Renal Failure) in diabetic population or Annual incidence of dialysis and/or transplantation (renal replacement therapy) in patients with diabetes.

#### **6.1 Incidence rate Per Million Population (pmp) for RRT (renal replacement therapy), cause of renal failure being diabetes (2011).**

The number of patients who have diabetes and End State Renal Replacement (ESRD) and are being admitted to renal replacement treatment (RRT) is increasing dramatically

worldwide, and in many countries, diabetes has become the single most frequent cause of ESRD.

**Source:** European Renal association (Era-EDTA), 2013.

### **6.2 Foot amputation incidence: Annual incidence of amputation (major + minor amputations) per 100.000 diabetic population.**

People with diabetes are far more likely to have a foot or leg amputated than other people. Many people with diabetes have peripheral arterial disease (PAD), which reduces blood flow to the feet. Also, many people with diabetes have nerve disease, which reduces sensation. Together, these problems make it easy to get ulcers and infections that may lead to amputation. Most amputations are preventable with regular care and proper footwear.

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

### **6.3 % of patients with HbA1c > 7. Diabetes type 1 and diabetes Type 2 (latest available period)**

It is in general recommended in guidelines a general target HbA1c of  $\leq 7.0\%$  for most patients. HbA1c targets however, need to be individualised for example, this may need to be higher for some people including children and the elderly.

Some countries report % of patients  $>7.5\%$  or  $>6.5\%$  HbA1c. In these cases, the study was lucky to find that the results could be inter- or extrapolated to  $>7.0$  with no ambiguities being introduced.

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

**6.4 Recorded prevalence of blindness among diabetics:** Diabetes is, or used to be, the leading cause of new cases of blindness in adults. This is a growing problem as the number of people living with diabetes increases.

Only 8 countries had data on prevalence of blindness among diabetics, numbers falling in the range 0.1 – 1 %. It was decided to score Green those countries which had data available.

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

## **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 following persons have taken part in the Expert Reference Panel work for EDI 2014:

Name	Affiliation
Jens Christiansen, Prof.	Professor of Medicine. Department of Endocrinology MEA Aarhus University Hospital, Aarhus. Denmark
Gabriel Gimenez, Dr.	Consultant endocrinology. Department of Endocrinology and nutrition. Granollers General Hospital. Barcelona, Spain
Ulrik Keller, Prof.	Professor of Medicine. FMH Endokrinologie-Diabetologie, Basel. Switzerland
Chantal Mathieu Prof.	<i>Chair of Endocrinology, Professor of Medicine at the Katholieke Universiteit. Leuven, Belgium.</i>
Valdis Pirags, Prof.	Head of the Clinic of Internal Medicine. Pauls Stradiņš Clinical University Hospital, Riga, Latvia
Gabriele Riccardi, Prof.	Professor of Endocrinology and Metabolic Diseases. Head of Diabetes Clinic and Metabolic Ward, Naples. Italy
Peter Schwarz, Prof	Prof. Dr. med. habil. Department of Medicine III. Prevention and Care of Diabetes University of Dresden, Germany
Vaidotas Urbanavicius, Prof	Professor of Medicine. Clinics of Internal Medicine Vilnius University Hospital, Vilnius, Lithuania

The Expert Reference Panel for a HCP Index has two core tasks:

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

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

## 10. Literature references

Anderson BJ, Rubin RR: Practical Psychology for Diabetes Clinicians: Effective Techniques for Key Behavioral Issues. 2nd ed. Alexandria, Va., American Diabetes.

Anderson RM, Funnell MM, Burkhart N, Gillard ML, Nwankwo R: 101 Tips for Behavior Change in Diabetes Education. Alexandria, Va., American Diabetes Association, 2002.

Avery L, Flynn D, Van Wersch A, Sniehotta F, Trenell M: Changing Physical Activity Behavior in Type 2 Diabetes; Diabetes Care 35:2681–2689, 2012.

- Bazzano L, Serdula M and Liu S: Prevention of Type 2 Diabetes by Diet and Lifestyle Modification, *Journal of the American College of Nutrition*, Vol. 24, No. 5, 310–319 (2005).
- Bazzano L, Li T, Joshipura K, and Hu F: Intake of Fruit, Vegetables, and Fruit Juices and Risk of Diabetes in Women, *Diabetes Care*. Jul 2008; 31(7): 1311–1317. doi: [10.2337/dc08-0080](https://doi.org/10.2337/dc08-0080)
- Buckley B, Harreiter J, Damm P, Corcoy R, Chico A, Simmons D, Vellinga A and Dunne F, on behalf of the DALI Core Investigator Group: Gestational diabetes mellitus in Europe: prevalence, current screening practice and barriers to screening. A review, *Diabet. Med.* 29, 844–854 (2012).
- Campmans-Kuijpers Marjo JE, Lidwien C Lemmen, Caroline A Baan, Kees J Gorter, Jolanda Groothuis, Klementine H van Vuureand Guy EHM Rutten: Defining and improving quality management in Dutch diabetes care groups and outpatient clinics: design of the study, *BMC Health Services Research* 2013, 13:129, doi:10.1186/1472-6963-13-129.
- Chen S, Liu J and Binkley J: An Exploration of the Relationship Between Income and Eating Behavior, *Agricultural and Resource Economics Review*, 41/1 (April 2012) 82–91.
- Cochrane Database Syst Rev. 2012 Jan 18;1:CD008101. doi: 10.1002/14651858
- Daley C and Gubb J; *Healthcare Systems: Switzerland*, Civitas. 2013. [www.civitas.org.uk/nhs/download/switzerland.pdf](http://www.civitas.org.uk/nhs/download/switzerland.pdf)
- De Bakker DH, Struijs JN, Baan CB, Raams J, de Wildt JE, Vrijhoef HJ, Schut FT: Early results from adoption of bundled payment for diabetes care in the Netherlands show improvement in care coordination. *Health Aff (Millwood)*. 2012 Feb; 31(2):426-33. doi: 10.1377/hlthaff.2011.0912.
- de Bruin Simone R., Sandra H. van Oostrom, Hanneke W. Drewes, Janneke T. de Jong-van Til, Caroline A. Baan, and Jeroen N. Struijs: Quality of diabetes care in Dutch care groups: no differences between diabetes patients with and without co-morbidity. *Int J Integr Care*. 2013 Oct-Dec; 13: e057.
- Delamater Alan M.; *Psychological care of children and adolescents with diabetes*, *Pediatric Diabetes Volume 8*, Issue 5, pages 340–348, October 2007.
- Diabetes Atlas 6th edition; 2013.
- Diabetes leadership forum; 2014.
- Drewes Hanneke W., Lidwien C., Lemmens, Mireille Helmers, Janneke T. de Jong, Caroline A. Baan, Jeroen N. Struijs: Implementing diabetes self-management support in a new organizational context: experiences within Dutch care groups. *Int. journal personal center med*. Vol 2, No 3 (2012).
- Dutch Diabetes manager programme; European healthcare innovation Leadership Network, Type 2 diabetes working group. 2011.
- Gudbjornsdottir S, Cederholm J, Nilsson Pm, Eliasson B: The National Diabetes registry in Sweden. *Diabetes Care*, Volume 26, Number 4, April 2003.
- Hammond, P; Improving Access to insulin pump therapy: The role of the Insulin Pump Network, *Journal of Diabetes Nursing Volume 17 No 5*, 2013. <http://www.biomedcentral.com/1472-6963/11/348>
- International profiles of healthcare systems, 2013: Commonwealth Fund pub. no. 1717 [www.commonwealthfund.org/~media/Files/Publications/Fund%20Report/2013/Nov/1717\\_Thomson\\_intl\\_profiles\\_hlt\\_care\\_sys\\_2013\\_v2.pdf](http://www.commonwealthfund.org/~media/Files/Publications/Fund%20Report/2013/Nov/1717_Thomson_intl_profiles_hlt_care_sys_2013_v2.pdf) .
- Kanavos P, Van den Aardweg S and Schurer W: Diabetes expenditure, burden of disease and management in 5 EU countries, LSE Health, London School of Economics, 2012.
- Khunti K, Gray LJ, Skinner T, Carey ME: Effectiveness of a diabetes education and self-management programme (DESMOND) for people with newly diagnosed type 2 diabetes mellitus: three year follow-up of a cluster randomised controlled trial in primary care, *BMJ* 2012; 344 doi: <http://dx.doi.org/10.1136/bmj.e2333> (Published 26 April 2012) Cite this as: *BMJ* 2012;344:e2333
- Langendam M<sup>1</sup>, Luijff YM, Hooft L, Devries JH, Mudde AH, Scholten RJ; Continuous glucose monitoring systems for type 1 diabetes mellitus. *Cochrane Database Syst Rev*. 2012 Jan 18;1:CD008101. doi: 10.1002/14651858.CD008101.pub2.
- Mackenbach JP. *Health inequalities: Europe in profile*. 2006. [http://ec.europa.eu/health/ph\\_determinants/socio\\_economics/documents/ev\\_060302\\_rd06\\_en.pdf](http://ec.europa.eu/health/ph_determinants/socio_economics/documents/ev_060302_rd06_en.pdf) (accessed 2012-03-06).
- Mc Hugh S, Marsden P, Brennan C, Murphy K, Croarkin C, Harkins V and Perry I; Counting on commitment; the quality of primary care-led diabetes management in a system with minimal incentives, *BMC Health Services Research* 2011, 11:348



OECD/WHO (2011), OECD Reviews of Health Systems: Switzerland 2011, OECD Publishing.  
<http://dx.doi.org/10.1787/9789264120914-en>

Peytremann-Bridevaux I, Bordet J and Burnand B: Diabetes care in Switzerland: good, but perfectible: a population-based cross-sectional survey. License BioMed Central Ltd. 2013

Renard E; Insulin pump use in Europe: Diabetes Technol Ther. 2010 Jun; 12 Suppl 1:S29-32. doi: 10.1089/dia.2009.0189.

Schmid A and Wyss S: e-Health Suisse. "Healthcare IT Management", Volume 6/ Issue 3/ 2011;

Struijs JN, de Jong-van Til JT, Lemmens LC, Drewes HW, de Bruin SR, Baan CA: Three years of bundled payment for diabetes care in the Netherlands: Impact on health care delivery process and the quality of care. RIVM Rapport 260013002, 2012.

Thomsen R, Friberg S, Nielsen J, Schroll H, Johnsen P: The Danish Centre for Strategic Research in Type 2 Diabetes (DD2): Organization of diabetes care in Denmark and supplementary data sources for data collection among DD2 study participants, Publisher and licensee Dove Medical Press Ltd. 2012



## Appendix 1. Questionnaire used in the survey for the Euro Diabetes Index 2014.

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

- Austria.
- Belgium.
- Bulgaria.
- Croatia.
- 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.

2. Which is your area of expertise?

- Clinician
- Nurse
- Public Health Expert
- Academic/researcher
- Patient Organization representative

- Accompanying person
- Press
- Other

Other (please specify)

## Case finding

3. In your country, is Diabetes screening recommended (and paid by public subsidy/reimbursed) for the following groups? (Please indicate in the table below all that apply)

<b>Specific age groups in General population</b>	
<b>Classic: polyuria, polydipsia, weight loss;</b>	
<b>People with BMI &gt; 30</b>	
<b>Large waist circumference</b>	
<b>A family history of the disease</b>	
<b>insulin resistance or conditions associated with insulin resistance: High blood pressure, High Lipid profile, Acanthosis nigricans, Polycystic ovary syndrome.</b>	
<b>Pre-diabetes patients</b>	
<b>History of CVD</b>	
<b>Previous test for IGT</b>	
<b>Birth of a baby <math>\geq 9</math> lbs</b>	
<b>Having had gestational diabetes while pregnant</b>	
<b>Members of specific migrant communities</b>	
<b>Specific ethnics groups</b>	
<b>HIV positive patients</b>	
<b>Hepatitis C patient or liver damage</b>	

4. Universal Screening for Gestational Diabetes?

- a) All pregnant women offered screening (Universal)

- b) Screening is not systematic, but it is normal to be screened by risk factors.
- c) Unsystematic offered / Often must pay for it themselves (Private testing)

Additional comments

## Range and reach of services (“Generosity”)

### 5. Does healthcare system provide specially adapted footwear for diabetics?

At least two pairs/year free of charge

Less than two pairs/year, or significant patient co-payment

Only if privately paid

### 6. Is podiatric and eye care for diabetics provided on the same terms as medical care?

Yes, on the same economic terms as a normal doctor’s appointment

Yes, with a lower subsidy (higher co-payment) as for a typical doctor appointment

Only if privately paid

### 7. Access to diabetes medication;

Drug group	Available	100 subsidised (free charge)	% of	Subsidised same as typical prescription drugs	Subsidised less than typical prescription drugs or not at all	Can these drugs be prescribed by the GP?
Gliptins (type2)						
GLP-1RA (Type 2)						
Intermediate/long acting insulins (type 1)						
Blood pressure medication						
Lipid lowering medication						
Proliferative Rethinopathy medication (antiVEGF)						

## Access to treatment/care

7. Is insulin pump therapy for DM type 1 refunded, if yes with (if any) which medical restrictions?

- No, Insulin pump therapy for DM type 1 is not refunded.
- Insulin Pump therapy for DM type 1 is only partially refunded.
- Yes, it is refunded if prescribed but only for some specific patients.
- Yes, it is refunded if prescribed for all patients, no medical restriction.
- others/additional comments

8. Is CGM (Continuous glucose monitoring) for DM T1 refunded, if yes with which medical restrictions?

- No, CGM for DM type 1 is not refunded.
- CGM for DM type 1 is only partially refunded
- Yes, it is refunded if prescribed but only for some specific patients (e.g. pregnant Type-1 patients).
- Yes, it is refunded if it is prescribed for all patients, no medical restriction.

Others/Additional comments

9. Are glucose meters and test strips refunded in DM T2 treated with OHAs?

10. Do patients have free access to Patient education ("diabetes school")?:

- a) Yes, essentially all patients
- b) Only patients treated by multidisciplinary diabetes teams; or only in some hospitals, centers or regions
- c) Typically No.

Additional comments

11. What would be the mean waiting time to participate in patient education?

- <3 months
- 3-6months
- >6months

Additional comments



4.8 Access to .....?	Universally available	Partially available	100 subsidised (free charge)	% of	Subsidised same as typical prescription drugs	Subsidised less than typical prescription drugs or not at all
Annual Lipid testing						
Annual Micro- and macroalbuminuria test						
Body weight and/or waist circumference						
Annual healthy lifestyle adaptation (Dietary advice, evaluation of quality of life, physical activity, smoking)						
Annual Adjustments of the existing treatment regimen						
Psychosocial care						

## Access to procedures

13. What % of patients receive annual HbA1c test?

- >75%  
 75-50%  
 <50%

Additional comments

14. What % of patients receive annual foot examination?

- >75%  
 75-50%  
 <50%

Additional comments

15. What % of patients receive annual Microalbuminuria check?

- >75%  
 75-50%  
 <50%

Additional comments

16. % of patients who have lipid levels measured at least annually?

- >75%  
 75-50%  
 <50%

Additional comments

17. What % of patients receive (dilated) Eye examination at least every two years?

- >75%  
 75-50%  
 <50%

Additional comments

18. What would be the typical waiting time for eye laser procedure or surgery?

- < 3 months  
 3-6 months  
 More than 6 months

19. Is there in your country a diabetes registry? (Please indicate all that apply)

- Specifies whether the patient has type 1 or Type 2 diabetes.  
 Regularly updated.  
 Yes, national  
 Yes, regional  
 Only in some regions  
 Only some hospitals  
 None

Additional comments