changing diabetes barometer

Report on Barometer Media Roundtable
Brussels, 7 November 2007

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Changing Diabetes Barometer

report

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The Changing Diabetes Barometer was launched at the International Press Centre (Residence Palace) in Brussels on 7 November 2007. The launch marked the first stage in Novo Nordisk's initiative to encourage systematic measurement of the extent and effectiveness of diabetes care around the world as an important step towards improving that care. The Changing Diabetes Barometer initiative and its First Report were presented to an audience of national and international journalists, national and European politicians, as well as representatives from industry, NGOs, Permanent Representations to the EU and patient associations.

Novo Nordisk CEO and president Lars Rebien Sørensen had made the commitment to establish the Barometer at the Global Changing Diabetes Leadership Forum in New York in March 2007. The launch presentation outlined the urgent need for an initiative to stimulate the recording and comparison of data on national provision of diabetes care, in order to identify weaknesses, share best practices, and bring about improvement.

Only by concerted effort involving many stakeholders can the worldwide diabetes pandemic be addressed effectively. The Changing Diabetes Barometer and its potential contribution were presented in the context of what it can offer healthcare professionals, policymakers and national governments, and also to people with diabetes. The programme also explored the political need for such an initiative, its importance for developing countries, and the experiences and views of two individual people with diabetes.

Apart from the media roundtable, guests had the opportunity to take a blood sugar test. Furthermore, a visually arresting exhibition was set up in an impressive art deco space outside the conference room. Various exhibits including the Novo Nordisk Media Prize wall, the Medical Ambition man and a shoe exhibition, provocatively illustrated the diabetes related complications to participants.

Time to turn on the lights

While many attempts have been made in different parts of the world to provide and improve diabetes care, for far too long these attempts have been working in the dark to address the growing diabetes pandemic. The time has come to turn on the lights; to assemble real results on what is being achieved and to be more organised and coordinated in strategies to improve care.

Lise Kingo

"We have been driving the fight against diabetes in the dark for far too long. We need to turn the lights on. We need to keep score of our shared efforts against diabetes to drive sustainable change. This is what the Changing Diabetes Barometer is about."
Lise Kingo, executive vice president at Novo Nordisk,
setting the background for the Changing Diabetes Barometer

The 246 million people with diabetes in the world in 2007 are expected to become some 380 million by 2025 – an increase of 55%. But the diabetes pandemic will grow most significantly in the parts of the world that have the greatest prevalence already, the weakest healthcare systems and the poorest opportunities to deal with diabetes. For example, an increase of 102% over 2007-2025 is predicted for South America; 80-81% increase for Africa and the Middle East, and 73% for India. The time has come to reverse this trend (Source: IDF).

It is also of vital importance that while the numbers of people with diabetes are increasing, so also is the proportion of people aged 20-70 affected by diabetes: from a world average of 6.0% in 2007 to a predicted 7.3% by 2025. People in this age group are at their most active and economically productive, so diabetes affects not only their livelihoods but also the productivity of their countries (for further discussion of the indirect costs of diabetes, see chapter 6 of the Changing Diabetes Barometer report).

The First Changing Diabetes Barometer Report details Novo Nordisk's commitment to develop a framework for tracking and discussing how diabetes is addressed around the world. Measuring what is done already is the foundation for improvement, and it enables comparison and an element of competition as national health ministries become able to see how their own performance compares with that of other countries. At the heart of the initiative is an aim to focus on quality of life for the individual person with diabetes, measuring how that person is cared for and how effectively they are treated to offer protection from the complications of diabetes and remove any diabetes-related barriers which might prevent them from living a full, productive life.

Curbing the diabetes pandemic will only happen through many partners working together. The Changing Diabetes Barometer initiative is one building block in the process, aiming to inject momentum to help translate the words of the recently adopted UN Resolution on Diabetes into action. It will help to structure the evidence base that is needed both to improve life for the individual person with diabetes and to make fully informed socioeconomic decisions on healthcare provision. Former US President Bill Clinton said at the Global Changing Diabetes Leadership Forum in March 2007 that we owe it to the next generation that they do not lead shorter lives because we did not take action.

The Changing Diabetes Barometer

In different countries around the world, multiple stakeholders are spending their time fighting diabetes. Measuring and comparing results will drive improvement. Healthy competition will encourage care providers to make improvements, and to learn from more effective outcomes achieved elsewhere and examples of best practice. Earlier and better treatment will lead to longer, better quality lives for people with diabetes, and will also reduce costs.

Jakob Riis

"Just like a meteorological barometer, the Changing Diabetes Barometer will give information about the current situation as well as guidance on what is to come."
Jakob Riis, senior vice president at Novo Nordisk, explaining the role of the Changing Diabetes Barometer

The Changing Diabetes Barometer is equally concerned with the prevention, progress and treatment of diabetes. In view of the rapidly accelerating pandemic, the outlook for diabetes incidence and treatment can never be improved unless it is possible to stem the flow of new patients. The ideal would be to diagnose as early as possible in the course of the disease, and rapidly supply proper treatment. Treatments should then be monitored to assess whether the outcome is adequate or how it can be improved. All three aspects together are essential components of improved care.

It is important that the Changing Diabetes Barometer should inspire comparisons between nations. But real changes to diabetes care and its efficiency will be made at the national level. Different countries will clearly show very different stages of development in diabetes care and different priorities for what needs to be measured. That must be respected, but it should still be possible to draw together data that is comparable.

Comparing the costs of care options

Diagnosing diabetes at an early stage and treating it effectively has profound implications, both for the experience of the person concerned, and for the costs to society. Jakob Riis contrasted two hypothetical cases ; two men, 'John' and 'Peter', both diagnosed with diabetes when aged 52. John, diagnosed 'by accident' through another investigation is already experiencing some minor symptoms at the time of diagnosis. His treatment for diabetes is managed through occasional visits to the doctor, and he has an HbA1c level of 9.0%. John's expected time to complications is 8-10 years (age 60-62) and his expected life span is 16 years from diagnosis (age 68).

In contrast, Peter's diabetes is diagnosed before any symptoms have developed, through routine GP monitoring. His treatment and monitoring are given through regular three-monthly consultations, and his HbA1c is 7.0%. Although diagnosed at age 52 like John, he expects 13 years with a good quality of before experiencing any complications (age 65-68) and has a life expectancy of 19 years (age 69-71).

Making and recording comparable measurements, and raising awareness of the benefits of improved care, would mean that a higher proportion of people with diabetes would have improved outcomes and an improved quality of life. Jakob Riis stressed that these cases are not unusual – out of all people with diabetes, about a third have an experience like John, a third like Peter and the remainder somewhere between the two. The risk of complications is lower and at a later stage for Peter: earlier detection and better treatment lead to a better and longer life. Inspiring countries to deliver this level of care is the intention of the Changing Diabetes Barometer.

As well as the effects on the individual person with diabetes, it is important to notice the effect on costs. More effective monitoring and treatment, as received by Peter, gives tighter control. As the largest part of the costs generated by diabetes is that of treating complications, Peter's lifetime healthcare costs will actually be lower. Peter will incur initially a slightly higher care cost related to medication and its administration, but if all newly diagnosed people with diabetes were to follow Peter's route then the break-even point (where healthcare expenditure under the improved scenario is the same as it would have been if things were left unchanged) comes within 10 years, followed by annual savings into the future. Overall, managing diabetes more effectively gives a reduction in the costs of care. There is therefore a sound economic basis for investing in managing diabetes well.

Achieving savings in practice

But does this theory work in practice? The Changing Diabetes Barometer's First Report gives a number of examples of how improvements in diabetes care actually reduce costs. One of these is from Israel, where the health maintenance organisation Clalit introduced strict guidelines on diabetes treatment and monitoring. Between 2001 and 2007, the proportion of people with diabetes in poor control was reduced from 28% to 14%, and costs savings of 25% were achieved.

The objectives of the Changing Diabetes Barometer are that all stakeholders must take action to drive change. Novo Nordisk will continue the Changing Diabetes Barometer initiative, working to collect more and better data and expand the number of countries reported. More examples of best practice cases will be identified to inspire action at the national level. Further Changing Diabetes Barometer reports will be published, with the intention to inspire stakeholders of many countries to achieve a real change in diabetes care.

How measuring helps improve diabetes care

An example of the impact of an effective measuring system in Italy was described by Professor Giacomo Vespasiani, former President of the Associazione Medici Diabetologi (AMD) .

The Italian initiative produces an annual account (the AMD Annali) of the quality of diabetes care. Founded in 2000, its main objective has been to improve the quality of specialist care. Its first task was for a group of experts to define a minimum data set – the individual types of measurement to indicate what care was being offered and its outcomes. The indicators were published in 2002 and the group decided how to collect this data in a manageable way. The results have been published in the AMD Annali since 2004.

Italy has about 670 diabetes treatment centres, of which an increasing number are contributing to the Annali. Two different approaches were used to make it as easy as possible for doctors to contribute data. The bottom-up approach can accept data presented in any type of software (bottom-up), and this is currently used by 95 centres all over Italy, covering 140,000 patients. The top-down approach is being used by 11 centres in the Le Marche region, using common software and a centralised system.

Professor Giacomo Vespasiani

The Annali aim to produce information that can be shared. They have developed a particular 'star plot' presentation; an easy way to see if each centre is meeting the target for the key indicators. The objective is not to define the best-performing centre, but to help each centre define where it can make improvements. For example, data on diabetes care in Sicily over a five-year period has enabled treatment centres to identify and correct weaker parts of the system.

Professor Vespasiani reported that the development of the Annali has helped to define the main challenges in setting up systems to measure diabetes care. It has been most important to motivate doctors to contribute, and to ensure that they can see their own performance in comparison with the national situation, without increasing their workload. The data has to be held by an independent, respected body to ensure confidence and security. Professor Vespasiani also suggests that it is essential to make information available to individual people with diabetes so they can be actively involved in self-monitoring and dialogue with doctors about the care they are receiving.

The political approach to dealing with diabetes

The political framework within the European Union (EU) for addressing the growth of diabetes was explored by Dr Adamos Adamou MEP (speaker) and by Frieda Brepoels MEP and Philippe Roux (who gave written presentations). All three made reference to a number of relevant initiatives which have already been put in place within the EU institutions. These are:

From the European Parliament:

- In its declaration of April 2006, the European Parliament called on the European Commission and the Council to prioritize diabetes in EU health policy and to encourage member states to develop national diabetes plans. It also called on the Commission and Council to develop an EU diabetes strategy on the basis of a Council recommendation on diabetes prevention, diagnosis and control, in the same way as concerted plans were made to combat cancer.
- The European Parliament's Diabetes Working Group has worked for some time to call attention to the need for screening, education, disease prevention, health promotion and disease management, partnership of stakeholders, patient empowerment and more European research.

From the European Commission:

- The Commission's actions include the Second Action Programme on Health (2008-2013) which aims at preventing major diseases and proposes action on health indicators and ways of conveying information to individual citizens on nutrition and exercise. The White Paper on a strategic approach to health for the EU 2008-2013 sets prevention, health protection and new technologies as key objectives. Also of direct relevance is the Commission's White Paper on nutrition and obesity.

- Research programmes: The Public Health Programme 2008-2013 specifically provides for systematic collecting, processing and analysis of comparable data in order to support health policy-making. One of the themes for projects to be supported under the Seventh Research Framework Programme (FP7) is concerned with optimizing the delivery of healthcare to European citizens, including translation of clinical outcome into clinical practice, enhanced disease prevention and better use of medicines.

Contributions from Members of the European Parliament

Dr Adamou is a physician and a member of the European Parliament Committee on the Environment, Public Health and Food Safety. He commented on the growing consensus that the time has come to deal with the growth in diabetes prevalence. Within the context of the EU institutions, although healthcare provision is the responsibility of the member states, and therefore the EU can only take initiatives in complementary cross-border actions e.g. public health threats, patients' rights and reducing health inequalities, he felt that the extent of concern about diabetes demanded that action should replace rhetoric. Only by sharing data and best practices, he felt, would EU citizens benefit fully from the separate efforts of their national governments in fighting diabetes. In 2007 over 25 million people in the EU are affected by diabetes, of which half are as yet undiagnosed. In Dr Adamou's own country – Cyprus – diabetes affects 10% of the adult population in 2007, which is a 5.2 % increase in relation to 2001.

This serious increase in diabetes is happening at a time when national resources for social care are constrained and under pressure for maximum efficiency. The ageing population and the rise in type 2 diabetes, especially among young people, through lifestyle changes represent a double problem requiring a new, different approach.

Adamos Adamou MEP

Dr Adamou stated that the European Commission should examine existing successful models to deal with this double burden, with appropriate regard for the principle of subsidiarity (the principle that the EU takes action only if and so far as the objective cannot be achieved by the member states) and recognizing that health issues are the responsibility of the member states. For example, development of national cancer plans with the help of the Commission has focused attention and resources on cancer. A similar approach on diabetes to encourage

national diabetes management plans could be a major step forward, encouraging the exchange of comparable and transparent data between the member states.

The Commission has a vital role in coordinating existing and future activities in this area. While health is the competence of the member states, there are now 27 different health systems and so there is a need for coordinated sharing of data. Investing money in prevention, early diagnosis and better treatment of diabetes will ultimately be profitable to Europe's economy; not only to the individual people with diabetes.

Frieda Brepoels MEP

Frieda Brepoels, from Belgium, is also a member of the European Parliament Committee on the Environment, Public Health and Consumer Safety. She outlined recent developments in the political call for action against diabetes, and discussed how the launch of the Changing Diabetes Barometer ties in with the political agenda of both the EU and its member states.

The Austrian Presidency in the first half of 2006 supported the prioritization of diabetes by the European Parliament's declaration, but the Council did not adopt a recommendation for an EU diabetes strategy. The Commission's actions until now have focused on the determinants of type 2 diabetes, e.g. in its White Paper on nutrition, overweight and obesity which focuses on the link between the rise on obesity and that of type 2 diabetes, its communication on alcohol-related harm and a number of projects under the Seventh Research Framework programme. The Commission is clearly taking supportive steps in the right direction, even though an EU strategy is not yet in place.

Frieda Brepoels stressed that the collection of data is of vital importance in order to define the weak points, to learn from others and establish a targeted approach. In Belgium, for example, the Belgian Diabetes Register records people with diabetes under the age of 40, so it is primarily concerned with type 1 diabetes and does not offer a complete view. The Changing Diabetes Barometer, she believes, can provide an important stimulus to encourage member states to fill in the gaps and accelerate change.

Cooperative action at EU level is also highly desirable, and an efficient EU strategy for prevention, diagnosis and control would add great strength to attempts at data collection and prevention. The EU is already supporting a number of public health research projects in this area, e.g. European Core Indicators in Diabetes (EUCID) and the European Diabetes Indicators Project (EUDIP) which preceded it, but a more unified approach is needed to collecting and sharing data. The Changing Diabetes Barometer could help to trigger this new approach.

A view from the European Commission

Philippe Roux is Deputy Head of the Health Determinants Unit, DG Health and Consumer Protection of the European Commission. This is one of seven units within Directorate C: Public Health and Risk Assessment; its mission is to improve the health of European citizens and reduce health inequalities through addressing health determinants, including lifestyle; and to develop initiatives to prevent diseases with a major impact, including diabetes. He described the unit's position as an 'honest broker' between the producers of data, the healthcare providers, the policymakers who are devising preventive strategies, and the politicians.

Philippe Roux

He explained that the Commission aims to strengthen links and partnerships with other players related to health and nutrition, for example the high-level group of experts in nutrition and physical activity, the EU platform on diet, physical activity and health and many others including the WHO. The Commission is also supporting public health improvements through relevant research initiatives.

In response to a question from Jakob Riis on the potential role the Changing Diabetes Barometer could contribute to the European Commission, Philippe Roux confirmed that this initiative to gather and exchange information was welcomed and was very close to some of the Commission's initiatives.

What diabetes means to the individual

Christian Petersen and Benny Schatz, two Danish people with diabetes, shared their individual experiences, which illustrate graphically the implications of an early and a late diagnosis.

Christian Petersen, now 26, was diagnosed with type 2 diabetes at 18 years through a routine health check related to obtaining his driving licence which showed HbA1c of 9.1%. At that time his former very active swimming regime had lapsed and his weight had gone up to 135 kg. He was referred to a diabetes centre, where following recommendations on diet and exercise he was able to reduce his weight by 30 kg and his HbA1c to 7.2%. Christian now feels well and has plenty of energy; he feels in control and is enjoying his life.

Benny Schatz is now 58 and was diagnosed with type 2 diabetes at age 38. His father also had diabetes and suffered a heart attack, but lived a further 25 years. Benny's early treatment was with diet; later with oral antidiabetic drugs and then insulin. At the beginning he was relieved at the treatment chosen, but looking back he wishes he had been given insulin much earlier. He is now suffering from a number of complications including trigger fingers, neuropathy, eye and kidney problems, and a rare complication involving collapse of bones in the foot requiring extended rest periods. Benny has had three periods of several months off work, ending with having to leave his job. He now feels that he has a good quality of life, with a lot of activities and energy, provided he can keep a good check on blood sugar, but feels concern at the prospects for his 19-year-old daughter.

Diabetes in the developing world

Professor Jean-Claude Mbanya, Vice Dean and Professor of Medicine and Endocrinology from the University of Yaoundé, Cameroon spoke about the implications of the diabetes pandemic for developing countries.

Out of the 246 million in the world who have diabetes today, becoming 380 million by 2025, more than 70% are in developing countries. Diabetes is not just a disease of rich countries. Over 400 million are at risk of developing diabetes if nothing is changed: to do nothing is no longer an option.

Professor Jean-Claude Mbanya

"Despite estimates showing that the number of people with diabetes will rise to 380 million worldwide by 2025, the Changing Diabetes Barometer report shows that only a handful of countries have the necessary systems in place to measure diabetes and its effects on the population. If we act now by taking lessons from the Barometer, we can improve knowledge, treatment and awareness of the disease."

Jean-Claude Mbanya, Vice Dean and Professor of Medicine and Endocrinology at the University of Yaoundé, Cameroon

The UN Resolution was an international recognition of diabetes as a major disease of the world, and it urged national governments to develop national diabetes programmes. If they

are to do this and to improve diabetes care, they need to develop measures to exchange and compare ideas on best practices. This is the beauty of the Changing Diabetes Barometer; that it will map what is happening in many countries and give data on best practices. Healthcare providers and policymakers in all countries will benefit, but especially those in developing countries who often lack the resources to develop their own plans for improvement.

Conclusion and next steps

Jacob Riis facilitated questions from the audience.

Asked how people with diabetes could use the Changing Diabetes Barometer to gain better care (Kajsa Wilhelmsson, Health Consumer Powerhouse), Professor Jean-Claude Mbanya explained that it is a tool for enabling dialogue with doctors. People with diabetes will have access to information on care available from other treatment centres, and will be able to discuss their own treatment more effectively with their own doctors. The panel was further asked when the country-by-country results would be available – these are expected to increase in quantity and flow over time, as healthcare professionals and policy-makers become more aware of the initiative's potential. Professor Vespasiani noted that in Italy, data collection is constantly increasing and has improved at every stage.

An audience member from France asked how GPs can use the Changing Diabetes Barometer to improve their diabetes care. The panel explained that GPs and specialist centres could use the information to identify which other GPs and clinics had better health outcomes, and to see how they were being achieved. This would identify the scope and specific areas for improvement, so patients would benefit. The Changing Diabetes Barometer would show the strengths and weaknesses of existing healthcare systems and identify, through the prevalence of complications, those where diagnosis is typically late.

Erick Savoye from the European Men's Health Forum believed the Changing Diabetes Barometer was an important initiative, and agreed that (relating to the economic examples) more 'Peters' would be ideal. However, he suspected that in practice there would be more 'Pauls', meaning people who are less well educated, poorer and need much more encouragement to seek medical care which would enable early diagnosis of diabetes. Targeted screening could be one answer to this problem, and Philippe Roux confirmed that the Commission would be examining the possibilities for screening to support earlier diagnosis of diabetes, in the context of the EU strategy for health. He also stressed that the EU Public Health Programme represented an important resource for people and organizations developing systems for collecting and sharing health outcomes data, and recommended that an approach to the Commission should explore development of the Changing Diabetes Barometer in that context. Similarly, the FP7 theme on healthcare delivery could be a useful route for initiatives to reduce inequalities in access to information and to healthcare.

In conclusion, Jakob Riis encouraged the journalists present to draw attention in their own countries to the diabetes pandemic, and to the Changing Diabetes Barometer as a tool in the process of measuring diabetes care in order to improve it.

In particular, five key aims for the Changing Diabetes Barometer were set out:

- To take action to drive change at the national level
- To collect more and better data
- To expand the number of countries covered
- To report examples of best practices to inspire action
- To publish further Changing Diabetes Barometer Reports annually.