Global Changing Diabetes Leadership Forum

executive summary

New York, 13-14 March 2007

changing diabetes

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1. Introduction

On 12-14 March 2007, Novo Nordisk hosted the Global Changing Diabetes Leadership Forum in New York. The Forum was supported by the International Diabetes Federation (IDF). The objective of the Leadership Forum was to spark a worldwide change in diabetes care by sharing knowledge and inspiring participants to address the diabetes pandemic in their home countries. To that end, 185 politicians, senior representatives of governments, international organisations, patient organisations, healthcare professionals, academia and media from more than 21 countries were invited.

The meeting commenced with two workshops. One in which Professor Elizabeth Teisberg shared her and Professor Michael Porter's ideas on redefining healthcare around value for patients over the full cycle of care – from prevention and diagnosis through recovery to long-term disease management. And one in which eight people with diabetes shared their personal experience of how diabetes has affected their lives.

Former President Bill Clinton set the stage for the plenum session with a passionate keynote address. President Clinton underscored that we need to confront the state of denial and inaction which surrounds diabetes. If we fail to give people with diabetes the long and healthy lives we are capable of giving them, we will not be forgiven.

Following President Clinton's speech, a distinguished faculty representing patients, thought leaders, diabetes experts and policy-makers in the format of a Socratic Dialogue discussed what our future would look like if the pandemic is not addressed and current predictions of a 2025 world with 380 million people with diabetes come true. Then they were challenged to imagine a different reality. One in which the pandemic is defeated, and to share their thoughts on how we got there.

Inspired by the Socratic Dialogue, the different national delegations were asked to formulate and commit to specific proposals for changing the state of diabetes in their home country.

The meeting concluded with a Commitment for change session and media briefing in which IDF and Novo Nordisk, among others, made a number of concrete commitments to changing diabetes.

This document pinpoints key conclusions of the conference, highlights comments from individual participants, and concludes by presenting commitments made by the national delegations, IDF and Novo Nordisk. Individual participants are not responsible for the conclusions drawn by Novo Nordisk or the setting in which their quotes have been placed.

The Challenge: current trend line of the diabetes pandemic

The current trend line of the diabetes pandemic is not sustainable. Diabetes could become the worst pandemic of the 21st century. Today, already more than 246 million people worldwide have diabetes. This number increases by 7 million people every year, killing as many people as HIV/AIDS.

If the pandemic is not confronted with new measures and brought under control we are likely to have a rate of diabetes of 20% in urban areas of the developing world by 2030. The rate will be so high that there will hardly be a single person on the planet that will not be affected in some way by diabetes. In Oman and Sri Lanka this scenario has already become reality and the same is true for certain neighbourhoods in New York.

Diabetes – and its frequent companion overweight – is already a heavy economic burden on society, and poor health could replace gender and race as the number one discrimination factor in the future. Hence, employees and insurance companies are already increasing their efforts to shield themselves from the burdens of employees and customers with poor health.

Now is the time to act. If we fail to confront the pandemic we will not be forgiven by the people who live shorter and poorer lives than they deserve. Neither will we be forgiven by the families and communities who will share and carry the human and economic burden of the disease.

Quotes:

Dr V Mohan, chairman of Diabetes Specialties Centre and director for Madras Diabetes Research Foundation [about situation in 2030 if the diabetes pandemic is not addressed]: *"The economy, which is growing very rapidly, has suddenly started slowing down, because the young people are getting involved and so the earning capacity has gone down, because the people that should be at their peak are now affected with kidney disease, eye disease, heart attacks, and aren't able to perform as they were doing 20 years ago."*

Malcolm Gladwell, journalist and author [about situation in 2030 if the diabetes pandemic is not addressed]: *"I would think that the biggest indication would be that health would replace race and gender as drivers of discrimination… If in this country [the United States, ed], for example, we didn't change our healthcare system. It would become so prohibitively expensive for businesses to have people with this disease on their payroll that they would start to take active steps to avoid hiring people at this risk in the first place."*

Dr Emilio Carrillo, New York Presbyterian Healthcare System: *"…the story 30 years from now is now, because you have neighbourhoods in New York populated dominantly with Latinos and African Americans with diabetes rates of 18%."*

Breaking the curve of diabetes and its complications

Diabetes could become the worst pandemic of the 21st century. In order to bring the pandemic under control and break the curve of people with diabetes and the curve of people suffering complications from diabetes, we have to simultaneously pursue a number of strategies and actions:

- We need to address the state of denial among policy-makers
- We need a concerted policy approach
- We need a global mindset and global action
- We need to inform and engage the public
- We need to take a full cycle approach
- We need to measure results at the level of the individual
- We need to promote transparency
- We need to get the private sector involved
- We need to address lifestyle and change the societal framework.

Solution 1:
We need to address the state of denial among policy-makers

It is a prerequisite for political and civil society action that the public and decision-makers understand the scale, causes and consequences of the diabetes pandemic. Although the facts speak a clear language, diabetes is surrounded by denial and ignorance. We have to move the facts into the public arena and drive the issue higher up on the political agenda.

Quotes:

Senator for Tasmania Guy Barnett: *"Before you can fix a problem, you have got to be able to acknowledge the problem."*

IDF President Martin Silink: *"The diabetes world has to develop a political voice. And if you look at the United States, there are 20 million people with diabetes. Every one of those has one, two or three relatives who are indirectly affected. So you're not dealing with 20 million, you're dealing with 40 or 60 million. And the sad reality is what an isolating disease diabetes is."*

Professor David Matthews, Oxford Centre for Diabetes, Endocrinology & Metabolism: *"Now if everybody who didn't get decent diabetes care dropped dead within three years, I can tell you that everyone would run around like headless chickens. But the problem is the chronicity of this and the political imperative to say: Well, it's not going to happen on our patch. It's going to be someone else's problem."*

Solution 2. We need a concerted policy approach

At the national level there is a need to move away from 'silo thinking' and cost-shifting. We can only defeat diabetes if the fight is given the highest priority and confronted with concerted policy efforts. Therefore defeating diabetes should not only be the concern of the health minister. It should be the concern of the whole government.

Quotes:

Former Mexican Health Minister Julio Frenk: *"Ministers of health need to be able to talk to ministers of finance and tell them that this is not just a humanitarian issue – which it is – but it's a fundamental economic issue that we will not grow our economies, we will not become competitive, we will not be able to participate in the global economy if we don't have a healthy workforce. We need to talk to prime ministers and presidents and show them that this is much more than a public health crisis. It's a security issue, and this is what diabetes is, because it does break the fabric of society."*

Solution 3: We need a global mindset and global action

We need to recognise that diabetes is not the problem of individual patients, communities or countries. In today's global world we are dependent on each other. Diabetes is not infectious, but modern lifestyles and humanitarian crises move quickly across borders. Global and local action needs to go hand in hand. We cannot get away from each other. And global solidarity is both a moral imperative and sound economic logic.

The recently adopted UN Resolution on diabetes is a chance to develop a political voice for the diabetes cause. And while diabetes is a slow and silent killer the diabetes world can learn a lot from the fight against HIV/AIDS both when it comes to securing funds, conveying the human story and making a convincing case that the disease is a global security and economic issue.

Quotes:

Former Mexican Health Minister Julio Frenk:
"We think of globalisation mostly in terms of movement of people and microbes. But it is also lifestyles. And if we do not act globally, what is going to happen is that this will become increasingly an epidemic of poor countries. The term 'globesity' is very accurate.

We were able to position AIDS not just as a public health problem but also as a barrier to economic development and as a global security issue. And this is what we need to do with diabetes."

IDF Youth Ambassador Clare Rosenfeld:
"The world is at a tipping point right now… We have an opportunity to create a political voice like we've never had before. With the UN Resolution, we have more legitimacy at this point in time as a cause than we have ever had.

Solution 4: We need to inform and engage the public

Lack of awareness and readiness to act is not restricted to decision-makers. There is a need for public campaigns targeted at the public at large – particularly with regard to type 2 diabetes and the related obesity problem. Here the challenge is to learn from successful campaigns aiming at changing mass behaviour such as campaigns against drunk driving. The difficulty is to create effective campaigns without stigmatising a group that is already at high risk of discrimination.

Quotes:

Malcolm Gladwell: *"…the three great success stories in behavioural change over the last 25 years are smoking, seatbelts and drunk driving. In each one of those cases, the real engine of success was stigmatisation of the behaviour. We made the smokers feel like bad people. We made the drunk drivers feel like criminals. And we made the people who didn't wear their seat belts feel like they were betraying their families. Now we have a question which is: Do we want to do this with diabetes? I do not think we do. But if we don't want to stigmatise the behaviour that carries enormous social and political costs, then we need another arrow in our quiver. We've taken away our most powerful social tool. Because the one thing we've proven we can do is stigmatisation as a means of driving behaviour.*

Solution 5: We need to take a full cycle approach

Too many healthcare systems are fractured. They undervalue preventive care and overvalue acute care. We need to recognise that the diabetes risk is a continuum that begins before birth and continues throughout the life cycle. Until we pay attention to the life of people over the entire cycle of the diabetes journey from prevention and to proper treatment of late-stage complications we pay a high price.

Just as with the efforts to deal with global warming, no single strategy will defeat diabetes. And just as with the efforts to cope with global warming a short-term cost-containment strategy can have serious medium and long-term consequences.

The point of departure should be prevention and access to care for all citizens - restricting coverage only drives up costs because people seek help too late, or even worse, do not receive treatment.

For those who are diagnosed with diabetes, treatment should be organised around practice units that integrate the talent required to deliver outstanding care over the entire care cycle.

Quotes:

Dr Francine Kaufman: *"We take a family and team approach; It is our belief that when a child has diabetes, the whole family actually has the disease. And by working in teams of doctors, nurses, nutritionists, social workers and community health workers, we can bridge the gap between the medical centre and the community. This is essential because treating diabetes is both disease and lifestyle management."*

Solution 6: We need to measure results at the individual level

Data on the relationship between treatment and treatment outcome for people with diabetes are sporadic even in the most developed countries. In effect, we are driving the fight against diabetes in the dark. High quality treatment and innovation builds on good outcome data at the level of the individual patient. And sound competition matching patients with excellent providers requires publicly available databases with aggregate data.

The lack of data leads to poor prioritisation of care for the individual patient over the diabetes journey and it is conducive to an environment where the actors in the healthcare system shift costs between them instead of focussing their efforts on providing the best possible health outcome for the individual citizen.

High quality measurement of outcomes is not science fiction. It is already being done within several therapy areas, and systematic collection of heart surgery statistics is probably the most prominent frontrunner.

Quotes:

Professor Elizabeth Teisberg: *"If you want to improve results for patients, you have to measure results. We all know in many aspects of our lives that what you measure will improve. You have to focus that attention."*

Dr Francine Kaufman, head of Center for Diabetes, Endocrinology and Metabolism at Children's Hospital Los Angeles: *"Some of the measures we use are quite hard, like the hbA1C and the cholesterol and the blood pressure and the height and weight. Others are process measures of what exactly we are doing in our clinic. Do we get the team members to see those patients as often as we want to?"*

Dr Jonathan Brown, senior investigator, Kaiser Permanente Centre for Health Research: *"I have studied Kaiser Permanente (KP), a large non-profit health plan, for some time and our findings are quite extraordinary. Rather than focussing on process, and paying physicians USD100 every time they do something, the focus at KP is on measuring outcomes. And it appears that the cost per person with diabetes in the KP system is about half of what it is in the rest of the country. With results that are generally superior, and in many cases a lot superior, to the average."*

Solution 7: We need to promote transparency

The lack of solid outcome data at the individual level makes it difficult for citizens to exercise enlightened democratic choices. In addition, the lack of transparency is a barrier to sound political prioritisation. It hides the size of the pandemic and hinders best practice learning within and between countries. Therefore we need to systematically collect information on the status of diabetes and diabetes treatment in all countries, and make this information easily available for the public, healthcare professionals and political decision-makers.

Quotes:

Former Mexican Health Minister Julio Frenk: *"You need to evaluate and compare providers. But you need to have assessment at the system level as well to drive change. No government wants to be shown to be neglecting such a big health problem or to have a huge problem of access, or lack of access on their part, or have its own citizens becoming impoverished because they cannot pay their care."*

Solution 8: We have to get the private sector involved

The private sector has an important role to play in defeating the diabetes pandemic. Diabetes is as much the issue of employers as anyone's. Employers are carrying a large part of the costs of poor health and they form part of the cornerstones of building communities. It is in the enlightened self interest of private companies to support healthy lifestyles and ensure early access to healthcare of their own employees.

Quotes:

Professor Elizabeth Teisberg: *"Some of the companies who have taken a broader view have started to ask: In addition to what we are spending on health benefits, what are we spending on*

the costs of poor health? And the companies that I have talked to have found that the cost of their employees poor health is 2.5–3 times higher than the direct cost of health benefits. So not investing in quality care is a short-sighted view and will end up costing more."

Malcolm Gladwell: *"…the group that has to play a much larger responsibility in this fight is the private sector. The CEO of General Motors should be on this panel…his shareholders are going to pay more for diabetes than any other single individual in the United State."*

Solution 9: We have to address lifestyle and change the societal framework

Changing diabetes is not only about diabetes management, it is at least as much about lifestyle management. And awareness campaigns will not do the job alone. We have to change the living environment of people and make healthy choices available. If fast food is the cheapest meal in the neighbourhood and grocery stores are few, we let people with few resources down. If workplaces where citizens spend most of their time do not take responsibility for creating an environment that stimulates exercise and a healthy diet too, few employees will succeed in living healthy lives. And if urban planning is made for cars instead of walkers, joggers and cyclists, only a minority of citizens will get the daily exercise they need.

Legal steps – such as banning commercials for unhealthy products or banning products entirely – are controversial. However, there are a number of encouraging examples where the fast food industry on a voluntary basis has accepted to strike deals concerning healthier food products.

Quotes:

IDF Youth Ambassador Clare Rosenfeld: *"I think we need to make sure that we have physical education courses for the students. And we need to stop feeding junk to kids in the lunch lines. If kids from a very young age are learning about how tasty salads are and there aren't candy machines in every hallway, and if they're getting physical activity every day, then that becomes a part of a life pattern."*

Dr Francine Kaufman: [about impoverished area in South Los Angeles, Watts, where 40% of the children are obese as opposed to a national rate of 17,1%]: *"They have one grocery store for 38,000 people versus the rest of LA that has one grocery store for 7,000 people. They have no place you can walk that's safe. And you can go on and on and on why some child could end up weighing 500 lb and die. We talk about personal responsibility, but that environment – we call it obesogenic – it's near fatal.*

Professor David Matthews: *"We have to look at Urban planning. If you take Denmark, for instance, Copenhagen is one of the most friendly cities for cycling. If you cycle in London your life expectancy is about four minutes. We also know that architects can design buildings where there are stairs as well as lifts. The reality is that we can get architects to do something, we can get schools to do something, we can get governments to do something."*

Senator for Tasmania Guy Barnett [about McDonald's issue, ed]: *" As a legislator, I would strongly protest against banning fast food. I think the way to go is to encourage the fast food industry to offer healthy food. And actually in Australia, McDonald's have provided and undertaken reforms to offer more healthy foods. They've lowered the sugar and fat and salt contents in all their food. So I think, let's not get the legislators to try and fix this problem by banning this or banning that. If we can get those industries to the table to talk about it, they can become part of the solution rather than part of the problem."*

Taking it home

The national delegations confirmed the conclusions of the Socratic Dialogue and detailed a number of concrete proposals for national actions. It was recommended that action should be anchored centrally in the decision-making process and characterised by cross-party and cross-sector cooperation. Among the top contenders for national focus areas and actions were:

- Campaigns to heighten the awareness of the disease at all levels – from the general public and to decision-makers
- Better data collection and transparency
- Intensified efforts to prevent diabetes – including healthier school lunch programmes
- Earlier detection through better education of healthcare professionals and/or screening programmes.

Also, the delegations from developing countries underscored that diagnosis and access to treatment are not a given in large parts of the world and must be addressed before we can even begin to address the issue of how we improve care.

Several delegations pointed to very specific activities that they were already engaging in or committed to pursuing in the future.

Three of these initiatives lay in the area of ensuring a concerted policy approach in dealing with diabetes:

- The Italian delegation singled out the need for cross-sector partnerships and a concerted government effort. In particular, they have committed to lobby for the establishment of a clearly defined government agency dealing with diabetes and metabolic diseases under the leadership of the health minister. One of the purposes of the agency would be to ensure cross-ministerial engagement for the fight against diabetes. In particular, the Italian delegation envisioned that the Ministry of Social Affairs and the Ministry of Finance should become closely involved in a more collective government effort.
- The US delegation recognised a need for a unified and coordinated effort across the entire federal government to align and maximise the return to federal spending. This effort should be led and coordinated by a new White House level National Diabetes Coordinator.
- The Australian delegation shared their positive experience of a very active bi-partisan Parliamentary Diabetes Support Group which was established in 2000 to raise awareness, promote policies that address the disease, and engage in dialogue on the issue with parliamentarians in other countries.

Among the other policy proposals were national resolutions to recognise the UN-observed Diabetes Day, tax deductions for expenses related to sports and tax incentives to grocery stores offering healthy food, and embedding a module on diabetes prevention in existing national food and nutrition programmes.

Commitments for change

A number of concrete commitments were taken at the Forum:

On behalf of IDF, Martin Silink committed to developing a stronger political voice, and making The Blue Circle of Diabetes as known as the Red Ribbon of AIDS. IDF will also explore the possibility to create a global diabetes fund. The objective of the fund would be to attract, manage and disburse additional funds through private-public partnerships based on model of the Global Fund to fight AIDS, TB and Malaria (GFATM). In addition, Martin Silink committed to:

- Updating the Diabetes Atlas and making it available electronically free of charge with annual updates
- Continuing the Unite for Diabetes campaign to ensure that the UN Resolution on diabetes is being implemented
- Conducting a Global audit (register) over countries with diabetes plans.
- Developing partnerships with governments, UN organisations, other NGOs, civil society such as Rotary, philanthropic organisations and industry.

Lars Rebien Sørensen, CEO and President of Novo Nordisk committed to publishing a diabetes barometer on an annual basis and launched first time on 1 November 2007. Mr Sørensen emphasised that better outcome data at the patient level are pivotal – things that get measured get done. The barometer will be a global and national baseline measuring both the policy efforts and the outcome of these efforts at the level of individual people with diabetes. In addition to that Lars Rebien Sørensen committed to:

- Driving change and best practice examples on the ground through pilot projects. The commitment has already resulted in four pilot projects in different parts of the world: a screening programme in India, an educational programme in Sweden, target setting for a national diabetes programme in South Korea and a University Partnership in the United Kingdom, all demonstrating improved outcomes.
- Creating an internal Novo Nordisk incentive scheme which will measure and reward country managers based on their ability to improve outcome at the patient level.
- Working closely together with other parties, including international organisations and patient organisations, to keep the momentum from the UN Resolution and the Leadership Forum.
- Making data and results publicly available to ensure transparency and measurability.

IDF Youth Ambassador Martin Salkow committed to setting up a youth network in his home country, South Africa, which would give young people with diabetes a voice and address the stigmatisation of the disease.

Dr Francine Kaufman committed to using her position as chair for the Governor of California's Diabetes Task Force to bring all stakeholders together to evaluate ways to measure outcomes and to mobilize local communities and hereby create a model of family education that could be copied throughout the nation.

Senator for Tasmania Guy Barnett emphasised the need to deal with obesity through better diet and exercise. He committed to dealing with the obesogenic environment: working with the fast-food and advertising industry to develop choices, providing better canteens and improve exercise opportunities for children. Another priority would be free medical check-ups of citizens above 45 and promotion of an obesity declaration with clear targets for the nationwide decrease of obesity.