Diabetes

EU POLICY RECOMMENDATIONS

ATTENTION
URGENT

FEND
Federation of European Nurses in Diabetes

International Diabetes Federation
European Region

FOREWORD

The International Diabetes Federation – European Region (IDF Europe) and the Federation of European Nurses in Diabetes (FEND) are pleased to present this paper *Diabetes: EU Policy Recommendations* as a contribution to the Austrian Presidency of the EU (January-June 2006), and as input to the future work of the European Commission on one of Europe's most critical public health issues, diabetes.

Diabetes has become a serious threat to both the lives and well-being of an increasing number of European citizens. Indeed, in the EU today, more than 25 million people are estimated to be living with diabetes, and all of them are at risk of developing the devastating, disabling complications associated with the disease such as kidney failure, blindness and amputation. Diabetes is also the major contributor to cardiovascular disease, the EU's biggest killer.

The results of the IDF Europe/FEND national diabetes policy audit in 2005 revealed stark inequalities in the prevention, diagnosis and control of the disease across the 25 EU Member States and highlighted the need for decisive EU policy action. The findings of this report (available at: www.fend.org or www.idf-europe.org) form the basis of a benchmarking process which should now be undertaken at EU level in order to share best practices and to raise standards in tackling the disease across Europe.

In the recent WHO report *Preventing Chronic Diseases: A Vital Investment (October 2005)*, it is emphasised that the increasing importance of chronic disease should be *'anticipated, understood and acted upon urgently.'* Furthermore, the report emphasises the need for *'a new approach by national leaders who are in a position to strengthen chronic disease prevention and control efforts'*. We believe such action to be essential in reducing the growing diabetes burden at a personal, societal and economic level.

IDF Europe and FEND are delighted with Austria's decision to make Type 2 diabetes one of its key public health priorities during its EU Presidency in the first half of 2006. We regard this as an encouraging step forward for people suffering from diabetes in Europe. To ensure that this unique opportunity will be used to deliver tangible and meaningful outcomes for those living with diabetes, there must now be a decisive move towards an EU policy framework in the form of a proposal for an **EU Council Recommendation on Diabetes Prevention, Diagnosis and Control**. This paper outlines a set of EU policy recommendations which we invite the Commission to draw upon in developing such a proposal.

We believe strongly that it is now time to move beyond awareness-raising and towards tangible EU policy action on diabetes. We call upon the EU's leaders to support these recommended actions for the benefit of those suffering from, treating, or affected by diabetes. This will also contribute to making the EU directly relevant to its citizens, which today is genuinely needed.

We take this opportunity to thank the Policy Working Group for their time and invaluable contribution to this initiative, which was coordinated by our EU public policy consultants, Burson-Marsteller Brussels, and supported by unrestricted educational grants from the corporate partners of IDF Europe and FEND. The findings, conclusions and recommendations are entirely the responsibility of the Policy Working Group of IDF Europe and FEND.

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WHY ACT ON DIABETES?

"Diabetes is the chronic disease health crisis of the 21st century"

The Independent newspaper, 6th October 2005

REDUCING THE INCIDENCE

Europe's growing obesity epidemic, its aging population and our increasingly sedentary lifestyle have led to an explosion in the incidence of diabetes, particularly Type 2 diabetes, across the European Union. With an average EU prevalence rate of 7.5%, a predicted growth rate of 16% by 2025, and up to 50% of diabetes cases currently undiagnosed[1], this crisis is a reality today and the time for every country in Europe to act – together with the EU itself - is now.

ADDRESSING THE INEQUALITIES

A recent policy audit on diabetes, carried out across the EU, revealed that only 11 out of the 25 Member States have a national framework or plan in place[2] and even these suffer from glaringly different levels of implementation. These stark differences have resulted in severe inequalities in the standards of diabetes prevention, diagnosis and control across Europe. Patients, both diagnosed and undiagnosed, are suffering needlessly as a result.

Preliminary results from the Eurodiale project, a prospective data collection study and analysis of healthcare models, indicate that the estimated foot amputation rate for people living with diabetes ranges from 6.6 per 1000 people in rural Germany, to 3.61 in the Netherlands and 2.6 in the UK. The study reveals that management strategies still need significant improvement in order to improve diabetic foot care and to prevent amputations.

Member States with the highest standards of healthcare now have the responsibility to raise the bar for all EU Member States, not only to share their best practices, but also to help reduce inequalities across the EU25 allowing patients equal access to high quality healthcare in their own countries. With the increase in patient and health professional mobility in an enlarged Europe, ensuring continuity of care for people with diabetes moving across borders is essential.

CONTAINING THE COSTS

One of the most compelling reasons for Member State governments to take immediate action on the prevention, diagnosis and control of diabetes, is to contain the dramatic rise in the costs of diabetes. These are projected to increase rapidly with growing prevalence rates and the disease's wide-ranging and invariably costly complications. Diabetes currently accounts for between 2.5-15% of total healthcare spending in Member States[3], representing up to €50billion in spending per annum.

Only half of the EU's Member States have even estimated their total healthcare expenditure on diabetes and, significantly, it is mainly these countries that have developed comprehensive national plans to tackle the disease. Finland is one country which has taken decisive action to address the diabetes epidemic. This followed an economic analysis in 1997 by the Helsinki Hospital District, which revealed that no less than 11% of healthcare spending could be attributed to diabetes and that this cost was estimated to increase to 19.3% by 2010 if prevalence rates continued to rise.

Putting policies in place to address the diabetes epidemic will not be without costs but Member States also need to assess the cost of inaction. Ignoring the growing numbers of people living with diabetes and relying on treating diabetes patients with complications as an instrument of policy is at least twice as costly as treating someone with controlled diabetes. Such compelling facts are as relevant to finance ministers and health ministers as they are to the individual citizens of Europe.

Diabetes must be recognised as a European public health priority and this requires a coordinated, integrated and sustained European public health strategy.

[1] Diabetes The Policy Puzzle: Towards Benchmarking in the EU - IDF/FEND Report (2005)
[2] Diabetes The Policy Puzzle: Towards Benchmarking in the EU - IDF/FEND Report (2005)
[3] Diabetes The Policy Puzzle: Towards Benchmarking in the EU - IDF/FEND Report (2005)

MEETING THE DIABETES CHALLENGE IN EUROPE?

"Respecting national responsibility does not mean doing nothing at European level"

David Byrne, former EU Health Commissioner

EU COMPETENCE ON HEALTH

While EU legislative authority over healthcare is limited, the European Commission recognises, as do European citizens, that there is a need to facilitate European cooperation on healthcare, while respecting the responsibilities of the Member States.

Article 152 of the EC Treaty provides that Community action is:

"to complement national policies and be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health. Such action shall cover the fight against the major health scourges, by promoting research into their causes, their transmission and their prevention, as well as health information and education. Community action in the field of public health shall fully respect the responsibilities of the Member States for the organisation and delivery of health services and medical care."

Despite this relatively limited competence, the European Commission has launched a number of initiatives which effectively lay the foundation for a coherent and more dynamic EU public health policy. These initiatives acknowledge the shared EU and national responsibilities over health, while also recognising the need to create mechanisms which promote greater cooperation and coordination among Member States to benefit all EU citizens on an equal basis. Health considerations are also to be taken into account in all areas of EU policy.

The Commission's proposal for a Programme of Community Action in the field of Health and Consumer Protection (2007-2013) is intended to:

"improve the health of citizens throughout their lives, improve health as a human right and encourage investment in health."

and refers explicitly to the need for:

"the promotion of policies which lead to a healthier way of life helping to reduce the incidence of major diseases."

Furthermore, the European Parliament's Environment, Public Health and Food Safety Committee recently agreed to amend the Programme, requesting the Commission to:

"submit, during the course of this Framework Programme, proposals for Council Recommendations on the prevention, diagnosis and control of major diseases"

EU COUNCIL RECOMMENDATION

One initiative, which has been used previously by the European Commission to promote a more coordinated approach to addressing the health needs of Europe, is through an EU Council Recommendation. Although not legally binding, such an EU legal instrument can create a significant incentive for coordinated action among Member States.

An EU Council Recommendation on Diabetes would:

- promote a tangible focus for action around which Member States, Associated States (EFTA), and Acceding and Candidate Countries (Bulgaria, Romania, the Former Yugoslav Republic of Macedonia, Turkey and Croatia), could improve their prevention, diagnosis and control of diabetes as a means of improving the health of citizens, in pursuance of the goal of the Programme of Community Action in the field of Health and Consumer Protection and the EU Treaty.
- identify measures for prevention, including action on lifestyle issues and access to screening and proper diagnosis; adequate training for diabetes specialist nurses, diabetologists, endocrinologists, general practitioners and others; appropriate investment in medical infrastructure; and improved disease management and control, in particular to ensure a high level of care for those with diabetes who move between Member States.
- support national governments in prioritising diabetes as a public health imperative and in establishing the necessary national action plans to tackle the disease effectively, recognising the contribution of better health to the goal of increasing European competitiveness, as set out in the Lisbon Agenda[4]. It is possible that such a strategy would also contribute to a better and more effective use of finite and limited healthcare resources.

The EU has a significant and justifiable role to play in taking tangible policy action on diabetes

[4] Suhrcke M, McKee M, Sauto Arce R, Tsolova S, Mortensen J. The contribution of health to the economy in the European Union. Brussels: European Commission, 2005

WHAT HAS BEEN DONE? WHAT ARE WE DOING NOW?

"Diabetes...needs to be recognised as a priority for action at European level"

Michéal Martin, former Irish Minister for Health

- On 2 June 2004, at the EU Health Council, Ministers of Health from the 25 Member States were informed of the need for a European strategy on diabetes, similar to the existing EU cancer and cardiovascular strategies. In the conclusions of the Health Council's information note to Ministers, it is stated that:

  "The fast rise in diabetes prevalence in Europe needs to be recognised as a European public health concern beyond merely awareness-raising. Progress made in cardiovascular and cancer strategies demonstrate the merit of addressing conditions like diabetes in a co-ordinated, strategic and comprehensive way across Europe...Indeed, a European strategy for diabetes, a major risk factor of other related diseases such as cardiovascular disease, could make an important contribution to the reduction of public health expenditures in all 25 EU member states."

- On 16 November 2004, during European Diabetes Week, EU Health Commissioner, Markos Kyprianou, and former Commissioner, David Byrne, received the *Otocec Declaration: A Call to Europe's Leaders to Act*. The Declaration, signed by more than 80 representatives of 35 EU and national diabetes associations (patients and professionals), calls upon the EU to take immediate steps to develop an EU Council Recommendation for diabetes prevention, diagnosis and control. On handover, Commissioner Kyprianou stated that he would *"give his full attention to the growing diabetes epidemic and assess how the European Commission can play a positive role in helping Member States to address the issue"*.

- In mid-2005, the Austrian Presidency of the EU (Jan-Jun 2006) announced that it would focus on diabetes as one of its two key public health priorities. Central to Austria's efforts is a planned EU diabetes conference on 15/16 February 2006 in Vienna, the conclusions of which are intended to feed into the informal EU Health Council in April and potentially into the formal Health Council in June 2006.

- In December 2005, in preparation for the Austrian Presidency, IDF Europe and FEND completed a policy audit of national diabetes frameworks in the 25 EU Member States, highlighting stark inequalities in the prevention, diagnosis and control of the disease across Europe. Based on the findings of this report, a set of draft EU policy recommendations on diabetes have now been developed, both as a contribution to the Austrian Presidency in 2006, and as input to the European Commission's ongoing and future work on this public health issue.

DIABETES: EU POLICY RECOMMENDATIONS

The following Recommendations were developed following consultation with key EU diabetes stakeholders and through the formation of an EU Policy Working Group, comprised of experts in the field and national and EU policy makers (members listed on page 8). This working group has reached a broad consensus on the ways in which the EU and its Member States can and should be addressing the diabetes epidemic.

DIABETES POLICY RECOMMENDATIONS

THE EUROPEAN UNION SHOULD:

1. Establish diabetes as a priority in Europe and encourage cooperation between Member States in the exchange of best practice as regards prevention, screening and control of diabetes with a view to raising standards and optimising healthcare resources.

While respecting the national competence of EU Member States, there are significant potential gains to be made from addressing diabetes in a comprehensive and coordinated manner across the EU. There are already examples of individual countries looking to other Member States for best practice in shaping their own national diabetes programmes. For example, Germany has collaborated with Finland in developing a new prevention programme, adapting and incorporating key elements of the well-respected Finnish prevention programme. This should be positively encouraged as a way to reduce the stark inequalities across the EU in addressing diabetes. A permanent forum for exchange of such best practices is required within the EU, in addition to the ad hoc forums created by Council Presidencies.

2. Examine the current epidemiological evidence on diabetes in the EU, by establishing a set of common criteria for the collection of comparative EU data and compiling and reporting on this information across all EU Member States.

If the EU is sincerely committed to 'reducing the incidence of major diseases'[5], there is a clear need for timely, accurate and comparable data on the impact of diabetes in Europe. However, this data is not currently available for diabetes and without it, the EU and its institutions do not have a clear picture of the real scope of the problem and cannot therefore begin to tackle the disease effectively.

3. Report on the existence and implementation of national diabetes plans and prevention programmes, on the basis of the information provided by Member States, assessing the extent to which the proposed measures are working effectively, and considering the need for further action.

The existence of a national diabetes framework or plan is a clear sign that diabetes has been made a government priority and that measures will be put in place to address the growing disease burden and its costly complications. Only 11 out of 25 Member States have an established framework or plan in place[6], varying significantly in their quality and comprehensiveness. Therefore, it is necessary for the EU to consider and highlight the policy gaps in diabetes care provision across Europe. National diabetes plans alone are not a measure of success in tackling the disease, therefore it is also essential for the EU to examine the level of implementation of the plans, their outcomes, and to make relevant proposals where appropriate. Such action is particularly relevant with regard to the increasing patient mobility within the EU and the right of all EU citizens to receive equal access to medical care.

4. Encourage the development and implementation of national diabetes prevention programmes

While the EU's recent initiatives in the area of obesity and chronic disease prevention, such as the EU Platform for Action on Diet, Physical Activity and Health and the European Commission's Green Paper on 'Promoting healthy diets and physical activity: a European dimension for the prevention of overweight, obesity and chronic diseases', are a positive step forward, there remains a limited number of EU Member States with established diabetes prevention programmes.

5. Facilitate and support European diabetes research in basic and clinical science and humanities of care. Ensure the wide dissemination of the results of this research across Europe.

The EU and its Member States collectively offer great potential for the effectiveness and relevance of quantitative and qualitative research in diabetes, its prevalence and associated risk factors. The EU could make a major contribution to research relating especially to the behavioural and epidemiological impact of diabetes in Europe. With appropriate support and funding in this area, genuine added value can be achieved, not least due to the territorial and numerical (population) scale of EU action.

[5] European Commission Proposal for an EU Health & Consumer Protection Programme (2007-2013) - COM(2005)115
[6] Diabetes The Policy Puzzle: Towards Benchmarking in the EU - IDF/FEND Report (2005)

DIABETES POLICY RECOMMENDATIONS

EU MEMBER STATES SHOULD:

1. Collect, register, monitor and manage, on a regular basis, comprehensive diabetes epidemiological data based on common measurement criteria.

In order to develop comprehensive and credible national diabetes policies, Member States require accurate and representative data on the extent and magnitude of the disease, as well as its projected growth rates in order to assess the most appropriate action. Where National Diabetes Registers exist, they are considered to be of significant value to the individual, public health authorities and policy planners at national and local level. The development of a standard dataset is also critical in producing genuinely comparable data between different Member States.

2. Collect, register and manage comprehensive health economic data on the direct and indirect costs of diabetes prevention and management.

While recognising that governments have limited financial resources to allocate to healthcare expenditure, in order to optimise those resources in the areas of diabetes and reach informed policy decisions, they require accurate and representative health economic data on the current and future financial impact of a disease. Only then are they able to assess the most appropriate and cost- effective interventions for tackling the disease. Currently, only 13 out of 25 Member States have estimates of their total expenditure on diabetes.[7]

3. Establish diabetes as a priority in national health policy through the development and implementation of national diabetes plans for evidence-based disease prevention, screening and control, which are founded on best practices. These plans should:

- Define measurable targets for timely implementation;
- Create an evaluation system for all programmes to track health outcomes and cost-effectiveness;
- Receive appropriate financial support.

National plans often lack specific targets and/or a monitoring system to assess the implementation and effectiveness of diabetes policies. Strong political commitment to invest in the necessary infrastructure and systems of care is essential to ensure the successful implementation of national policy, to ensure equity of access and to provide quality of care to people with diabetes throughout the EU. There must be adequate allocation of both human and financial resources to achieve this.

4. Develop and implement public awareness and primary prevention programmes, targeting the population as a whole, as well as individuals at a higher risk of developing diabetes. These programmes should:

- Promote public awareness of diabetes and diabetes-related risk factors;
- Promote a healthy diet and physical activity as key elements of a healthy lifestyle;
- Include specific programmes which identify, and are targeted towards, those at increased risk of developing obesity and diabetes;
- Include specific programmes for children, ethnic minorities and the elderly.

In order to increase the prevention and early detection of diabetes, it is essential to raise public awareness on diabetes and its serious complications By focusing on nutritional interventions and increased physical activity, the risk factors for developing Type 2 diabetes, for example obesity and metabolic syndrome, can be reduced across the entire population. High risk individuals (disglycaemia, hypertension, overweight/obese, family history of diabetes) benefit particularly from more intensive lifestyle intervention which has been shown to delay and even prevent the onset of Type 2 diabetes.

5. Develop and implement targeted and systematic primary screening and diagnosis programmes for high risk populations. These programmes should:

- Identify high risk populations according to national considerations such as epidemiology, health service delivery, population and available resources
- Provide appropriate diagnostic testing following positive screening tests, according to best practice guidelines
- Offer those people with screen-detected diabetes the appropriate treatment, care and self-management skills including structured, therapeutic patient education
- Be supported by local protocols and guidelines, public and healthcare professional education campaigns
- Provide centralised data systems

[7] Diabetes The Policy Puzzle: Towards Benchmarking in the EU - IDF/FEND Report (2005)

The early detection and diagnosis of individuals with existing but, as yet, undiagnosed diabetes through screening, as well as individuals at increased risk of developing diabetes in the future, is recommended internationally as an important strategy for minimising the risk of developing serious complications. Appropriate screening strategies should be defined according to national considerations and diagnostic methods and criteria set according to internationally accepted guidelines, for example, the Global Guideline for Type 2 Diabetes[8] and the Control to Goal Programme[9].

6. Develop and implement secondary prevention programmes aimed at detecting and preventing the development of diabetes cardiovascular, renal, ocular or foot complications in patients with diagnosed diabetes. These programmes should:

- Establish and implement evidence-based, nationally agreed guidelines with targets for disease management;
- Define relevant parameters for monitoring and time intervals for screening;
- Monitor and measure the health outcomes and review policies in this context;
- Address the female gender-specific issues of diabetes including gestational diabetes, diabetes in pregnancy and menopausal/post menopausal states;
- Establish affordable and equitable access to appropriate monitoring and treatment.

Newly diagnosed diabetes should be managed effectively in order to prevent the development of complications – these are not only devastating to the individual, reducing their quality of life, but they are also extremely costly to treat – often up to five times as expensive as controlled diabetes without complications.[10] Through the implementation of secondary prevention programmes and instruction on intensive lifestyle management, these unnecessary costs can be saved.

7. Establish a holistic management approach to people with diabetes. This should:

- Ensure a multi-disciplinary and multi-sectoral approach including primary care, secondary care (specialists), community care, social services and education services;
- Address the issue of discrimination in all areas, including schools, the workplace, driver licensing, insurance, sports and in the provision of healthcare.

People living with diabetes should be empowered to enhance their personal control over the day-to-day management of their condition in a way that enables them to experience the best possible quality of life. Children, young people and adults with diabetes should receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. There is a need for change in political attitudes and legislation on discrimination across Europe in order to reflect changes in the nature and treatment of diabetes.

8. Provide comprehensive and accredited training of healthcare professionals at all levels and in all concerned disciplines including physicians, diabetes-specialist nurses, dieticians, podiatrists, and other specialists. These programmes should:

- Provide ongoing education and training to all healthcare professionals in order to maintain safe practice.
- Establish quality of care measurement as part of normal practice for healthcare professionals

Professional development through accredited post-graduate education should be seen as a continuous process for all health professionals to ensure the delivery of high quality prevention, screening and disease control. This is particularly relevant to diabetes due to the changing nature of the disease and responsibilities for the training of other colleagues.

[8] Global Guideline for Type 2 Diabetes, International Diabetes Federation (2005)
[9] Control to Goal, The Global Partnership for Effective Diabetes Management (2005).
[10] Cost of Diabetes in Europe-Type 2 (CODE-2) Study, 2002

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