

Diabetes Action Now:

WHO and IDF working together to raise awareness worldwide

✎ Nigel Unwin and Amanda Marlin

Even among policy makers at an international and national level, awareness about the public health and clinical importance of diabetes remains low. Diabetes is widely perceived as a condition of low importance to the poorer populations in the world. In the low- and middle-income countries, the impact of diabetes is largely unrecognized. Yet the world is facing a dramatic rise in diabetes prevalence, most of which will occur in the low- and middle-income countries.

This will have a major impact on the quality of life of hundreds of millions people and their families, overwhelm the capability of many national health-care systems, and impact adversely upon the economy of those countries that are in most need of development. In this article, Nigel Unwin and Amanda Marlin report on Diabetes Action Now, an international initiative to raise awareness about the condition and stimulate effective measures for its surveillance, prevention and control.

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Diabetes Action Now is a joint initiative of the World Health Organization (WHO) and the International Diabetes Federation (IDF). The proposal for the Programme was developed as part of the work of a joint IDF-WHO working group, and was made possible by substantial support from the World Diabetes Foundation (WDF). The joint IDF-WHO working group continues to play an important role in *Diabetes Action Now*, forming the Programme's steering group.

Diabetes Action Now

The overall purpose of *Diabetes Action Now* is to raise awareness about the importance of diabetes, particularly in low- and middle-income countries, and to stimulate effective measures for the surveillance, prevention and control of the condition. The funding from WDF is initially for 3 years. However, the size and nature of the problem demands activities over a longer period of time; additional financial support will be sought. >>

Diabetes is a life-threatening condition

- ◆ Worldwide, 3.2 million deaths are attributable to diabetes every year.
- ◆ One in 20 deaths is attributable to diabetes; 8700 deaths every day; six deaths every minute.
- ◆ At least one in ten deaths among adults between 35 and 64 years is attributable to diabetes.
- ◆ Three-quarters of the deaths among people with diabetes aged under 35 years are due to their condition.

Source: *Diabetes Action Now*, World Health Organization, International Diabetes Federation, 2004

For the initial 3-year period of *Diabetes Action Now*, five areas of activity have been identified:

- ◆ work to achieve a major increase in awareness about diabetes, its complications, and its prevention, particularly among health policy makers in low- and middle-income countries and communities
- ◆ initiate and support projects to generate and widely disseminate new knowledge on awareness about diabetes and its economic impact in low- and middle-income communities
- ◆ produce and widely disseminate a

new scientifically-based review on the prevention of diabetes and the complications of diabetes

- ◆ produce up-to-date, practical guidance for policy makers in low- and middle-income countries on the contents, structure and implementation of national diabetes programmes
- ◆ provide and maintain a web-based resource to help policy makers implement national diabetes programmes.

Much of the feedback represented the joint views of multi-disciplinary groups who came together to discuss diabetes issues.

Consultation

These five areas of activity for *Diabetes Action Now* were decided upon after a period of consultation with a broad range of potential partners.

Consultation documents were sent to WHO regional offices and country offices, WHO collaborating centres, IDF regional offices, and the members of IDF task forces. Recipients were asked for three broad types of response:

- ◆ critical comments on the planned programme of work
- ◆ information about relevant work, including planned or ongoing activities
- ◆ suggestions for ways in which the respondents might participate in the Programme.

Around 100 responses were received from people in 43 of the 191 countries that are Member States of WHO; the

majority represented low- and middle-income countries. Many submissions represented the joint views of a number of groups who had come together to discuss the issue. For example, in Belize representatives of the Ministry of Health, Ministry of Education and the National Diabetes Association met to consider their response.

The feedback

Overall scope

The feedback on the proposed programme of work was supportive. However, it was commented that the overall scope appeared to be ambitious, particularly for an initial 3-year period. This emphasized the need for a clear definition of the objectives of the first 3 years.

The primary prevention of Type 2 diabetes forms an important element of the Programme.

Despite concerns about a focus on care rather than prevention, the primary prevention of Type 2 diabetes forms an important element of the Programme. Work in this area will support initiatives of general relevance to the primary prevention of chronic conditions, such as the *WHO Diet and Physical Activity Strategy*.

Awareness-raising

Respondents noted the need to address the perception that diabetes is not a major problem among the people of the developing world. This misleading notion plays an important

role in the low priority given by the major international funding bodies to diabetes and other non-communicable diseases.

A number of people shared experiences of awareness-raising activities in their local areas. However, few examples were presented in which levels of awareness had been measured and awareness-raising activities evaluated. Thus the need was confirmed for new knowledge on the nature and levels of awareness about diabetes.

Feedback confirmed the need for new knowledge on the nature and levels of awareness about diabetes.

The world is facing a growing diabetes epidemic of potentially devastating proportions. Its impact will be felt most severely in the developing countries. WHO and IDF are working together to support ongoing initiatives to prevent and manage diabetes and its complications, and to ensure the best quality of life possible for people with diabetes worldwide. Together we are helping to provide countries with the means to face the challenges that lie ahead. It is time for diabetes action now.

Pierre Lefebvre, President of IDF

Robert Beaglehole, Director of the Department of Chronic Diseases and Health Promotion, WHO



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Communication

A recurring theme in the feedback was the need for printed materials in local languages. It was suggested that the materials which are produced in one country be made available to the people of the same ethnicity and language who live in other parts of the world.

It was also suggested that WHO or IDF act as a 'clearing house' for guidelines, training packages and other materials in order to make these generally available for adaptation and use elsewhere.

Traditional healers and situation analyses

A call was made to consider the role of the traditional healers who are often consulted by people with diabetes. Related to this is the need

for tools to analyze the current approaches to diabetes care and prevention in each country or region. Several examples were cited of rapid assessment protocols which had been used in order to do this (to read more about rapid assessment protocols, see the article by David Beran on page 20 of this issue).

Schools programmes

The importance was stressed of ensuring that diabetes prevention messages reach the schools. One suggestion was to build an awareness-raising campaign around school projects, with, for example, the children preparing posters for some of the key prevention messages.

Standards of care

The need was widely voiced for practical guidance on the implementation of national programmes for the prevention and control of diabetes.

Partnerships

The need was emphasized for collaboration within WHO and IDF, and with other stakeholder groups. New initiatives are unlikely to succeed in the longer term unless effective partnerships are formed.

Our response

The feedback received was valuable in defining the five main areas of work for *Diabetes Action Now* and identifying potential partners for specific actions. A report which >>



The advocacy booklet *Diabetes Action Now* is available free of charge on the IDF and WHO websites: www.idf.org and www.who.org.



diabetes action now

An initiative of the World Health Organization and the International Diabetes Federation

provides a summary of the feedback and gives details of our response can be found at www.who.int/diabetes.

The fact that some of the important points which were raised in the feedback have not been addressed in the plans for the first 3 years of the Programme reflects the need to prioritize, and focus on objectives that are achievable within this initial stage.

Sentinel sites (regions or countries which have been chosen as locations to carry out the work of the Programme in the field) are being identified for the assessment of diabetes awareness and local awareness-raising activities. These sites will provide settings for studies to assess the economic impact of diabetes in low- and middle-income countries.

The key awareness-raising messages

The Programme benefits from the work of the IDF Task Force on Public Awareness. The key messages about

diabetes which were identified by this group have been adapted to reflect the focus of *Diabetes Action Now* on low- and middle-income countries:

- ◆ Diabetes is a life-threatening condition.
- ◆ Diabetes is a common condition and its frequency is dramatically rising all over the world; the biggest impact is on adults of working age in developing countries.
- ◆ A full and healthy life is possible with diabetes.
- ◆ In many cases, diabetes can be prevented.

Action now and in the future

Diabetes Action Now was established in October 2003. In May 2004, WHO and IDF launched the Programme with a joint publication, 'Diabetes Action Now'. This short advocacy booklet presents the key messages about diabetes, supports these messages with new data on prevalence and mortality attributable to diabetes, and outlines the plans for the *Diabetes Action Now* Programme over the next three years. The booklet received international

media coverage and is available free of charge in print and electronic format from the IDF and WHO websites.

Sentinel sites

Work is underway to finalize plans for work in at least four sentinel sites. These have been chosen on the basis of a number of criteria:

- ◆ the burden of diabetes in the chosen setting and its potential increase in the near future
- ◆ the availability of local expertise to undertake the required actions
- ◆ the extent of multi-sector support in the area for this work.

In two of these sites, awareness-raising activities will be undertaken. Assessment of diabetes awareness before and after these activities will help to determine the extent to which increases in awareness have been achieved. These two sites will be Chennai, India, and Dakar, Senegal. In another two sentinel sites, health economics studies will be undertaken to provide much-needed information about the costs of diabetes and related complications in low- and middle-income countries. This work will be carried out in collaboration with the IDF Task Force on Health Economics. It is anticipated that the results obtained

and the methodologies used to achieve these will be of use in other settings. At the time of writing we are in the process of reaching agreement with potential sentinel sites for the health economics studies.

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Prevention

Research and writing is underway to publish a new evidence-based review on the prevention of diabetes and its complications within the next 12 months.

Practical guidance

Diabetes Action Now will also produce up-to-date, practical guidance on the contents, structure and implementation of national diabetes programmes. The guidance will contain two main sections:

- ◆ a generic section that will apply to health-system requirements for all chronic medical conditions, including cardiovascular disease and chronic respiratory disease
- ◆ a section highlighting the specific needs for diabetes prevention and care.

This work will be undertaken in collaboration with the other relevant groups in WHO. The decision to address chronic diseases in an integrated manner is in line with current public health practice. This approach also responds to feedback reporting that this is the best way for

health systems to manage these conditions.

Web-based support

Diabetes Action Now will establish and maintain a web-based resource to assist policy makers in the implementation of national diabetes programmes. This resource is likely to include:

- ◆ educational materials
- ◆ treatment guidelines and training manuals developed in different settings
- ◆ an up-to-date source of practical evidence-based information
- ◆ online access to expert advice.

It is appreciated that in many areas Internet access is poor and that in the longer term, hard-copy materials will be produced. In the short term, however, it is felt that this is a method which will allow us to provide information quickly to health policy makers who, according to our consultation feedback, are likely to have some online access.

Assessing *Diabetes Action Now*

Various ongoing measures will be taken to determine the progress of *Diabetes Action Now*. Whenever press releases or new publications are issued, the distribution and uptake will be monitored in order to determine whether those people who are in most need of the information are being reached. We will also use a number of communication channels to ensure that we are in close contact with our key stakeholders and able to respond to their feedback.

In 2001, WHO undertook a survey of countries to determine their national capacity to prevent and control non-communicable diseases; only 43% of countries reported having a national diabetes programme. This survey will be repeated to determine if there has been an increase in the number of countries with national diabetes programmes.

Three years is a short time to measure success, yet there are many groups working throughout the world to improve the prevention and management of chronic diseases, including diabetes. It is hoped that these activities, plus the work of *Diabetes Action Now*, will result in a greater number of effective national programmes in the very near future.

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