Diabetes Action Now
Outcomes from the consultation process

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Scope of the consultation

Consultation documents were prepared in English, French and Spanish. They comprised a 6 page outline of the proposed programme goals, outputs and activities, a one page summary and a powerpoint presentation. The consultation documents were made available on both the WHO and IDF web sites and publicized in a World Health Organization press release on World Diabetes Day, November 14 2003. They were also sent electronically to the following groups and individuals: WHO regional offices (noncommunicable disease focal points) and country offices, WHO collaborating centres, IDF regional offices, members of IDF task forces. All recipients were asked to pass the documents on to others who may be interested in them. 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; and suggestions for ways that they might participate in the programme, including as sentinel sites.

Over 90 responses were received, from groups and individuals representing activities in 41 of the 191 countries that are Member States of WHO, the majority of which represented low and middle-income countries. Groups who responded included WHO regional and country offices, IDF regional offices and member organizations, national Ministries of Health, individual health professionals, researchers and individuals with diabetes or with a close family member with diabetes. 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 together: in China a group of health workers gathered to consider their response.

A general overview of the feedback

**Overall scope of the programme**
Overall the feedback was very supportive of the proposed programme of work, with the need to raise awareness being widely recognized but with the caution that the greatest impact is likely to be achieved by keeping the messages simple and few. Several respondents commented that the overall scope of the proposed programme appeared to be very ambitious, particularly for what is initially a three year period. Undoubtedly achieving the programme goals requires much longer than three years and obviously we need to be clearer about what specifically we aim to achieve within the first three years. This is given in greater detail in the next section.

There was concern from some respondents that the programme appeared to be largely about diabetes care and not about primary prevention. Again this is an issue on which we need to communicate better as the programme is designed to cover the primary prevention of diabetes and health care for it. Another concern was that we had not distinguished in the document between Type 1 and Type 2 diabetes and the fact that at present prevention is possible for proportion of the latter but not the former. This concern was linked to the danger of appearing to “blame the victim” i.e. to suggest that some diabetes is avoidable might be seen as suggesting that those who develop it are partly to blame.

**Communication**
A recurring theme in the feedback was the need for printed materials in local languages, whether for people with diabetes, health carers or advocates. One interesting suggestion in this regard was whether WHO could act to help make materials produced in one country for people of the same ethnicity and language living in another country. A related suggestion was that WHO could act as a “clearing house” for guidelines, training packages and other materials, helping to make these generally available for adaptation and use elsewhere.

**Traditional healers and situation analyses**
There was a plea from several respondents from different parts of the world (e.g. Africa, China, Iran and the Caribbean) to consider the role of traditional healers, who often play a large role in the care of people with diabetes. Linked to this is the need to have tools to help undertake a situation analysis of current approaches to and opportunities for diabetes care and prevention within a country or region of a country. Several respondents were able to cite examples of rapid assessment methods that they had used, or knew of, in order to do this.
**Schools programmes**

Respondents from several different parts of the world flagged the importance of getting the message about prevention into schools. An interesting suggestion was to build an awareness-raising campaign around school projects, with for example the children preparing posters and acting as spokespeople for some of the key prevention messages.

**Setting standards of care**

The suggestion that WHO and IDF should set standards for minimum levels of care generally received favorable comment, but it was noted by some that this might be controversial and might be better left to national governments. However, the need for practical guidance on the implementation of national programmes for the prevention and control of diabetes received widespread support.

**Diabetes – a condition of importance to the poor**

The need to vigorously address the misperception that diabetes is not of importance to the poor of low and middle-income countries was flagged by several respondents. This misperception plays a large role in the very low priority given to diabetes, and other non-communicable diseases, by major international funding bodies. The awareness-raising campaign of Diabetes Action Now must aim to help redress this balance.

**Joined up working**

The need to collaborate effectively within WHO and IDF and groups outside was emphasized. Within WHO, for example, it is important that collaboration occurs within Geneva, for example, by involving other groups with relevant expertise, and with the Regions and Country Offices. Although this can make establishing new initiatives time-consuming, they are unlikely to succeed in the longer term unless this is done.

**Feedback on specific areas and the response of the programme**

**Awareness raising**

The need to raise awareness, particularly among the general public, with governments, and with the major international donor organizations, whose agendas are currently dominated by infectious diseases, was widely acknowledged. In particular, several respondents noted the need to address the misperception that diabetes is not a major problem amongst the poor of the developing world. WHO and IDF were perceived as being well placed to coordinate such awareness-raising activities.

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

Common themes included the need to use a variety of media and partnerships with a broad range of stakeholders to raise awareness. An overwhelming number of respondents from developing countries made the comment that access to the internet outside major institutions and organizations was often poor. Therefore, a mixture of electronic and printed materials was thought to be essential. Many respondents requested generic information in a format that could be easily adapted and translated for local use.

**Taking into account the consultation it was decided that:**

- Awareness raising should remain a major focus of Diabetes Action Now
- The major messages that will be communicated will be those in the IDF Awareness Raising Strategy. The appropriateness of these messages will be evaluated
- Over the first two years of the project awareness raising will take place on two main levels.
  - The first level will involve global and regional activities. These activities will be based around a booklet, currently in preparation, summarizing important facts and figures around the 4 key messages from the IDF Awareness Raising Strategy. The booklet is designed in particular for media briefings with the aim of increasing the level of high quality media coverage about diabetes as a public health problem. This booklet will be used to launch the programme globally in early May. Launches of the programme within at least four WHO Regions using a version of the booklet modified to reflect the regional situation will take place over the coming 12 to 18 months. The success of the global and regional campaigns will be evaluated by undertaking media content analyses before and after the campaigns.
  - The second level of awareness raising activities will be at country level, within two sentinel sites. At the time of writing it is hoped that one site will be within India and the other in Africa. Within these sites awareness raising activities targeting health policy makers and the lay public will be undertaken, with surveys of these groups undertaken before and after these activities.
New knowledge from low- and middle-income communities

Valuable examples of work with low- and middle-income communities were described. Little of this work has been documented, particularly in peer reviewed journals, and the need to do so was mentioned by a number of respondents. Various groups described possible research that they would be able to undertake if funding was available. As described above, the lack of systematic documentation on awareness about diabetes was confirmed. It was noted that many countries still lack good data on the prevalence of diabetes and its risk factors, and that the vast majority lack any data on the economic impact of diabetes in low and middle countries. Several respondents noted that a robust estimated of the real contribution of diabetes to global mortality could greatly assist in raising awareness about the public health impact of diabetes.

Taking into account the consultation it was decided that:

- Collection of new knowledge in the first two years of the programme should concentrate on:
  - The economic impact of diabetes
  - Awareness
- These data will be collected using standard protocols within four sentinel sites, two sites for awareness assessment and two for the economic studies.
- The economic studies will be undertaken in close collaboration with the health economics group of the IDF.
- The protocols developed for these studies will be made available for adaptation and use elsewhere.
- A realistic assessment of the contribution of diabetes to overall mortality will be produced using in house WHO methods and submitted for publication.
- A session dedicated to awareness about diabetes will be held at the 5th International Congress for the Prevention of Diabetes.

Review of prevention guidelines

An update of the WHO technical report on the prevention of diabetes and its complications was perceived as an urgent need, that would be useful to a broad audience, from policy makers, to health carers and to groups advocating better diabetes prevention and care.

Taking into account the consultation it was decided that:

- Production and dissemination of the revised technical report on the prevention of diabetes and its complications should be a priority activity for the first year;
Further work will be undertaken, using the technical report as the basis for developing practical guidance appropriate to low and middle-income countries.

Guidance on National Non-communicable Disease and Diabetes Programmes
Many respondents provided information about national and regional programmes, with several comments that although programmes were in place “on paper”, in practice little was happening on the ground. This highlighted the need for clear, practical guidance, which provides clear direction on the types of changes that need to occur. In addition, whether or not a “national diabetes programme” is in place on paper is much less important than what is actually happening in practice. Many respondents also spoke of the importance of basing the prevention and care for diabetes within the broader framework of non-communicable diseases. The general comment was that the overlap between approaches to the prevention and care for several non-communicable diseases is so large that separate programmes for each is both impractical and wasteful of resources. This comment is in complete agreement with current approaches within WHO to advising on Health Systems for non-communicable diseases.

Taking into account the consultation it was decided that:

✓ Diabetes Action Now will provide practical guidance for policy makers on the content and implementation of National Diabetes Programmes in low and middle-income countries, using the updated prevention technical report as the evidence base for what needs to be done. The WHO guidance on National Diabetes Programmes published in 1991 provides a starting point for doing this. However, in keeping with the feedback received, the guidance will have two main sections. The first will specify guidance that applies to the prevention and health system requirements for most non-communicable diseases, and the second section will identify those areas that are specific to diabetes. This work will be undertaken in collaboration with colleagues specializing in health systems for chronic disease care within WHO.
✓ This work will take place over the next 18 months.
✓ The guidance will be supported through the development and maintenance of a web based resource (see below).

Tools for improving diabetes prevention and care
Respondents provided many examples of tools that had been developed for improving care in low and middle-income settings, such as locally developed guidelines, health education materials and training packages. Many respondents indicated the importance of making any tools available in locally used languages. Many also noted that web based materials were often inaccessible to people actually delivering the care, because of poor internet access and printing facilities – hence the need for hard copies.
Taking into account the consultation it was decided that:

- While acknowledging the importance of having hard copy materials available for health carers, the focus of the programme over the first two years will be on the development of a web based resource to support the implementation of National Diabetes Programmes.
- The rationale for this is that a web-based resource should be accessible to national policy makers in all parts of the world, and provides the most efficient means of making materials available.
- The web based resource is likely to include the following:
  - Practical guidance on the implementation of national NCD and diabetes programmes,
  - A forum for exchanging experiences in the implementation of programmes or parts of them,
  - An expert forum, in which questions can be asked and responses gained online from an international group of experts,
  - A clearing house for materials provided by users of the website, such as guidelines, health education materials, and training packages
- There will be a strong commitment to ensuring that as many of the materials as possible are made available widely in all languages, including the 6 official languages of the United Nations.

The choice of sentinel sites

At the time of writing this summary negotiations are underway to work in four sentinel sites. As indicated above this requires the agreement not only of the sites themselves but also the WHO Regional and Country Offices and appropriate IDF offices. We hope to be able to announce within the next 2 to 4 weeks where the sentinel sites are and the nature of work within each.

Further information

We aim to regularly update the information on the programme website, with the latest information about work in progress and the programme plans.