

IMPLEMENTING NATIONAL DIABETES PROGRAMMES

**Report
of a
WHO
Meeting**



Edited by H. King, W. Gruber and T. Lander



**World Health Organization
Division of Noncommunicable Diseases
Geneva
1995**

© World Health Organization 1995

This document is not a formal publication of the World Health Organization (WHO), and all rights are reserved by the Organization. The document may, however, be freely reviewed, abstracted, reproduced and translated, in part or in whole, but not for sale nor for use in conjunction with commercial purposes.

The views expressed in documents by named authors are solely the responsibility of those authors.

Contents

	Page
Introduction	1
1. The National Diabetes Programme	3
1.1 The burden of diabetes	3
1.2 WHO action to promote national diabetes programmes	4
1.3 Economic considerations	6
1.4 Socioeconomic and cultural factors	9
1.5 Approaches to the implementation of national diabetes programmes	11
1.6 Difficulties experienced in the implementation of national diabetes programmes	13
2. Reducing the Burden: Preventing Diabetes in the Community	17
3. Implementation: The Principles	21
3.1 Prerequisites for national programme development	21
3.2 General considerations for diabetes programme development	22
3.3 Initiating a National Diabetes Programme	23
4. Implementation in practice: the parties involved	33
4.1 People with diabetes	33
4.1.1 Needs	33
4.1.2 Barriers to appropriate diabetes care	36
4.1.3 Overcoming barriers to appropriate diabetes care	38

	Page
4.2 Health care providers and allied agencies	41
4.2.1 Needs of health care providers	41
4.2.2 Barriers encountered by health care providers	42
4.2.3 Overcoming barriers encountered by health care providers	44
4.2.4 Contribution of allied agencies to the implementation of national diabetes programmes	49
4.3 National and international administrative structures	54
5. Conclusions and recommendations	57
References	61
Further reading	65
Glossary	67
Annex 1	
Mandate and officers of working groups at the meeting	75
Annex 2	
World Health Assembly resolution WHA42.36. Prevention and Control of Diabetes Mellitus	77

First global meeting on the implementation of national diabetes programmes

Geneva, 30 May - 1 June 1994

Participants

Professor Y. Akazawa, Department of Clinical Nutrition,
Suzuka University of Medical Science and Technology,
Kishiokacho Suzuka, Japan

Dr K. Al-Rubeaan, College of Medicine, King Saud
University, Riyadh, Saudi Arabia

Dr M. Ali, Diabetes Institute, Cairo, Egypt

Professor A. Ametov, Chief, Chair of Endocrinology, Central
Institute for Advanced Medical Studies, Moscow, Russian
Federation

Mr J. Apfel, British Diabetic Association, London, United
Kingdom

Professor J.-Ph. Assal, Head, Diabetes Treatment and
Teaching Unit, Hôpital Cantonal Universitaire, Geneva,
Switzerland

Dr M. Asfour, National Diabetes Centre, Royal Hospital,
Muscat, Oman

Professor J.R. Attali, Hôpital Jean-Verdier, Service
d'endocrinologie (Endocrinology Service), Bondy, France

Professor J.S. Bajaj, Planning Commission, Yojana Bhavan,
Sansad Marg, New Delhi, India, (*Co-Chairman*)

Ms J. Baldwin, Australian Diabetes Society, Deakin,
Australian Capital Territory, Australia

Dr P.H. Bennett, Phoenix Epidemiology and Clinical Research Branch, NIDDK, National Institutes of Health, Phoenix, United States of America

Dr K. Borch-Johnsen, Steno Diabetes Center, Gentofte, Denmark

Ms L. Etu-Seppälä, Finnish Diabetes Association, Tampere, Finland

Dr J.J. Gagliardino, CENEXA, Facultad de Ciencias Medicales - UNLP, La Plata, Argentina

Professor P. Home, Department of Medicine, The Medical School, Newcastle upon Tyne, United Kingdom

Professor T. Johnson, College of Medicine, University of Lagos, Lagos, Nigeria

Dr T. Kangas, President, Finnish Diabetes Association, Vantaa, Finland

Dr L. Kleinebreil, Hôpital Jean-Verdier, Service Diabétologie-Nutrition, Bondy, France

Dr S. Mabrouk, United Nations Relief and Works Agency, Amman, Jordan

Ms M. MacKinnon, Diabetes Center, Sheffield, United Kingdom

Dr H. Mahtab, Bangladesh Institute of Research and Rehabilitation in Diabetes, Endocrine and Metabolic Disorders (BIRDEM), Dhaka, Bangladesh

Dr M. Massi-Benedetti, Istituto di Patologia Speciale Medica, Università di Perugia, Perugia, Italy

Professor O. Mateo de Acosta, Instituto de Endocrinología y Enfermedades Metabólicas, Hospital "Cmdte. Fajardo", Havana, Cuba

Dr J.-C. Mbanya, Faculty of Medicine and Biomedical Sciences, University of Yaoundé I, Yaoundé, Cameroon

Professor Z. Metelko, Institute for Diabetes, Endocrinology and Metabolic Diseases, "Vuk Vrhovac", Zagreb, Croatia

Professor E. Mora Morales, Endocrinology Unit, Hospital Calderon Guardia, San José, Costa Rica

Professor E. Morrison, Department of Biochemistry, The University of the West Indies, Kingston, Jamaica

Dr K. Piwernetz, DiabCare Office, Munich, Germany

Dr G. Reiber, Department of Veterans Affairs, Seattle VAMC, Seattle, United States of America

Dr G. Roglic, Institute for Diabetes, Endocrinology and Metabolic Diseases, "Vuk Vrhovac", Zagreb, Croatia

Dr U. Rosenqvist, Department of Endocrinology, Karolinska Hospital, Stockholm, Sweden

Professor J. Rybka, Internal Clinic of the Postgraduate Medical Institute, Internal Clinic ILF, Zlín, Czech Republic

Dr A. Saad, Service des Maladies Métaboliques et Endocriniennes, Direction de l'Epidémiologie, Ministère Santé Publique, Rabat, Morocco

Professor A.S. Shera, Diabetic Association of Pakistan, Karachi, Pakistan

Dr E. Sous, Diabetes Institute, Cairo, Egypt

Professor A.M. Sow, Service de Médecine Interne, Hôpital
Communal Abass Ndao, Dakar, Senegal

Dr M.H. Tan, Canadian Diabetes Advisory Board, Halifax,
Canada

Dr C. Trautner, Medical Clinic E, University of Düsseldorf,
Düsseldorf, Germany

Ms M. Van de Wetering, European Diabetes Nurse Working
Group, Leiden, Netherlands

Dr F. Vinicor, Division of Diabetes Control, Centre for
Preventive Services, Centers for Disease Control, Atlanta,
United States of America, *(Co-Chairman)*

Professor D.R.R. Williams, Division of Public Health,
Nuffield Institute for Health, Leeds, United Kingdom

Ms M. Wise, Department of Public Health, University of
Sydney, Sydney, Australia

Representatives of other organizations

Professor J. Jervell, Rikshospitalet, Department of Medicine,
Oslo, Norway (President-Elect, International Diabetes
Federation)

Professor H.M.J. Krans, Department of Endocrinology and
Metabolic Diseases, University Hospital, Leiden, Netherlands
(Chairman, European Region, International Diabetes
Federation)

Ms H. Williams, Executive Director, International Diabetes
Federation, Brussels, Belgium

Observers

Ms E. Dempsey Becker, Novo Nordisk A/S, Bagsvaerd,
Denmark

Mr L. Ellingson, Lilly Corporate Center, Indianapolis, United
States of America

Mr A. Elphick, Novo Nordisk A/S, Athens, Greece

Dr N. Jersch, Boehringer Mannheim GmbH, Mannheim,
Germany

Ms S. Lion, LifeScan, Boulogne, France

Dr J. Llewellyn, Eli Lilly Export S.A., Vernier, Switzerland

Ms E. North, Miles Inc., Elkhart, United States of America

Dr S. Pramming, Novo Nordisk A/S, Bagsvaerd, Denmark

Ms Y. Shahkhalili, Nestlé S.A., Vevey, Switzerland

Dr J. Thiery, Boehringer Mannheim GmbH, Mannheim,
Germany

Secretariat

Dr A. Alwan, Regional Adviser, Noncommunicable Diseases,
WHO Regional Office for the Eastern Mediterranean,
Alexandria, Egypt

Dr D.E. Barmes, Associate Director, Division of
Noncommunicable Diseases, WHO, Geneva, Switzerland

Dr W. Gruber, Diabetes and Other Noncommunicable
Diseases Unit, WHO, Geneva, Switzerland

Dr E. Gulyaeva, Diabetes and Other Noncommunicable Diseases Unit, WHO, Geneva, Switzerland (*Temporary Adviser*)

Dr I. Gyarfas, Chief, Cardiovascular Diseases Unit, WHO, Geneva, Switzerland

Dr I. Kalo, Quality of Care and Technologies Unit, WHO Regional Office for Europe, Copenhagen, Denmark

Dr N.G. Khaltayev, Acting Chief, Diabetes and Other Noncommunicable Diseases Unit, WHO, Geneva, Switzerland

Dr H. King, Medical Officer, Diabetes and Other Noncommunicable Diseases Unit, WHO, Geneva, Switzerland (*Secretary*)

Dr V. Koroltchouk, Scientist, Cancer and Palliative Care Unit, WHO, Geneva, Switzerland

Dr I. Martin, Medical Officer, Cardiovascular Diseases Unit, WHO, Geneva, Switzerland

Dr M. Neira, Geneva, Diabetes and Other Noncommunicable Diseases Unit, WHO, Geneva, Switzerland (*Temporary Adviser*)

Mr T. Prentice, Office of Information, WHO, Geneva, Switzerland

Dr K. Staehr-Johansen, Regional Adviser, Quality of Care and Technologies, WHO Regional Office for Europe, Copenhagen, Denmark

Introduction

Recognizing the growing number of countries which are currently in the process of introducing measures to prevent and control diabetes mellitus, a first global meeting on the implementation of national diabetes programmes was held at World Health Organization Headquarters in Geneva from 30 May to 1 June 1994. Thirty-two countries, from all WHO regions, were represented at the meeting. It was opened by Dr D. Barmes, Associate Director, Division of Noncommunicable Diseases, on behalf of the Director-General of WHO.

The goals of the meeting were:

- To exchange experiences and motivate the staff of existing national diabetes programmes
- To consider the evaluation and further promotion of these programmes
- To stimulate the development of new national diabetes programmes
- To define educational needs
- To prepare a report with practical recommendations and guidelines.

This report represents the consensus of the meeting with respect to the practical issues involved in implementing a national diabetes programme. In this respect, it is a companion, and a sequel, to the WHO booklet "Guidelines for the development of a national programme for diabetes mellitus" (1), a planning manual issued by WHO Headquarters in 1991.

Background information, preventive strategies, and general principles of programme implementation are considered in sections 1 - 3 of this report. The major part of the meeting was spent with the participants organized into three working groups

which considered the roles of people with diabetes (Section 4.1 of this report), health care providers and supporting agencies (Section 4.2), and the national and international administrative structures (Section 4.3) (see also Annex 1). The meeting's conclusions and recommendations are summarized in Section 5. A reading list is included in addition to the references quoted in the text. Technical terms are explained in the Glossary.

Although the focus of attention in this report is the national programme, prevention and control of diabetes may take place in any administrative or geographical unit. Generally, the same considerations would apply to a local, district or provincial diabetes programme, although the administrative structure would necessarily differ. Above the national level, intercountry and regional activities are coordinated by the six WHO regional offices, two of which have already set regional goals and targets for diabetes control, in collaboration with the respective offices of the International Diabetes Federation (IDF).

Whilst the topic under consideration is diabetes mellitus, many of the recommendations would apply to other disease control programmes as well, especially those for other noncommunicable diseases, for which diabetes has often been used as a model. A flexible attitude to programme planning is recommended, taking into account the many local circumstances which will dictate the most suitable course of action in each case.

The meeting was made possible by generous financial support from Boehringer Mannheim GmbH, Eli Lilly Export S.A., Hoechst A.G., LifeScan Europe, Miles Inc., Nestle S.A., Novo Nordisk A/S and Pfizer Inc. The document was prepared and typeset by Mrs G. Minjoot-Pereira.

1. The National Diabetes Programme

1.1 The burden of diabetes

Diabetes is a growing threat to the world's public health. Formerly described as a "disease of affluence", it has now become apparent that, owing to demographic changes, cultural transition and population aging, diabetes is now also a "third world problem" (2).

Since 1988, WHO has been collecting standardized information on the prevalence of diabetes and impaired glucose tolerance (IGT) in adult communities worldwide. Within the age range 30-64 years, diabetes and IGT were found to be absent or rare in a small number of traditional communities in Melanesia, East Africa and South America. In populations of European origin, the prevalence of diabetes and IGT lay in the range 3-10% and 3-15% respectively, but migrant Indian, Chinese and Hispanic American groups were at higher risk (15-20%). The highest prevalence was found in the Pima Indians of Arizona and in the urbanized Micronesians of Nauru, in whom approximately one-half of the population in the age range 30-64 years had diabetes (3).

The prevalence of total glucose intolerance (diabetes and IGT combined) was greater than 10% in almost all populations, and was within the range 11-20% for European and United States white populations. However, the prevalence of total glucose intolerance reached almost 30% in Arab Omanis and in United States blacks and affected one-third of all adult Chinese Mauritians, migrant Indians, urban Micronesians and lower income urban United States Hispanics. In Nauruans and Pima Indians, approximately two-thirds of all adults in the age 30-64 years range were affected.

Thus, the highest prevalence of diabetes is now to be found in the developing countries, and in the ethnic minorities and disadvantaged populations of the industrialized countries.

According to the estimation of the last WHO Study Group on diabetes, at least 100 million people will be affected by diabetes by the end of this century, if present trends continue (4).

Direct and indirect costs associated with diabetes are disproportionate, compared with the cost associated with many other diseases. They are now thought to amount to more than 90 billion dollars per year in the United States of America alone (5). This enormous figure reflects the very costly nature of the chronic complications of diabetes, which include blindness, kidney failure, gangrene and amputation of the extremities, in addition to a substantially increased risk of cardiovascular disease.

1.2 WHO action to promote national diabetes programmes

Recognizing that action was required, the Forty-second World Health Assembly adopted a resolution entitled "Prevention and Control of Diabetes Mellitus" in 1989 (WHA42.36). This resolution invited all Member States to assess the problem of diabetes in their country, and to implement prevention and control measures (for full text see Annex 2).

The resolution also invites Member States to implement population-based measures, appropriate to the local situation, to prevent and control diabetes. Convinced that the basis for such action lies in the development of national diabetes programmes, WHO produced the planning document *Guidelines for the development of a national diabetes programme for diabetes mellitus* in 1991. This booklet (1) has been translated into all WHO official languages and has been widely distributed.

In Europe, a meeting of government representatives, the health care sector, and diabetic people, organized jointly by the WHO Regional Office for Europe and the European Office of the IDF in November 1989, led to the now famous *St Vincent Declaration Action Programme: Diabetes Care and Research in Europe* (EuroDiabCare) (6). This provided the first official initiative for

the development of plans and policies for the improvement of diabetes care at the regional level. The St Vincent declaration was ratified in a resolution adopted at the Forty-first session of the WHO Regional Committee for Europe in Lisbon in May 1991. A follow-up meeting, held in Budapest in March 1992, endorsed technical guidelines and called for the implementation of national diabetes programmes in all European countries. To facilitate this, governments have nominated national liaison persons to cooperate with the St Vincent Steering Committee, established by IDF and the WHO Regional Office for Europe. This group of liaison persons met in Oslo, Norway in June 1992 and elaborated further steps for the implementation of national diabetes programmes in Europe.

In November 1991, a Task Force met at the WHO Regional Office for the Eastern Mediterranean in Alexandria, Egypt, to prepare an action plan for diabetes within that region (7). Several activities were recommended by WHO, including situational analysis and setting of achievement targets by Member States, and support for the development of national programmes, training, health-systems research, and reinforcement of centers of excellence. An intercountry meeting on diabetes programme development was held in Karachi, Pakistan, in December 1992. A meeting to establish guidelines for the management of NIDDM was held in Alexandria in July 1994 (8) and a project to prepare regionally appropriate educational materials was also undertaken in 1994.

These regional initiatives have resulted in considerably greater contact and cooperation on diabetes between WHO Headquarters in Geneva and the WHO Regional Offices, as well as between the global and regional offices of WHO and the IDF.

In a number of countries, national diabetes programmes have already been introduced by official decree.

1.3 Economic considerations

A comprehensive review of the available data on diabetes health economics was published in 1989 (9). The trends envisaged then seem to have held true to a large extent: globally, the prevalence of diabetes mellitus continues to increase, owing to aging in industrialized countries and to demographic and socioeconomic changes in many developing countries. The cost of caring for persons with diabetes is 2-4 times the amount spent on nondiabetic people in most health care systems.

A study by the American Diabetes Association (5) shows an enormous increase in the total cost of diabetes (both direct and indirect) in the USA between 1987 and 1992 (US\$ 21 billion → US\$ 92 billion) with only a relatively small increase in the number of diagnosed diabetic persons (6.8 million → 7.2 million). The increase in the direct incremental cost of care for people with diabetes (US\$ 9.6 billion → US\$ 45.2 billion) is mainly due to issues which had been neglected (outpatient hospital visits, emergency room visits) or grossly underestimated (additional or extended hospitalization due to unrelated conditions) in the 1987 study. Steep increases in the cost of hospital days (+ 180%) and general practitioner (GP) visits (+ 140%) also contributed. The rate of hospitalization due to diabetes and to chronic complications, as well as GP visits, stayed constant. The increases in the cost of drugs (+48%), nursing homes (+49%) and testing/monitoring (+42%) while substantial, are nevertheless moderate in comparison.

A more recent study (10) concludes that in 1992 more than US\$100 billion was spent on the overall health care of people with diabetes in the USA - one out of every seven dollars spent on all health care for the entire population. This figure is higher than that given in the ADA study because of the even higher incremental direct per capita cost for diabetes and the inclusion of costs relating to diabetic persons not recorded in routine statistics.

The major component of direct costs (> 80%) was found to be the cost of hospitalization, mainly resulting from "unrelated conditions" but also for treatment of chronic complications (approx. US\$ 10 billion). This was 2.5 times higher than the cost of hospitalization "due to diabetes alone".

The prevention of complications is therefore of major concern in diabetes care. The Diabetes Control and Complications Trial (DCCT) (11) has finally demonstrated that complications in patients with insulin-dependent diabetes mellitus (IDDM) are indeed preventable to the extent claimed by many experts, for instance in the goals and targets of the St Vincent Declaration. It was calculated that intensified therapy for people with IDDM was three times more costly than conventional therapy. But the trial predicted considerable savings during the lifetime of these subjects due to the avoidance of complications (12).

There are a number of areas where substantial cost savings are possible:

Hospitalization due to diabetes: Some studies (13) have shown that structured patient education programmes can rapidly reduce the need for acute hospitalization of persons with IDDM by more than 50%. It has been claimed that an overall reduction of acute hospitalizations for all persons with diabetes by education is feasible, which would bring substantial savings. The argument has been accepted by some purchasers of health care, such as those in Germany, which now remunerate the cost of patient education by health care teams. Such reductions in the burden of diabetes on the health services may provide opportunities for redirecting resources to other areas of need, rather than creating direct financial savings.

Amputations: Data from industrialized countries with similar age structures (United States of America, Scotland, Czech Republic, Finland) suggest an annual amputation rate of 0.8% of all people with diagnosed diabetes. Most of the amputations are the end result of neuropathy, and diabetic persons have about 15 times the risk of amputation of the normal population. It has been

shown by various centres (e.g. Geneva, Zlín), districts (e.g. Umbria) and countries (e.g. Denmark) that the rate of amputations can be reduced by more than 50% within a few years by educating patients about foot care (choosing suitable footwear, checking regularly for numbness or minor injuries, improved hygiene, etc.). The resulting savings could be substantial (e.g. US\$1 billion in the United States of America).

Nephropathy and end-stage renal disease: In the United States of America an increase in end-stage renal disease (ESRD) of approximately 15% annually was observed between 1985 and 1989 (14), presumably owing to the aging of inadequately treated persons with diabetes. In 1989 the prevalence of the complication was 0.6% among persons with diagnosed diabetes. Similar figures are available in other countries. Some studies (15) suggest that nephropathy can be controlled in the long term, e.g. by annual testing for, and early treatment of, microalbuminuria, leading to substantial savings (e.g. DM 500/year for each IDDM patient in Germany, at 5% annual discount rate). Another recent study (16) indicates that the rate of nephropathy leading to ESRD can be reduced by 50% by treatment with certain angiotensin-converting-enzyme (ACE) inhibitors, independent of blood pressure and HbA_{1c} levels.

Retinopathy and blindness: The prevalence of blindness in persons with diabetes in different countries ranges from 0.2 to 0.6% (17). The preventability of retinopathy was clearly shown by the DCCT study. For patients using insulin, annual screening and treatment of early lesions is at least cost-neutral at a discount rate of 6% of future savings (18). The discounting procedure used in these calculations reflects the future value of present money. A new publication (19) claims an important potential for cost savings through screening for, and treatment of, eye disease in persons with non-insulin-dependent diabetes mellitus (NIDDM) as well.

Pregnancy: Scandinavian countries, in particular, have reduced the infant mortality and malformation rates resulting from diabetic pregnancy to the rate of the general population. The

cost/benefit ratio for this prevention is not clearly established (20) but the gain in quality of life to mother and child are obvious.

The economic aspects of different strategies for prevention also need to be considered. Most economic studies have focused on tertiary prevention, i.e. treatment of diabetic complications. There have also been publications on the cost-effectiveness of secondary prevention, especially the screening of high-risk groups for early detection of the disease (21). Many health care planners believe that primary prevention - minimizing causative risk factors by behavioural and lifestyle changes - is the best choice for decreasing the incidence of diabetes, which also reduces the cost of treating later complications.

To sum up: reducing costs by improving diabetes care seems achievable, especially for acute hospitalization and amputations in the short term, and for nephropathy, and probably also retinopathy, in the longer term. However, more data, and national monitoring of complication rates and costs, are needed to prove these claims. Basically, the economic issue is not whether these interventions save money, but whether they will improve the health of the population at a reasonable cost compared with other possible interventions.

1.4 Socioeconomic and cultural factors

It is well known that the incidence of noncommunicable diseases, including NIDDM, is strongly influenced by behavioural and cultural factors. An "epidemic" of diabetes, obesity and cardiovascular diseases is frequently observed as populations change from a traditional to an industrialized way of life. Socioeconomic factors influence this situation in several ways.

Firstly, health care is not free of charge in many countries. Even insulin, which is classified by WHO as a lifesaving drug, is not readily available or affordable in many Third World countries. A recent survey by the International Diabetes Federation indicated that insulin was frequently unavailable in some African

countries, especially in small towns and rural areas (22). Moreover, in some developing countries the cost of a vial of insulin is much higher than it is in Europe and North America - approximately US\$ 10 in Africa and US\$ 12 in Latin America, as compared to approximately US\$ 2.5 in Western Europe. The recent WHO report on the prevention of diabetes (4) called on governments to abolish all taxes on insulin.

Economic considerations also limit the availability of all other aspects of diabetes care, from devices to monitor metabolic control to patient education materials, and even the availability of adequate footwear and appropriate diet. Such deficiencies result in a greatly increased risk of the long-term complications of diabetes. This suggests how beneficial it could be to introduce even limited improvements in care through a national diabetes programme, especially in developing countries.

Another socioeconomic issue is the availability of *choice*. Most primary and secondary prevention programmes in Western countries aim to educate the public to avoid high-risk behaviour, and adopt health-promoting lifestyles. In practice, this implies that members of the community have the economic freedom to choose between healthy and unhealthy ways of living. However, in many poor countries, members of the community have little control over these aspects of life: their food and their pattern of work are determined by harsh necessity, and life is a day-to-day struggle for survival. Fearful of losing precious income in the short term, the family breadwinner will often refuse treatment because it necessitates absence from work, even though the result will be greater disability and economic hardship in the long term.

Thus, advocating a healthy lifestyle will not meet with success unless the means to obtain it can be provided. A diabetes programme needs to address such issues at the outset, and to bring about the necessary political and social processes which can lead to such improvements.

There are also some cultural factors in non-Western societies which play a more positive role. Family bonds and support systems are often much more highly developed in needy communities. To some extent, they may take the place of absent social services. Since diabetes is a disease which affects the whole family, a caring attitude on the part of family members can greatly enhance the ability of people with diabetes to come to terms with their condition, and to manage it correctly.

1.5 Approaches to the implementation of national diabetes programmes

Most countries have used the "top-down" approach for the planning of national diabetes programmes. A central planning group or advisory committee, is often set up on the initiative of a diabetes specialist. In some countries with predominantly centralized health care systems, this group has been convened by the national health authorities. In most other cases, it has been nominated by the diabetes societies and only subsequently approved - and possibly funded - by ministries of health. In some countries the original planning was a private initiative by one, or a small number, of opinion-leaders. Using their own networks, they have brought the interested parties together and found funding - mainly from the pharmaceutical industry, which in general has been very supportive of such planning efforts.

There are major differences between the plans which have been drawn up. Most countries - especially those with centralized health care systems - again use a top-down approach with the initiative beginning with the central authority, which then involves the diabetes specialists and centres. These then take action at the second level of health care and, in turn, influence diabetes care at the primary care level. Generally, only one centre is involved at first, e.g. in the "Croatian model" and in Albania, Bangladesh, Cuba and Oman. This model is still recommended for developing countries, where success may be achieved by one (or a few) centre(s) of excellence in the first instance. Initial tasks will include education of professionals and

attention to health care logistics, as well as taking care of the local clientele of persons with diabetes.

Other countries have used a "bottom-up" approach to planning, as in Costa Rica, where the major clinics in the country were asked to develop their own plans. These were then coordinated and brought under the common umbrella of the national social security system.

Another group of countries have used a more "horizontal" approach, in which centres start up activities at the district level, which are then "seeded" into adjacent districts of the same country, or even to other countries, e.g. from Umbria to other districts of Italy, Bulgaria and Albania.

The same categories - top-down, bottom-up, and horizontal - can now be seen in the implementation of these national plans. Countries with decentralized health care systems are especially likely to use the bottom-up approach (e.g. Germany) or the horizontal approach (e.g. Spain). These approaches have the advantage of giving more opportunities and challenges for private initiatives, more delegation of responsibility, and more decentralized ownership of the programmes. However, coordination and the monitoring of progress is much more difficult.

The top-down approach to implementation, as used in most of the developing countries, has the advantage of more effective planning possibilities and a more directive approach to implementation, together with the potential for optimal use of resources. However, it is not feasible in decentralized health care structures. Regional activities, e.g. those of the St Vincent Group in Europe, or in the Eastern Mediterranean Region, have also used the top-down approach successfully.

Regardless of the approach used, success is mainly dependent on the commitment of those persons and institutions involved in the implementation. The process is relatively easy to initiate, but it

is difficult to maintain momentum and thus, to reach the goals and targets.

1.6 Difficulties experienced in the implementation of national diabetes programmes

The following major difficulties experienced during the implementation of national diabetes programmes were identified from questionnaires filled in by the participants of the meeting.

Government support is frequently inadequate, owing to:

- Low perception of priority of noncommunicable diseases
- No public health tradition for chronic disease control
- Reluctance/resistance to cooperate in programmes
- General administrative barriers and bureaucracy.

Particular barriers exist in some countries with political instability and civil conflict.

General needs are:

- To demonstrate that diabetes is a major health problem
- To convince and motivate governments
- To gain higher priority, more support and better cooperation for diabetes programmes, e.g. in setting up steering committees, approving plans, etc.

Similar needs exist in respect of national, district and local authorities.

Financial Resources are inadequate in most countries, owing to:

- Low perceived priority of noncommunicable diseases
- Economic recession in many countries and a critical economic situation in others
- Restrictions on health care spending, and on redirecting resources.

Concerns are:

- Availability of insulin, drugs and diagnostic equipment
- Payment for medical appliances, nursing care, self-testing, etc.
- Initial funding of new activities/programmes.

General needs are:

- Reallocation of existing resources according to priority
- Additional resources for developing countries
- Reimbursement systems corresponding to the quality of care delivered.

Health care systems/infrastructure. Insufficiencies exist owing to:

- Economic constraints in most countries
- Health care reforms in many countries, e.g. privatization of health care
- Decentralized health care systems in some countries
- Inadequate health care in other countries.

Concerns are:

- Inadequate access to health care
- General uncertainty among care providers
- Finding and maintaining adequate standards
- Assessing uniform strategies
- Running registries
- Getting valid data for process and outcome evaluation.

General needs are:

- To get diabetes programmes accepted/promoted and established within the health care system
- To get them adequately evaluated.

Professionals

Major concerns are:

- Human resources: inadequate staffing at various levels of care, especially physicians in developing countries and diabetes nurses, who are frequently lost to other occupations in both developing and industrialized countries
- Motivation
- Achieving conviction and commitment rather than reluctance and resistance.
- Cooperation:
 - resistance of stakeholders
 - competition between the levels of care
 - deficiencies in referral, especially in reporting and feedback
 - team spirit to establish diabetes programmes.
- Administration:
 - conflict between administrators and professionals.
- Improving quality of care:
 - lack of understanding, knowledge and motivation
 - resistance to evaluation
 - reluctance to collect and communicate data.

General needs are:

- Greater financial and human resources
- Support and/or direction from health authorities and patient organizations
- Conviction
- Behavioural changes.

Patients

Major concerns:

- Limited access to care (in some countries less than 10% of patients have access to "minimum standards of care"; in others, major regional or urban/rural differences exist).
- Insulin, other medications and supplies for testing metabolic control
- Involvement of patients and families
- Lack of awareness of the importance of education
- Lack of awareness of the challenge of self-management
- Reluctance to become empowered and self-managing
- Standards and materials for education
- Opportunities for reimbursement
- Social discrimination (insurance, driving licences).

General needs:

- More involvement of patients in defining the quality of their care
- Activation of patient associations
- Advocacy by the public.

This list is probably not exhaustive, but similar problems may be encountered in all countries during the implementation of national diabetes programmes. Therefore, management and implementation committees may use this section as a checklist to identify issues of major local importance. Strategies and tactics recommended to circumvent these problems may be found in later sections of this document.

2. Reducing the Burden: Preventing Diabetes in the Community

A WHO Study Group on the Prevention of Diabetes Mellitus met in Geneva in November 1992. The report of this meeting (4) provides a detailed summary of expert opinion on the prevention of diabetes and its complications.

Opportunities for prevention occur at three levels: *Primary prevention* aims to reduce the incidence of the disease, usually through community-based activities to modify the behaviour and/or lifestyle of high-risk individuals (the high-risk approach), or society as a whole (the population approach). The goal is to reduce the prevalence of causative risk factors *before* the disease develops.

The fact that several of the risk factors for NIDDM are potentially modifiable (overweight and obesity, physical inactivity and inappropriate nutrition) has led to a growing belief in the importance of primary prevention. The successful reduction of cardiovascular disease mortality in a number of industrialized countries over the past two decades has demonstrated the potential effectiveness of this approach.

The rising incidence of diabetes in developing countries appears to be associated with changes in lifestyle (diet, physical activity) which, in turn, are associated with economic development. It is true that there is no clear evidence that it is possible to reduce the incidence of diabetes using primary preventive measures. However, it is important that a national programme to prevent and control diabetes should not overlook the importance of primary prevention.

Furthermore, changes in patterns of nutrition and physical activity, along with reductions in smoking and obesity, could be expected to have significant effects on reducing the prevalence of complications in people with diabetes. In all countries, the main objective of primary prevention must be "making healthy

choices easy choices" rather than simply educating individuals about lifestyle.

The modifiable risk factors for diabetes are similar to those for cardiovascular disease. The implementation of measures to modify these risk factors should be undertaken in collaboration with professionals concerned with cardiovascular and other noncommunicable diseases, thereby maximizing the use of scarce resources and enhancing the chances of success.

Secondary prevention aims to reverse the disease, or to halt its progression. Screening for diabetes is an important tool in secondary prevention. It can be conducted using either the high-risk or the population approach. Some factors which need to be considered are the sensitivity and specificity of the screening test, its acceptability to the community, the yield (the number of cases identified per unit cost) and the estimated benefits of early detection.

Screening family members for incipient IDDM is of growing importance because intervention is increasingly likely to delay or prevent the disease in such individuals.

Screening for IGT and NIDDM is not generally recommended for the general population, but it may be cost-effective in high risk populations/communities, and in individuals with one or more of the following risk factors:

- Obesity
- Hypertension/hyperlipidaemia
- Age over 40 years
- Previous gestational diabetes
- Previous IGT
- Family history of diabetes.

Screening for diabetes is recommended for all pregnant women during the 24th-28th week, using an oral glucose tolerance test, if resources permit.

Tertiary prevention aims to prevent or delay the development of the complications of diabetes. Because the chronic complications of the disease cost so much to treat, there is considerable interest in tertiary prevention at the present time. Some believe that it could lead to overall cost reductions for health services on its own, following the introduction of a comprehensive diabetes programme. Tertiary prevention activities generally take place at the level of direct patient care and include improved education, better metabolic control and screening and early treatment of complications. The positive and conclusive results of the Diabetes Control and Complications Trial (DCCT) have amply demonstrated the efficacy of both secondary and tertiary prevention through improved metabolic control. Specific intervention studies targeting foot care, eye screening, etc. have proved their potential for enormous reductions in end-stage complications (see Section 1.3).

Preventive action, as well as health programming generally, may be restricted to a single disease (the "vertical approach") or may aim to address several diseases with common features simultaneously (the "horizontal approach"). Because of the growing evidence that diabetes shares many common risk factors with other noncommunicable diseases, the horizontal approach to primary prevention is widely recommended. Activities aimed at secondary and tertiary prevention tend to be more disease-specific, but they may also benefit from some integration (for example, in the case of diabetes and hypertension).

Many countries have chosen to commence their planning and programming for noncommunicable disease prevention and control by using a single disease as a model, and diabetes has often been chosen. Some of the features which make diabetes suitable in this regard are the general consensus over its diagnosis, treatment and care, the need for intersectoral cooperation because of its diversity, and the obvious potential for cost containment through the control of complications.

Any national health programme will benefit from the setting of specific goals and targets for primary, secondary and tertiary

prevention, and from the definition of horizontal and vertical programme components. Diabetes represents a particularly suitable subject for such an approach.

3. Implementation: The Principles

A *programme* may be defined as "a coherent set of policies, strategies, activities and investments to achieve a specific time-bound objective, or set of objectives". Thus, a working definition of a national diabetes programme might be:

A series of planned activities at the national, district or local level which has

- The approval of the national authorities
- Stated objectives
- A written protocol
- A fixed time-scale
- A means of evaluation.

3.1 Prerequisites for national programme development

Resolution WHA42.36 on the prevention and control of diabetes encourages all countries to develop national plans or programmes for this disease. To achieve this, certain basic requirements must be fulfilled.

Information about the burden of diabetes is needed in order to define needs and raise awareness about the prevalence of the disease and its complications.

Political will: National diabetes programmes cannot proceed without full government endorsement.

Resources: Needs and availability will vary between countries, but the aim should be to decide on the relative priority of diabetes and other health programmes, and thus, to create a rational process for resource distribution.

Leadership: Much will depend on the qualities and strength of character of the executive director of the programme and of the people in charge of specific components.

Intersectoral teamwork: The effective implementation of a diabetes programme involves many professions within the health sector (i.e., it requires an interdisciplinary approach). However, it also requires the active involvement and commitment of people from many other areas of expertise, such as education, the media, insurance and economics (i.e., it also requires an intersectoral approach).

Guidelines: WHO has developed global and (in some cases) regional guidelines for the development of national diabetes programmes. Clinical practice guidelines for the management of diabetes have been developed in several countries and on a regional basis in Europe and the Eastern Mediterranean. These need to be adapted to the national and/or local situation.

Advocacy: In the fields of disease prevention and health promotion, much will depend on the success of attempts to alert the attention of both diabetic persons and the general public to the proposed activities and convince them of their value.

3.2 General considerations for diabetes programme development

Certain guiding principles may prove useful for the development of a national diabetes programme:

Diabetes is a heterogeneous disease requiring *detection, prevention, and control* measures tailored to local cultural and practical considerations.

A substantial part of diabetes care is *patient self-care*. Thus, patients must be educated, empowered and entrusted with the responsibility of daily management of their condition.

Good diabetes care can *prevent or delay* both acute and long-term complications. Thus, diabetes care programmes may result in substantial reductions in morbidity, mortality and cost.

Diabetes control programmes do not work in isolation. *Close linkage* with other chronic disease programmes is encouraged.

Diabetes control programmes are not limited in time. They have short-term and longer-term targets, but ideally they should be *permanent activities* requiring continuous evaluation and development.

3.3 Initiating a National Diabetes Programme

Setting goals and targets

Diabetes programmes should aim to *prevent* the disease in susceptible individuals and communities.

They should maintain the *health and quality of life* of individuals with diabetes through effective care and education.

They should provide suitable *education for health care providers*.

They should aim to reduce specific *complications of diabetes*, thereby lowering morbidity, mortality and the cost of diabetes to individuals and the community.

Wherever possible, they should support *research* to prevent and control the disease.

Both the European and the Eastern Mediterranean regional diabetes programmes have set goals and targets in terms of the reduction of long-term diabetic complications. The European programme has set these targets for all countries, while the Eastern Mediterranean programme has set somewhat more modest targets for a proportion of Member States. Other national programmes, e.g. in Australia, also have their specific goals and

targets. Clearly, targets should be realistic with regard to local circumstances and resources. Targets will also depend on the outcome of the baseline situational analysis.

Situational analysis

An essential prerequisite for the development of diabetes programmes is an epidemiological assessment of the current situation with respect to the frequency of the major forms of diabetes, their morbidity and mortality, and associated costs. Knowledge of the distribution of risk factors for diabetes and of its chronic complications is also necessary to determine the best preventive actions at the community level.

In some cases, epidemiological data may already exist. However, in the absence of resources for special surveys, the initial situational report may have to rely on routinely available health statistics and limited ad hoc enquiries.

For IDDM, routine registration of all new cases is an effective epidemiological strategy for research, surveillance and patient monitoring. For NIDDM, field surveys are required to give an accurate epidemiological profile of the disease, since many cases remain undiagnosed in routine clinical practice. However, registers may also be a valuable aid to surveillance and patient management of NIDDM. Routine data on morbidity, mortality and disability need to be made more reliable.

Resources for diabetes care must be assessed, including educational facilities, personnel, drugs and diagnostic/monitoring equipment, as well as local and national policies, and allied agencies working in the field.

Short-, medium- and long-term planning

Objectives and strategies should be defined by a policy planning body, to meet the specific needs of the country, as derived from the situation analysis. This committee should also propose priorities, define responsibilities and time-scales and prepare a

budget. It should report on the expected benefits and costs to the health authorities and/or health care financing agencies and gain approval for the necessary expenditure. In many countries, it has proved feasible and beneficial to achieve a broad consensus of all interested parties, before seeking government approval.

One key activity will be the development of effective teams, units and centres. A team consists of, at least, a physician and a professional educator, and is the basic configuration for diabetes care. Units and centres have greater resources and provide secondary and tertiary services: the diabetes centre offers state-of-the art specialist facilities. Units have an intermediary role. Ideally, there should be at least one diabetes centre supporting every diabetes programme.

A consensus should be reached to determine minimum standards of care at each level of the health care system. These, and the resources available, will determine the level to which existing and/or newly established teams/units/centres are able to provide services at a minimum, desirable or optimal level (Figure 1).

These services may benefit from access to people with expertise in health promotion, who will assist with the development of effective patient education programmes, and link the services with community-based preventive activities.

Implementation will define and address primary, secondary and tertiary prevention. There is great potential for tertiary prevention in diabetes, especially with regard to blindness, limb amputation and adverse pregnancy outcomes. However, rehabilitation and special assistance will still be required by those who do develop disabling complications.

Figure 1. Options for level of diabetes care, given level of development and resources.

<u>Level of care</u>			
	Primary	Secondary	Tertiary
Minimal	Paramedical staff basic diagnostics essential drugs	Physician basic education basic treatment of complications	Diabetes team
Desirable	Physician basic education basic treatment of complications	Diabetes team	Diabetes unit
Optimal	Diabetes team	Diabetes unit	Diabetes centre

Source: (1)

Every national programme should have a diabetes surveillance system. Such a system may:

- Serve as an aid to management by rationalizing care and improving the efficiency of patient referral
- Track morbidity and mortality from diabetes
- Thereby help to formulate appropriate control strategies
- Assist with the translation of research findings into programme activities
- Assist with both cross-sectional and longitudinal epidemiological investigations

- Assist with the translation of research findings into programme activities
- Assist with both cross-sectional and longitudinal epidemiological investigations
- Assist with the redefinition of goals and strategies.

Evaluation

Programme evaluation is a continuation of the planning and implementation cycle, based on the monitoring of overall programme efficiency and effectiveness. The evaluation process is simplified by the use of measurable performance indicators. At the conclusion of each phase of the programme, it will be necessary to re-examine goals, objectives, priorities and resources, as well as considering the effect of strategies and activities, and the status of official commitment to the programme.

Any health programme requires regular evaluation. However, all too often, evaluation is perceived as complex, costly or threatening, and it is avoided on this account. Evaluation should be seen as a positive learning experience, exemplified by the principle "better the devil you know than the devil you don't".

Evaluation need not be complicated or time-consuming. If an appropriate clinical record is used, formatted in a standardized way in order to collect a limited set of data, it will provide information for subsequent evaluation at minimal cost. The data thus obtained can help to meet the need for broader population-based information on late outcomes, such as amputation.

Other types of evaluation (e.g. evaluating quality of life, professional behaviour or education programmes) will take more time, and it is better to carry out the evaluation on a sample basis, using a number of key indicators. Case and topic review by the care team (operating as a "quality circle") can also be effective as part of a quality management programme and in reducing psychological barriers to self-evaluation.

The two principal types of evaluation measures are *process* and *outcome*. Process indicators test the extent to which the planned implementation has taken place: hiring staff, purchasing equipment, preparing educational materials, conducting seminars, etc. Process measures can be evaluated at almost no cost, in both the short- and the long- term.

Outcome measures reflect the extent to which the goals and targets of the programme have been accomplished. Medium-term measures of outcome include reduction of acute complications, hospital admissions and hospital bed-days, and improved metabolic control. Regular (annual) testing of haemoglobin A_{1c} concentration in a random sample of the target population may be a cost-effective measure of programme success in many instances.

Long-term outcome measures are reductions in incidence of disease, incidence of complications and disease-related mortality. Evaluating these can be difficult and quite costly, and take a long time, but they are the ultimate test of the benefit of the programme.

The role of the patient

Successful diabetes care requires the close involvement of the person with diabetes in the daily management of the condition. This has led to consideration of their role, and not merely that of their medical adviser(s), in the process of care.

In Europe, the St Vincent Declaration Steering Committee, on behalf of the European offices of WHO and IDF, has issued the document "Your guide to better diabetes care: rights and roles". Similar charters have been developed in other countries (e.g. Canada), which likewise describe important patient responsibilities. The expectations expressed in these documents may be overambitious for some countries, but the concept should be generally applicable, even if the content needs to be adapted to the individual national situation.

In developing a diabetes programme, it is useful to define the level of support which people with diabetes can expect from the health services, and the responsibilities which they should accept themselves.

Quality of care

Improvement of diabetes care is an exercise in quality development. However, given the extent of ill-health, and even social disorder, in many countries, the concept of quality may seem overambitious or even daunting.

In such circumstances it may be preferable to use the concept of *minimum standards of care*. This implies that there are certain *basic* needs for the provision of health services. Availability of insulin is an obvious example, with availability of diabetes education as another important objective.

Other aspects which should be considered are screening for hyperglycaemia during pregnancy, and frequency of screening for early complications. Although monitoring of metabolic control is considered of high importance, especially for people using insulin, it is unaffordable in many communities.

In many settings, diagnostic agents are not available at the primary level of care. Under such circumstances, primary care providers should have a clear knowledge of the symptoms, signs and risk factors of diabetes, so that they can recognize and refer people who display them to the next level of care.

The health care team

Because diabetes care involves many specialities and disciplines, it provides an excellent opportunity for interdisciplinary and intersectoral teamwork.

At the level of direct patient care, the interdisciplinary approach (i.e. a team of health care providers from different disciplines) may be sufficient. However, when considering the needs of the

population as a whole, the intersectoral approach, in which teams consist of a wider group of professional and nonprofessional participants, is necessary.

Often, people from diverse backgrounds and training find it difficult to communicate and to work together. Training is therefore required to help team members to understand and accept their roles. Further details for the various parties involved will be found in Section 4 of this report.

Information

A reliable system for the exchange of accurate information is essential to the national diabetes programme. People with diabetes and their families need information about the disease, how they can control it, and the health care services which are available to them. The community needs information about ways of reducing individual and community risk. Health care providers need information about prevention, early detection and the management of people with diabetes. Politicians and health planners need convincing evidence that diabetes is a major health issue, in order to justify expenditure of resources for its prevention and control.

In order to be useful to the above groups, information must be technically correct and reliable, and presented in a form which is accessible and attractive to the target audience (who in some cases will be illiterate). Pilot-testing will be required to confirm its usefulness before it is distributed on a large scale. The information must then be widely disseminated through a variety of channels, e.g. health professionals, pamphlets, television, video, radio, newspapers, comics and popular magazines. However, it should be remembered that the transmission of information is a two-stage process. It is not enough for the sender to create and transmit the information: the audience must also be motivated to receive it.

Managing change

The implementation of a national diabetes programme involves significant changes in organization, attitudes and behaviour for many people. The health care system and its constituent parts (e.g. hospitals or clinics) are complex institutions, so management procedures appropriate for complex change should be employed.

The proposed changes must be based on an analysis of the existing situation and the extent to which change is actually feasible. Realistic needs and priorities must be determined. It is important to find ways to motivate the people who will be affected, so that they will cooperate with the changes. A feasibility study should be carried out before changes are introduced on a large scale.

Change will not always be welcome. Resistance is a natural reaction, particularly since most change is aimed at attitudes and behaviour, which are the most difficult to change anyway.

Basic concepts for the implementation of national diabetes programmes

Understand

- Your health care system in terms of tasks, responsibilities, cooperation and communication
- The network of partners involved in, and affected by, the programme and the underlying driving forces
- The priorities of the parties involved and the benefits they may gain from the programme.

Respect others' priorities

- Other people also have high professional profiles
- They may have other priorities at the time
- There may be other important programmes competing for the same resources.

Build teams

- With all the skills required (including political skills)
- With representatives from many disciplines (people with diabetes, professionals, paraprofessionals, nongovernmental organizations) and all levels of the organizational hierarchy
- Using existing potential, in order to establish cooperation and to exploit synergies wherever possible.

Create and support

- Willingness to change
- Ownership of the change process
- Role models for demonstration purposes.

Allow for

- "Random" ideas in order to sustain action. Clear goals must be set, but then it is important to broaden the approach, in order to bring in as many new ideas as possible and to focus on new targets for the next phase of the programme. This rewards innovation and keeps the programme active and attractive.

4. Implementation in practice: the parties involved

This section deals with the various parties involved in the implementation of the national diabetes programme: people with diabetes themselves, health care providers and allied agencies, and national and international administrative structures. It represents the principal reports of the three working groups of the meeting.

4.1 People with diabetes

4.1.1 Needs

Basic needs and rights

For the person with insulin-dependent diabetes, a guaranteed supply of insulin is an absolute necessity. The insulin supplied should be of a quality appropriate to the resources available for its purchase, and should be of a consistent type and strength. Compatible syringes and needles and suitable diagnostics must also be supplied.

It is not generally appreciated that NIDDM can be a much more malignant and complicated condition to manage than IDDM. The resources needed to help people with NIDDM manage their condition are accordingly greater. Oral hypoglycaemic drugs are valuable in achieving metabolic control and, with some limitations, can alleviate the need for insulin. Newer oral hypoglycaemic agents have no major advantage over some older and cheaper drugs (such as tolbutamide).

People with diabetes have a right to the highest quality of life possible, given the continuing presence of their diabetes, and they should be helped to achieve this.

People with diabetes have a right to information concerning the status and progress of their condition. They should be treated

with honesty and openness by their medical advisers at all times, both as a basic right and because otherwise they may not fully appreciate the importance of day-to-day metabolic control and other strategies in preventing the late complications of diabetes.

Discrimination and prejudice against people with diabetes can be found everywhere: in insurance, motor vehicle licensing, job seeking and educational opportunities. The right to play a normal role in society and to enjoy equal social conditions needs recognition and endorsement.

There is often considerable cultural and social diversity within countries or regions. Diabetes care in general, and education programmes and materials in particular, need to reflect this diversity, as well as the problems created by deficiencies in population education.

People with diabetes have a right to receive care at an appropriate site without prolonged or recurrent hospitalization (except in emergencies). Access to care and necessary supplies needs to be geographically convenient.

Medical needs

Self-monitoring equipment enables people with diabetes to control their metabolic disturbance and thus meet the aims of a high quality of life and protection from late complications. Blood monitoring normally allows the highest command of this difficult-to-manage condition, but urine testing can be used to achieve some metabolic control at considerably less expense, although it cannot discriminate between normal and low blood glucose values.

The management of diabetes goes beyond the management of the metabolic condition and the maintenance of quality of life: freedom from complications cannot be guaranteed. The risks of major arterial disease are enhanced in people with diabetes. Thus, there is a need for regular advice about reducing arterial disease risk factors, including dyslipidaemia, smoking, obesity,

physical inactivity and hypertension. People with diabetes should be examined at appropriate intervals to detect early complications, and appropriate interventions should be available to reduce their impact.

People with diabetes, insulin-treated or otherwise, occasionally need urgent, specialist advice. Attention should therefore be paid to ensuring that they have ready access to a suitable member of the health care team.

Educational needs

Education is the cornerstone in empowering people with diabetes for self-management of their condition. The acquisition of knowledge and skills in diet, exercise, medication and self monitoring is of utmost importance for the quality and quantity of their future lives. Education is also necessary for them to achieve the self motivation necessary to change personal conduct in order to attain personal goals. It enables them to become partners in the health care team.

Diabetes is for life, and self-management is not easy to maintain. The circumstances of people with diabetes change. Patient education, like professional education, is thus a continuing process. It should be adapted to meet individual needs and made as user-friendly as possible: for instance, diabetes education sessions should be organized close to the person's home.

Emotional needs

At diagnosis, and sometimes for the rest of their lives, people with diabetes can feel isolated and perplexed. This often means that comprehensive diabetes education must be delayed while counselling needs are being met. Provision of contact with other people with diabetes may be helpful.

Children with diabetes have their own specific needs, including the need for psychological guidance.

Carers, in particular parents and spouses, play a major role in the quality of life and metabolic control achieved by some people with diabetes. Therefore, it is important to ensure that they are involved in the education and care of people with diabetes, and that their own emotional needs are met as fully as possible.

4.1.2 Barriers to appropriate diabetes care

This section addresses the barriers which may be encountered in trying to meet the needs described above.

Barriers affecting basic needs and rights

One fundamental barrier in some communities is the insecurity of insulin supplies, and to some extent, of the supply of syringes, needles, oral antidiabetic agents and diagnostics. Cost is also a factor: some people whose life depends on insulin cannot afford to buy it. These problems are exacerbated by import duties, taxes and the rigidity of some national distribution systems. Gifts of insulin can be lifesaving, but supply is frequently erratic, or is inconsistent in the preparations offered or in quality.

A general perception that NIDDM is "mild diabetes" still persists, despite the observation that the prevalence of complications is higher in this form, and the proportionate reduction in life expectancy is greater in many developed countries. This misunderstanding can severely interfere with consistency, coordination and continuity of care. It can make appropriate and continuing evaluation of the success of care almost impossible.

Discrimination and lack of understanding form another major barrier. Both family members, and society at large, may be reluctant to support people with diabetes when they make significant financial or behavioural demands connected with the management of their condition. This reluctance can be enhanced by a lack of understanding of the principles of management. It may be a major reason for social discrimination against people with diabetes.

Sociocultural factors affect the management of diabetes in any community, and their impact is often a negative one. Furthermore, there may be cultural and language barriers between professionals and some people with diabetes, particularly those from ethnic minority groups.

Medical barriers

The person with diabetes has limited means of self-evaluation, even if self-monitoring to assess blood glucose control is feasible. Failure to gain access to all the information available about one's health status (biochemical measurements, risk factors, complications) can lead to incorrect goals and hence, to inappropriate action.

Educational barriers

Even among those with some perception of the importance of diabetes education, the mistaken idea persists that it is principally about the delivery of knowledge, rather than helping people to achieve their self-care and lifestyle aims. As a result, some health care education programmes are poorly conceived and delivered, and are inadequately evaluated.

Education materials must also be available where they will be used. Considerable effort has gone into a very large number of initiatives to provide materials and tools for the enhancement of diabetes education. Unfortunately, all too often they fail to reach those at the site of delivery of care, who may be unaware of their existence or unable to command the funds to buy them.

Failure of those involved in funding or providing care to appreciate the central importance of education is common. Cost-effective approaches, such as group sessions, may not be seen as "real" medicine. This leads to a failure to provide education for future patient educators. It can be a particular problem for people with NIDDM, who constitute the overwhelming majority of people with diabetes in most communities.

Emotional barriers

Particularly at the time of diagnosis, the person with diabetes may be discouraged from acquiring appropriate self-care strategies by two internal factors:

- Perception of health care in terms of the classical model, in which a doctor provides the treatment. Self-care is severely undermined by the view that others are responsible for one's health.
- Misconceptions, or lack of perception, about vulnerability to future health problems. The person's perception of his/her vulnerability is an important part of motivation for optimal self-care.

The classical health belief model (as above) and unfamiliarity and insecurity in dealing with the health care system can mean that people with diabetes fail to gain as much as they could from their contacts with the health care team. Lack of contact with other people with diabetes can make the person feel isolated with his/her problems. Frequently, insufficient psychological support is provided, especially in the case of children with diabetes. The problem can be sustained or exacerbated by the inappropriate views of "significant others", whether relatives or friends.

4.1.3 Overcoming barriers to appropriate diabetes care

Overcoming basic barriers

In order to improve insulin supplies, structures which add cost (import taxes, distribution monopolies, inflexible distribution systems, etc.) should be identified and dismantled. Where resources are limited, purchasing should be restricted to a selected list of generically identified insulin preparations, syringes and needles, oral hypoglycaemic agents and diagnostics. Continuity of supply of these items must be ensured. Tendering centrally can help to control costs, but may disrupt continuity of supply if inappropriately handled. As supply and purchasing systems vary considerably from country to country, local review

may be necessary, and the advice of manufacturers and the international agencies should be sought in overcoming the problems identified.

To overcome potential discrimination against people with diabetes, patient associations should raise the awareness of the public and bring pressure to bear on the authorities responsible for change.

Professional awareness of potential cultural and social barriers, and the means of identifying them, is a specific function of professional education (whether basic, specialist or continuing). When specific difficulties arise, help from ethnically similar health care workers, interpreters and culturally appropriate literature is frequently an effective response. Often cultural and religious organizations can be involved to good effect.

Less obviously, support systems should be developed for those with special needs, such as visually disabled people requiring insulin, those whose carer has died, and people with diabetes no longer able to live with their family or in their own home. Geographical considerations, as well as availability of resources, are important if equity in access to health care is to be achieved.

Overcoming medical barriers

If resources are insufficient for blood testing strips to be made available to all those who would benefit from them, (as is often the case in developing countries) urine testing reagent strips are recommended as a method of achieving important benefits of self-monitoring, but they do not give warning of hypoglycaemia.

Provision of self-testing equipment for glucose monitoring should be seen only as one element of self care. Most other measurements made in diabetes care (from blood pressure to the results of retinopathy surveillance) should be made available to the person with diabetes, using an appropriate record system (such as a modern care card) and with individualized targets and explanations.

Overcoming educational barriers

Well-designed patient education programmes should address areas such as health beliefs and perceived vulnerability in addition to models of care. They should be based on well-developed theories (e.g. the social learning theory, the health belief model and the social support theory), which will help to ensure that they address issues such as the sense of self-efficacy, the knowledge and the skills of all persons with diabetes, including older people and adolescents. Adult learning theory, too, will help diabetes educators to develop effective programmes, using a variety of educational methods.

Evaluation of diabetes care includes the evaluation of education programmes. At the basic level, knowledge assessment may be useful, but as the underlying aim of such programmes is to enable people with diabetes to achieve their self-care and lifestyle aims, more direct approaches through the evaluation of attitudes, skills and achievements are indicated.

When educational tools are developed at national or regional levels, or by industrial organizations, knowledge of their availability must be disseminated, and funds made available for their continuing purchase.

Overcoming emotional barriers

Effective diabetes education programmes based on appropriate theory should act as a means of empowerment, helping people to overcome barriers and obtain the maximum reasonable benefit from the health care system. They should be aimed at carers and "significant others" as well as people with diabetes themselves. Other simple strategies, such as encouraging people with diabetes or their carers to write down questions before meetings with physicians or other members of the health care team, can help to ensure that the best possible use is made of contact time with providers.

Group meetings and events, participation in local patient association activities, or even patient association mailings can help to reduce feelings of isolation and enhance self-evaluation and self-care, as well as increasing confidence and self-assurance. Camps and group holidays are useful in the younger age groups. Provided that they are chosen for their ability to recognize the needs of others, people with diabetes themselves can provide valuable counselling, particularly at times of crisis, such as the period immediately after diagnosis.

4.2 Health care providers and allied agencies

4.2.1 *Needs of health care providers*

If health care providers are to contribute fully to the implementation of the national diabetes programme, they will need the following:

- The right staff
- Efficient integration, both between the various levels of diabetes care and with other sectors
- Appropriate training and professional education
- Adequate funding for essential supplies and equipment
- Suitable reimbursement.

The primary health care team (physicians, nurses, chiropodists, dieticians, educators, etc.) is one of the most important components of health care provision. The emphasis now placed on shared care (self-care by the person with diabetes, plus care and advice from the health care team) means that the team's principal role is that of a consultant. The primary health care team needs:

- A fixed base, even if care is delivered in widely dispersed sites
- Responsive and accessible secondary care
- Protection from competing demands.

There is a need to ensure the clinical effectiveness and cost-effectiveness of the care being delivered. In turn, this implies a

need for agreed standards and protocols for care, appropriate to local resources but also consistent with international guidelines. Professional codes of conduct and disciplinary measures may also be needed to avoid malpractice.

4.2.2 Barriers encountered by health care providers

Staffing

One major barrier is a lack of human resources. There may be simply a shortage of people with appropriate basic training who could become skilled in diabetes care, because of an overall shortage of health workers and/or the competing needs in other sectors. Or diabetes health care personnel may lack essential skills (general medical skills, specialist diabetes skills or counselling, education and evaluation skills). Sometimes the available skills are not appropriately used, mostly due to organizational problems.

In some cases, the accepted diabetes practice is inconsistent with the global consensus. While it is possible that the local practice is, in fact, more effective than that provided elsewhere, it may use scarce resources disproportionately, and people with diabetes may suffer side-effects from neglect of other negative aspects of care.

Diabetes care can become part of a "power game" in health care systems. This is particularly true if the professional income of specialists and general practitioners depends on the number of patients seen, or the frequency of visits. The same problem can exist between physicians and diabetes education nurses or dietitians. Another potential problem is professional malpractice or misappropriation for reasons of personal gain which, sadly, do still occur in diabetes care.

Integration

The conventional strict separation of secondary and tertiary care from primary care is never really appropriate. Some activities

(e.g. those of the chiropodist) may be carried out at several levels of health care, sometimes even by the same individual. Professionals who should logically form a single health care team are often based in different centres if they are funded separately rather than under a single budget. This can seriously affect the consistency, coordination and continuity of care and make appropriate and continuing evaluation of the success of care almost impossible.

Needs - and the ways in which they can be met - are specific to the local situation. Programming must be interdisciplinary and intersectoral in nature. Solutions need to be flexible, and part of that flexibility must be to avoid "the best becoming the enemy of the good". For example, health planners should not be deemed to have failed if there is no tertiary diabetes centre in the country concerned. This simply may not be possible in the local circumstances, and the "next best thing" will be infinitely better than nothing.

Training

Some care providers remain unfamiliar with the modern approach which emphasizes self-care by the patient, with the health team in the role of consultant, and continue to deliver care according to more classical medical models. A sound initial training, backed up by regular refresher courses, will help to prevent this and many other problems.

Funding

A simple lack of resources, or the wasting of resources on ineffective and inefficient programmes, can be a major barrier to diabetes care.

4.2.3 Overcoming barriers encountered by health care providers

Staffing

Planning for the appropriate provision of trained professionals is inevitably a long-term strategy. A review of the available personnel with a view to skill substitution may provide a means of fulfilling needs more rapidly and cost-effectively, if training programmes are adequately supported. In many parts of the world, it is obvious that people with the potential to develop and make use of enhanced skills are "trapped" in jobs below their potential. Flexible working and sharing of roles can also enhance the efficiency of diabetes teams. Specialist skills, particularly in management, education and preparation of materials, are often available from medical enterprises involved in the field of diabetes care, if their help is sought.

Where local health care guidelines and practice deviate from global practice without obvious reason (examples include excessive inpatient care and hyperbaric oxygen therapy), the resources so used should be released for more conventional diabetes care, unless the therapies in question are being critically evaluated. The medical industry may be approached to cooperate in such an evaluation, when commercial products are involved.

The reckless and deliberate provision of inappropriate care, or the diversion of health care resources for personal gain, should be made matters liable to forfeiture or restriction of a professional's licence to practise. Conversely, professionals who expose administrative and managerial incompetence or malpractice should be protected from individual sanctions.

Recognition of quality health care delivery can be a factor in further enhancing the quality of that care and in providing confidence for open professional evaluation. In some circumstances, professionals will derive financial benefit from this. What constitutes a level of endorsement of quality health care would need to be discussed with the relevant professionals in the

country concerned. Suitable bodies to provide such certification might include patient associations, professional bodies responsible for standards, and international organizations, with assistance from WHO and the IDF, as necessary. Eventually, it might prove appropriate to compile lists of providers who have been recognized as providing quality diabetes care.

Integration

Integration involves not only the three levels of diabetes care (primary, secondary and tertiary) but also other sectors and disciplines. It is important to provide the professionals who logically form a single health care team with a joint base, even if they are funded by separate budgets.

Preventing diabetes and improving people's access to support and resources to enable them to maintain their health will require those responsible for the diabetes programme to align themselves with professionals addressing similar issues for other noncommunicable diseases. For example, the common arterial risk factors identified in many noncommunicable disease programmes (central obesity, dyslipidaemia, hypertension, family history of arterial disease or diabetes, physical inactivity) are all found in people with diabetes at a prevalence several times that of the background population. The prevalence of NIDDM and ischaemic heart disease (and other arterial disease) correlate highly within populations. This makes diabetes care an excellent model for an integrated noncommunicable disease programme with a cost-effective approach which is attractive both to primary health care providers and to commissioners of health care.

Table 1 gives specific examples of the strategies developed to meet particular integration needs and the short-term action taken to implement the strategy.

Table 1.

Strategies and action developed to meet specific integration needs

Need: improved overall integration, in this case aimed at reducing the incidence of lower-extremity amputations

<i>Strategy</i>	<i>Action</i>
Determine the current (baseline) level of amputations	Using simple means such as audits, determine (a) the current situation (b) how it falls short of that desired (c) what is needed to put it right
Define short-term indicators (e.g. highest-risk patients)	Provide preventive footwear and intensive ulcer treatment
Identify long-term (outcome) indicators	Review and reprogramme for improved efficiency

Need: better integration of secondary and tertiary providers through improved communication

<i>Strategy</i>	<i>Action</i>
Determine current accuracy and adequacy of communications system	Track a random sample of patient care encounters and referrals. Was the system accurate? Modify as needed.

Table 1 (cont'd.)

Need: better integration between primary, secondary and tertiary care

<i>Strategy</i>	<i>Action</i>
Overlapping system allowing interdisciplinary approaches.	Achieve economy of scale by working with other chronic disease control programmes.
Increase contact between primary, secondary and tertiary care providers and people with diabetes	Formalize communication and coordination networks. Design pilot and demonstration programmes involving members of health care team - build on successful elements. Build in ways of increasing provider satisfaction and financial incentives

Need: integration with other providers, administrators, planners, patients, etc.

<i>Strategy</i>	<i>Action</i>
Mutual education	Continue multiprofessional education (diabetes content as well as interpersonal skills)
Strive for partnerships at provider and organizational level	Break down barriers by organizing collaboration between providers, administrators, etc.
Utilize existing educational information, materials and programmes as far as possible	Assess existing materials and use if suitable. Divert resources saved to higher-priority tasks

Table 1 (cont'd.)

Communicate providers' needs to medical industry	Meet representatives of medical industry. Agree on coordination of roles and avoidance of competition. Involve industry in disseminating standards of care. Use available skills in communication, disease burden assessment, etc.
Improve resource utilization	Compare options for resource allocation in diabetes programmes. Encourage frank speaking. Avoid unrealistic expectations of savings from prevention programmes
Improve patient tracking	Establish patient registry if feasible. If not, avoid wasting valuable resources.

Training

A lack of appropriate skills remains a major deficiency worldwide, and strategies to deal with this are a core part of any diabetes programme. It is necessary to ensure that those responsible for basic, specialist and continuing education for any group of professionals are aware not only of the need for classical medical skills, but also of the need for the skills required to advise patients about optimal self-care, development and delivery of patient education programmes, and methods for evaluation of the success of continuing diabetes care. Funding is important for continuing education programmes. People with diabetes are themselves a useful resource in the appropriate education of diabetes professionals.

Funding

Provision of funding for the care process remains a powerful incentive to professionals to provide that care. This could extend to education programmes as well as to complications surveillance and risk factor management. Quality is likely to improve more quickly if funding depends on the *outcome* of care, but at present variations in disease severity between populations may make this difficult, even at the primary health care level. However, funding could be provided on the condition that such outcome data be made available in the future.

Administrators, commissioners and purchasers of health care will generally respond to unfamiliar management strategies if there is a clear health gain which can be achieved cost-effectively. Thus, patient education - a key example - is most likely to be funded where the evidence supporting its role has been demonstrated, and where it has been endorsed by a consensus of professional opinion as important to an adequate (rather than ideal) diabetes care service. Evidence of attention to cost-effective approaches (e.g. outpatient-based group activities) is helpful here.

4.2.4 Contribution of allied agencies to the implementation of national diabetes programmes

There are many non-medical agents who can make a valuable contribution to the national diabetes programme. They include pharmacists, as well as the media, the general public and associations of professionals and people with diabetes. Even traditional and alternative healers should be considered. Although these can hardly be included in a conventional intervention plan, in certain areas they represent the only, or the most esteemed, suppliers of health care. Therefore, it is essential to gain their cooperation, as far as possible, and to encourage them to refer to mainstream medicine those people whose life or functions are threatened by diabetes and its complications.

Pharmacists

Pharmacists have much valuable information to offer because they have direct, regular contact with people with diabetes. They may contribute to patient education (both directly and through the distribution of leaflets, etc.), act as a contact point between people with diabetes and the various levels of care, provide information about patient needs, participate in screening and case finding activities, and distribute supplies and instruments (meters, pens, etc.).

Nongovernmental associations

These may be:

- Scientific associations
- Professional associations, both medical and nonmedical
- Lay associations.

In some countries, the categories are combined, but in others they form a federation, or they operate completely separately. Whatever their structure, the different parties should join forces to play their part in the design and implementation of the diabetes control programme at the national or district level. Any conflicts which may exist must be resolved in the interests of a coherent message and common action.

Scientific associations should promote research into improved methods of care and the monitoring and documentation of their implementation. Appropriate research into educational issues and the different requirements of developed and developing countries should also be encouraged. Cooperation with the medical industry in the research field may be very valuable.

Professional associations can provide valuable leadership for training. They may need to abandon their usual emphasis on "high-tech" tertiary care and place greater emphasis on the value of primary services.

Lay associations have a vital role to play in the design and implementation of national diabetes programmes. They can identify the needs of the diabetic population and promote acceptable methods of implementation. They can fulfill a vital watchdog role and help to evaluate the outcome of programme measures. Finally, they have a powerful advocacy function. If they are to play their part to the full, they must recruit as many members as possible. They need training and education, not only in the technical aspects of diabetes and diabetes care, but also in the techniques of running an organization efficiently (information, advocacy, recruitment). The IDF has provided valuable management advice to its member associations (23).

Purchasers of health care

Purchasers of health care (both public and private) need to ensure that the care their clients receive is both high in quality and cost-effective. Their contribution to the national diabetes programme may include the provision of valuable statistics on the magnitude and scope of the diabetes problem as well as monitoring and outcome data.

If purchasers of health care fail to support core elements of diabetes care, encourage inefficient aspects of care, or adopt practices inconsistent with those of similar organizations in the same country, then use should be made of mechanisms to review their performance or make others aware of their inadequacies.

Medical industry

A good relationship with the medical industry is considered a key factor for the success of a national or district diabetes programme, because of the resources that industry can provide (including expertise in communication and persuasion). As a prerequisite for this cooperation, the objectives of both sides must be explicitly declared and agreed: in particular, market and regulatory constraints must be clarified in advance. A "code of conduct" should be developed, indicating the accepted boundaries for cooperative initiatives. The International Federation of

Pharmaceutical Manufacturers Associations (IFPMA) has recently issued a general code of pharmaceutical marketing practices (24).

If commercial enterprises cannot agree on a joint representative to sit on a steering committee, they should, at least, have the status of "external partners". In addition, their contribution to the design of the plan may be highly beneficial, especially in the information field and in programme management, because of the medical industry's long experience in these areas.

Mass media

Messages on diabetes conveyed by the media must be accurate and avoid sensationalism. The media considered in this section are:

- Specialist diabetes journals (scientific publications, educational journals for professionals or people with diabetes, and informative journals for people with diabetes)
- General journals (daily, weekly, etc.) with occasional articles on diabetes and related problems in widely differing formats
- Other media, including television, radio and computer networks.

Journals of all kinds can contribute to the implementation of diabetes programmes, by publicizing new initiatives in diabetes care and by promoting the standardization of methods and procedures. The educational and informative journals may contribute to the empowerment of people with diabetes.

General journals can inform the public about the scope and achievements of the diabetes programme. The information they contain must be simple, concise and adapted for a general readership.

The support of other media, such as radio and television, is considered particularly important, both for the large-scale

dissemination of information and for their expert contribution to education programmes, especially at a local level. Special items on diabetes may be broadcast if costs can be kept low. Professional support for these activities is highly recommended. Computer networking, where resources permit, also appears to be a promising field for the exchange of experiences and information.

Powerful allies

Diabetes does not spare the political and administrative elite, and indeed in many countries the disease is more prevalent in such groups. They are more likely to make the effort to understand the problems of implementing quality diabetes care, and may be willing to provide the contacts and support needed for implementing general strategies or solving specific problems. Sometimes, they may even initiate the programming process.

The public

The general public can help to increase awareness of diabetes and related problems and may play a watchdog role, reporting infringements of the social rights of the diabetic population, especially in respect of employment, or of particularly disadvantaged groups such as the elderly and the disabled. The public can participate actively in prevention programmes and may also support the diabetes programme by promoting it to the authorities, fundraising, etc.

If the public is to contribute fully, it must be given balanced, appropriate and consistent information about the risks associated with diabetes and current treatment and risk reduction practices. It is important to use language which can be easily understood by the target population and to avoid raising unrealistic expectations which cannot be fulfilled. The information supplied should also have some entertainment component in order to maintain people's interest (the term "infotainment" has been coined in Jamaica to cover this concept).

4.3 National and international administrative structures

This section deals with the administrative structures involved in the planning and implementation of the national diabetes programme, including international bodies such as WHO and IDF. The original impetus may come from the Ministry of Health of the country in question, or the programme may be developed in other quarters and merely submitted to the Ministry for approval.

Goals and targets must be clearly defined if the programme is to enjoy the full support of all parties. While many of the objectives may be long-term ones, it is also important to decide on shorter-term goals which can be evaluated for success of implementation and cost-effectiveness: the programme should therefore include a component relating to the costs of diabetes and the economics and effectiveness of improved diabetes care. These shorter-term objectives are those which are most likely to interest the Ministry of Health, central health planners and administrators.

The organizational structure of the programme may vary from country to country. It has, however, proved helpful to set up, at least, the following elements:

- Policy planning body and/or
- Management and implementation body (steering committee, advisory board)
- Specific task groups (as needed).

Ministry of Health

In most countries, the Ministry of Health plays a pivotal role in the development and success of a national diabetes programme. Although the programme may be drawn up by other sectors of the health system, the Ministry's endorsement of the proposed activities is vital for further development and implementation and the political will which is of utmost importance to the success of

the programme. Furthermore, the Ministry can often provide expertise in the field of health planning and economics, which may facilitate both the development and the evaluation of the programme.

The Ministry should integrate the programme into the overall health plan and allocate appropriate resources to it. Although the programme will use existing human resources and facilities as far as possible, any additional support is likely to compete directly with other health programmes. Therefore, conviction of the health authorities of the burden of diabetes, supported by valid data, is essential.

Policy planning body

The policy planning body has the overall responsibility for the development of the programme. It decides on the objectives, obtains the approval of decision-makers at the political level, and negotiates to obtain the resources needed. The key agencies and departments connected with diabetes care should all be represented on it.

Steering committee

The programme should be directed by a steering committee which is responsible for overall implementation and management. The programme director (see below) should be an *ex officio* member. The other members should come from a broad range of disciplines, including communications and education. The committee should meet frequently to discuss the implementation of the programme and to identify needs, problems and possible solutions. It should report regularly to the health authorities.

The programme director is responsible for managing the day-to-day activities of the programme. He/she ensures that all the components of the programme are established and functioning effectively, coordinates the activities of the separate components, evaluates needs and deficiencies and, wherever possible,

provides a solution to the problems encountered. The programme director must take a leadership role to ensure that the programme runs smoothly and efficiently. He/she should report regularly to the steering committee.

International organizations

WHO has played a major facilitating role in the development and adoption of national diabetes programmes. Upon request, WHO provides valuable help to countries wishing to initiate such programmes by continuing to develop materials which relate to various components of the programmes. WHO staff may also provide direct assistance, especially in the initial stages of programme development. Advisers and consultants, often recruited through WHO, can provide additional support for the development, implementation and evaluation of programmes.

The IDF has promoted national diabetes programmes directly, in cooperation with WHO and its regional offices (e.g., the St Vincent Declaration initiative in Europe) and through its member associations. It has been shown that strong member associations, under the guidance of IDF, are very important instruments in promoting social rights and the development of national diabetes programmes.

WHO and IDF should combine their efforts, for example in reporting directly to Ministries of Health on the perceived strengths and weaknesses of the country's diabetes programme.

Other international organizations could make a useful contribution, e.g. the International Labour Organization (ILO) could advise on appropriate social rights and other safeguards for people with diabetes; the United Nations Children's Fund (UNICEF) could advise on the special needs of children with diabetes.

5. Conclusions and recommendations

The national diabetes programme

Activities to improve diabetes care in all countries should be directed and coordinated within a national diabetes programme. This programme should be devised by a policy planning body and managed by a strong programme director under the guidance of a steering committee. The programme should be based on a situational analysis assessing the burden of the disease and the resources available.

An appropriate level of diabetes care for the specific country should be defined. From these two elements targets should be derived and prioritized.

A programme plan should be conceived which is accepted by all parties involved. This plan should:

- Be approved by the government
- Include responsibilities, timescales and milestones
- Consider cost containment, including measures for the reallocation of resources and budgets
- Be implemented accordingly
- Be evaluated, reviewed and reappraised regularly.

People with diabetes

People with diabetes should lead as normal a life as possible. They need adequate care, supplies, education and information. They should:

- Acknowledge that they are responsible for managing their diabetes
- Become an active and empowered member of their health care team
- Seek improvements in care (e.g. through patients' associations).

Health care providers

Many of the measures included in a typical national diabetes programme involve health care providers. Their quantity and quality are major determinants of the programme's outcome. Providers should be committed to the programme and to evaluating and improving the quality of care. They should strive towards greater integration between their work and that of others, both inside and outside the national diabetes programme.

Allied agencies

The allied agencies can contribute greatly to the promotion of the national diabetes programme. They include:

- The medical industry
- Pharmacists
- Health care providers in other noncommunicable disease programmes
- Influential national personalities who could promote the programme
- The media
- The general public

The *mass media* should disseminate information which is simple, concise, easily understood and attractive to a nonspecialized audience. The information the media receive from health professionals and other sources should already meet these criteria, as far as possible.

The *general public* has to bear the financial and human burden of diabetes. The public should:

- Be properly informed
- Become involved in prevention
- Seek improvements in diabetes care.

National and international administrative structures

In most countries, *health authorities* are crucial to the success of the programme. They should:

- Decide on the priority to be allocated to diabetes care
- Provide expertise in health planning and economics
- Support planning and implementation of the programme
- Make decisions on resource reallocation
- Decide upon financial incentives to encourage care providers to improve quality of service
- Participate in programme evaluation and redirection.

National "focal points" may be accredited to facilitate the programme. They should:

- Establish links between health authorities and other parties involved
- Act as a focus for discussion among professionals
- Serve as ombudsmen, especially before the programme is established.

The *World Health Organization* (WHO) plays a major role in the promotion of national diabetes programmes. The Organization should continue to prepare and publish information on:

- The magnitude and scope of diabetes and its complications
- The availability of effective strategies for diabetes prevention
- Well-coordinated approaches to health care, including national diabetes programmes.

In cooperation with the WHO Regional Offices, the Diabetes Programme at WHO Headquarters should provide national governments with general guidelines and with training and expertise to help them to:

- Improve existing national diabetes programmes
- Develop new programmes (in countries which request them).

In addition, WHO Headquarters and the Regional Offices can act as clearinghouses/information centres (globally and regionally) for data collection and monitoring and the exchange of experiences about national diabetes programmes. They should develop and disseminate new methods of programme evaluation and support their appropriate use.

The *International Diabetes Federation* (IDF) should help member patient organizations to:

- Increase their membership
- Publicize themselves better
- Oppose malpractice and discrimination
- Lobby for improvements in care through national diabetes programmes
- Contribute to the development, implementation and evaluation of national programmes

WHO and IDF (both centrally and regionally) should cooperate closely to provide ongoing leadership in:

- Advising health authorities
- Epidemiology, quality management and public health aspects of diabetes care
- Training of diabetes educators and diabetes nurses.

References

1. REIBER G, KING H. Guidelines for the development of a national programme for diabetes mellitus. Geneva, World Health Organization, 1991 (WHO/DBO/DM/91.1).
2. KING H, REWERS M. Diabetes in adults is now a third world problem. *Bulletin of the World Health Organization*, 1991, **69**(6):643-648.
3. KING H, REWERS M. Global estimates for prevalence of diabetes mellitus and impaired glucose tolerance in adults. *Diabetes care*, 1993, **16**:157-177.
4. *Prevention of Diabetes Mellitus: report of a WHO Study Group*. Geneva, World Health Organization, 1994 (WHO Technical Report Series No. 844).
5. AMERICAN DIABETES ASSOCIATION. Direct and indirect costs of diabetes in the United States, 1992. Alexandria, VA, American Diabetes Association, 1993 (ISBN 0-945448-32-5).
6. KRANS HMJ, PORTA M, KEEN H., eds. Diabetes care and research in Europe: the St Vincent Declaration action programme. Copenhagen, WHO/IDF Europe, 1992 (EUR/ICP/CLR055/3).
7. ALWAN A, ed., Diabetes prevention and control: a call for action. Alexandria, WHO Regional Office for the Eastern Mediterranean, 1993, (WHO-EM/DIA/3/E/G).
8. ALWAN A, ed., Management of diabetes mellitus: standards of care and clinical practice guidelines. Alexandria, WHO Regional Office for the Eastern Mediterranean, 1994, (WHO-EM/DIA/6/E/G).

9. LAING W, WILLIAMS DRR. Diabetes, a model for health care management. London, Office of Health Economics, 1989, (series no. 92, ISSN 04738837).
10. RUBIN JR, ALTMAN WM, MENDELSON DN. Health care expenditures for people with diabetes mellitus, 1992. *Journal of clinical endocrinology and metabolism*, 1994, **78**:809A-F.
11. DIABETES CONTROL AND COMPLICATIONS TRIAL RESEARCH GROUP. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England journal of medicine*, 1993, **329**:977-986.
12. HERMAN W. Economics of DCCT. (Paper presented at ADA meeting, New Orleans, 1994).
13. ASSAL J-P ET AL. Patient education as the basis for diabetes care in clinical practice and research. *Diabetologia*, 1985, **28**:602-613.
14. DIABETES SURVEILLANCE 1991. US Department of Health and Human Services, 1991.
15. BORCH-JOHNSEN K ET AL. Is screening and intervention for micro-albuminuria worthwhile in patients with insulin-dependent diabetes? *British medical journal*, 1993, **306**:1722-1725.
16. LEWIS EJ ET AL. for the Collaborative Study Group. Effect of angiotensin - converting enzyme inhibition on diabetic nephropathy. *New England journal of medicine*, 1993, **329**:1456-1462.
17. DASBACH E ET AL. Cost-effectiveness of strategies for detecting diabetic retinopathy. *Medical care*, 1991, **29**:20-31.

18. HERMAN W, AMBER RW, DULL HB. Closing the gap: the burden of unnecessary illness. Oxford, Oxford University Press, 1988.
19. JAVITT JC ET AL. Preventive eye care in people with diabetes is cost-saving to the Federal Government. *Diabetes care*, 1994, 17(8).
20. EVERETT WD. Screening for gestational diabetes: an analysis of health benefits and costs. *American journal of preventive medicine*, 1989, 5:38-43.
21. SONGER T. The economic costs of NIDDM. *Diabetes/metabolism reviews*, 1992, 8:389-404.
22. DEEB L, TAN MH, ALBERTI KGMM. Insulin availability among International Diabetes Federation member associations. *Diabetes care*, 1994, 17:220-223.
23. INTERNATIONAL DIABETES FEDERATION TASK FORCE ON MEMBER ASSOCIATION DEVELOPMENT. Together we are stronger: how to build successful diabetes associations. Brussels, International Diabetes Federation, 1994.
24. INTERNATIONAL FEDERATION OF PHARMACEUTICAL MANUFACTURERS ASSOCIATION (IFPMA). IFPMA code of pharmaceutical marketing practices, Geneva, IFPMA, 1994.

Further reading

A desktop guide for the management of non-insulin-dependent diabetes mellitus (NIDDM) (Revision). European NIDDM Policy Group. Brussels, International Diabetes Federation, 1993.

Consensus guidelines for the management of Insulin-dependent (Type 1) diabetes. European IDDM Policy Group. Brussels, International Diabetes Federation, 1993.

Canadian Diabetes Advisory Board. Clinical practice guidelines for treatment of diabetes mellitus, and a quick reference guide for primary care physicians. *Canadian Medical Association journal*, 1992: 147 (5).

American Diabetes Association. *Minimum standards of care*, 1992.

Diabetes Australia. *National action plan for diabetes*. Canberra, Australian Diabetes Society, 1993.

Diet, nutrition and the prevention of chronic diseases. Report of a WHO Study Group. WHO Technical Report Series, no. 797. Geneva, World Health Organization, 1990.

Guidelines for the management of diabetes mellitus in Singapore. Singapore National Diabetes Commission, 1993.

Kohner EM, Porta M., eds. *Screening for diabetic retinopathy in Europe: a field guide book*. Brussels, International Diabetes Federation, 1992.

Learning together to work together for health. WHO Technical Report Series, no. 769. Geneva, World Health Organization, 1988.

National Diabetes Advisory Board. *The prevention and treatment of five complications of diabetes* (HHs 83-8392). Atlanta, GA, US Centers for Disease Control, 1983.

National Diabetes Task Force. *Status of diabetes in Canada*. Health and Welfare Canada, 1985.

Persatuan Diabetis Malaysia. *Non-insulin-dependent diabetes mellitus: the Malaysian consensus*, 1992.

Background materials for the St Vincent Declaration Action Programme (Available from the WHO Regional Office for Europe/QCT, 8, Scherfigsvej, DK-2100 Copenhagen Ø, Denmark):

DiabCare Monitoring Group. *DiabCare: basic information sheet*. 1992.

DiabCare Monitoring Group. *DiabCare: continuous quality improvement. Feasibility phase*, 1992.

Implementation of the St Vincent Declaration. (Joint WHO/IDF meeting), Budapest, 1992.

National and regional implementation of the St Vincent Declaration targets. (Meeting, Oslo), 1992.

EuroDiabCare: diabetes action programmes for the CCEE's. Copenhagen, WHO Regional Office for Europe, 1992.

Your guide to better diabetes care: rights and roles. International Diabetes Federation, Brussels, 1991.

Glossary

Adult learning (training) theory. For this theory there are two principal approaches - one which is based on learning by conditioning (Pavlov, Skinner) and one which is based on learning through response-building by the learner (Piaget, Bruner, Vygotsky).

Annual discount rates. Percentages used to discount the monetary value of cost-saving results of interventions, which are expected with delay in time, mainly due to inflation. Health economists unanimously use annual discount rates of 5-6% now, irrespective of the counter argument that the benefits are not expected in cash but, for example, in the avoidance of complications like amputations, for which the cost may rise at similar rates.

Care providers. All persons engaged in the provision of care, e.g. nurses, health educators, general practitioners, specialized clinicians, etc.

Cost of diabetes.

direct cost = cost of health care for persons with diabetes, including in- and out-patient costs, nursing homes, drugs, diagnostic devices, etc. Not included is health care-related cost, e.g., for research.

indirect cost = earnings lost due to morbidity, early retirement and mortality.

total cost = direct cost + indirect cost.

incremental cost = cost due to diabetic conditions, i.e. cost spent for persons with diabetes minus cost spent for the health care of an equal group of persons without the disease.

Cost-effectiveness of interventions. Benefits of the specific intervention, calculated in monetary terms, minus discounts for the delay in time for the intervention to achieve results and compared with the cost of the intervention.

DCCT. Diabetes Control and Complications Trial. A prospective multicenter study, conducted in the USA for approximately 10 years comparing the outcome of intensified versus conventional insulin therapy among more than 1400 IDDM patients. The results, published in 1993, demonstrated a risk reduction for retinopathy, neuropathy and nephropathy of approximately 50% in subjects given intensified therapy.

Diabetes care team. Interdisciplinary group of care providers, e.g. nurses, health educators, dietitians, podiatrists, GPs, taking care of persons with diabetes, counselling them in all aspects of their disease treatment and empowering them for self-management.

Diabetes education. Patients need to be instructed in all aspects of their condition, since it is a lifelong disease which they must manage themselves on a day-to-day basis. Education is therefore one of the most important aspects of diabetes control.

Diabetic nephropathy. Renal disease due to damage to small vessels of the kidney which may lead to renal failure. May be exacerbated by hypertension, and delayed by antihypertensive therapy.

Diabetic neuropathy. Damage to nerves which may lead to sensory loss as well as impotence in men and gastrointestinal problems. Neuropathy is an important cause of diabetic foot problems, especially in communities which have poor footwear.

Diabetic retinopathy. Eye disease which may lead to loss of sight. May be arrested/delayed by early detection and treatment with laser photocoagulation.

Discrimination. All facts, opinions and actions which adversely influence the chances of specific people, e.g. persons with diabetes, to live a life as near normal as possible.

Effectiveness. The effects of the activity and the end-results, outcomes or benefits for the population achieved in relation to the stated objectives.

Efficiency. The effects or end-results achieved in relation to the efforts expended in terms of money, resources and time.

Empowerment. All measures needed for persons with diabetes to gain the ability for self-management and to live a nearly normal life, i.e. by education and training, psychological and social support, etc.

Evaluation. A highly structured approach to monitor the state and progress of activities using predetermined parameters and tools and having a watch-dog function towards the targets. Evaluation is an essential part of every programme.

GP. General practitioner, a medical doctor, mainly involved in provision of primary care.

Health belief model. An applied psychosocial theory initially developed in the field of preventive medicine in the 1950s and used to predict health-related behaviours. Revised and adapted many times, it is currently used for chronic diseases (diabetes, asthma, hypertension, etc.) to discover why certain patients are not motivated to follow treatment.

Health care purchasers. All parties which directly pay money for the provision of health care, e.g. private or public health insurers, government agencies, and also uninsured patients.

Horizontal programming. An approach whereby activities are developed simultaneously for several diseases or programme areas which show some common features, risk factors or preventive strategies.

IDDM. Insulin dependent diabetes mellitus. The less frequent form of diabetes (approximately 10% of all persons with diabetes), resulting from the destruction of insulin producing cells in the pancreas by auto-immune processes, frequently with onset in childhood or youth. Daily insulin treatment is always required.

ILO. International Labour Organization. A specialized agency of the United Nations system with its headquarters in Geneva.

Impaired glucose tolerance (IGT). Intermediary category between normal tolerance and diabetes, defined as 2-hour plasma glucose concentration after 75g oral glucose load in the range 7.8-11.0 mmol/l. IGT imparts an increased risk of subsequent diabetes and cardiovascular disease.

Incidence. Number of new cases of a specified condition which occur in a defined population in a specified period of time (usually expressed as number of cases per given number of person-years).

Interdisciplinary action. Cooperation of persons with different specialist training and responsibilities within the same discipline, e.g. nurses, podiatrists, medical doctors, etc., for the achievement of a common good.

Intersectoral action. Action in which the health sector and other relevant sectors collaborate for the achievement of a common goal, the contributions of the different sectors being closely coordinated.

Metabolic control. Efforts to keep blood glucose concentration close to normality.

NDP. National Diabetes Programme. A national activity for the improvement of diabetes control and prevention in a specific country. Defined as a series of planned activities which has the approval of the national authorities, stated objectives, a written protocol, a fixed time-scale and a means of evaluation.

NGO. Non-Governmental Organization. An agency installed by private initiatives and not directly responsible to national governments or international authorities. The IDF is an NGO, which is in official relations with WHO.

NIDDM. Non-insulin dependent diabetes mellitus. The most frequent form of diabetes (Approximately 90% of all people with diabetes), mainly due to insulin resistance of the target organs, with onset usually in adult life, incidence strongly increasing with age. Prevalence is correlated with obesity, but has a strong genetic determinant. NIDDM is no longer a disease of affluence but has become a severe Third World problem. Intervention includes diet and exercise, oral drug application, but insulin is also needed in some cases.

Prevalence. Proportion of a defined population who have a specified condition at a particular point in time (usually expressed as a percentage).

Primary health care. Essential health care made accessible at a cost the country and community can afford, with methods that are practical, scientifically sound and socially acceptable.

Primary care providers. Those providing the first level of health care to the community. For diabetes, a WHO Study Group suggested in 1992 that all persons with diabetes should be seen by a general practitioner for confirmation of the diagnosis and establishment of treatment. Persons with IDDM, or with specific complications, should be referred to a specialist (diabetologist, endocrinologist) or a diabetes centre.

Primary prevention. Measures taken to reduce disease incidence by reduction of causative risk factors before disease onset. Usually, activities aimed at modification of lifestyle are introduced in the community as a whole. Common risk factors among noncommunicable diseases recommend an integrated approach to primary prevention.

Programme evaluation. The systematic assessment of the relevance, adequacy, progress, efficiency, effectiveness, and impact of a programme.

Quality circle. A relatively unstructured formation of people with a common goal to improve quality, who exchange experience, raise ideas, make plans, derive actions, evaluate results, etc.

Quality management programme. An activity to plan, reach, secure and maintain a predetermined quality objective in any sector of private or public interest, by all means needed, e.g. education, analysis, evaluation, etc.

Referral. Process whereby a patient with a particular problem/complication may be sent to an appropriate facility at a more central level for advice/treatment of a specialist in that area. It is important that the usual care provider be informed of the result of a referral, for treatment to be optimised.

Region/regional. These terms are used in this report in the sense of WHO Regions, which are a group of countries in a particular part of the world, or in one continent. Parts of countries, sometimes also referred to as regions, are termed "districts" in this report.

Rehabilitation. Measures to enable persons who have chronic complications, or an acute exacerbation, to return to a life as normal and independent as possible.

Secondary health care. Care of a more specialized kind than can be offered at the most peripheral level. May be provided by a medical doctor, with postgraduate training in a particular discipline (e.g. diabetology) or a specific complication (e.g. nephropathy).

Secondary prevention. Measures taken to reverse the disease, or to halt its progression. Screening and early detection are

important strategies, especially in high risk populations and individuals with established risk factors.

Self-management. Ability of persons with diabetes to manage their disease in daily life, using diet, exercise, and appropriate treatment with insulin or oral agents, even in stress situations, e.g. travel, sickness, etc.

Self-monitoring. Regular self-testing of blood (or urine) glucose concentration by the person with diabetes, now mainly using disposable test strips, usually in combination with hand-held meters, detecting colour or electrical changes.

Social learning theory. When learning is an active and individual process, social interaction and differences in cognitive approach play a fundamental role. This theory stresses the important role of individual interactions in promoting behavioural change.

Social support theory. According to this concept the individual's environment, which was once considered as a source of stress, can also be seen as protective under certain conditions. The social support for a given individual consists of everything which allows for them to feel appreciated and valued by the group, and to belong to it.

Tertiary health care. Specialized care delivered at centres equipped with all facilities to treat complicated diabetic conditions. They should also be engaged in training of professionals, health care research and evaluation.

Tertiary prevention. Measures taken to prevent, or delay the development of diabetic complications. These include screening for complications, specific treatments, patient education, and improvement in metabolic control.

UNICEF. United Nations Children's Fund. Functions in parallel with the World Health Organization in developing health-related activities in Member States, with special reference to children.

Vertical programming. An approach whereby activities are restricted to a single disease or programme area.

WHO. World Health Organization. A specialized agency of the United Nations system with headquarters in Geneva, regional offices for six regions worldwide and representatives in more than 140 of its 189 member countries, counselling national authorities in all aspects of health care and providing international leadership in public health. The WHO Regions and Regional Offices are: Africa - Brazzaville, Congo; The Americas - Washington, D.C., USA; Eastern Mediterranean - Alexandria, Egypt; Europe - Copenhagen, Denmark; South-East Asia - New Delhi, India; Western Pacific - Manila, Philippines.

Annex 1

Mandate and officers of working groups at the meeting

The first working group considered the role of people with diabetes and their primary medical advisers in the implementation of national diabetes programmes.

Chair: Professor J. Jervell
Rapporteurs for workshops: Mr J. Apfel
Dr T. Kangas
Professor P. Home

The second working group considered the role of secondary and tertiary health care providers and allied agencies.

Chair: Dr M.H. Tan
Rapporteurs for workshops: Professor D.R.R. Williams
Dr G. Reiber
Dr M. Massi-Benedetti

The third working group considered the role of ministries of health, health planning authorities and administrators and the international organizations. It also contributed material on evaluation, information and managing change to Section 3.

Chair: Professor J.S. Bajaj
Rapporteurs for workshops: Dr P.H. Bennett
Professor Z. Metelko
Dr K. Piwernetz

Annex 2

World Health Assembly resolution WHA42.36

Prevention and Control of Diabetes Mellitus

The Forty-second World Health Assembly,

Recognizing that diabetes is a chronic, debilitating and costly disease attended by severe complications including blindness and heart and kidney disease;

Noting that diabetes already represents a significant burden on the public health services of Member States, and that the problem is growing, especially in developing countries;

Aware of the support of the International Diabetes Federation and the WHO collaborating centres on diabetes;

1. Invites Member States:

- to assess the national importance of diabetes;
- to implement population-based measures, appropriate to the local situation, to prevent and control diabetes;
- to share with other Member States opportunities for training and further education in the clinical and public health aspects of diabetes;
- to establish a model for the integrated approach to the prevention and control of diabetes at community level;

2. Requests the Director-General to strengthen WHO activities to prevent and control diabetes, in order:

- to provide support for the activities of Member States with respect to the prevention and community control of diabetes and its complications;

- to foster relations with the International Diabetes Federation and other similar bodies with a view to expanding the scope of joint activities in the prevention and control of diabetes;
- to mobilize the collective resources of the WHO collaborating centres on diabetes.

(Adopted at the thirteenth plenary meeting, 19 May 1989)