The Diabetes Foundation report on implementing national diabetes programmes in sub-Saharan Africa

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The views expressed in this report are those of the author alone and not necessarily those of the Diabetes Foundation or any of the International Insulin Foundation’s other contributors or partners.

Executive Summary

The International Insulin Foundation (IIF) was established to study the barriers to access with regards to insulin and care for people with Type 1 diabetes. Through its work in Mali, Mozambique and Zambia it has been able to assess these barriers and propose in-country solutions.

This report was prepared using the IIF’s field experience, discussions with key opinion leaders, a thorough review of the literature and the proceedings of two meetings organised by the International Diabetes Federation Africa Region and World Health Organization AFRO held in Nairobi (2-3 March 2006) and in Bamako (29-30 June 2006). The aim of this report is to look at the 11 key elements needed to implement a national diabetes programme and propose concrete actions.

These 11 elements are:
1. Organisation of the Health System
2. Data Collection
3. Prevention
4. Diagnostic tools and infrastructure
5. Drug procurement and supply
6. Accessibility and affordability of medicines and care
7. Healthcare workers
8. Adherence issues
9. Patient education and empowerment
10. Community involvement and diabetes associations
11. Positive policy environment

Based on the IIF’s experience, strong political will is necessary in order for a national diabetes programme to be established. This political will can be generated through different means, but one of the necessities is data on the size and scope of the problem of diabetes. The role of a diabetes association is also essential in pushing this forward.

Once political will has been established, the development of a national diabetes programme/policy is needed in order to ensure continuity and guiding principles. This should help establish organisation of the health system for care, medicines and other tools necessary for diabetes management. This should also include such elements as prevention and address the issues of accessibility and affordability of medicines and care.

In parallel, education for healthcare workers needs to be implemented, both for those in training and those already practising. Healthcare workers need to work towards patient education and empowerment, in conjunction with the diabetes association.

Different countries will be at various stages of organising care for diabetes. The aim of this report is to serve as a guide for a specific part of this implementation process or alternatively to serve as a recipe for countries with nothing in place.

This document is an overview of a more complete report that discusses the different elements presented in further detail and provides examples from different sources. The full report can be downloaded and/or ordered from the IIF’s website www.access2insulin.org.
Implementing national diabetes programmes in sub-Saharan Africa

Introduction

Many African countries are now facing a growing challenge of an increasing number of people with hypertension, stroke, coronary heart disease and diabetes (1) in addition to communicable diseases. This has been called the ‘double disease burden’ and poses challenges to resource-poor countries, in part because of the demands it places on health systems to invest in the provision of both the ongoing delivery of medicines and the knowledge and training of health care workers in managing chronic disease.

Problems identified by the World Health Organization (WHO) (2) related to healthcare organisation and Non Communicable Diseases (NCDs) are:

• Failure to organise care for chronic conditions;
• Health care workers lack tools and expertise;
• Practice is not informed by scientific evidence;
• Failure to address prevention;
• Information systems are not in place;
• Failure to connect with community resources.

This report was prepared using the IDF’s field experience, discussions with key opinion leaders, a thorough review of the literature and the proceedings of two meetings organised by the International Diabetes Federation (IDF) Africa Region and WHO AFRO held in Nairobi (2-3 March 2006) and in Bamako (29-30 June 2006). The aim of this document is to provide a guide to countries in sub-Saharan Africa wishing to implement a National Diabetes Programme.

Organisation of Health Systems

Health systems in sub-Saharan Africa are currently organised for the treatment of acute and not chronic conditions (3). The management approach to a chronic disease differs significantly from the approach used for an acute condition, in that the person with diabetes plays an active role in their own care (4). In addition, people with diabetes need long-term follow-up and treatment, continuity of care and uninterrupted access to medicines, supplies and specialist services.

In order to achieve lasting change towards proper care for diabetes, political will is necessary and sector wide changes need to be implemented. The WHO’s Innovative Care for Chronic Conditions Framework (5) provides eight essential elements for taking action in order to shift the health system’s focus from acute to chronic conditions:

1. Support a Paradigm Shift – The paradigm shift needs to take systems that are currently organised around acute care and design them to manage people with diabetes and other chronic conditions.
2. Manage the Political Environment – The Ministry will need to ensure that diabetes and chronic conditions are on the government’s agenda.
3. Build Integrated Health Care – Each level of the health system has a role to play in diabetes care. This means that a certain level of organisation and coordination between different levels of the health system and different sectors within the same institution (inpatient and outpatient services, pharmacy, laboratory, etc.) is needed.
4. Align Sectoral Policies for Health – For effective management of chronic conditions, policies need to be aligned with others that impact health.
5. Use Health Care Personnel More Effectively – Organise the health system and specialised clinics in order to optimise the use of healthcare workers available.
6. Centre Care on the Patient and Family – Because the management of diabetes requires lifestyle and daily behaviour changes, care should be focused on the patient and his/her family.
7. Support Patients in their Communities – The main community involvement in diabetes care is often through the diabetes associations. Involvement of other community members such as local government officials, village chiefs or elders, as well as traditional healers is important.
8. Emphasise Prevention – For Type 1 diabetes the only form of prevention possible in sub-Saharan Africa is tertiary prevention, the prevention of complications and death. This needs improvements in the health system and increased training. These improvements will also benefit people with Type 2 diabetes and other chronic conditions.

“...the health system encompasses all the organisations, institutions and resources that are devoted to producing health actions whose primary intent is to improve health.”

World Health Organization (2)
Data Collection

Besides providing information on mortality and morbidity, data collection is also key in operationalising: (7)

- Policy implementation;
- Planning;
- Monitoring;
- Evaluation.

Data is needed at different levels for planning and organisation purposes. Data serves a different role at each level of the health system from reminding a healthcare worker about the last blood glucose a patient had to calculating the number of people with diabetes in a given area.

Patient registers can be used to organise patient and population data to facilitate efficient and effective care by for example, providing reminders for providers and patients of appointments (8). Registers also allow for improved epidemiological surveillance (9).

The WHO AFRO Region calls for the establishment of a local database on the burden of morbidity, risk factors and principal determinants of NCDs (10). This would enable countries to address the emerging challenge of diabetes.

Information with regards to the patient needs to be collected. This can take the form of a patient file, kept at the health facility and/or a patient notebook that the patient is required to keep and bring with them at every consultation.

Standardised registers should also be kept at each facility. These can then be regrouped at a district or regional level and then finally at a national level.

In addition, different tools are available which can assist governments to assess the current rates of chronic diseases and their risk factors and also assess their health systems, such as the WHO’s STEPWisE (11) approach and the Rapid Assessment Protocol for Insulin Access (12) developed by the IIF.

“An essential step towards improving health is to understand the distribution of disease, death and disability. This requires the systematic collection, analysis, and dissemination of timely, and accurate information on mortality, morbidity, and risk factors.”

World Bank (6)
Prevention

Prevention of a disease can be tackled at three levels. Primary prevention is targeted at preventing the onset of the disease. Secondary prevention aims to detect the disease at an early stage and try to reverse its course. Finally, tertiary prevention aims to prevent and delay complications and death.

Prevention is needed not only to avert much suffering for people with diabetes, but also to prevent increased use of and costs to the health system engendered by complications. Recent data shows that people with diabetes use the health system more than twice as frequently as people without diabetes, at over double the cost to the person or to the system.

For Type 2 diabetes, Primary prevention should be focused on weight loss and exercise. Culturally sensitive programmes need to be developed and the changes brought about need to be lasting changes to person’s behaviour. Primary prevention should take place within the community and close to the home of the individual.

Early diagnosis, improving care and constant monitoring of patients should be the focus of Secondary and Tertiary prevention. These levels of prevention should take place in the appropriate health facilities depending on the organisation of care within the country.

The best way to tackle diabetes in developing countries is a population based approach to decrease the emergence of risk factors by promoting healthy life-styles in combination with early diagnosis and cost effective management (14).

A three-step approach is described by the WHO for the prevention of chronic conditions. The first step is a planning step, which includes collecting data and looking at the burden of and risk factors for disease. The next step is to formulate a 5–10 year plan for action on prevention and control of major chronic diseases. Identifying the most effective means for implementing these policies forms the third step in this model (15, 16).

Diagnostic tools and infrastructure

Urine and blood glucose measurements are used for diagnosis and follow-up of diabetes. Monitoring these measurements is necessary in order to adapt and optimise treatment. Urine test strips, glucometers and laboratory tests are therefore essential for diagnosis and treatment. The cost of testing equipment to the health system and the individual may be an important constraint on their care.

Ideally, each level of the health system needs some means of measuring glucose levels at a location that is close to the patient.

The government agency responsible for purchasing monitoring equipment and the necessary tools for treatment should standardise the types of instruments available. Staff will need training on how to use these tests and interpret the results.
Drug procurement and supply

Medicines play an essential part in the provision of healthcare. For chronic conditions, such as diabetes, medicines need to be available at all times to ensure proper care and to prevent complications and death. On the WHO’s Essential Drug List (19) Glibenclamide, Metformin and various insulin formulations are present, highlighting the importance of access to these medicines. The WHO identifies four factors necessary for proper access: (20)

- Rational use;
- Sustainable financing;
- Affordable pricing;
- Reliable health and supply systems.

Selection of medicines should be done based on the WHO Essential Medicines List. These medicines should then be purchased through tenders or pooled procurement, in a way to minimise total cost.

Tendering needs to be improved with grouped tendering and other such approaches investigated where possible. Other possibilities such as the Novo Nordisk LEAD Initiative should be explored with manufacturers. Quantification, procurement systems and distribution need to be improved in order to prevent unnecessary waste.

Adequate training for both prescribers and dispensers (Pharmacists) is also necessary. Therapeutic guidelines can be developed in order to promote good prescribing practice.

Better training of healthcare workers, pharmacists and patients in the treatment of diabetes can reduce non-compliance.

Accessibility and affordability of medicines and care

Despite the fact insulin has been available since 1922, many people with diabetes in sub-Saharan Africa still cannot access insulin when they need it (22-24).

In many countries diabetes and other chronic diseases place a large financial burden on the individual and their families, leading households into poverty. For example in Sudan the total median cost for diabetes care was US$283, of which one third was spent on insulin (25). This may have widespread consequences for extended family as well as for the household in question (26). Ways need to be found to alleviate the overall financial burden on patients so as to ensure that adherence is not affected by financial barriers.

Medicines for diabetes care should be accessible at the proper public facilities and it should be made clear to patients where they are able to get their medication and other supplies. Depending on resources and policy considerations, each government should ensure that clearly defined and applied exemption criteria or means of financing care for patients are in place. These are needed for consultation fees, laboratory tests and medicines, and should be based on age, income, type of disease and employment status. It is also important that the criteria are easily verifiable and that these do not cause delays in the treatment of the patient.

Healthcare workers

The healthcare worker plays a key role in the management of diabetes. Besides coordinating treatment, he/she must also be part of the process to educate the patients on how to care for themselves. Additionally, healthcare workers need to play an active role in prevention, prescribe lifestyle changes and be willing and able to care for a patient with a chronic condition (29).

Disease specific training is needed for all healthcare workers. This training needs to be adapted to different workers and their roles in providing care. IDF Africa has developed training modules and clinical practice guidelines that can be used for this. They also provide various training courses.

Two different aspects need to be addressed, namely training for future healthcare workers and training/updating for healthcare workers already in practice. In addition to disease specific education, training in the management of all people with chronic conditions is necessary.

A team approach to diabetes care should be fostered including the person’s family and community as well as healthcare workers and ancillary staff. Pharmacists, laboratory technicians and other ancillary staff should receive the appropriate training with regards to their designated role in the provision of diabetes care.
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Adherence issues

The goal for diabetes treatment is to keep blood glucose levels as near to normal as possible. Therefore, people with diabetes must carefully balance food intake, insulin, other medications and physical activity in order to prevent complications. Adherence to diabetes self-care is an active, responsible and flexible process of self-management.

Many factors previously considered in this report, such as health service organisation and accessibility of care, will impact adherence.

Studies have shown that cost of treatment is often the main barrier for adherence to care and therefore this needs a great deal of attention (29).

Proper adherence also requires the patients to have enough appropriate information. Patients need to be able to know when their condition worsens and when they need to use health facilities (5).

The role of the healthcare provider becomes that of teacher and partner, with the need to learn skills necessary to enable behaviour changes. In assessing a patient’s adherence, the level of adherence to each sub-component of treatment, e.g. diet, exercise, administration of medicines, etc. must be considered as each of these can have a negative and cumulative effect on a patient’s overall outcome (30).

Patient education and empowerment

People are empowered when they have the knowledge, skills, attitudes and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives (32).

For adherence to be successful the patient has to have the desire to avoid illness or to get better and needs to be aware of the specific health action that will lead to success. Behavioural changes require knowledge, skill and motivation (33) and these must be taught to patients.

Patient education should focus on prevention as well as treatment. For a person with diabetes, the healthcare worker should discuss the severity of the condition, what needs to be done to control it, the organisation of the health system and its role in caring for the patient, the different roles of staff, and where to get assistance should they need it. Perceived and actual barriers need to be addressed by both the patient and the team of healthcare workers. Culturally appropriate materials for both patient information and prevention is necessary, especially for children and illiterate patients.

Community involvement and diabetes associations

Illness causes loss of family income due to the loss of a productive member and also the fact that more of the family income goes towards caring for that person (6). In many countries in sub-Saharan Africa the family extends to the community at large and therefore the suffering of one member of the community can have an impact on all members.

The healthcare system, the provider and the community need to be organised for proper care of chronic conditions (8). The local community and families of people with diabetes need to be educated with regards to diabetes and how to care and support for people with this condition. Communities can also be organised to provide monetary support for patients or ways of lessening their financial burden (5, 35).

Traditional healers need to be integrated into the formal system of care and trained appropriately to cooperate with and provide appropriate referral to the formal health sector. The role of the Diabetes Association can be to facilitate care, but also to provide advocacy on issues such as cost and availability of treatment. Diabetes Associations have a role in bringing to the Ministry’s agenda the growing epidemic of diabetes in most developing countries. When Diabetes Associations also provide care, it is important that this supplements the role of the formal health sector, and that it is fully integrated within it. World Diabetes Day provides a yearly opportunity for the diabetes association to raise awareness about diabetes among the general public and the authorities.
Positive policy environment

Many countries in sub-Saharan Africa lack a policy framework with regards to NCDs and diabetes. Such a framework needs to incorporate a variety of factors including prevention, organisation of care, the provision of subsidies for medicines and care and the allocation of appropriate resources for diabetes.

The World Health Report in 2000 (2) emphasised the need for policies on NCDs in developing countries to include proper financing and the development of intersectoral links, improved monitoring and continuing education. It is also vital that the bilateral and multilateral donors recognise the growing burden of NCDs and diabetes in developing countries. The IDF has recently launched the “unite for diabetes campaign” (www.unitefordiabetes.org) with the aim of getting a United Nations resolution on diabetes. This resolution would help in raising the profile of diabetes and assist in getting it on the international agenda.

A high level of political commitment is necessary in order to address the multiple challenges that diabetes places on a country and its health system. Wider issues that affect diabetes prevalence also need considering, such as the types of foods people are able to afford, the promotion of cash crops that have detrimental effects on what foods are available and affordable to people and increasing levels of urbanisation and urban sprawl, which impact the ability of people to walk and exercise safely. A focal person within the Ministry of Health working on NCDs and diabetes is a way to ensure that these policies are implemented (35, 36).

The African Declaration on Diabetes calls on governments, non-government organisations, international donor agencies, industry, health care providers and all partners and stakeholders in diabetes to ensure:

- Adequate, appropriate and affordable medications and supplies for people with diabetes;
- Earlier detection and optimal quality of care of people with diabetes;
- Effective efforts to create healthier environments and prevent diabetes.

Government action to control prices, abolish import duties and introduce price controls for medicines and other tools necessary for diabetes care is needed.

With regards to the organisation of healthcare, the inclusion and regulation of traditional healers and the private sector is needed. Rules allowing nurses to perform certain new roles, e.g. prescribing medicines may also need to be developed.
Conclusion

Examples from countries such as Tanzania and Cameroon show that diabetes in sub-Saharan Africa can be tackled. The different ingredients needed to do this, are highlighted in this report.

As stated by Olusegun Obasanjo, President of the Federal Republic of Nigeria (16):

“Governments have a responsibility to support their citizens in their pursuit of a healthy, long life… I believe, and the evidence supports me, that there are clear links between health, economic development and poverty alleviation. If my government and I are to build a strong Nigeria, and if my brothers and sisters throughout Africa are to create a strong continent, then we must include chronic diseases in our thinking.”

Building on this, the African Declaration on Diabetes envisages a future for diabetes in Africa in which:

- Diabetes and the associated risk of related NCDs are widely recognised as a health priority and resources are allocated accordingly.
- Politicians, donors, planners and providers of health care along with all government sectors, industry, business, non-government organisations, professional associations and patient organisations unite and co-ordinate to prevent diabetes.
- The capacity of health systems and the health workforce is equal to the task of treating and managing diabetes to prevent complications and achieve optimal health and well being for people with diabetes.

Based on the IIF’s experience, strong political will is necessary for a national diabetes programme to be established. This political will can be generated through different means, but one of the necessities is data on the size and scope of the problem of diabetes. The role of a diabetes association is also essential in pushing this forward. The development of a national diabetes programme/policy is needed to establish a comprehensive organisation of the health system for care, medicines and other tools necessary for diabetes care. This should also address prevention and issues of accessibility and affordability of care. In parallel, education for healthcare workers needs to be implemented, both for those in training and those already practising. Finally, healthcare workers and the diabetes association need to work towards patient education and empowerment.

Different countries are at various stages of organising care for diabetes. The aim of this report is to serve as a recipe for countries embarking or proceeding along this path. This report also aspires to address some of the barriers that contribute to the complexity of diabetes care in sub-Saharan Africa, leading to excess mortality. In 1995 Huddie said, “Because of poverty, ignorance, lack of healthcare facilities and personnel the diagnosis of diabetes in some Africans is equivalent to a death sentence” (37). In 2006 this is unfortunately still the case. It is hoped that the IIF’s work and this document, will positively contribute to ending this scenario in Africa, so that the diagnosis of diabetes is no longer a death sentence.
References


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