

THE DIABETES FOUNDATION REPORT ON INSULIN-REQUIRING DIABETES IN SUB-SAHARAN AFRICA



Prepared by the International Insulin Foundation

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List of abbreviations

AMLD	Association Malienne de Lutte Contre le Diabète (Malian Association for the Fight Against Diabetes)
AMODIA	Associação Moçambicana dos Diabéticos (Association of Mozambican Diabetics)
CIF	Cost, Insurance, Freight (INCOTERM meaning that the insurance and delivery of goods to the destination is paid for by the supplier. Buyer is responsible for the import customs clearance and other costs and risks.)
DAZ	Diabetes Association of Zambia
GDP	Gross Domestic Product
HIPC	Highly Indebted Poor Country
IDDM	Insulin Dependent Diabetes Mellitus
IDF	International Diabetes Federation
IIF	International Insulin Foundation
IU	International Unit
NCD	Non Communicable Disease
NGO	Non Governmental Organisation
NIDDM	Non Insulin Dependent Diabetes Mellitus
RAPIA	Rapid Assessment Protocol for Insulin Access
SDM	Santé Diabète Mali
STD	Sexually Transmitted Disease
UTH	University Teaching Hospital, Lusaka, Zambia
WDF	World Diabetes Foundation
WHO	World Health Organization

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The views expressed in this report are those of the authors alone and not necessarily those of the Diabetes Foundation or any of the IIF's other contributors or partners.

Executive Summary

This report looks at the current situation of insulin-requiring diabetes in sub-Saharan Africa and proposes concrete actions that can be taken to tackle this problem.

It is based on the work carried out by the International Insulin Foundation from November 2002 until December 2004 in Mali, Mozambique and Zambia, three Highly Indebted Poor Countries in sub-Saharan Africa, using a newly developed needs assessment tool the **Rapid Assessment Protocol for Insulin Access**.

From these assessments the IIF was able to collect information allowing it to initiate a collaborative process between national and international stakeholders to find means to improve the welfare of people with insulin-requiring diabetes. The goal was to mobilise different areas of expertise and resources to frame practical proposals to help these countries provide the care needed for people with insulin-requiring diabetes.

This report adds significantly to the current data on diabetes and its care in sub-Saharan Africa and provides a pointer to how health services for diabetes, and other chronic diseases, might be strengthened. It is meant as a reference for health planners, clinicians, diabetes associations and other interested parties involved in improving the care for people with diabetes in sub-Saharan Africa.

Key Findings

The IIF's findings need to take into account that sub-Saharan Africa faces major problems of development, with poverty as a key thread. The Heavily Indebted Poor Countries, of which 33 of 41 are in sub-Saharan Africa, spend around US\$8 per person per year on health care. Meanwhile these countries face major burdens of disease from AIDS, malaria, TB and problems of maternal and child mortality. Underdevelopment of health services, in terms of staffing, infrastructure and equipment, as well as resources for medicines influence the ability of countries to deal with all these problems.

- **Insulin:**
- Insulin was present on the Essential Drug Lists of all three countries, but problems of quantification and ordering lead to severe problems of availability, especially away from capital cities
- Insulin is purchased either through international tenders (Mozambique and Zambia) at around \$4.50 per vial or from private wholesalers (Mali/Mozambique/Zambia) at around 75%-100% higher prices.
- Mozambique and Zambia have measures for patients to receive free or subsidised insulin, in Mali no such assistance exists.
- **Syringes:**
- The majority of syringes were purchased through the private sector. Patients in rural areas had the most difficulty accessing syringes.
- **Tools for diagnosis and follow-up:**
- Glucose and ketone testing equipment is unavailable at 75%-90% of health units in Mali and Mozambique.
- In all three countries when available, most patients had to pay a fee for urine or blood glucose test in public facilities, at costs up to \$2.38 per test.
- This financial barrier is coupled with problems of availability of these tools at different levels of the health system.

- **Diabetes Care:**
- There are no national guidelines or official referral pathways in any of these three countries.
- **Healthcare worker training:**
- Lack of training for healthcare workers. For example of the healthcare workers interviewed in Zambia only 9% received some form of special training on diabetes and only 33% felt adequately trained to treat a patient with diabetes.
- **Diabetes Associations:**
- A diabetes association was present in Mali, Mozambique and Zambia. They all had some links to the International Diabetes Federation.
- Their activities ranged from training, to advocacy, events for World Diabetes Day and also provision of care. Where the associations were strongly involved in advocacy this was associated with higher political profile for diabetes care by Ministries and health care systems
- **Policy framework:**
- All three countries are at different stages of developing a national policy on Non-Communicable Diseases. None has yet developed a National Diabetes Program.

All these factors lead to substantial differences in care, and in prognosis, for people with insulin-requiring diabetes. **It is estimated that over half of all such patients die within a short interval from presentation outside the major conurbations in many African countries**, implying a life expectancy similar to that in Europe or North America before the insulin era.

We estimate that for \$1,000, the amount of money calculated, by the World Health Organization, as necessary to prevent a child's death by immunisation, it would be possible to provide 8 years' life sustaining treatment to a child with insulin-requiring diabetes.

Specific recommendations, based on the country-specific needs assessment, have been made by the International Insulin Foundation in these three countries focused primarily on:

- Purchase, supply and distribution of insulin and other supplies
- Developing and strengthening Diabetes Associations
- National policies and programmes with regards to diabetes, including education and training, and service development, employing and integrating the expertise of the World Health Organization and the International Diabetes Federation
- Improving healthcare delivery
- Data and registers

This report analyses the patterns of problems as they apply to diabetes, and to other chronic diseases, in these and similar countries in sub-Saharan Africa, in order to develop a data-based methodology for improving care of chronic disease in resource-poor countries.

Analysis and Conclusion:

- The work carried out by the International Insulin Foundation on insulin-requiring diabetes can serve as a model to help develop health system for the management of chronic conditions.
- Concerted action through international organisations (World Health Organization and International Diabetes Federation), Donors, Ministries of Health, healthcare workers and Diabetes Associations is needed to strengthen health systems for chronic disease in resource poor countries.

- The health systems in these three countries need to be strengthened and a system wide approach needs to be taken to improve these systems so they can cope with chronic conditions. In particular the emphasis on primary care must not detract from the needs of adequate care at secondary level, with referral systems in place for managing patients across the spectrum of disease.
- The RAPIA proved to be a valuable tool to enable vital information on the situation that people with diabetes face to be collected in very different settings, thereby enabling health policies to be based on existing strengths and weaknesses in a system.
- The RAPIA is the first step in the paradigm shift needed from acute to chronic care as it identifies where the system is lacking the necessary tools for this shift and proposes concrete actions to address them.

1. Introduction

This report aims to look at the current situation of insulin-requiring diabetes in sub-Saharan Africa and propose some concrete actions that can be taken to tackle this problem. It intends to also show that improving health systems for the delivery of care for insulin-requiring diabetes has implications for all patients with diabetes and other Non Communicable Diseases (NCDs), but also chronic conditions such as HIV/AIDS and TB.

It is based on the work carried out by the International Insulin Foundation (IIF) from November 2002 until December 2004 in three Highly Indebted Poor Countries (HIPC) in sub-Saharan Africa.

The IIF has implemented a Rapid Assessment Protocol for Insulin Access (RAPIA) in Mali, Mozambique and Zambia. The RAPIA is structured as a multi-level assessment of the different elements that influence the access to insulin and care for people with diabetes in a given country.

From these assessments the IIF was able to collect information allowing it to initiate a collaborative process between different national and international stakeholders to find creative means to improve the welfare of people with Type 1 diabetes in the three countries. The goal of this was to mobilise different areas of expertise and resources to frame practical proposals to help these countries provide the care that people with Type 1 diabetes require.

Health services in Mali, Mozambique and Zambia, as in other countries in sub-Saharan Africa, face an enormous task of tackling communicable diseases (1). Many African countries are now facing a growing challenge from the increasing numbers of patients with hypertension, stroke, coronary heart disease and diabetes (2). This has been called the 'double disease burden' and poses challenges to the healthcare of resource-poor countries, in part because of the demands it places on the need to invest in systems to provide both ongoing delivery of medicines and the knowledge and training of health care workers in managing chronic disease.

In South Africa infectious diseases account for 28% of years lost while chronic diseases account for 25% (3). A new thinking about diseases has now also come about with diseases not being classified as communicable and NCDs, but as chronic and acute conditions. This is because such diseases as HIV/AIDS and Tuberculosis need long term management of patients in a similar way to diabetes and asthma (4).

This work was made possible thanks to a generous grant from the Diabetes Foundation. More information about the Diabetes Foundation can be found in Appendix 1.

2. Mali, Mozambique and Zambia

Mali, Mozambique and Zambia are 3 countries located in sub-Saharan Africa. They are all defined as HIPCs by the World Bank on the basis that the demands for debt repayment heavily exceed their ability to generate income, and as a consequence, programmes of social investment including health are suffering.

These are three representative countries, one of which has been affected by civil war, two by famine and the HIV/AIDS epidemic. For more information on these three countries, refer to Appendix 2.

3. Diabetes

Diabetes Mellitus is a metabolic disorder caused by different factors characterised by a chronic high level of blood sugar with disturbances to carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both (5).

Type 1 diabetes or Insulin Dependent Diabetes Mellitus (IDDM) is a life-long condition, affecting children, young people and adults world-wide. The disease is recognised by a loss of control over the use of the body's glucose and other fuels and is due to the destruction of insulin producing cells in the pancreas (pancreatic islet beta cells). Inadequate care leads to serious health complications such as blindness, kidney failure, nerve disease, limb amputation, heart attacks, strokes and premature death. Although the classic patterns of destruction of insulin producing cells associated with Type 1 diabetes are less commonly found in insulin-requiring patients of African origin (6,7), insulin-requiring diabetes represents 10-30% of cases in Africa (8).

In 2000 it was estimated that the prevalence of diabetes for all age groups world-wide was 2.8% and is projected to be 4.4% in 2030 (9). Most of this increase is due to obesity and its close link with Type 2 diabetes. However, the incidence of childhood diabetes is increasing in many countries in the world with an estimated annual increase of around 3%. Incidence is rising more in low prevalence countries and increases in Europe are greatest in younger children (10).

There are few good estimates of incidence of Type 1 diabetes in sub-Saharan Africa. A study in Tanzania estimated a figure of 1.5 per 100,000 population aged 0-19 years (11) and in Nigeria Olatunbosun (12) found similar values. While a range of 4-10 per 100,000 population has been reported for Arabic North African populations such as Libya (8). This is in comparison to 10.3 per 100,000 population in African Americans (13) and 18 per 100,000 population in the UK (14).

Insulin is vital for the survival of people suffering from Type 1 diabetes and in some people suffering from Type 2 or Non Insulin Dependent Diabetes Mellitus (NIDDM). However, also of central importance are the means to administer the medication (syringe/needles), the means to monitor the response to insulin (blood/urine tests) and an understanding of how insulin acts and affects life and work of the individual.

In their conclusion McLarty et al. (15) state that diabetes in patients in sub-Saharan Africa is a serious disease with poor prognosis. Most deaths are due to preventable causes and to address this efforts are needed to increase public awareness of diabetes and to improve patient detection, management, and follow up.

4. Insulin

Insulin is the body's hormone, normally made by the pancreas, which regulates glucose metabolism. Insulin is a treatment for diabetes and not a cure and is administered by daily injections throughout the life of the patient. Without insulin, people with Type 1 diabetes die very quickly. Dosage of insulin injected by the patient varies from person to person based on, age, nutritional status and activity.

The World Health Organization (WHO) estimates that world-wide as many as 2.5 billion or half the world's population have little or no regular access to essential drugs (16). Insulin is classified by the WHO as an essential drug (17). In 2000 alone treating diabetes with insulin has lengthened the life of an estimated 5.1 million people world-wide with Type 1 diabetes

by about 1.5 years (18). However, this essential medicine still fails to reach people in developing countries.

5. Type 1 diabetes and insulin in developing countries

Leonard Thompson, a Canadian child, was given his first injection of insulin on 11 January 1922 (19). He was the first patient to be treated with insulin for Type 1 diabetes. Having survived some 2½ years from his diagnosis, he had done better than most Type 1 diabetic patients in the pre-insulin era.

Very little primary data exists on Type 1 diabetes in developing countries and most information is based on anecdote. It appears, nevertheless, that three quarters of a century after its discovery, insulin is still not available on an uninterrupted basis in many parts of the developing world (20-22). A survey in 25 countries in Africa found that in half of them insulin was often unavailable in the large city hospitals, while in only 5 countries was insulin regularly available in rural areas. In some countries, insulin is not included on the national formulary (23). Restricted access to insulin is not only due to lack of availability, but also to cost. Chale and McLarty (24) found that the annual direct cost for an insulin-requiring patient in sub-Saharan Africa was equivalent to US\$229, with almost 70% of this amount for the purchase of insulin. In consequence, the life expectancy of a child with newly diagnosed Type 1 diabetes in much of sub-Saharan Africa may be as short as one year (25,26). In addition, restricted access to insulin may result in debilitating complications such as amputations and blindness and a much reduced life expectancy.

While good data on the epidemiology of Type 1 diabetes in Africa are lacking (10), it is clear that it is much less prevalent than in temperate countries, both because of a lower incidence and a poorer prognosis. It is estimated that in the 41 poorest nations in the world there are 19,000 Type 1 diabetic patients (27), almost all of whom find the availability or cost of insulin difficult. Even when insulin is available, its purchase may consume as much as half of the family's weekly income. The current situation for many patients with Type 1 diabetes in developing countries mirrors that of patients in the industrialised world some 80 years ago. A financial burden is also present for Ministries of Health in these countries where as little as \$2 is spent per year on medicines. Therefore providing insulin for one child with Type 1 diabetes (at a cost of \$100-\$150 per year) may mean not providing essential medicines to as many as 50 to 100 others.

For the purpose of this report, *insulin-requiring diabetes* has been defined as diabetes diagnosed before age 30 and with insulin treatment being commenced within 1 month of diagnosis.

This term is used instead of the commoner Type 1 diabetes, both because scarcity of ketone testing makes for difficulties with the term 'ketosis prone', and because of differences in the spectrum of insulin-requiring diabetes between African and Caucasian patients (6,7).

6. Incidence and Prevalence of diabetes in sub-Saharan Africa

No figures exist for the incidence of Type 1 diabetes in Mali, Mozambique and Zambia, but the International Diabetes Federation (IDF) use the figure of 1 per 100,000 each year (14) based on studies by Olatunbosun et al. in Nigeria (12) and by McLarty et al. in Tanzania (28). For more information see Appendix 3.

7. The International Insulin Foundation (IIF)

The IIF (UK Registered Charity No. 1099032) was established by leading academics and physicians in the field of diabetes with the aim of prolonging the life and promoting the

health of people with diabetes in developing countries by improving the supply of insulin and education in its use.

In order to achieve these objectives, a clear analysis of the constraints to insulin access and diabetes care is needed. The IIF's view is that increasing the supply of insulin through donations or other means, however generous, may offer only temporary relief and that the root of the problems of insulin supply and diabetes care need to be identified and tackled. This led the IIF to develop the RAPIA.

8. Rapid Assessment Protocol for Insulin Access (RAPIA) – method of assessment

The health system comprises all the organisations, institutions and resources that are aimed at producing health actions whose primary intent is to improve health. The four vital functions of health systems have been defined as: (29)

1. Service provision: encompassing both formal and informal service providers, whether public or private, and also service organisation both at the level of service delivery and higher up the chain of management
2. Resource generation: encompassing key inputs such as human resources, physical capital, drugs and medical supplies
3. Financing: the volume and sources of financial resources available for the health system, together with the mechanisms for pooling resources and transferring them to service providers
4. Stewardship: the role of oversight of the health system which falls to the government, and encompasses defining the vision and direction of health policy, exerting influence through regulation, and collecting and using key data

The RAPIA studied each of these four factors and related them to care for insulin-requiring diabetes and identified where the system was lacking certain elements.

The aim of the RAPIA is to provide a practical field guide to assist teams in the collection, analysis and presentation of data to evaluate and inform the development of health care services for diabetes management in resource poor settings. The framework of the RAPIA studies the path of insulin from its arrival in the country to the point that it reaches or fails to treat the patient effectively and thereby identify how and where the system works and/or fails.

The RAPIA attempts to investigate possible barriers to insulin access that exist in a particular country. The questionnaires developed below serve as a guide and can be adapted according to the structure of the country. In order to achieve the broad aim, the RAPIA has the following objectives:

- To provide a range of data collection tools, from which research teams can select those appropriate to their own situation
- To provide suggestions of data items to collect
- To provide suggestions on data sources, data collection, data analysis and data presentation for each of the tools presented.

The approach to the evaluation of health care services described in this guide draws on the principles of Rapid Assessment Protocols (RAP) which have been developed and implemented in different areas. The method of RAP has been used extensively to assess services for communicable diseases, including malaria, tuberculosis and STDs, for the purpose of developing interventions. The approach chosen here is to adapt existing protocols to suit the assessment of access to insulin (30-32).

The main principles of the RAP are (33):

Speed – the methods are intended to provide relevant information quickly, upon which decisions about health care interventions can be made.

- Uses of multiple data sources – different methods are used to access different sources of data to get a balanced overview.
- Pragmatism – the methods should provide adequate information, without necessarily being ‘scientifically perfect’. Triangulation, or cross-checking between different sources of data is used to establish the validity and reliability of the data collected.
- Cost-effectiveness – the focus is on research instruments that provide information cheaply, and are not labour and time intensive. Where possible, use is made of existing data.

The RAPIA provides the tools to enable a research team to collect information on the structure and functioning of insulin supply services/practices and also to conduct an assessment of the quality of care currently provided to people with insulin-requiring diabetes. This information is gathered through the different questionnaires detailed in Appendix 4, site visits, document reviews and discussions.

The RAPIA is structured as a multi-level assessment of a health system and is divided into 3 levels. The Macro level aimed at the Ministries of Health, Finance and Trade, national Diabetes Associations, educators, Central Medical Stores and private wholesalers of medicines and medical equipment. A Meso level designed for Regional and District Health offices, health facilities, including pharmacies and laboratories, as well as private clinics, pharmacies and laboratories. Finally interviews with healthcare workers, traditional healers and patients comprise the Micro level. The Meso and Micro levels are carried out in three distinct geographical locations, the capital city, a large city or urban area and a predominantly rural area chosen by local partners to represent different geographical and economic situations.

The RAPIA provides a variety of information with regards to health service structure and functioning with regards to procurement of medicines and diabetes management. It also looks at any policies with regards to diabetes and chronic conditions and studies how they are enacted. With regards to insulin, the RAPIA looks at its availability, price and distribution. This is also done for related supplies such as syringes and testing equipment. In looking at the entire health system the RAPIA is also able to identify other problems that hamper the access to proper insulin and care.

Appendix 5 shows the specific areas that the different RAPIA questionnaires target.

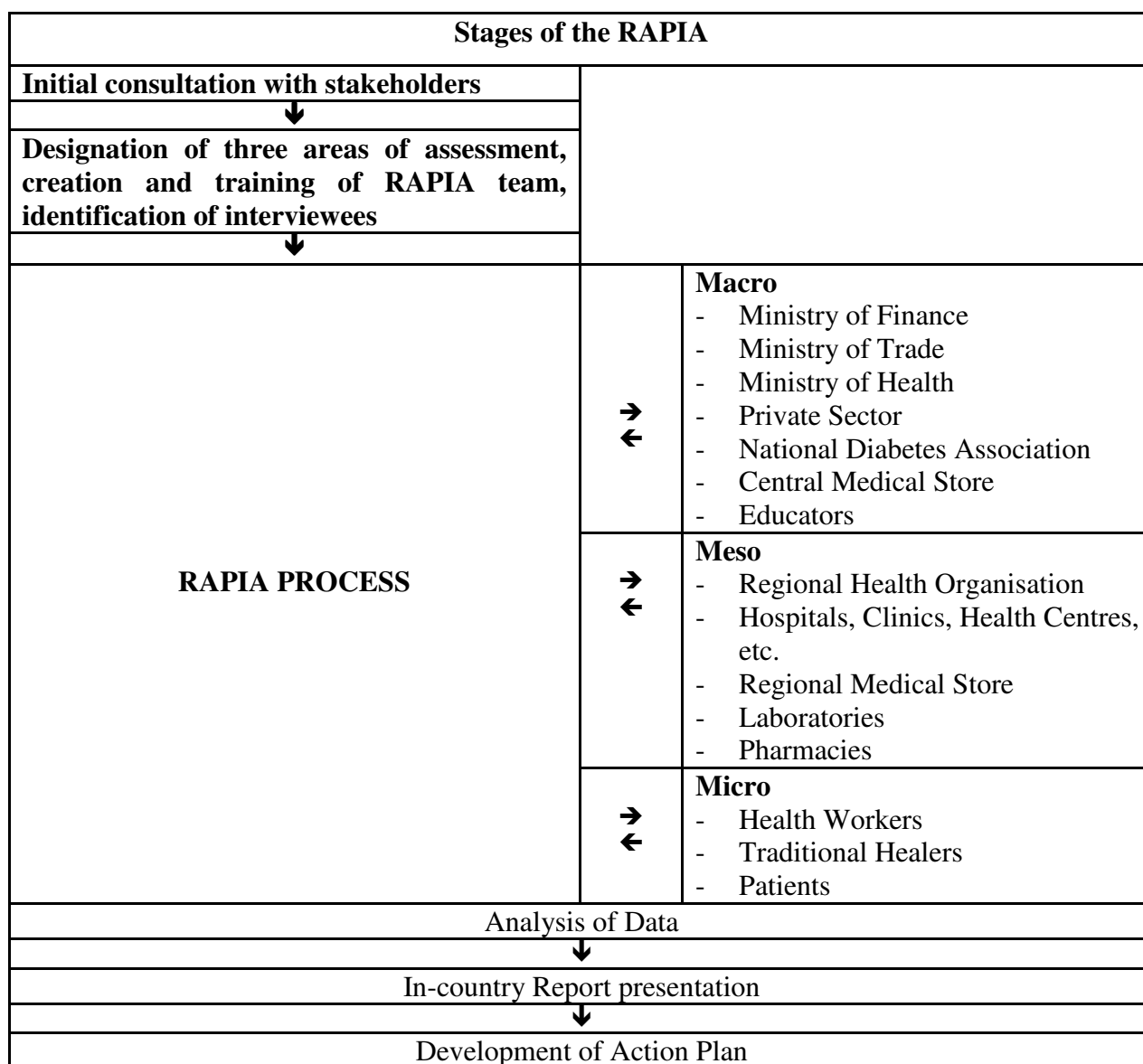
Each interview had as its main aim to obtain the person's perspective on the problems faced by people with diabetes in the given country in gaining access to insulin and proper diabetes care, rather than seeking precise statistical information. Through the overlap in the areas of questioning and by using other sources of information (site visits, discussions and document reviews) the information gathered can be cross-checked and triangulated between different sources and types of information. For example, the frequency of insulin being out of stock in a setting would be ascertained from patients, health workers, and pharmacists. Similarly, patient numbers attending a facility would be ascertained from nurse and doctor records, clinic registers, and patient reports on frequency of follow-up. These different interactions also allowed for new sources of information to be identified and used accordingly.

Different steps were necessary for the RAPIA to be carried out in each country. An initial planning visit by the Project Coordinator, led to the material for the RAPIA to be adapted to

the country's specifications. In parallel local partners identified key people to interview and organised logistics. The Project Coordinator then returned to the country and carried out the RAPIA. Once the RAPIA was completed the Project Coordinator then wrote up the findings, which were distributed to local partners prior to the Chairman and the Project Coordinator of the IIF returning to present the results.

Figure 1 shows a diagrammatic representation of the process and a more detailed outline can be found in Appendix 6.

Figure 1 – Stages of the RAPIA



9. Implementing the RAPIA in Mali, Mozambique and Zambia

Mali, Mozambique and Zambia were chosen due to their geographical, historical and socio-economic differences. Implementing the RAPIA in these three HIPCs was to see how a sustainable solution could be found to the issues of access to insulin and proper diabetes care under extreme conditions of scarce resources in the health sector.

Mozambique was chosen as a pilot country due to strong local support and willingness from the World Diabetes Foundation (WDF), who funded the development of the RAPIA and its implementation.

The Project Coordinator together with a team of local interviewers from the respective national diabetes associations carried out the RAPIA in these three countries. In Mozambique the RAPIA took almost 2 months, in Zambia one month and in Mali 7 weeks.

The table below shows the number of different questionnaires answered in the different countries.

Table 1 – The number of different questionnaires answered during the RAPIAs in Mali, Mozambique and Zambia

Country	Patient	Pharmacy	Healthcare worker	Traditional Healers	Health Facilities	Regional level	National level	Total
Mali	39	20	24	20	16	11	20	150
Mozambique	20	7	25	5	13	8	27	105
Zambia	38	25	60	19	22	4	35	203
Total	97	52	109	44	51	23	82	458

Appendix 7 shows the different areas where the RAPIA was carried out in these three countries.

10. Health Systems in Mali, Mozambique and Zambia

All three health systems are financed through the Ministry of Health's central budget with some cost recovery through payment of consultation fees and/or medicines. The Ministries of Health in Mali, Mozambique and Zambia develop and implement health policies. In Mali and until recently in Zambia National Health Directorates were responsible for the execution of national health policies.

Each of the countries has an administrative division between national and regional/provincial health organisations. The role in each case of these regional structures is to implement the national policies. All three countries have embarked on decentralisation of their health systems so regional health authorities are gaining more and more responsibilities. The regional level is then subdivided into the equivalent of districts, with district health authorities in charge of the lowest level of health provision. In Mali the lowest level of healthcare provision is being devolved to the community with the creation of community health associations. All these countries have three levels of care with national referral hospitals, regional/provincial hospitals and health centres. It should be noted that the capital cities in these three countries enjoy special status with regards to health and form regions of their own.

Private provision of care is present in all three countries and is predominantly found in the capital city or large urban areas. Some denominational facilities exist in all three countries. Those who can afford to will seek care in the private sector or even abroad, for example in South Africa (Mozambique and Zambia) or even Europe (Mali, Mozambique and Zambia).

Of large importance in these three countries is the provision of care through traditional healers. Traditional healers offer proximity medicine in different forms, from geomancy to herbal remedies and incantations. These practitioners are more important in rural areas in part due to distance from allopathic care.

In parallel to the lack of resources (infrastructure and human) most health facilities even in the capital cities also suffer from a lack of “paper and desks to medical equipment and medicines” (quote from a healthcare worker in Mozambique). Supply of equipment and medicines is organised at a central level. Most medicines and equipment are purchased through tenders. In all three countries lengthy and bureaucratic tender processes led to many problems. Each country has a Central Medical Store, which is part state, part privately owned. They have contracts with the Ministries of Health to provide medical supplies and medicines throughout the country. The supply of medicines is organised from a central, then regional/provincial level and finally to the districts.

A private sector is present with private wholesalers and private pharmacies complementing the public sector. The private sector also sells to the public sector when necessary.

Prices of medicines in the public sector are controlled in all three countries. In Mozambique and Zambia some medicines are provided free or at subsidised prices to certain age groups and people suffering from certain conditions. Mali has a system of “social diseases” (HIV/AIDS, TB and Leprosy) where medicines are provided free. Limited price controls are present in the private sector in all three countries.

Quantification of needs in the public sector poses problems in all three countries as this is determined by past orders and consumption. However, as past orders may have over- or underestimated needs, and these estimates will in turn impact consumption, this leads to a vicious cycle of waste of medicines or shortages. This is also due to a lack of data and registers on specific conditions including diabetes.

11. Diabetes in Mali, Mozambique and Zambia

A lack of registers and data exist on the incidence and prevalence of diabetes in these three countries. Information is collected on certain communicable diseases and other health indicators, but no data is gathered on diabetes or other NCDs.

During the RAPIAs estimates on prevalence were calculated using data collected in registers in different hospitals and also with discussions with clinicians. Table 2 shows approximate numbers of patients with insulin-requiring diabetes in different regions of the 3 countries.

Table 2 – Estimates of patients with insulin-requiring diabetes based on interviews with healthcare workers in Mali, Mozambique and Zambia

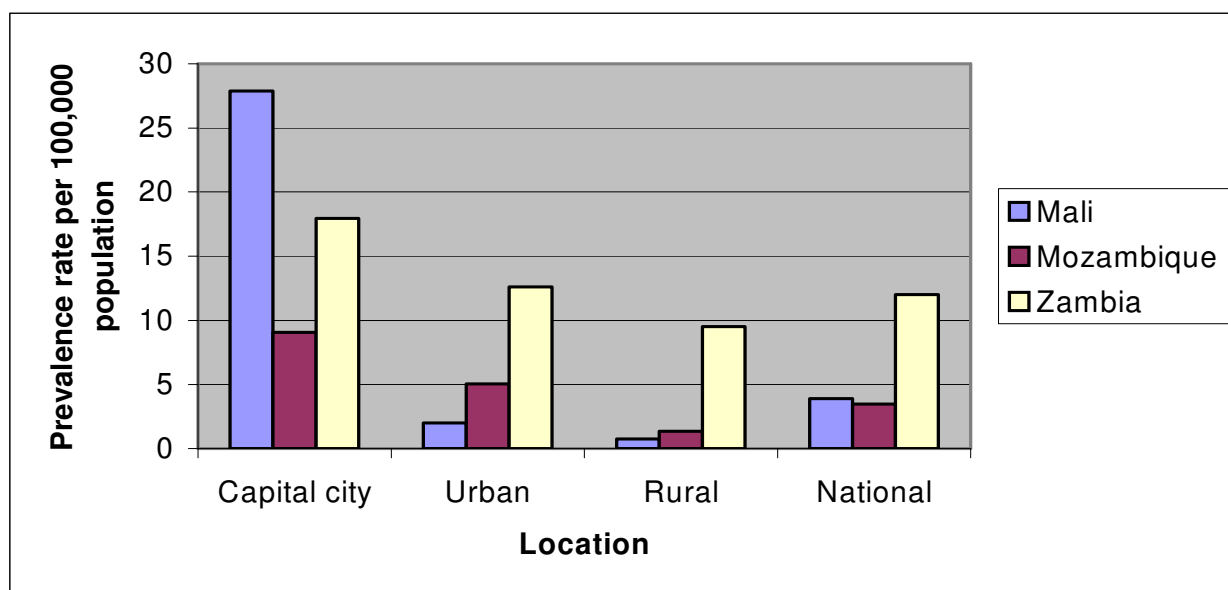
Location	Population	Number of patients with insulin-requiring diabetes	Prevalence of insulin-requiring diabetes per 100,000 population
Bamako, Mali (Capital city)	1,112,002 (34)	310	27.9
Sikasso, Mali (Urban Area)	1,888,162 (34)	34	1.8
Timbuktu, Mali (Geographically inaccessible area)	464,376 (34)	13	2.9
Kadiolo, Mali (Rural area)	147,432 (34)	2	1.4
Douentza, Mali (Rural area)	164,437 (34)	0.3	0.2
Mali National (extrapolation)	12,559,000 (34)	488	3.9
Maputo, Mozambique (Capital city)	2,000,000 (35)	181	9.1
Beira, Mozambique (Urban area)	397,368 (35)	20	5.0
Lichinga, Mozambique (Rural area)	148,560 (35)	2	1.4
Mozambique National (extrapolation)	18,991,000 (35)	660	3.5
Lusaka Province, Zambia (Capital city and surrounding province)	1,498,381	269	18.0
Copperbelt Province, Zambia (Urban area)	1,699,384	214	12.6
Eastern Province, Zambia (Rural area)	1,400,466	133	9.5
Zambia National (extrapolation)	10,754,000	1,022	12.0

Assumptions:

- Patients attended clinics for their diabetes care once a month
- No overlap in patients from different facilities within the same area

Figure 2 shows a comparison of the aggregated data from Table 2 to compare the capital city, urban and rural area, and national prevalence for the three countries surveyed. The national prevalence for Mozambique and Zambia was calculated using the respective proportion of populations living in rural and urban areas and applying the calculated prevalence to this population. For Mali an average was taken of the prevalence outside Bamako (capital city) and applied to the remainder of the population.

Figure 2 – Comparison of the prevalence of insulin-requiring diabetes in the capital city, urban and rural areas of Mali, Mozambique and Zambia



What is evident from this graph is the variation between the different locations within a given country. This variation is largest in Mali, with Bamako having a prevalence rate 38 times higher than in rural Mali. This shows a factor that was seen to varying degrees in all countries with patients seeking care in the capital city.

A most noticeable observation was a lack of children with diabetes. Anecdotal information was collected with regards to:

- Children dying due to poor initial diagnosis, in some cases being placed on a glucose drip having been misdiagnosed as having malaria
- Children being diagnosed, but their families no longer able to pay for their medication
- Complications leading to death

In Mali only 5% of patients interviewed were under the age of 15 compared to 18% in Mozambique and 86% in Zambia.

12. Insulin quantification and supply

All three countries determine the quantity of insulin they need based on historical consumption. Lower levels of the health system express their needs to the regional/provincial level and these are collated and submitted to the national level. In looking at regional distribution of insulin one can see that the capital cities are allocated a higher proportion of insulin relative to their population. Table 3 shows this for Mozambique where 77% of the country's total insulin is supplied to institutions in the capital.

Table 3 – A comparison of insulin orders and population in Mozambique

Province	Population (35)	Insulin Ordered¹	Insulin ordered as a percentage of total
Niassa	893,000	150	0.3%
Sofala	1,485,000	1,697	2.8%
Maputo Province	2,000,000	46,130	77.3%
Total	17,655,000	59,657	

¹ - Based on quantities requisitioned for 2002 from Central Medical Stores (Mozambique)

The same is true in Mali where 52% of insulin is ordered in Bamako. This may be due to many people coming from other areas of the country to the capital city to get their insulin, or having family members in the capital city purchase their insulin.

Insulin was exempt from any taxes and duties in Mozambique and Zambia. Insulin and all other medicines in Mali are subject to 2.5% duty.

Mali, Mozambique and Zambia's Essential Drug List all listed insulin. Both Actrapid (fast acting) and Insulatard (slow acting) 100 IU/ml are present on all 3 lists. In addition Mozambique has Intermediate and Mixed insulin present on its formulary.

Insulin is supposed to be available at Hospitals and the equivalent to Referral Health Centres. Only in Zambia was it present at some Referral Health Centres. In Mozambique insulin was present at most hospitals and in Mali only the two national referral level hospitals in Bamako had insulin present.

Insulin is purchased by the government through tenders (Mozambique and Zambia), through local wholesalers (Mozambique and Zambia) or directly at a wholesaler based in France for Mali. When purchased through tenders insulin can take a few months to be purchased compared to a matter of days when it is bought through local wholesalers.

In both Mozambique and Zambia the Central Medical Stores were the main supplier of insulin to the public sector. In Mali private wholesalers sold directly to the public sector. A purchase of insulin in August 2004 (the first in 2-3years) by the Central Medical Stores in Mali was destined to the public sector. At the time of the RAPIA, September-November 2004, some of this insulin had been distributed directly to patients, the Association Malienne de Lutte Contre le Diabète (Malian Association for the Fight Against Diabetes, AMLD) and the Regional Medical Store in Timbuktu.

Insulin was sold in private pharmacies in almost all areas visited in the three countries. In Mali the AMLD also sold insulin to patients visiting its clinic.

The only apparent problem with the cold chain during the RAPIA was in Timbuktu where insulin was shipped by truck from Bamako, a 900km journey in above 30°C temperatures. In Mali the private sector employed flights to transport insulin to Timbuktu, and coolers elsewhere. In Zambia coolers were used in trucks for insulin distribution. In Mozambique insulin was flown to regional medical stores.

Despite the three countries' policy of generic purchasing insulin purchased in all countries was produced by Novo Nordisk and identified by its trade name. Only Zambia had a small quantity of generic insulin produced by an Indian manufacturer.

13. Price of insulin

Based on Novo Nordisk's LEAD initiative (Leadership for Education and Access to Diabetes care) (36) Novo Nordisk has established a new "best pricing" policy which offered insulin to public health systems in the 50 poorest countries at prices not exceeding 20% of the average price in North America, Europe and Japan. Novo Nordisk is a Danish company with the broadest diabetes product portfolio in the industry.

The implication for Mozambique of this Initiative was a drop in price of insulin from \$9.00 in 2001 per vial to around half of this price in 2002. Even though all three countries visited during the RAPIA should benefit from this Initiative, Mali does not. The insulin Mozambique purchased through a local private wholesaler cost on average \$6.56 with a range from \$5.47 to \$9.91 for Mozambique. Zambia purchased Novo Nordisk insulin through private wholesalers at a price of \$10.05 and generic insulin at \$8.00 per vial. Insulin purchased locally at higher cost was due to miscalculations in quantities necessary when purchasing insulin internationally through tender.

Table 4 shows how cost improvements could be made with improved quantification and tendering. Had the 10,260 additional vials been purchased through the tender process, this would have saved \$38,000, or around 15% of total insulin costs.

Table 4 – Total public expenditure on insulin in Zambia

Source	Total vials	Percentage of total quantity	Cost	Percentage of total cost
Tender	39,353	79%	\$181,810.86	68%
Private local wholesaler	10,260	21%	\$85,489.15	32%
Total	49,613		\$267,300	

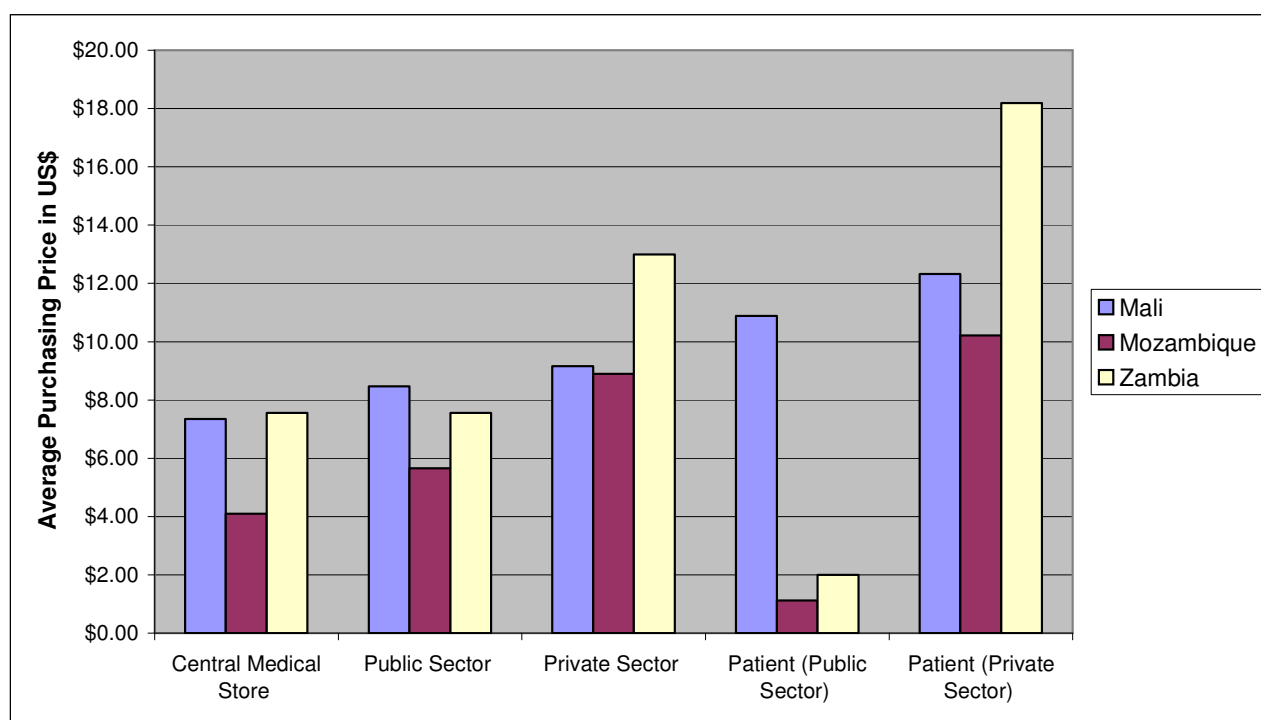
In Mali the Central Medical Stores purchased insulin at \$7.36 from a wholesaler in France. The main supply of insulin in Mali is from two local private wholesalers who sell insulin at \$9.17. Even at its lowest price to the public sector in Mozambique, \$4.31, one vial of insulin can represent more than what is spent on medicines per person per year in these countries.

14. Price of Insulin to patients

Mozambique and Zambia have measures for patients to receive free or subsidised insulin even though these are not standardised or clear to patients. In Mali no such assistance exists and patients need to bear the total cost of their insulin. It should also be noted that insulin from abroad is often sent to these countries as donations or from family members abroad who help their relative with diabetes.

The figure below shows the different average prices of insulin at different stages in its path to reach the patient.

Figure 3 – Graph showing the different prices of insulin in Mali, Mozambique and Zambia



In Mali the Gross Domestic Product (GDP) per capita in real terms in 2000 was \$371 (37). This means that a year's supply of insulin would account for approximately 39% of a family's income. Even at subsidised prices insulin in Mozambique and Zambia is a financial burden to families.

15. Syringes

Syringes are vital for the delivery of insulin. In all countries syringes had some form of Value Added Tax on them. The public sector in Mali, Mozambique and Zambia rarely had any syringes. The majority of syringes were purchased through the private sector. Patients in rural areas had the most difficulty accessing syringes.

Table 5 – Comparison of the price range per syringe in Mali, Mozambique and Zambia

Country	Price range per syringe
Mali	\$0.20-\$0.60
Mozambique	\$0.04-\$0.20
Zambia	\$0.15-\$1.50

There was substantial variation in the reported duration of single use syringes.

16. Tools for diagnosis and follow-up

Another financial hurdle for patients is the cost of the necessary blood and urine tests. In Mali on average a urine glucose test will cost \$0.89 and a blood glucose test \$2.38. In Mozambique laboratory tests for inpatients are free and outpatients sometimes needed to pay some fee. This fee varied, but on average a blood glucose test costs about \$0.21. Children in Zambia and elderly patients had their diabetes monitored for free. Others, depending on whether they have one or more urine and/or blood tests per month or their own glucometer, can paid anywhere from \$1.06 to \$51.06 per month for their monitoring costs.

This financial barrier is coupled with problems of availability of these tools at different levels of the health system. According to different essential lists and policy documents each level of the health system in Mali, Mozambique and Zambia, should have equipment for blood and urine glucose measurements at all levels.

There was not only the problem of the availability of the actual tool, glucometer, spectrophotometer, etc., but also the reagents and consumables for these.

Table 6 – Availability of various diagnostic tools in Mali, Mozambique and Zambia at different health facilities visited

Country	Number of interviewees	Presence of urine glucose strips	Presence of ketone strips	Presence of a glucometer	Presence of a spectrophotometer or other laboratory equipment for blood analyses
Mali	30	54%	13%	43%	23%
Mozambique	37	18%	8%	21%	8%
Zambia	49	61%	49%	54%	10%

Besides a lack of consumables, there is also a general lack of adequately trained laboratory staff.

17. Diabetes Care

A lack of training is also a problem with healthcare workers. In each country there were only 2 specialised doctors in the field of diabetes, with another 5-10 healthcare workers having received some form of training.

The capital cities provide the gold standard of care in each country and the highest level of referral. In the two main hospitals in Bamako, the Central hospitals in Maputo and Beira and in most hospitals in Zambia structured diabetes clinics exist. In Mali and to a lesser extent in Mozambique the 2 specialised doctors are known throughout the country and many patients seek to get care from them. The most efficient clinic visited during this work was at University Teaching Hospital (UTH) in Lusaka at the paediatric clinic held once a week. Patients arrive, have their urine tested for sugar and ketones, BP measured and if their urine glucose level is high they also get a blood test. The patient is then reviewed by a physician. There is a good collaboration with the hospital, laboratory and pharmacy. All health workers in the paediatric ward know to refer patients to this clinic and tell the physician in charge of any new cases. Some nurses and doctors have also received specialised training in the management of patients with diabetes.

A patient's care in all three countries will depend on:

- His/her financial resources
- Whether he/she lives in an urban or rural area
- Where he/she is diagnosed
- Where he/she is referred

Consultations in the public sector for diabetes based on the interviews cost on average \$1.20 in Mali, \$2.08 in Mozambique and \$1.00 in Zambia. In rural areas not only is the care of lesser quality, but access to diagnostics and referrals are more difficult. When the patient is

able to attend a diabetes consultation they often complain of long waiting times and doctors who are unable to spend enough time with them.

There are no national guidelines or official referral pathways in any of these countries. Most patients are referred, but some are delayed at low levels of the health service due to lack of knowledge. For example many patients told the story of how they were diagnosed as having malaria at a health centre and only after a few days, during which their condition worsened, were they referred to the main Hospital. A lack of coordination between medical staff exists in all countries. Problems with follow-up are omnipresent as a patient is not treated by the same doctor or goes to different hospitals for treatment.

In both Mali and Mozambique the clinics run by the diabetes associations are only in the capital cities. Both employ their own staff. The AMLD runs a full clinic and also prescribes medicines. The Associação Moçambicana dos Diabéticos (Association of Mozambican Diabetics, AMODIA) provides mainly guidance with regards to diet and basic check-ups for patients as it lacks medicines and tools for the treatment and diagnosis of diabetes.

18. Healthcare worker training

Many doctors said that they were scared of insulin and diabetes. This is mainly due to a lack of training. Zambia is the only country where the national Diabetes Association (Diabetes Association of Zambia, DAZ) offers continuing training to healthcare workers. Besides this the only training healthcare workers will receive is during their university training. Of the healthcare workers interviewed in Zambia only 9% received some form of special training on diabetes and only 33% felt adequately trained to treat a patient with diabetes.

Most people interviewed highlighted the point that health workers in general recognise the most common diseases in their setting. Healthcare workers have also learnt how to treat common diseases well with the resources they have. One issue that was discussed in all 3 countries was the fact that medical students learn within a protected environment meaning that they are ill equipped to cope with the realities of the health system in the field.

No formal diabetes training is in place for nurses and most nurses with knowledge of diabetes, have gained this experience through training sessions with the diabetes association or working closely with any of the doctors specialised in diabetes present in their respective countries.

19. Diabetes Associations

A diabetes association was present in Mali, Mozambique and Zambia. They all had some links to the IDF.

In Mali the Association Malienne de Lutte contre le Diabète (AMLD) is based in Bamako, with a few branches in the early stages of development in Kayes, Mopti, Segou, Sikasso and Timbuktu. The AMLD in Bamako runs two main activities:

- Activities for World Diabetes Day
- Diabetes clinic

It has 1,000 members in Bamako. The main benefit for their members is a cheaper consultation at the clinic run by the AMLD. The Association's main source of funds is from consultation fees from the clinic and the Lion's Club. The Association's membership comprises doctors and patients. The stated aims of the Association include data collection, education and care, training, and peer support. In Sikasso and Timbuktu the associations are organised as support groups and each have about 50 members.

The Associação Moçambicana dos Diabéticos (AMODIA) during the RAPIA was primarily based in Maputo where it has 323 members. Since the RAPIA a new branch has been established and is extremely active in Beira and has 100 members. As in Mali AMODIA Maputo's main roles are the provision of care through its clinic and also information and events for World Diabetes Day.

DAZ was created in 1987 and comprises patients and healthcare workers. It has as its aim "to create and promote quality health care for all diabetic patients in Zambia." It provides a voice for people with diabetes in Zambia and is active in organising training for healthcare workers, Youth Camps for Type 1 patients and events around World Diabetes Day. In the large hospitals the diabetes association is well known among healthcare workers, but not necessarily with patients. The Diabetes Association is currently funded by donations from government, businesses and fundraising. The association has one paid employee at the association's headquarters in Lusaka. There are branches in Chipata, Chingola, Kabwe, Katete, Manze, Mufulira and Ndola that operate closely with the large health facilities in their area.

There are different perceptions among the individuals in the Diabetes Associations as to their main role. The diabetes associations in Maputo and Bamako and to a certain extent in Timbuktu view their role as a care provider as well as support and information provider. Those in Sikasso, Beira and in Zambia view their role as primarily advocacy, information and support of patients. In all instances the driving force behind the diabetes association has been physicians. In Bamako, Maputo and at the DAZ headquarters physicians are still responsible for the decisions of the association and in all three countries the physicians involved with the association were also politically well connected.

20. Policy framework

Currently the focus on communicable diseases in sub-Saharan Africa, means that little attention and money is spent on NCDs. In Unwin et al. (38) a three pronged approach for NCDs in sub-Saharan Africa is suggested. This includes:

- Surveillance
- Treatment
- Prevention

These three elements are currently serving as a basis for NCD policies in these three countries.

In Mozambique and Zambia the provision of free or subsidised medicines is part of general policies on chronic conditions. As of yet none of the three countries have formal NCD policy documents. In Mali's new health policy document, three NCDs have been chosen for attention:

- Diabetes
- Hypertension
- Sickle Cell Anaemia

This document aims to tackle a growing challenge of NCDs in Mali and provides an excellent basis as a working document. The policy document includes a wide range of actions and is extremely ambitious. It does not take into account various regional differences and also the existing capacity in these regions. For example it includes the proposal that care of diabetes should be dispensed at Community Health Centres. However, during the RAPIA it is apparent that this level of Mali's health system does not have the material and human

resources to tackle this. Also in the document there is no mention of how to tackle the issue of availability and cost of medicines and treatment.

Following the RAPIA in Zambia a working group on NCDs was established and a draft document is being created. In Mozambique a position within the Ministry of Health has been created for NCDs and a policy document and programme is being worked on in collaboration with the WHO. Finally, in Mali, following the RAPIA, a committee established to coordinate and develop programmes for diabetes based on the IIF's recommendations.

21. Traditional Healers

Traditional Healers are an integral part of the health systems in Mali, Mozambique and Zambia. National associations exist to represent the healers and at the Ministries of Health in each country a division deals with the role of traditional medicine within the health system.

Different levels of interaction and trust were seen between modern and traditional medicine. A majority of healthcare workers stated that Traditional Healers never referred patients to them. Table 7 shows the numbers of Traditional Healers who are also members of the national association and the proportion of times they refer patients to western medicine.

Table 7 – Traditional Healers in Mali, Mozambique and Zambia

Country	Percentage of Traditional Healers interviewed who are member of the national association	Healers who refer patients to western medicine		
		Always	Sometimes	Never
Mali	83%	28%	44%	28%
Mozambique	60%	20%	80%	0%
Zambia	89%	16%	74%	10%

Many traditional healers had heard of diabetes and knew at least that the disease was characterised by excessive thirst and urination. In all countries they also stated that they would welcome closer collaboration with allopathic medicine and to learn more about diabetes.

22. Other observations

Other observations from the 3 country studies are summarised in Table 8.

Table 8 – Other observations from the RAPIAs in Mali, Mozambique and Zambia

Observation	Observation present in:		
	Mali	Mozambique	Zambia
General lack of resources	X	X	X
Lack of control or concern for sustainability with regards to donations of medications and materials	X		
Strong political will all at all levels and recognition of diabetes as a Public Health problem	X	X	X
WHO involvement with NCDs	X	X	X
Other NGOs working in the field of diabetes	X		
Activities for World Diabetes Day generate a substantial amount interest and publicity around diabetes	X	X	X
No earmarked funds for Chronic diseases/diabetes	X	X	X
Social distance between doctor and patient	X	X	X
Distribution of medicines works well until the regional/provincial level		X	X
No problems with cold chain		X	X
Travel distance and cost	X	X	X

23. Direct and indirect costs of diabetes

Healthcare has to meet the needs of different population groups as well as taking into account the financial burden on households and on the national health budget (39). Nationally it is hard to estimate the direct costs of diabetes on the health system. From March 2001 until March 2003 expenditure on insulin for Mozambique represented from 1.7-2% of total expenditure on medicines (US\$ 30-35 million) or 10% of government expenditure on medicines (US\$ 6 million).

In Mali it was estimated that on average per month a patient in Bamako spent \$21.24 on diabetes care (assuming 1 blood glucose measurement per month, 8 syringes per month, 1 vial of insulin at an average cost of \$10.88 in the public sector, 1 monthly consultation, and travel costs). Similar costs seem to apply in other countries. This represents nearly 70% of per capita GDP.

24. Complications

Complications of diabetes are:

- Ketoacidosis and comas
- Heart disease
- Blindness
- Kidney failure
- Foot ulcers

Real prevalence and incidence rates are unknown. The RAPIA did not collect direct information on complications and costs of these, but many patients were initially diagnosed with diabetes following the onset of complications. Many patients interviewed had problems with their sight and in discussions with clinicians amputations due to poor wound care were extremely common.

It should be noted that certain serious complications, especially with regards to heart disease and kidney failure, are death sentences for patients unable to get care in certain private clinics or outside of the three countries visited.

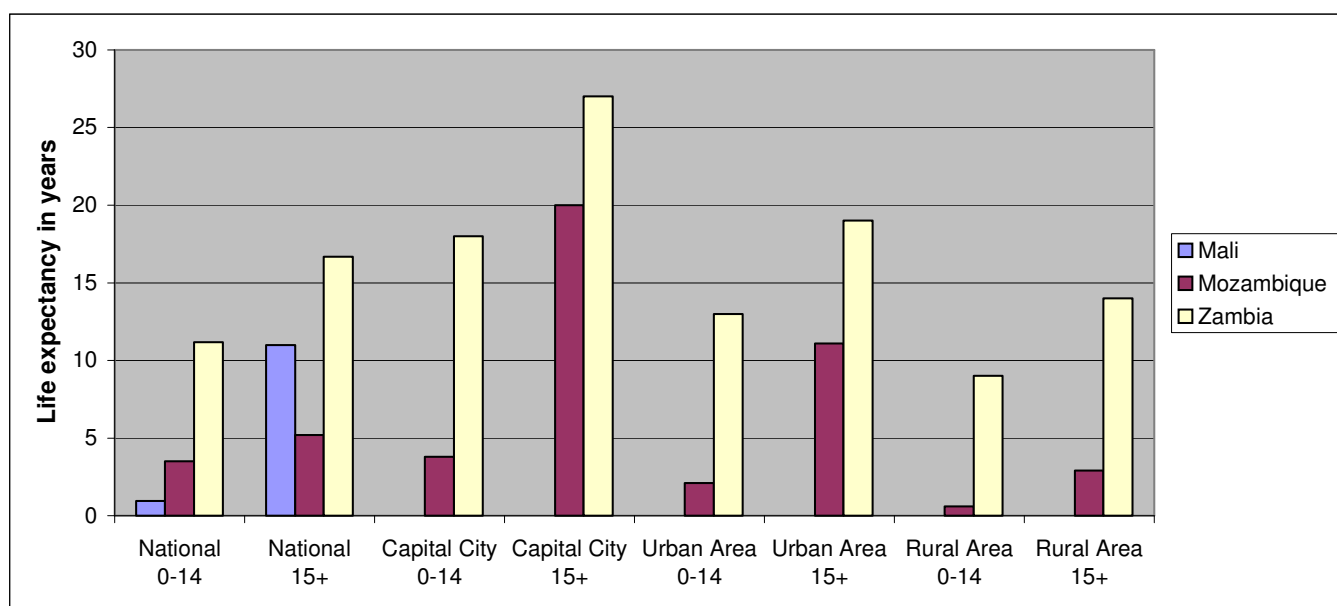
25. Reduced life expectancy

In the United Kingdom it has been estimated by Diabetes UK, that life expectancy is reduced on average by more than 20 years in people with Type 1 diabetes (40) bringing it to 58.3 years compared to 78.3 (41) for the remainder of the population.

The life expectancy of a child with newly diagnosed Type 1 diabetes in much of sub-Saharan Africa may be as short as one year (25,26). Using the estimated national prevalence rates from the figures above, and assuming the incidence rates from Olatunbosun et al. in Nigeria (12) and McLarty et al. in Tanzania (28) estimates were calculated for life expectancy in the three countries.

This calculation was done using the formula $\text{Prevalence} = \text{Incidence} \times \text{Life Expectancy}$. This was calculated using the proportion of each population under and above the age of 15 (41), the Incidence rate of 1 per 100,000 for children under the age of 15 and 0.67 per 100,000 for people age 15+ (14) and the proportion of patients with insulin-requiring diabetes that were diagnosed under the age of 15 based on interviews during the RAPIA.

Figure 4 – Differences in calculated life expectancies for people with insulin-requiring diabetes from different areas of Mali, Mozambique and Zambia



The patterns of care in Mali, where it is estimated that 90% of the country's known insulin-requiring diabetic patients receive care in the capital city, precludes calculation of regional rates for this country.

Zambia had the overall highest life expectancy and the least variation between the different areas of the country. For Mali and Mozambique, prognosis for an adult with insulin-requiring diabetes is substantially worse than in Zambia. However on a national level, there is an enormous difference for the prognosis for a child with insulin-requiring diabetes between these 3 countries. In Mozambique and in Mali, the onset of insulin-requiring diabetes in childhood will mean an average life expectancy of 12 months and of 30 months

respectively. In Zambia, however, despite similar degrees of poverty and levels health service development, the newly presenting diabetic child can expect around 5-10 times better prognosis. It is clear, then, that it is feasible to care for insulin-requiring diabetes in the context of health care systems in sub-Saharan Africa.

26. Country-Specific Recommendations

Based on these findings the IIF proposed a series of recommendations to each of these countries. These recommendations were presented by the IIF to a panel of local stakeholders, including representatives from the Ministry of Health, Central Medical stores, Clinicians, Diabetes Association and patients. The aim of this presentation was to get local input and also a list of priorities for the different stakeholders in the country. Once this list of priorities was established the IIF in collaboration with IDF Africa (Mozambique and Zambia) elaborated an Action Plan. This process was done only with local stakeholders in Mali.

Table 9 shows the top 10 priorities for each country based on the recommendations the IIF put forward in its report.

Table 9 – Ten priorities for each country based on the IIF’s report

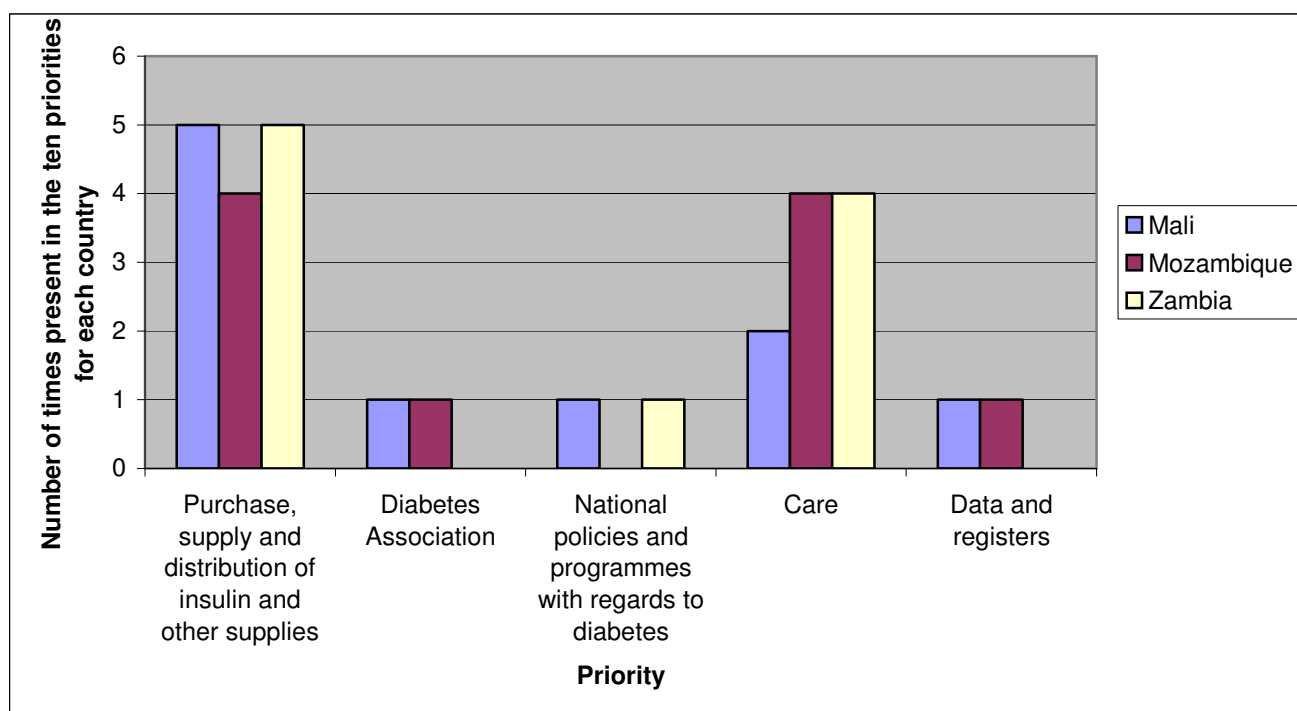
	Mali	Mozambique	Zambia
1	Improve purchasing and distribution mechanisms for diabetes medications, syringes and monitoring equipment at the Central Medical Stores	Improvement of access to insulin and syringes for patients	Add syringes to essential drug list and supply insulin and syringes together
2	Join the Novo Nordisk LEAD Initiative and initiate registration of generic insulin manufacturer	Improve existing training for healthcare workers and train specialists in the area of diabetes	Information and guidelines for patients about where they can receive their insulin
3	Add syringes to essential drug list	Identify specialists and creation of specialised diabetes clinics	Remove VAT and duty from any items linked to diabetes care
4	Organisation Diabetes Association (AMLD) as a national entity	Create guidelines and referral pathways for the treatment of patients	Develop diabetes clinics based on the model of University Teaching Hospital paediatric clinic
5	Establishment of a working group on diabetes in Mali	Clarification/enforcement of Regulations of the Social Fund for Medicines and Food Supplements (on subsidies for medicines for patients with Chronic Conditions)	Development of National Guidelines for diabetes care
6	Adapt IDF clinical care guidelines to Mali	Increase in availability of diagnostic tools where necessary	Establishment of quantification and proper purchasing mechanisms
7	Carry out a basic survey to assess the prevalence of diabetes in Mali	Empowering patients and their families through the establishment of teaching and training facilities	Clear Statement from the Zambian Government whether treatment for diabetes is free
8	Develop a sustainable Essential Equipment list for each level of the health system	Clear statement of role and purposes of AMODIA as a Diabetes Association with requests to IDF for support	Define role of each type of facility in diabetes care
9	Develop a supply chain for laboratory materials	Creation of a register/surveillance system for all diagnosed diabetes patients	Development of an Integrated Competence Training manual on diabetes and NCDs
10	Improve basic healthcare worker training to include more on diabetes care and NCD management	Better reporting and control mechanisms between Central Medical Stores and end users	Far reaching NCD policy framework

In looking at these recommendations and placing them in 5 broad categories of areas of improvement:

- Purchase, supply and distribution of insulin and other supplies
- Diabetes Association
- National policies and programmes with regards to diabetes
- Care
- Data and registers

One can see that a majority of recommendations are aimed at improving the supply and distribution of insulin and other supplies (total of 14) and improving care (total of 10).

Figure 5 – Number of times each area of improvement is present in the ten priorities for each country



These recommendations will impact different categories of patients present in these three countries.

Figure 6 – Different types of patients with insulin-requiring diabetes in Mali, Mozambique and Zambia



These categories summarise the types of people with insulin-requiring diabetes met in the three countries studied. The first category is mostly found in urban areas, have some form of steady income and access to a hospital or the diabetes association clinic. The care they receive can be considered the gold standard for the given country they live in. The people who fall into the second category face different financial and non-financial barriers to care, such as travel distance, costs of insulin and testing, etc. Finally the last category are those people who have insulin-requiring diabetes and are undiagnosed and may die undiagnosed.

In developing recommendations, policy makers and other involved stakeholders need to decide which category of person they would want to target, based on Figure 6, and develop appropriate measures to address the issues that people in different situations will face. Ideally the measures and programmes developed will impact all three categories of patients in Figure 6.

It will be noted that most of the recommendations prioritised, from the IIF's report by local partners, target the first two categories of people. This is likely to be because of the very nature of the problem – as patients who die with undiagnosed diabetes are an invisible problem for health authorities.

27. The RAPIA, lessons learnt

The RAPIA proved to be an extremely useful tool which enabled vital information to be collected in very different settings on the situation that people with diabetes face.

In each country close collaboration with local stakeholders Ministry of Health and Diabetes Association (Mozambique and Zambia) and in Mali adding the field experience of a local NGO (SDM) were primordial for successful outcomes. This enabled local partners to be involved throughout the project as well as access to different sources of information.

In the three countries local teams were used. These comprised University students affiliated to the diabetes association (children or relatives of members) in Mozambique, patients and carers from DAZ in Zambia and local project workers from SDM in Mali. By involving local interviewers closely implicated with diabetes meant that the researchers knew the subject

well and also gained insight into the problem from different perspectives. In Mozambique and Mali there was one team carrying out all the interviews, where as in Zambia there were three teams. The only difference this led to was that interviewer comparisons between the three areas were not possible, but this had no impact on the overall outcome.

The RAPIA also enabled a comparison of the three health systems with regards to their ability to provide adequate care for people with diabetes.

The table below details the criteria used.

Table 10 – Criterion for comparison of health systems for care of insulin-requiring diabetes

Country	National prevalence	Magnitude difference in prevalence from low to high (per 100,000 population)	Availability of insulin at public facilities surveyed	Average price of insulin to patients in the public sector	Availability of testing material at public facilities (glucometer)
Mali	3.9	38	17%	\$10.88	43%
Mozambique	3.5	6.5	20%	\$1.13	21%
Zambia	12.0	1.9	75%	\$2.00	54%

National prevalence – shows the overall ability of the health system to treat people with insulin-requiring diabetes

Magnitude difference in prevalence – illustrates how equitable the care provided is between different areas of the country

Availability of insulin at public facilities surveyed and availability of testing material at public facilities – can be used to measure how the health system is able to provide essential tools for the care of a specific condition

Average price of insulin to patients – shows the government policy towards providing an essential drug

It has been suggested that illnesses such as insulin-requiring diabetes may represent a ‘tracer’ condition for effective health care systems (42), such that the management of patients with insulin-requiring diabetes could act as a benchmark against which the components of a fully functioning and effective health care system might be judged. Therefore these measures can be used for all chronic conditions as they measure different elements necessary for a successful health system. Based on the information presented in Table 10 the following rankings were possible.

Table 11 – Rankings based on criterion in Table 10

Country	National prevalence	Magnitude difference in prevalence from low to high (per 100,000 population)	Availability of insulin at public facilities surveyed	Average price of insulin to patients in the public sector	Availability of testing material at public facilities (glucometer)	Overall Rank
Mali	2	3	3	3	2	3
Mozambique	3	2	2	1	3	2
Zambia	1	1	1	2	1	1

This would mean that based on the findings from the RAPIA, Zambia would provide the best overall care for patients with insulin-requiring diabetes. It should be noted that in the eyes of the Project Coordinator Zambia had the strongest diabetes association and this organisation provided the best support and voice for patients with diabetes in the 3 three countries surveyed.

28. Stakeholders in Improving Diabetes Care in Poor Countries

As stated by Alberti (43), “Diabetes tends to be ignored in the face of major disasters, ..., but people with IDDM have a right to life; and at a relatively small cost per patient by Western standards many more could have a productive life – and, indeed, could live.”

Patients, local communities and diabetes associations need to be the starting point of all programmes to address diabetes in their communities and develop community specific actions. This needs the input from the formal health system, the Ministry of Health and Ministry of Finance for human and financial resources.

However, only few developing countries have devoted significant resources to chronic disease control (3). Official overseas development aid to the health sector amounted to \$2.9 billion in 2002 of which only 0.1% was officially allocated to chronic diseases (3). This lack of interest from international organisations and donors leads insulin-requiring diabetes and chronic conditions not to receive the attention they deserve.

Therefore, the input from Regional and International stakeholders, such as the WHO and IDF and their regional offices, is necessary to raise the profile of diabetes and also assist local stakeholders in developing regional and national programmes as local resources are non-existent.

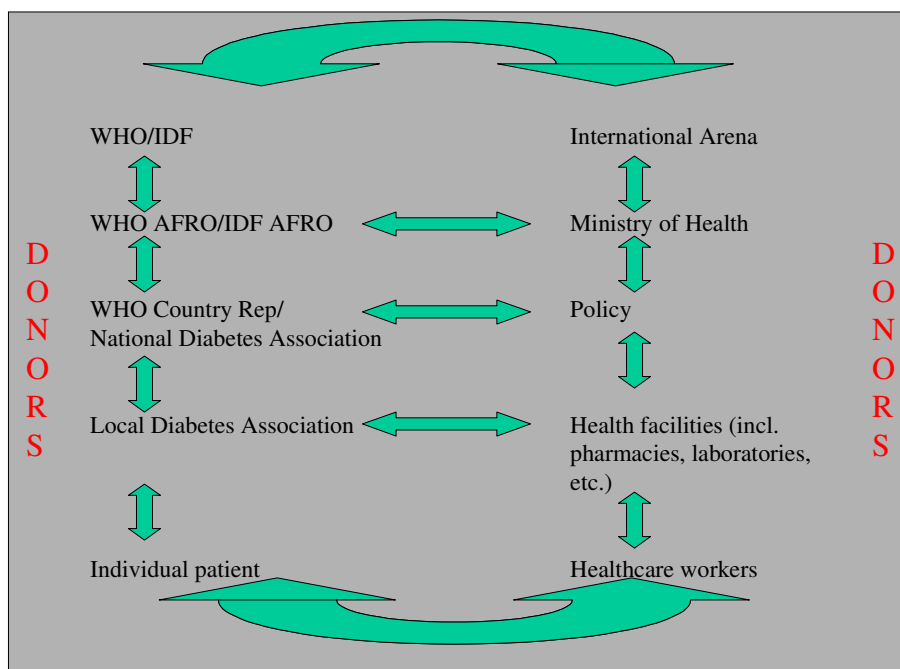
The draft version of the **WHO AFRO and IDF African Region African Declaration on Diabetes** calls on governments, NGOs, donors, industry, health care providers and all partners and stakeholders in diabetes to ensure:

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

These aims need interventions at all 3 levels of the health system (Macro, Meso and Micro) and different stakeholders to work together. The RAPIA provides the tool that enables the barriers to these aims to be identified. Currently a small number of innovative projects and

programmes are taking place addressing the issues surrounding diabetes and chronic conditions. A more coordinated and committed overall programme and agenda are needed.

Figure 7 – The interactions necessary to successfully address the problems of diabetes and chronic conditions in sub-Saharan Africa



29. The WHO's Framework on Innovative Care for Chronic Conditions

As chronic conditions are now the leading cause of death in the world (3) health systems need a **paradigm shift** from an acute care model to a health system that can manage patients with chronic conditions (4). Within this shift from acute to chronic care health systems also need to:(49)

- **Develop a suitable policy environment**
- **Integrate** the system of health delivery
- **Align** all government policies with the aim of reducing the burden of disease
- **Optimally use** health personnel
- Put **patient and family at the centre** of care
- Promote **community support** for patients
- Encourage **prevention** of disease and prevention of complications

During the work of performing the RAPIA in these 3 countries, the IIF has followed this template in its approach, and relevant findings are included in the following summary.

These eight essential elements for taking action as defined by the WHO are: (4)

1. **Support a Paradigm Shift** – Health systems in developing countries are now facing a “double burden” of disease, due to shifts in disease patterns and ageing population. The paradigm shift needs to take systems that are currently organised around acute care and design them to manage patients with insulin-requiring diabetes and other chronic conditions. In order to tackle these chronic conditions, including HIV/AIDS and tuberculosis, it is going to be necessary to strengthen health care systems in sub-Saharan Africa. Chronic conditions need continued monitoring of the patient and a continuum of testing, medicines and care. The RAPIA has identified the areas of improvement to enable the paradigm shift to occur and by raising the issue of insulin-requiring diabetes

has brought to the attention of the local stakeholders involved the importance of addressing chronic conditions.

A paradigm shift is also needed from donors from emergency funding and vertical programmes to long-term capacity building. For example the World Bank has provided over the last 5 years \$4.25 billion in loans to countries for health sector work, about 2.5% which was allocated to NCD prevention and control programmes all of which were in Eastern Europe (3).

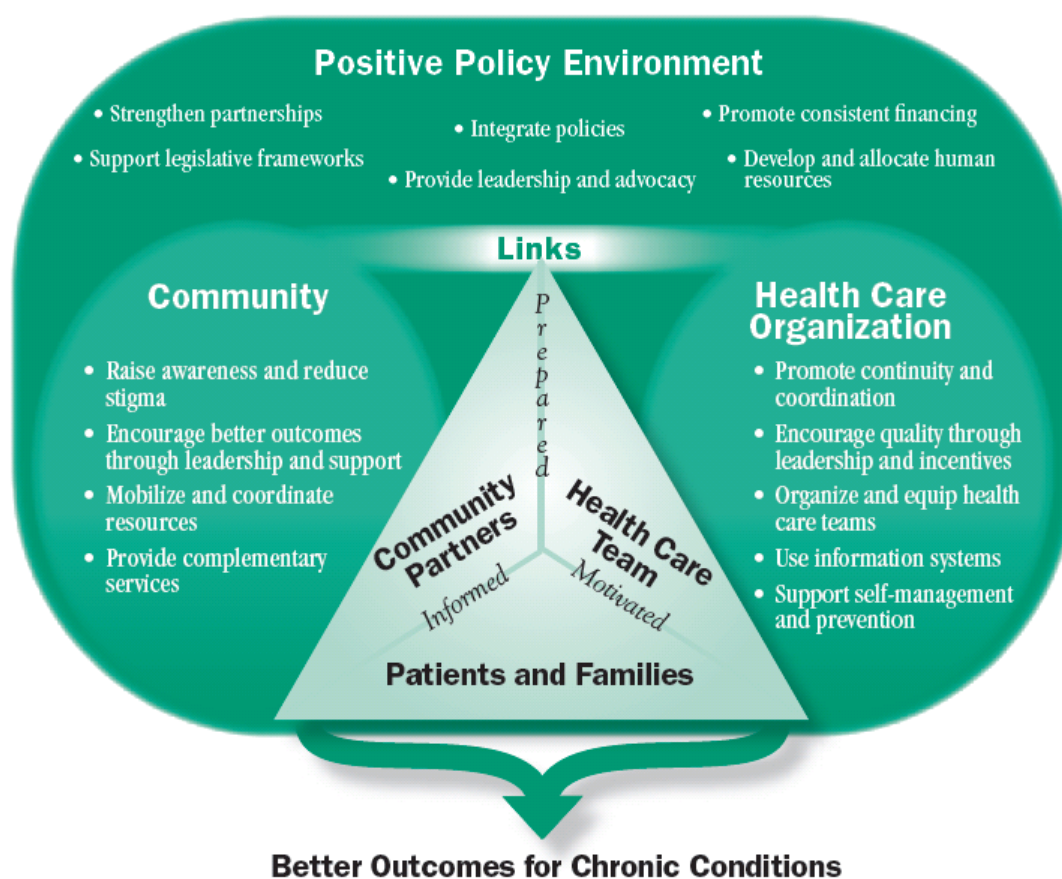
- 2. Manage the Political Environment** – In order for an effective health system to be put into place that can manage chronic conditions, a suitable policy environment needs to be in place. The IIF aimed to influence policy by raising the importance of insulin-requiring diabetes and other chronic conditions with a variety of stakeholders, including the Ministry of Health, IDF Africa, WHO AFRO, as well as diabetes associations. The RAPIA in all three countries provided a basis from which NCD policy documents could be formulated and other policies, such as Mozambique's on subsidies for chronic conditions, clarified.
- 3. Build Integrated Health Care** – For appropriate management of insulin-requiring diabetes an integrated health system needs to be in place. Each level of the health system has a role to play in diabetes care, and thus needs certain material and human resources present. Also 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.) need to be in place for patient management and referral. Thanks to its multi-level format the RAPIA was able to identify problems between different levels of the health system. By interviewing different stakeholders it was possible to see the problems each person in his/her role in providing/receiving health faced. The RAPIA however did not address any financial aspects of this problem.
- 4. Align Sectoral Policies for Health** – For effective management of chronic conditions other policies need to be aligned with those impacting on health. One such example of addressing the multi-sectoral approach to create a favourable policy environment for people with insulin-requiring diabetes was trying to remove any taxes on materials used by people with insulin-requiring diabetes.
- 5. Use Health Care Personnel More Effectively** – Using healthcare workers effectively ensures that the patient benefits from a higher level of care. In all three countries where the RAPIA was employed, the main barrier to this was training of health personnel. In parallel to this the training of nurses to care for patients with diabetes was present in very few facilities. In Mali, for example, the two leading specialists review patients who only need to get their blood glucose checked and renew their prescription. This is linked to point 3 and needs a better organisation of health overall and on a facility level basis.
- 6. Centre Care on the Patient and Family** – Because the management of insulin-requiring diabetes requires lifestyle and daily behaviour changes care should be focused around the patient and his/her family. Many patients complained that they had lack of knowledge about their condition. The only formal training patients were seen to receive was in Zambia through DAZ with sessions held at the association or a youth camp organised once a year. In Mali one of the hospitals also had information sessions for newly diagnosed patients. These also included family members. It is extremely important to include the family in the care of patients with insulin-requiring diabetes in societies with

close-knit family units. The main problem identified is that social distance between carers and patients and the level of education of many patients makes this extremely difficult.

7. **Support Patients in their Communities** – The main community involvement in diabetes care was through the diabetes associations found in these three countries. Involvement of other community members such as local government officials, village chiefs or elders as well as traditional healers is important.
8. **Emphasise Prevention** – Prevention of insulin-requiring diabetes in these settings can only be done at the tertiary level, which is the prevention of complications. Through improving the health system and increasing training these can be prevented. These improvements will also benefit Type 2 diabetes and other chronic conditions.

The WHO Framework is shown diagrammatically in Figure 8, representing the paradigm shift and the other inputs necessary to move health systems away from an acute model to one that can address the issue of chronic conditions.

Figure 8 – WHO Framework on Innovative Care for Chronic Conditions (4)



The model above describes the necessary elements that need to be present in order to provide patients with the best level of care for their chronic condition, be it insulin-requiring diabetes or HIV/AIDS.

This model comprises 3 levels:

- Micro (the triangle)

- Meso (the two ovals)
- Macro (the sphere surrounding the other shapes)

The RAPIA follows a similar three tiered approach in its assessment and for each level has identified the clear problems and developed specific recommendations.

In an ideal setting the following elements would be present at each level of the health system:

Micro

- Interaction and communication between healthcare workers and patients that lead to changes in behaviour, the patient understanding their condition thereby improving adherence
- Empowering the patient

Meso

- Organisation of care around chronic conditions
- Presence of adequate tools at the right levels of the health system
- Availability of effectively trained healthcare workers
- Guidelines and referral pathways
- Registers and tools for data collection
- Inclusion of traditional healers and communities in care

Macro

- NCD Policy
- Coordination and financing

Thus the WHO model, based on the 8 principles for health care for chronic disease outlined above, resembles in many regards the conclusions of the RAPIA process. The RAPIA, through the process of collecting country-specific information, and thereby identifying strengths and weaknesses of individual countries, provides a first step in tackling the problem of diabetes in sub-Saharan Africa.

30. The RAPIA's implications this far

The RAPIA has already had implications in the three countries it has been implemented in. Besides the data and concrete action plans for diabetes care in the three countries, the following has also been a result of the RAPIA:

- **Mozambique:**
 - Increased awareness around diabetes
 - Improvement in insulin supply and distribution
 - Creation of a new diabetes association in Beira
 - Renewed activity at AMODIA Maputo
 - Active participation from Mozambique with IDF Africa activities
 - Secured funding from the WDF for the implementation of some of the IIF's recommendations
- **Zambia**
 - Development of a NCD policy
 - Increase in availability of insulin at main hospitals
 - Higher profile of diabetes association with local authorities
- **Mali**
 - Investigation into joining LEAD Initiative
 - Creation of a working group on diabetes

- Inclusion of RAPIA findings into NCD Policy

The RAPIA provided an assessment of the different elements that can influence the access to insulin and diabetes care in these three countries. These data can then be used to inform changes in specific areas of health provision. **In addition the RAPIA raised the profile of diabetes associations and awareness around diabetes and NCDs in countries where most funding and projects are focused on communicable diseases.**

31. Future directions and planning

As stated by former US President Bill Clinton (50) “Until we build the human and physical infrastructure needed to deliver effective treatment, programmes will not succeed.” This specific quote was referring to HIV/AIDS, but the same is true for insulin-requiring diabetes, diabetes as a whole and all chronic conditions.

The health systems in these three countries need to be strengthened and a system wide approach needs to be taken to improve these systems so they can cope with chronic conditions.

Based on the findings from the **RAPIA** a **health system needs** the following elements to provide adequate care for insulin-requiring diabetes in a developing country:

- Country specific data
- Collection of epidemiological data and development of registers
- Appropriate resources (material and human) at suitable levels of the health system
- Diagnostic tools
- Effective drug procurement and distribution systems, including stock-keeping
- Means to ensure that patients are able to access medicines at affordable prices
- Treatment protocols
- Trained healthcare workers
- Adherence to treatment guidelines
- Referral pathways and secondary/specialist care institutions
- Patient education and empowerment
- Community support and/or a diabetes association
- Positive policy environment including identification of funding

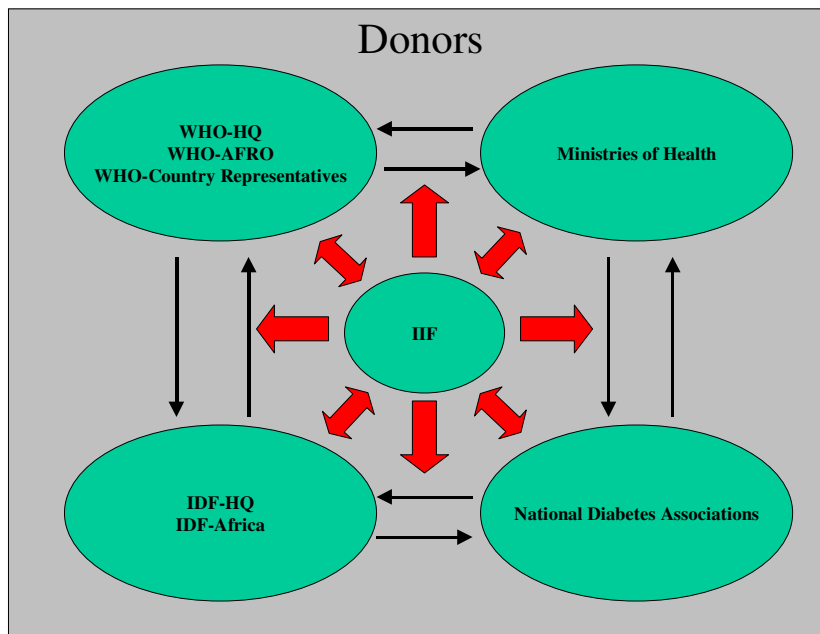
All the barriers identified by the RAPIA, with regards to access to insulin and other supplies, need to be addressed in parallel to the general shift needed within the health system from acute to chronic care.

Because of the necessity of diabetes service planning to be based on assessment of current patterns of care and of service provision, the RAPIA could act as a as a first step for countries wishing to embark on national diabetes programmes as a means of gathering basic epidemiological and health systems data as this would ensure that projects are being carried out are targeting a specific need. This work needs to take place in an environment fostered by donors such as the **WDF** (the WDF are the only major donor in the area of diabetes).

For the past two and half years the **IIF** has acted as a catalyst and collected basic health systems data in three countries in sub-Saharan Africa. It hopes to be able to continue its work as an agent for change with regards to insulin-requiring diabetes, expand its work to other countries and assist Mali, Mozambique and Zambia with the implementation of its recommendations. However, the future of the **IIF** is dependent on future funding and the views of the **WHO**, **IDF** and other stakeholders on its role in tackling diabetes in sub-Saharan Africa.

The **IIF** has been able to bring together many of these stakeholders to discuss the issue of diabetes and insulin in sub-Saharan Africa as detailed in the diagram below:

Figure 9 – The RAPIA and IIF catalysts for change



This collaboration needs to be formalised and expanded in order to ensure that diabetes and chronic conditions are tackled on an international and national level in a coordinated manner.

The **IIF** has received a further grant from the Diabetes Foundation to prepare a document on how to develop a national diabetes programme in sub-Saharan Africa. This document is being prepared in collaboration with the WHO and IDF.

32. Conclusion

The World Health Report 2000 (29) defines a health care system as a system which encompasses all the activities whose primary purpose is to promote, restore and maintain health.

The **IIF** alone cannot address the problems faced by people with diabetes in Africa. A coordinated programme and funding approach is needed with stakeholders such as the WHO and IDF working at an International level (WHO and IDF Headquarters) in collaboration with Regional (WHO and IDF Regions) supporting activities at a National level by governments and ministries and WHO country offices and by Diabetes Associations. This needs funding, for example from the WDF and also other large donors to be aware of the plight of diabetes in Africa and its future impact on the health and economies of this continent.

The RAPIA and the **IIF**'s activities have tried to emphasise the plight of people with insulin-requiring diabetes in parallel to promoting the concept that improving health systems for insulin-requiring diabetes will have ramifications for Type 2 diabetes, all NCDs and all chronic conditions. The **IIF** believes that the RAPIA has provided the Ministries of Health in Mali, Mozambique and Zambia, with baseline data on how their health system works with regards to diabetes care and also the care of chronic conditions. In parallel it has helped

diabetes association gain better knowledge about the situation of people with diabetes in different parts of their countries and exposure with the health authorities.

The RAPIA is also the first step in the paradigm shift needed from acute to chronic care, proposed by WHO as it identifies where the system is lacking the necessary tools for this shift and proposes concrete actions to address them.

In these three countries should the proper measures with regards to healthcare organisation and insulin purchase be established the direct patient costs per year would be less than \$150. By ensuring that patients can access trained healthcare workers and insulin at all times avoids complications, hospitalisations and death, which are more costly to the patient, health system and society as a whole.

In 1901 Dr. Cook wrote in his notes on diseases met in Africa "... diabetes is very uncommon but very fatal...". (Quote taken from Vexiau, F. et al.(51)). The IIF's hope is that through improved diagnostic facilities and healthcare worker training diabetes will become more common in Africa and improved medicine supplies and strong diabetes associations will make it less fatal.

Appendices

Appendix 1 – The Diabetes Foundation

The Diabetes Foundation is a UK registered charity (Registered Charity No. 292317). Its aims are to support and advance research in the field of diabetes and particularly juvenile (insulin-dependent) diabetes in the United Kingdom and throughout the world and to provide material of an educational and informational nature to persons who are interested in and affected by diabetes.

Appendix 2 – Mali, Mozambique and Zambia

Figure 10 – Map of Africa



Mali gained its independence in June 1960. After independence Mali merged with Senegal to form a short-lived federation. Mali was a dictatorship until 1992 when multiparty elections were held and Alpha Konaré was elected. President Konaré was reelected by a landslide in 1997, but could not run for a third term and stepped down in 2002 in favour of Amadou Toumani Touré.

More than half the population in Mali lack access to drinking water and more than three-quarters are illiterate. From 1994 onwards 70% of the population were defined as income poor. In 2000 after the adoption of a Poverty Reduction Strategy Paper by the Malian government, 80% of the government's budget was covered by external donors (52).

Mali is divided into 8 regions and the Capital District of Bamako and borders Senegal, Guinea, the Ivory Coast, Burkina Faso, Niger, Algeria and Mauritania.

Mozambique's almost 19 million inhabitants, live in 10 provinces, divided into 3 regions (South, Central and North) spread over 799,380 km².

When Mozambique gained independence in 1975, after 500 years as a Portuguese colony, it was beset by a prolonged civil war, which ended in 1992. This combined with regular droughts and floods have left the country has had an impact on the population's health and the country's health care infrastructure.

After 1992 the government embarked on a reconstruction of the health sector under Health Services Recovery Programme. In parallel it established key relationships with donors and the health sector in order to co-ordinate efforts to improve the health of people in Mozambique.

Of Mozambique's total government budget 55-60% is covered by donors. The remainder comes from national revenues. Each ministerial budget is discussed to see what can and will be covered by donors and by the government. Most donors provide funds for specific areas, such as Health, Environment and Education.

The **Republic of Zambia** gained independence in 1964 had has enjoyed no civil strife since then. Zambia's economy has been impacted by a decline in the purchasing power of its copper resources and a decline in per capita income from US\$752 in 1965 to US\$351 in 2002 (53).

Zambia is divided into 9 provinces: Central, Copperbelt, Eastern, Luapula, Lusaka, Northern, North-Western, Southern and Western.

An estimated 73 percent of the population lived below the official poverty line in 1998 compared to 70 percent in the early nineties (53).

In 2002, 39.5 percent of central government expenditures were financed through foreign grants and loans (53).

Zambia has been hit hard by HIV/AIDS which has further weakened its ability to reduce poverty over the past decade (53).

Table 12 – Comparison of Mali, Mozambique and Zambia

	Mali	Mozambique	Zambia
Population (July 2004 estimate) (41)	11,956,788	18,811,731	10,462,436
Infant mortality rates (total per 1,000 live births) (41)	117.99	137.08	98.4
Life expectancy at birth (total) (41)	45.28	37.1	35.18
HIV/AIDS adult prevalence rate (2003 estimate) (41)	1.9%	12.2%	16.5%
GDP per capita in real terms (2003) (37)	\$371	\$230	\$413
Population below poverty line (2001 estimate) (41)	64% (2001 estimate)	70% (2001 estimate)	86% (1993 estimate)
Total health expenditure as % of GDP (2001) (41)	4.3%	5.9%	5.7%
Number of Doctors per 100,000 people (54)	4.7	3.4	6.9
Rank out of 177 on the United Nations Development Programmes Human Development Index 2004 (55)	174	171	164

Appendix 3 – Incidence and Prevalence of Type 1 diabetes

In looking at the global distribution of Type 1 diabetes there are large variations between areas. These differences may in part be explained by differences in the genetic pool and exposure to environmental factors. The main factor though for the large variation in the African continent is the lack of studies. High levels of mortality in children are also not accounted for and thus impact the incidence and prevalence (10).

Incidence is the measure of how many people within a certain population will get a disease within a certain time. The incidence of diabetes in children varies greatly from country to country.

The prevalence is the proportion of a population at a given time that has a certain disease. For a lifelong condition like diabetes this will depend, as well as on the incidence, on how long someone with the condition survives after being affected. Before the discovery of insulin the prevalence of Type 1 diabetes was very low, although the incidence may have been high. This is because new cases of diabetes were dying very soon after disease onset, as there was no appropriate treatment for them. In developing countries, the incidence is difficult to assess, as survival may be very short, and many people will die undiagnosed.

One other factor which comes into play is whether patients developing the disease are diagnosed. In some parts of the developing world, patients with weight loss, fatigue and other symptoms of Type 1 diabetes may be misdiagnosed, for example, with AIDS, or those presenting in diabetic coma as having malaria. This will artificially lower estimates of incidence.

Appendix 4 – Questionnaires that make up the RAPIA

Level	Issues Addressed in each RAPIA questionnaire
MACRO	
- Ministry of Health	<ul style="list-style-type: none"> - Organisation of delivery of diabetes care - Resources available for diabetes and insulin - National Programs for diabetes and insulin - Pricing of insulin - Distribution of insulin - Funding for insulin and diabetes - Insulin tendering and purchase
- Ministry of Trade	<ul style="list-style-type: none"> - Trade issues (laws, barriers to trade) - Trade infrastructure
- Ministry of Finance	<ul style="list-style-type: none"> - Funding of health system - Taxes on insulin - Funding for insulin and diabetes
- Private Sector	<ul style="list-style-type: none"> - Pricing of insulin - Distribution of insulin
- National Diabetes Association	<ul style="list-style-type: none"> - Issues with diabetes and insulin
- Central Medical Store	<ul style="list-style-type: none"> - Insulin tendering and purchase - Insulin distribution and storage - Insulin pricing
MESO	
- Regional Health Organisation	<ul style="list-style-type: none"> - Issues with diabetes and insulin - Organisation of care for people with diabetes
- Hospitals, Clinics, Health Centres, etc.	<ul style="list-style-type: none"> - Treatment and management of people with diabetes - Access to appropriate tools to diagnose and treat patients - Infrastructure present and/or lacking for insulin provision
- Laboratory	<ul style="list-style-type: none"> - Infrastructure present and/or lacking for proper diagnosis and follow-up
- Pharmacy	<ul style="list-style-type: none"> - Insulin distribution and storage - Insulin pricing
MICRO	
- Health Workers and Traditional Healers	<ul style="list-style-type: none"> - Problems encountered in diagnosis and treatment of patients - Training - Infrastructure present and/or lacking - Tools present and/or lacking
- Patients	<ul style="list-style-type: none"> - Diagnosis - Access to treatment - Cost of treatment

Appendix 5 – Target areas of each RAPIA questionnaire

Target questions with regards to insulin and diabetes care	Questionnaires														
	Ministry of Trade	Ministry of Finance	Ministry of Health	Private Sector	National Diabetes Association	Central Medical Store	Educators	Regional Health Organisation	Regional Central Medical Store	Hospitals, Clinics, Health Centres, etc.	Laboratories	Pharmacies	Health Workers	Traditional Healers	Patients
Funding for diabetes care and insulin		X	X			X		X	X	X					X
Taxes and Import restrictions on insulin	X	X	X	X	X	X			X			X			
Labour Resources			X					X		X					
Organisation of care			X		X			X		X			X	X	X
Supply of insulin and related supplies (cost, mark-ups, taxes, “black market”)	X		X	X	X	X		X	X	X	X	X	X		X
Infrastructure			X	X		X		X	X	X	X	X	X		
Tools for monitoring and administration diabetes care			X		X			X		X	X		X		X
Training			X		X		X						X	X	
Awareness and education			X		X		X				X	X	X	X	X
Prevalence, Incidence number of cases seen			X		X		X	X		X	X	X	X	X	
Process of care (from diagnosis to treatment)			X		X			X		X	X	X	X	X	X

Appendix 6 – Steps in the RAPIA process

In each country the following steps were carried out to ensure a successful project:

- A few months before the start of the RAPIA the project coordinator visited the specific country
- The aim of this visit was to:
 - Garner local support
 - Establish contacts and adapt RAPIA accordingly
 - Identify RAPIA teams and prepare training
 - Get questionnaires translated as well as a back translation to verify comprehensibility if necessary
 - Obtain any official credentials necessary for interviews within official structures
 - Identify 3 areas of study with local partners
- The Project Coordinator then prepared the RAPIA and other materials accordingly in parallel local partners identified key people to interview and organised logistics
- The Project Coordinator then returned and began the RAPIA, with the following steps:
 1. Train local teams
 2. Establish working schedule
 3. Contact necessary interviewees
 4. Carry out interviews, site visits, document reviews and discussions
 5. Feedback to local partners as the work progressed
 6. Debriefing session with local teams to get their impressions
- Once the RAPIA was completed the Project Coordinator then wrote up the findings
- These were then distributed to local partners prior to the Chairman and the Project Coordinator of the IIF returning to present the results
- Once the results presented Action Plans were developed. In Mozambique and Zambia these were done with the input of Dr. Kaushik Ramaiya, President of the IDF Africa Region and Trustee of the IIF.

Appendix 7 – Areas where the RAPIA was carried out in Mali, Mozambique and Zambia

The Project Coordinator together with a team of local interviewers from the diabetes association carried out the RAPIA in Mozambique over a period of almost 2 months.

In total 76 interviews and approximately another 30 informal meetings and discussions were held in three distinct geographical areas in Mozambique - Maputo, Beira and Lichinga and their surroundings. These three areas were chosen by local stakeholders due to their geographical distribution and differences in economic situation.

Figure 11 – Map of Mozambique and areas where the RAPIA was carried out



In collaboration with the Diabetes Association of Zambia (DAZ) and the support of the Central Board of Health, and the financial support of the Diabetes Foundation and the WHO, the IIF carried out the RAPIA in Zambia.

The Project Coordinator together with a team of local interviewers carried out the RAPIA in Zambia over a period of a month. In total 182 interviews and approximately another 40 informal meetings and discussions were held in three provinces in Zambia – Lusaka, Copperbelt and Eastern Province and their surroundings. These three areas were chosen by local stakeholders due to their geographical distribution and differences in economic situation.

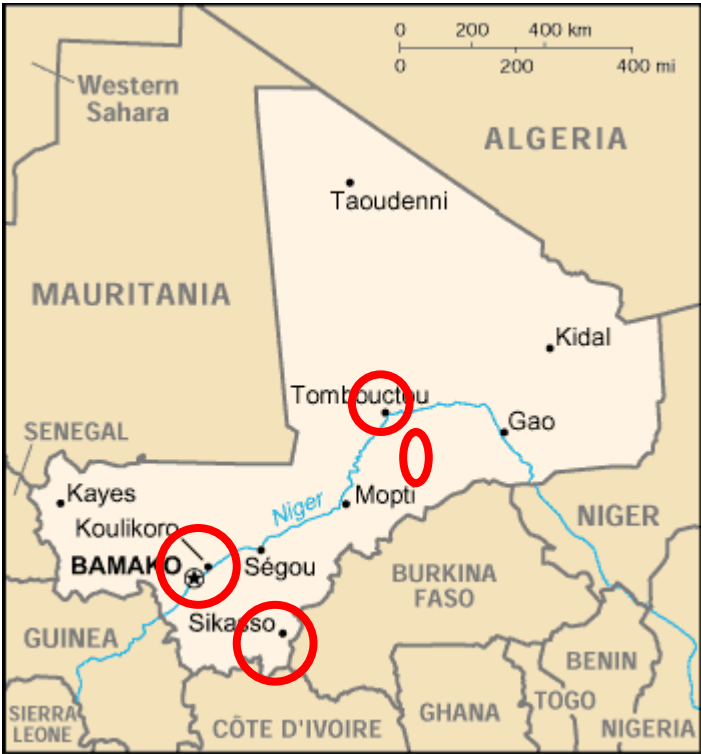
Figure 12 – Map of Zambia and areas where the RAPIA was carried out



In collaboration with Santé Diabète Mali (SDM) and the support of the Ministry of Health, the Direction Nationale de la Santé, Dr. A. Nientao and the financial support of the Diabetes Foundation the IIF carried out the RAPIA in Mali.

The Project Coordinator in collaboration with SDM carried out the RAPIA in Mali over a period of a 7 weeks. In total 110 interviews and approximately another 40 informal meetings and discussions were held in 4 distinct areas of Mali – District of Bamako (City of Bamako), Sikasso (City of Sikasso and Cercle of Kadiolo), Timbuktu (City of Timbuktu) and Mopti (Cercle of Douentza). These four areas were chosen by local stakeholders due to their geographical distribution and differences in economic situation.

Figure 13 - Map of Mali and areas where the RAPIA was carried out



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References

1. Ezzati M, Lopez AD, Rodgers A, Vander Hoorn S, Murray CJ. Comparative Risk Assessment Collaborating Group. Selected major risk factors and global and regional burden of disease. *Lancet*. 360: 1347-60 (2002).
2. Beaglehole R, Yach D. Globalisation and the prevention and control of non-communicable disease: the neglected chronic diseases of adults. *Lancet*. 362: 903-8 (2003).
3. Yach D, Hawkes C, Gould, CL, Hofman KJ. The Global Burden of Chronic Diseases. *JAMA*. 291 (2): 2616-2622 (2004).
4. World Health Organization. Innovative Care for Chronic Conditions: Building Blocks for Action. Geneva, World Health Organization, 2002.
5. Alberti KGMM, Zimmet P for the WHO Consultation. Definition, Diagnosis and Classification of Diabetes Mellitus and its Complications. Geneva, World Health Organization, 1999.
6. Mauvais-Jarvis F, Sobngwi E, Porcher R, Riveline JP, Vaisse C, Charpentier G, Guillausseau JP, Vexiau P, Gautier JF. Ketosis-Prone Type 2 Diabetes in Patients of Sub-Saharan African Origin: Clinical Pathophysiology and Natural History of {beta}-Cell Dysfunction and Insulin Resistance. *Diabetes*. 53 (3): 645-653 (2004).
7. Swai A, Lutale J, McLarty DG. Diabetes in tropical Africa: a prospective study, 1981-7 I. Characteristics of newly presenting patients in Dar es Salaam, Tanzania. *BMJ*. 300: 1103-1106 (1990).
8. Sobngwi E, Mauvais-Jarvis F, Vexiau P, Mbanya JC, Gautier JF. Diabetes in Africans. Part 1: epidemiology and clinical specificities. *Diabetes Metab*. 27 (6): 628-34. (2001).
9. Wild S, Roglic G, Green A, Sicree R, King H. Global prevalence of diabetes: estimates for the year 2000 and projections for 2030. *Diabetes Care*. 27 (5): 1047-53 (2004).
10. International Diabetes Federation. *Diabetes Atlas*. ed. D. Gan. Brussels, Belgium, 2003.
11. Swai AB, Lutale JL, McLarty DG. Prospective study of incidence of juvenile diabetes mellitus over 10 years in Dar es Salaam, Tanzania. *Bmj*. 306 (6892): 1570-2. (1993).
12. Olatunbosun S, Ojo PO, Fineberg NS, Bella AF. Prevalence of diabetes mellitus and impaired glucose tolerance in a group of urban adults in Nigeria. *J Natl Med Assoc*. 90 (5): 293-301 (1998).
13. Lipton R, Keenan H, Onyemere KU, Freels S. Incidence and onset features of diabetes in African-American and Latino children in Chicago, 1985-1994. *Diabetes Metab Res Rev*. 18 (2): 135-42. (2002).
14. International Diabetes Federation. e-Atlas, International Diabetes Federation, 2003. www.eatlas.idf.org (accessed 20 December 2004)
15. McLarty DG, Kinabo L, Swai AB. Diabetes in tropical Africa: a prospective study, 1981-7. II. Course and prognosis. *BMJ*. 300 (6732): 1107-1110 (1990).
16. World Health Organization. The World Drug Situation. Geneva, World Health Organization, 1988.
17. World Health Organization. WHO Model List 13th edition, World Health Organization, 2003. www.who.int/medicines/organization/par/edl/eml.shtml (accessed 17 January 2005)
18. Owens DR, Zinman B, Bolli GB. Insulins today and beyond. *Lancet*. 358 (9283): 739-46. (2001).
19. Burrow G, Hazlett BE, Phillips MJ. A case of diabetes mellitus. *N Engl J Med*. 306: 340-343 (1982).

20. McLarty D, Swai ABM, Alberti, KGMM. Insulin availability in Africa: an insoluble problem? *International Diabetes Digest*. 5: 15-17 (1994).
21. Savage A. The Insulin dilemma: a survey of Insulin treatment in the tropics. *International Diabetes Digest*. 5: 19-20 (1994).
22. Deeb L, Tan MH, Alberti, KGMM. Insulin availability among International Diabetes Federation member associations. *Diabetes Care*. 17: 220-223 (1994).
23. Alberti KGMM. Insulin: availability and cost. *World Health Forum*. 15: 6 (1994).
24. Chale SSJ, McLarty DG. The Economics of Diabetes Care: Africa. In: Alberti KGMM, Zimmet P, DeFronzo RA, Keen H, ed. *International Textbook of Diabetes Mellitus*. London, John Wiley & Sons Ltd, 1997.
25. Makame M for the Diabetes Epidemiology Research International Study Group. Childhood Diabetes, Insulin, and Africa. *Diabetic Medicine*. 9: 571-573 (1992).
26. Castle W, Wicks A. A follow-up of 93 newly diagnosed African diabetics for 6 years. *Diabetologia*. 18: 121-123 (1980).
27. Yudkin JS. Insulin for the world's poorest countries. *Lancet*. 355: 919-21 (2000).
28. McLarty D, Kitange H, Mtinangi B, Makene W, Swai A, Masuki G, Kilima P, Chuwa L. Prevalence of diabetes and impaired glucose tolerance in rural Tanzania. *Lancet*: 871-874 (1989).
29. World Health Organization. The World Health Report 2000: Health Systems: Improving Performance. Geneva, World Health Organization, 2000.
30. Manderson L, Aaby P. An epidemic in the field? Rapid assessment procedures and health research. *Social Science and Medicine*. 35: 839-50 (1992).
31. Rhodes T, Stimson GV, Fitch C, Ball A, Renton A. Rapid assessment, injecting drug use, and public health. *Lancet*. 354: 65-8 (1999).
32. Scrimshaw SCM, Hurtado E. Rapid assessment procedures for nutrition and primary health care. Anthropological approaches to improving programme effectiveness. Tokyo, The United Nations University, 1997.
33. World Health Organization. SEX-RAR guide: the rapid assessment and response guide on psychoactive substance use and sexual risk behaviour. Geneva, Switzerland, World Health Organization, 2002.
34. Direction National de la Sante, Statistique 2000.
35. Instituto Nacional de Estatistica. Statistical Yearbook. Maputo, Instituto Nacional de Estatistica, 2002.
36. Novo Nordisk. Sustainability Report 2003. Bagsværd, Novo Nordisk, 2003, pp. 28.
37. World Bank Group. Data & Statistics, World Bank Group, 2003.
www.worldbank.org/data/quickreference/quickref.html (accessed 8 February 2005)
38. Unwin N, Setel P, Rashid S, Mugusi F, Mbanja JC, Kitange H, Hayes L, Edwards R, Aspray T, Alberti KGMM. Noncommunicable diseases in sub-Saharan Africa: where do they feature in the health research agenda? *Bulletin of the World Health Organization*,. 79 (10): 947-953 (2001).
39. Hjortsberg CA, Mwikisia CN. Cost of access to health services in Zambia. *Health Policy and Planning*. 17 (1): 71-77 (2002).
40. Diabetes UK. Diabetes in the UK. London, Diabetes UK, 2004, pp. 20.
41. Central Intelligence Agency. World Factbook, Central Intelligence Agency, 2004.
www.cia.gov (accessed 12 January 2005)
42. Kessner DM, Carolyn EK, Singer J. Assessing health quality: the case for tracers. *N Engl J Med*. 288: 189-94 (1973).
43. Alberti KGMM. Insulin dependent diabetes mellitus: a lethal disease in the developing world. *BMJ*. 309 (6957): 754-5. (1994).
44. World Health Organization. Diabetes Action Now, World Health Organization, 2005.
www.who.int/diabetes/actionnow/en/n (accessed 19 January 2005)

45. The International Diabetes Federation. About the International Diabetes Federation, 2005. www.idf.org/home/index.cfm?node=3 (accessed 19 January 2005)
46. World Health Organization - Regional Office for Africa. Chronic Diseases, World Health Organization - Regional Office for Africa, 2001. www.afro.who.int/cdp/index.html (accessed 8 March 2005)
47. International Diabetes Federation. About the Africa Region, International Diabetes Federation, 2005. www.idf.org/home/index.cfm?node=3 (accessed 19 January 2005)
48. World Diabetes Foundation, World Diabetes Foundation, 2005. www.worlddiabetesfoundation.org (accessed 19 January 2005)
49. World Health Organization. Innovative Care for Chronic Conditions. Geneva, World Health Organization, 2002.
50. Clinton WJ. Turning the tide on the AIDS pandemic. *N Engl J Med.* 348 (18): 1800-2. (2003).
51. Vexiau P, Sobngwi E, Mauvais-Jarvis G, Mbanya JC, Gautier JF. Diabetes in Africans. *Diabetes Metab.* 27: 629-634 (2001).
52. United Nations Development Programme. UNDP Poverty Report 2000, 2000. www.undp.org (accessed 19 December 2004)
53. World Bank. Memorandum of the President of the International Development Association to the Executive Directors on a Country Assistance Strategy for the Republic of Zambia. Washington, D.C., World Bank, 2004.
54. World Health Organization. WHO Estimates of Health Personnel. Geneva, World Health Organization, 1998.
55. United Nations Development Programme. Human Development Report 2004. New York, United Nations Development Programme, 2004.