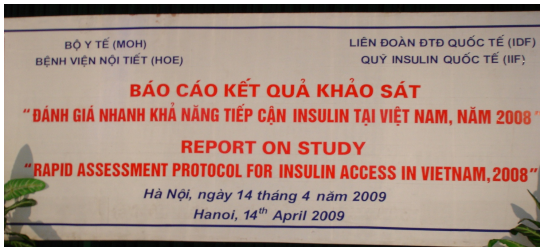
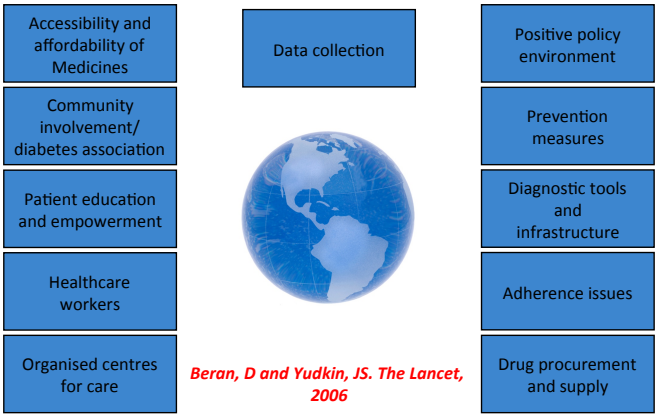
Key lessons learnt from the implementation of the Rapid Assessment Protocol for Insulin Access as a tool for policy change



A positive diabetes environment



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Acronyms

AMLD	Association Malienne de Lutte Contre le Diabète, Mali's Diabetes Association
AMODIA	Associação Moçambicana dos Diabéticos, The Association of Mozambican Diabetics
CAH	Congenital Adrenal Hyperplasia
CLAN	Caring and Living as Neighbours
CVD	Cardiovascular Disease
FMC	Family Medicine Centre
GAP	Global Action Plan for the Prevention and Control of NCDs
ICCCF	Innovative Care Chronic Conditions Framework
IDF	International Diabetes Federation
IIF	International Insulin Foundation
LEAD	Leadership for Education and Access to Diabetes care – A Novo Nordisk initiative
LMIC	Low- and middle-income countries
NCD	Noncommunicable Disease
RAP	Rapid Assessment Protocols
RAPIA	Rapid Assessment Protocol for Insulin Access
WHO	World Health Organization

Executive Summary

The challenge of Noncommunicable diseases has been recognised by the global community with the United Nations High-Level Meeting on Noncommunicable diseases and the First Global Ministerial Conference on Healthy Lifestyles and Noncommunicable Disease Control in Moscow. The World Health Organization's response has been the development of an "Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable diseases" and a "Prioritized Research Agenda for Prevention and Control of Noncommunicable diseases".

Highlighting that "research is fundamental to generate knowledge and information for formulating evidence-informed policies and practices in support of global public health and health equity", the Sixty-third World Health Assembly, in May 2010, in resolution WHA63.21, endorsed the World Health Organization Strategy on Research for Health and established the role and responsibilities of World Health Organization in health research. Within this strategy, the "Prioritized Research Agenda for Prevention and Control of Noncommunicable diseases" was developed to align with this global research agenda.

In this context it is important to understand the influences on the decision making process of health systems research and its impact on the policy process. The International Insulin Foundation developed the Rapid Assessment Protocol for Insulin Access recognising the fact that merely increasing insulin supply would not improve the prognosis for people with diabetes, and the root of the problems within the health system needed to be assessed.

The Rapid Assessment Protocol for Insulin Access is structured as a multi-level assessment tool for health systems research of the different elements that influence the access people with diabetes have to care in a given country. To date the Rapid Assessment Protocol for Insulin Access has been implemented in six countries (representing four World Health Organization Regions) by the International Insulin Foundation: Kyrgyzstan, Mali, Mozambique, Zambia, Nicaragua and Vietnam. The Rapid Assessment Protocol for Insulin Access was able to provide local stakeholders with a clear view of the challenges to diabetes care in their country, but also propose concrete solutions. By doing so the Rapid Assessment Protocol for Insulin Access process was able to bring diabetes care to the forefront and contribute to making the case for resource poor countries to start addressing the issue of diabetes and NCDs.

In order to assess the depth and breadth of the impact of the International Insulin Foundation's work a multi-stage approach was taken. The first stage included a documentary review including peer-reviewed publications, reports and other published materials, which included results from the Rapid Assessments or reference to the International Insulin Foundation's work. An online questionnaire was designed and sent to people who had worked with the International Insulin Foundation or used or referenced the International Insulin Foundation's work in order to get their perspectives of its impact. "Key people" were interviewed using a discussion guide developed based on the results of the documentary review and online questionnaire. These individuals were "key people" in the different countries where the Rapid Assessment Protocol for Insulin Access was implemented, stakeholders from the World Health Organization and International Diabetes

Federation and other individuals involved in different aspects of the Rapid Assessment Protocol for Insulin Access process both globally and in specific countries.

The lessons from this project were that the Rapid Assessment Protocol for Insulin Access was viewed as methodologically strong leading to multiple research outcomes including reports and peer-reviewed publications. A strength of the process was the close collaboration between the International Insulin Foundation and the local research team. Both these elements led to the credibility of the research process and findings. Each implementation and research outcome contributed to the overall credibility of the process.

From this research context specific results were obtained and provided an overall view of the situation with regards to access to insulin and diabetes care. Although there was an active use of the results by the International Insulin Foundation and local partners dissemination was viewed as the main weakness of the Rapid Assessment Process. Interviewees highlighted that it was important for dissemination to be done at local, national and global levels.

The recommendations proposed by the International Insulin Foundation were viewed very positively in terms of being targeted, grounded in local data and the local context. Again though a lack of funding for implementation was viewed as a barrier. Overall the impact of the Rapid Assessment Protocol for Insulin Access was on policy and programme implementation, providing situation specific data that was used locally and globally and other parallel/collateral impacts

As highlighted by other studies looking at research into and a quote from the Global Diabetes Advocate, “it is hard to say which changes in diabetes were due to the Rapid Assessment Protocol for Insulin Access and which were due to changes in other diabetes initiatives.” The policy process and the use of research to inform it are constantly changing and therefore current methods that only enable a snapshot miss vital information. Methods to help gain a clearer overview need to include multiple data sources and approaches. This project attempted to do this using documentary reviews, an online questionnaire and in-depth interviews. It allowed for certain key lessons to be highlighted and show that the Rapid Assessment Protocol for Insulin Access had varying impacts in the countries where it was implemented and globally thanks to strong recognised methods, implemented in collaboration between the International Insulin Foundation and strong local colleagues, generating useful and credible results, that despite problems with dissemination allowed for targeted recommendations to be developed.

Chapter 1 – Introduction

The challenge of Noncommunicable diseases (NCD) has been recognised by the global community with the United Nations High-Level Meeting on Noncommunicable diseases and the First Global Ministerial Conference on Healthy Lifestyles and Noncommunicable Disease Control in Moscow. The World Health Organization's (WHO) response has been the development of an "Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable diseases"[1] and a "Prioritized Research Agenda for Prevention and Control of Noncommunicable diseases".[2]

The Action Plan was endorsed at the Sixty-first World Health Assembly in May 2008 and seeks to build on existing WHO strategies, such as the Global Strategy for the Prevention and Control of Noncommunicable diseases, endorsed at the Fifty-third World Health Assembly in May 2000, the WHO Framework Convention on Tobacco Control and the WHO Global Strategy on Diet, Physical Activity and Health. This Action Plan aims to direct Member States, the WHO, and the international community in establishing and strengthening initiatives for the surveillance, prevention and management of NCDs. At the 66th World Health Assembly Member States approved the WHO Global Action Plan for the Prevention and Control of NCDs 2013-2020 (GAP).[3] This plan includes actions to help achieve 9 globally agreed targets for NCDs, which include a reduction in premature mortality from NCDs by 25% in 2025. The action plan also includes a monitoring framework, with 25 indicators to help assess mortality and morbidity; progress in addressing risk factors, and evaluate the implementation of national strategies and plans.

Highlighting that "research is fundamental to generate knowledge and information for formulating evidence-informed policies and practices in support of global public health and health equity"[2], the Sixty-third World Health Assembly, in May 2010, in resolution WHA63.21, endorsed the WHO Strategy on Research for Health and established the role and responsibilities of WHO in health research. Within this strategy, the "Prioritized Research Agenda for Prevention and Control of Noncommunicable diseases" was developed to align this global research agenda with the "2008–2013 Global Strategy Action Plan".

These two documents highlight the importance of health systems, health system research and researching issues around access to care in addressing the challenge of NCDs. In parallel, the WHO Essential Medicines and Pharmaceutical Policies Department has carried out in-depth analyses of the affordability and availability of medicines for NCDs.[4, 5] The target established by the GAP is of "80% availability of the affordable basic technologies and essential medicines, including generics, required to treat major NCDs in both public and private facilities."[6]

This global agenda is aligned to the aims of the Alliance for Health Policy and Systems Research (hereafter the Alliance), which promotes the use of health policy and systems research as a way of improving the health of people living in developing countries. The Alliance carries out this work by developing and using existing research methods and approaches to improve the quality of research and its use by decision makers.

Of interest to the Alliance is how certain issues get on the policy agenda and what role research and health systems research can play in this. In addition the Alliance aims to bring

together health policy and health systems research, which are sometimes viewed as separate areas, but are clearly interlinked.

In the WHO's report "World report on knowledge for better health: strengthening health systems" it is stated that there is the need for new methods in health systems research to address the complexity of health systems as well as the increasing challenge of NCDs.[7] This report goes on to define health systems research as the investigation of ways of improving health service delivery.

The use of health systems research in policy formulation has as its aim to improve the health of populations.[8] Through research policy makers are exposed to the current situation and options for change. The challenge though is the use of research by policy makers and how the "worlds" of health systems research and policy making coexist. A variety of challenges exist including:

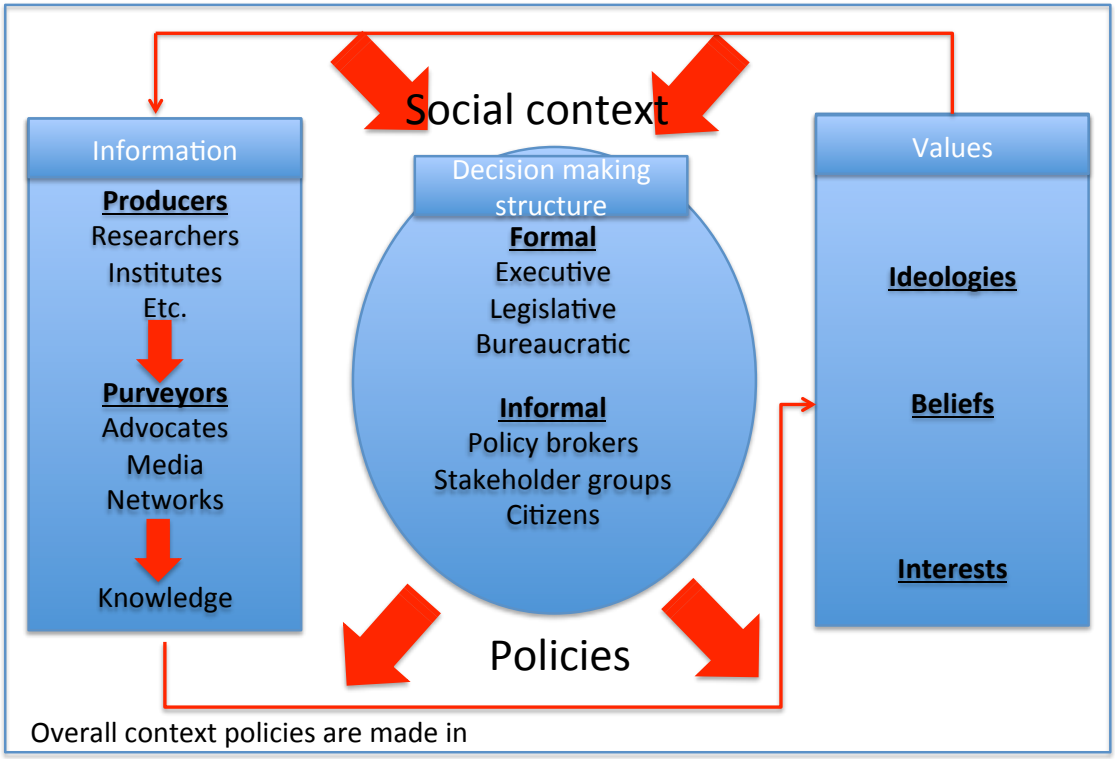
- The view of research by policy makers
- The view and how quality of research is judged
- Are research and its results being brought to the attention of policy makers
- Are policy makers able to understand the research results and use them effectively

Any analysis of the use of health systems research in policy making has to include two factors:

1. What are the wider factors that impact policy makers
2. What analysis of health system problems can contribute to improving health through informed policies

Within this it is important to understand the influences on the decision making process. As detailed in Figure 1 the overall issues in the world and country will have an impact on the policy making process. Changes mentioned above in terms of the NCD agenda form part of these. The actual information generated and who has generated it also plays an important role. But this information also needs to be disseminated and there are a variety of ways this can happen. Through the media, academic journals, presentations, etc. This then translates into knowledge that can be used, but it will be used in a context where values come into play. These values of course can dictate the type of information that is created. These two elements if they come together can then impact (or not) the policy process.

Figure 1 – Schematic view of the policy making process – adapted from Lomas[9]



Gilson[10] defines health policies as "actions through which efforts are made to strengthen health systems in order to promote population health". Therefore both health policy and health systems research share the same aim. Health policies are the formal documents, rules and guidelines that highlight the decisions made by policy makers in order to strengthen the health system and improve the overall health of the population.

The International Insulin Foundation (IIF) a registered charity in the United Kingdom developed the Rapid Assessment Protocol for Insulin Access (RAPIA) recognising the fact that merely increasing insulin supply would not improve the prognosis for people with diabetes, and the root of the problems within the health system needed to be assessed.[11]

The RAPIA is structured as a multi-level assessment tool for health systems research of the different elements that influence the access people with diabetes have to care in a given country. The data collection process provides a situation analysis regarding the supply of medicines and diabetes care, which highlights the strengths and weaknesses of the health system and proposes concrete actions.[12-14] To date the RAPIA has been implemented in six countries (representing four WHO Regions) by the IIF: Kyrgyzstan, Mali, Mozambique, Zambia, Nicaragua and Vietnam.[15-20] An additional implementation was carried out under the guidance of the IIF in the Philippines.[21]

The process of implementing this research is just as important as the results it aims to generate. As highlighted by Hanney et al. [8] much of the previous work in the area of linking research with policy has stressed the importance between the interactions between researchers and policy makers. This is argued to be linked to the fact that policy makers will not act on research if it "just arrives on their desk". Besides these relationships between researchers and policy makers priority setting discussions can also assist in this.

As of the RAPIA's planning stages local stakeholders and policy makers are involved in the process of identifying regions of the country to study, logistics, etc. Throughout the research process there is constant feedback and discussion about the findings. Once the research is completed a presentation of the results to all local stakeholders is held as well as a session defining and prioritising recommendations. This process aims to have buy-in at all levels of the findings and their outcomes.

As stated by the WHO very little is known about how to facilitate the use of research in developing countries and therefore the example of the IIF is in a sense unique as it provides an example of an organisation with a specific area of focus (access to insulin and diabetes care in resource poor settings), which carried out health systems research using a standardised tool. Therefore this research project had as its objective to take a novel methodological approach to identify and assess different aspects of the impact of the RAPIA process and IIF's work that possibly influenced policy makers in Kyrgyzstan, Mali, Mozambique, Nicaragua, Vietnam and Zambia.

1.1. International Insulin Foundation

The establishment of the IIF, by leading academics and physicians in the field of diabetes in 2002, was intended to embark on a concerted effort to improve the prospects of people with Type 1 diabetes in the world's poorest countries. The IIF was established with the aim of prolonging the life and promoting the health of people with diabetes in low- and middle-income countries (LMIC) by improving the supply of insulin and education in its use.

The IIF is in "Official Relations" with the WHO and was active on International Diabetes Federation's (IDF) Task Force on Insulin, Test Strips and Other Diabetes Supplies until end of 2012 and an IDF Associate Member until 2013.

As stated by the Alliance accountability and legitimacy of civil society are important factors in defining their role in the policy process.[22] Based on the literature the two areas of legitimacy that the IIF had was on one hand "moral" as the values and imperative was focusing on an issue of concern to many, access to insulin and diabetes in resource poor settings. In addition the legitimacy of the IIF was also strongly built on "technical" legitimacy in both the make up of the Trustees as leading experts in the field of diabetes, the technical and academic approach in country in carrying out the assessment and with each assessment one could argue gaining more legitimacy based on previous experience.

The IIF developed the RAPIA recognising the fact that merely increasing the insulin supply would not improve the prognosis for people needing insulin, and the root of the problems needed to be assessed. The RAPIA's framework studies the path of insulin to the point where it reaches or fails to reach the individual. Although it initially focused on insulin and patients with insulin-dependent diabetes, after its first two implementations (Mozambique and Zambia) its later implementations (Mali, Nicaragua, Vietnam and Kyrgyzstan) included oral diabetes medicines and patients with non-insulin-dependent diabetes. More information about the RAPIA can be found in Appendix 1.

These country assessments have produced in-country reports and presentations to help shape diabetes projects, diabetes action plans and national NCD policies. In addition results from the RAPIA have been presented in a variety of conferences as well as being published in peer reviewed publications, such as the Asia Pacific Journal of Public Health[23], BMC Health Systems Research[11], Bulletin of the World Health Organization[13], Diabetes Care[24], Diabetes Research in Clinical Practice[25], Diabetic Medicine[26], Diabetologia[27] and the Lancet[28]. A list of these articles is included in Appendix 2.

In addition this protocol has now been adapted by WHO into a manual entitled "How to investigate access to care for chronic noncommunicable diseases in low- and middle-income countries" and is being used for the first time in Peru in a project supported by the Alliance.

The implementation of the RAPIA in these different countries was led by the IIF in collaboration with local partners. In each of these countries these partners had expressed interest in the RAPIA approach and had strong links with other local stakeholders.

1.2. Impact of the RAPIA

Besides providing valuable information on access to insulin, syringes, monitoring and care, (as presented in Appendix 1) the RAPIA was able to sketch a picture of the health care system and its ability to treat people with diabetes. In all countries where this tool was used the involvement of local stakeholders resulted in the process acting as a catalyst in bringing diabetes to the attention of the health authorities. The RAPIA also raised the profile of diabetes associations and awareness around diabetes and NCD diseases in countries where most funding and projects are focused on communicable diseases.

The RAPIA was able to provide local stakeholders with a clear view of the challenges to diabetes care in their country, but also propose concrete solutions. By doing so the RAPIA process was able to bring diabetes care to the forefront and contribute to making the case for resource poor countries to start addressing the issue of diabetes and NCDs.

Implementations of the RAPIA have resulted in the following changes with regards to policies and activities based on discussions with local stakeholders, the reassessment in Mozambique with the RAPIA and an evaluation project in Mali:

- Improvements in access to insulin (Mali, Mozambique and Zambia)
- Development of NCD policies (Mozambique and Zambia
- Inclusion of RAPIA recommendations in government policies and programmes (Kyrgyzstan, Mali, Mozambique, Nicaragua and Vietnam)
- Improvement and increase in visibility of Diabetes Associations (Mali, Mozambique, Nicaragua and Zambia)
- Inclusion of RAPIA recommendations in projects and programmes of national NGOs (Mali and Nicaragua)
- External funding and support for diabetes programmes (Mozambique, Zambia and Vietnam)
- Use of RAPIA for monitoring and evaluation (Mozambique)

To highlight the impact of the RAPIA the experience in 3 of the countries where it has been implemented is detailed below.

1.3.1. The example of Mozambique

Mozambique was the first country where the RAPIA was implemented in 2003. It is interesting to note that the 2003 implementation of the RAPIA was led by the Association of Mozambican Diabetics (Associação Moçambicana dos Diabéticos, AMODIA) and the reassessment by the Ministry of Health. Following this, recommendations were prioritized by AMODIA and the Ministry of Health in Mozambique. In order to address these recommendation the IIF provided technical support and the World Diabetes Foundation provided in-country funding for a variety of projects. In 2006, a team from Diabetes UK joined the IIF in Mozambique to assess the feasibility of a twinning project between Diabetes UK and Mozambique. The proposal was accepted by the Diabetes UK Executive Board, and the Programme was initiated in January 2007. The activities included in this programme were:

- A training of trainers programme
- Specialised training
- Development of patient education materials
- Organisation of World Diabetes Day events
- Advocacy and policy support to Ministry of Health
- Development of diabetes association

The influence of the Programme was assessed by repeating the RAPIA in August–September 2009, in the three original areas where the RAPIA had been implemented in 2003—Maputo, Beira and Lichinga—as well as in Gaza Province in southern Mozambique. The RAPIA interviews were identical between the two assessments. Because the information collected was largely qualitative and semi-quantitative, no formal statistical comparison between the two RAPIAs was performed. However it was concluded that “Much progress has been made in Mozambique with regard to diabetes and NCD diseases. Besides the direct impact of specific activities supported by Diabetes UK, this project allowed for ‘collateral’ benefits in the overall provision of diabetes care.” Results also showed that the diabetes association had increased its membership 8-fold, 265 health workers had been trained in diabetes care in all provinces, the development of patient education materials and the expansion of public awareness, particularly from events associated with World Diabetes Day had been achieved.

The initial assessment using the RAPIA therefore gave baseline data and indicators against which these projects could be monitored. In addition, the Ministry of Health developed a National NCD Plan which included data from the initial RAPIA and had as one of its activities to carry out another RAPIA assessment in order to monitor and assess progress.

As well as these programmatic successes a variety of health system factors had also improved over the period 2003-2009. These are described in the table below.

Figure 2 – Comparison of key indicators from RAPIA 2003 and 2009 in 2009 standardised prices (adapted) [26]

Indicator	2003	2009	Implication(s)
Insulin			
Ministry of Health expenditure on insulin for 18 months	$706,550	$271,800	- Better tender price - Less wastage
Average tender price per vial of insulin (18 months)	$8.03	$4.50	- Decrease in tender price
Total quantity of insulin purchased (18 months)	115,800	60,400	- Less wastage
Insulin expenditure as %age of total spending on medicines by the Ministry of Health	1.73%	0.54%	- Better use of finite resources
Proportion of total amount of insulin in Capital City	77%	46%	- More equitable/better distribution
Time for tender (maximum) for insulin	12 months	9 months	- Improved tendering practices
Insulin always present at %age of hospitals	20%	100%	- Improved availability
Average price per vial of insulin to public pharmacies	$6.62	$4.50	- Decrease in facility purchase price - More resources available
Average price per vial of insulin to patient (private)	$10.40	$12.39	- Decreased affordability in the private sector
Average price per vial of insulin to patient (public)	$1.32	$0.20	- Increased affordability in the public sector
Syringes			
Price of syringes private sector	$0.23	$0.34	- Decreased affordability in the private sector
Presence of diagnostic tools at health facilities			
Blood glucose machine	21%	87%	- Improved availability
Consumables available for the blood glucose machine	6%	27%	- Improved availability, but not in line with improved availability of Blood glucose machines
Urine testing strips	18%	73%	- Improved availability
Ketone strips	8%	73%	- Improved availability
Healthcare workers			
Number of healthcare workers who have received training in diabetes (2003 basic, 2009 specialised)	52%	65%	- Increase in number of trained personnel - Impact on diagnosis and management of people with diabetes

These improvements in the health system and its delivery of a variety of aspects linked to diabetes care (insulin, healthcare worker training and diagnostics) meant that estimated

life-expectancy for someone with Type 1 diabetes had increased during the period 2003-2009.[26]

These indicators clearly show that the RAPIAs results had an impact on the development of different health system and policy factors including the development of a NCD Strategic Plan which refers to the RAPIA results.[29, 30] This plan includes CVD, including hypertension, diabetes, asthma and some cancers. Projects and interventions developed based on the RAPIA focused on diabetes and hypertension in order to develop models that could be replicated for other conditions. For example the development of "chronic consultations", "health fairs" and NCD focal points in each Province.

1.3.2. The example of Vietnam – experts and action plan

Together with two international experts David Beran (DB; former Project Coordinator, IIF), Marg McGill (Senior Vice President IDF) and Valla Tantayotai (Dean, School of Nursing, Walailak University, Secretary, Thai Association of Diabetes Educators and Co-ordinator, Diabetes Care Knowledge Management Network) presented the results of the RAPIA in Vietnam as well as sharing and discussing experience of diabetes management in other settings. Following the presentation of the results to local stakeholders and a discussion of these different action plans were developed for each level of the health system. These are described in Appendix 3.

1.3.3. The example of Vietnam – use of the RAPIA for another NCD

Congenital Adrenal Hyperplasia (CAH) is the most common adrenal condition of childhood, with cortisol and aldosterone replacement essential to survival. The RAPIA was conducted in Vietnam by the IIF in 2008 to explore barriers to insulin access and diabetes care. CLAN took this opportunity to implement an adapted protocol and clearly identify barriers to accessing medicine and care for children with CAH in Vietnam. Although the exact incidence of CAH in Vietnam is not yet known, initial new-born screening trials in 2007 suggest it may be higher in Vietnam (closer to 1:6,000, as is found in the Philippines) than Australia, the United States, and the United Kingdom (generally around 1:18,000).

The CAH RAPIA was a multi-level assessment of factors influencing access to medicine and care for people living with CAH in Vietnam, and had three components: macro (ministerial levels, private sector), meso (provincial levels and health care settings), and micro (caregivers and people living with CAH). Data were collected in Hanoi, Ho Chi Minh City, Thai Nguyen Province, and Dong Nai Province. 204 interviews (for diabetes and CAH) were conducted. Participants were selected on the basis of role (ministerial and health sector) and convenience sampling (CAH families) from the four provinces (two mainly urban and two relatively wealthy and urban). Key policy aspects focused on registration and importation of hydrocortisone and fludrocortisone and on the financial burdens on CAH families.

Although health care workers interviewed stated that more young children with CAH were surviving what was striking was the lack of older children with CAH (over 90% of children with CAH were younger than 15). The majority of families (60%) identify financial burdens (cost of medicines in the main) as their greatest concern. Barriers to affordable access to hydrocortisone and fludrocortisone were a mix of national and international factors: neither

drug was included in the WHO Essential Medicines List for Children, neither drug was registered in Vietnam, leading to and variable pricing and quality. Barriers to care included lack of access to trained health professionals, particularly beyond major centres; travel costs; health systems not developed for paediatric chronic disease; clinical infrastructure unavailable; and a mismatch between actual and insurance-approved referral pathways. One positive aspect found was that CAH family support clubs were effective for education and support.

1.3.4. The example of Kyrgyzstan

Following the completion of the RAPIA in September 2009, a presentation of the initial findings was made in November 2009 to the Ministry of Health. Following this, a draft Diabetes Action Plan was developed with the input of the Health Policy Analysis Centre. This plan was presented during the visit in March 2010 and detailed the priorities of the Ministry of Health in addressing diabetes based on the recommendations from the RAPIA. The main points from this Action Plan are:

1. Training of doctors and nurses
    a. Address the issue of fragmented services delivery
    b. Practical training
2. Equipment and medicines
    a. Development of a tool-kit adapted to each level of the health system
    b. Improve access to metformin
    c. Insulin – address the issues of analogue vs human insulin and penfill vs. syringes as a means of delivery
3. Recommendations for healthcare workers and people with diabetes
4. Increase the role Diabetes Association/Community/Village Health Committees
5. Diet/Education/Lifestyle
    a. Upstream measures (primary prevention)
    b. Advice to at risk people
6. Diabetes Register

Comments were provided to this draft plan during a visit including experts from the IIF, IDF and Diabetes UK. It could be argued that this work may have influenced the inclusion of diabetes as part of the existing CVD programme, thereby expanding the area of NCDs within Kyrgyzstan's next health programme, 'Den Sooluk'.[31]

Chapter 2 – Getting research into policy

Health systems research is a neglected area and needs to address two issues on one hand how can this research be seen as important to policy makers and secondly how can it be used to help shape policy as research and policy exist in "different worlds" and have very few opportunities to interact.[7, 22, 32-34] This enabled this work to be "rooted and responsive to national needs"[32] both in terms of using a flexible methodology to adapt to the local setting as well as collecting country specific data in country.

However it is important to distinguish the two elements of the IIF's work. On the one hand as a "producer of knowledge" in terms of an understanding of local challenges to the delivery of diabetes care and in a wider sense raising awareness of a topic that was not widely addressed.[22] Policy making is a complex political process and many have argued that

policy makers do not necessarily have the capacity to use research to inform their decisions.[22] This challenge may be even stronger in some of the countries where the IIF has worked.[35] The issue though is how, if any did the RAPIA and the IIF's use of this research impact policies. The question though is also which policies. Global policies on the issue of access to insulin? Local policies on diabetes and NCDs? The issue then becomes how to measure this impact.

In order to impact programmes and policies the results of this needs to be "grounded" in data that is relevant to the given country.[7] Besides the need for local data to highlight the local problems this is also needed to develop local solutions (grounded in the local reality).[33] Although there is agreement on the issue of strengthening health systems there is currently no established framework for doing this in developing countries.[36] The focus as well on health systems research has been on the macro view of the system with very little focus on the component parts.[36] The RAPIA addresses this by having many questionnaires targeted at different levels of the health system and their interactions and their impact on individuals. There is also the issue of capacity in research methods that are not standardised and the need for new methods to be developed.[36] The IIF addressed this by using local teams, training them and developing standardised yet flexible tools to collect the breadth and depth of data needed to understand the complexity of health systems.

This helps in developing recommendations that are linked to locally collected data and relevant to the local situation thereby providing policy makers with "reasonable and justifiable policy solutions".[33] In parallel there is also the need for this information to be communicated and disseminated to policy makers.[37] This was assessed by looking at conferences and publications produced as these help with the diffusion of this information.

Assessing whether research has had an impact require not only reviewing the number of papers and reports produced, but also:[7]

- Funding of research
- Who is involved in the research process
- How are beneficiaries involved in the research process
- How are the results of the research shared with local partners
- How are the results used to improve health

To study the impact of research on policy making qualitative methods have been used.[38] Other studies have used document reviews and key informant interviews using an interview guide.[39] Others suggest bibliometric analyses and how this data is included in other studies, documentary analysis and interviews.[8]

As stated by the WHO very little is known about how to facilitate the use of research in developing countries and therefore the example of the IIF is in a sense unique as it provides an example of an organisation with a specific area of focus (access to insulin and diabetes care in resource poor settings), which carried out health systems research using a standardised tool. Therefore, the objective of this research was to identify and present the factors that enabled the RAPIA process to inform and influence policy makers in Kyrgyzstan, Mali, Mozambique, Nicaragua, Vietnam and Zambia and develop a series of key lessons learnt that can be applicable to health system research.

2.1. Methods

In order to assess the depth and breadth of the impact of the RAPIA and the IIF's use of this research for advocacy a multi-stage approach was taken. The first stage included a documentary review including both peer-reviewed publications, reports and other published materials which included references to the results of the RAPIA.

For peer-reviewed publications Web of Knowledge and PubMed were used to assess the number of citations these articles had. In addition for articles published in BioMed Central the number of accesses was found.

As the importance of this research is not only to inform academic audiences, the main users of peer reviewed publications, but policy makers a general search strategy using Google was developed. This search strategy used the search terms shown in the table below. Each term was combined using the term "AND". For example "International Insulin Foundation" AND "NCD Alliance". This search was to assess which organisations referenced the results from the RAPIAs.

Table 1 – Search terms for Google search

Search terms	NCD Alliance	IDF	WHO	UN HLM	Mozambique	Zambia	Mali	Nicaragua	Vietnam	Kyrgyzstan
International Insulin Foundation										
Rapid Assessment Protocol for Insulin Access										
Yudkin										
Beran										

In addition the title of the RAPIA report in French (Mali), Portuguese (Mozambique), Russian (Kyrgyzstan) and Vietnamese (Vietnam) was entered into a Google search. In carrying out these searches it was also found that certain books referenced the results of the RAPIA work. An additional search using similar terms as presented in Table 1 was used in "Google Books".

It can be argued that this scientific, research and project output helped people involved in the IIF be invited to a variety of meetings. A listing of the meetings attended by the Chairman of the IIF (John S. Yudkin: JSY) and former Project Coordinator (DB) are also included. This is based on the news section of the IIF's website as well as a listing kept by DB.

In order to get the perspectives of people who had used or referenced the RAPIA results and the impact of the IIF's work using this information an online questionnaire was designed. A copy of this questionnaire can be found in Appendix 4.

This questionnaire was then posted online using Survey Monkey and a link was sent to 167 individuals' e-mail addresses. An introductory e-mail described the study and gave the individuals 3 weeks to respond. A reminder was sent after 2 weeks. This data was then analysed to help inform more in-depth interviews with key informants.

"Key people" were interviewed using a discussion guide developed from the documentary review and online questionnaire. These people were "key people" in the different countries where the RAPIA had been implemented, stakeholders from the WHO and IDF and other individuals involved in different aspects of the RAPIA process both globally and in specific countries.

Chapter 3 – Results Impact of the Rapid Assessment Protocol for Insulin Access

3.1. Documentary review

A key source of information is the IIF's website: www.access2insulin.org. This website received a total of 3,888 individual visits from the 15th of April until the 15th of May 2013. In looking at the influence of the findings from this research one aspect is the types of publications and where these results are published. The table below highlights the different peer reviewed publications published as a result of the RAPIA and IIF's work using the results from these studies, the impact factor of the journal where these were published, as well as other information such as citations and views. The data presented is up until the 1 May 2013.

Table 2 – Peer reviewed publications on the results of the RAPIA or the IIF's work

Article	Impact Factor of Journal	Citations (Web of Knowledge)	Google Scholar	Accesses on BioMed Central
Beran D and Higuchi M. Delivering diabetes care in the Philippines and Vietnam: Policy and Practice issues. ***Asia-Pacific Journal of Public Health***, 2013, 25(1):86-95.	1.056	0	1	NR
Silva-Matos C and **Beran D**. Non-communicable diseases in Mozambique: risk factors, burden, response and outcomes to date, ***Globalization and Health***, 2012, 8(1): 37. e-pub ahead of print.	2.65	0	0	1,867
Beran D, Basey M, Wirtz V, Kaplan W, Atkinson M and Yudkin JS. On the road to the insulin centenary, ***Lancet***, 2012, 380 (9854): 1648.	38.28	0	0	NR
Beran D, Abdraimova A, Akkazieva B, McKee M, Balabanova D and Yudkin JS. Diabetes in Kyrgyzstan: changes between 2002 and 2009, ***International Journal of Health Planning and Management***, 2012, 5 November e-pub ahead of print.	0.64	NR	0	NR
Beran D. Health systems and the management of chronic diseases: lessons from Type 1 diabetes, ***Diabetes Management***, 2012, 2(4):323–335.	NA	NR	0	NR
Lipska K and **Beran D**. Letter. Promoting the use of DPP-4 inhibitors in Asia, ***Diabetes Research in Clinical Practice***, 2012, 7 May e-pub ahead of print.	2.754	NR	0	NR
Beran D and Yudkin JS. Letter. Apply criteria to improve health systems in developing countries, ***BMJ***, 2012; 344:e546.	14.093	0	0	NR
Beran D. Improving access to insulin: what can be done? ***Diabetes Management***, 2011, 1(1):67-76.	NA	NR	2	NR
Gill GV, Yudkin JS, Keen H and **Beran D**. The insulin dilemma in resource-limited countries. A way forward? ***Diabetologia***, 2011, 54(1): 19-24.	6.814	8	10	NR
Beran D, Silva Matos C and Yudkin JS. The Diabetes UK Mozambique Twinning Programme. Results of improvements in diabetes care in Mozambique: a reassessment 6 years later using	2.902	4	6	NR

Article	Impact Factor of Journal	Citations (Web of Knowledge)	Google Scholar	Accesses on BioMed Central
Yudkin JS, Holt RIG, Silva-Matos C and **Beran D**. Twinning for better diabetes care: a model for improving healthcare for non-communicable diseases in resource-poor countries. ***Postgraduate Medical Journal***, 2009, 85(999): 1-2.	1.939	4	7	NR
Beran D, McCabe A and Yudkin JS. Access to medicines versus access to treatment: the case of type 1 diabetes. ***Bulletin of the World Health Organization***, 2008; 86(8): 648-9.	5.459	5	14	NR
Sidibé AT, Besançon S and **Beran D**. Le diabète : un nouvel enjeu de santé publique pour les pays en voie de développement : l'exemple du Mali. ***Médecine des maladies Métaboliques***, 2007; 1(1): 93-8.	0.201	NR	10	NR
Beran D and Yudkin JS. Diabetes Care in sub-Saharan Africa. ***Lancet***. 2006; 368(9548):1689-95.	38.28	44	99	NR
Beran D, Yudkin JS and de Courten M. Assessing health systems for type 1 diabetes in sub-Saharan Africa: developing a 'Rapid Assessment Protocol for Insulin Access', ***BMC Health Serv Res***, 2006; 6(1):17.	1.66	11	21	5,297
Beran D and Yudkin JS. Letter. A theme issue by, for and about Africa: Tackling the challenge of diabetes, ***BMJ***, 2005; 331:779-80.	14.093	1	1	NR
Beran D, Yudkin JS and de Courten M. Access to care for patients with insulin-requiring diabetes in developing countries: case studies of Mozambique and Zambia. ***Diabetes Care***, 2005; 28(9):2136-40.	8.1	24	60	NR
Beran D. Type 1 diabetes as a "Tracer" condition in developing countries. ***Diabetologia,*** 2004; 47(1): A340.	6.814	0	0	NR
Yudkin JS and **Beran D**. Letter. Prognosis of diabetes in the developing world. ***Lancet***, 2003; 362(9393): 1420-1.	38.28	2	4	NR

NA – Not Available
NR – Not Referenced

The results from the Google search found that organisations such as Health Action International, the WHO at Headquarter, Regional and National level, IDF, NCD Alliance, NCD Child, Novo Nordisk (leading insulin manufacturer), Rand Health and Hanoi School of Public Health either referenced the above publications detailed in Table 2 or one of the RAPIA country reports.

The WHO Essential Medicines and Health Products website includes a list of IIF publications. In addition the WHO at Headquarter, Regional and Country levels have referenced or used data produced by the IIF. This is summarised in the table below.

Table 3 – Use of IIF materials by the WHO

Level of WHO	Title of document
Headquarters	Prioritized Research Agenda for Prevention and Control of Noncommunicable Diseases
Headquarters	Essential Medicines for Noncommunicable Diseases
Headquarters	Equity, social determinants and public health programmes
WHO AFRO	WHO African Region Ministerial Consultation on Noncommunicable Diseases background document
WHO EMRO	Noncommunicable Diseases, Poverty and the Development Agenda
WHO SEARO	Technical report on Social disparities in health in the Maldives
WHO Country Office Kyrgyzstan	Report included on website
WHO Country Office Vietnam	Medicines Prices: Policy options for Vietnam

It is interesting to note that the RAPIA report for Kyrgzytsan was included on the WHO Country Office in Kyrgyzstan and the specific page that this report was on had received 1,489 hits. A World Bank Report on "What Makes Cities Healthy?" mentions the IIF's work published in the Lancet. The NCD Alliance referenced material from the IIF in some of its position statements as did NCD Child in its advocacy paper entitled "A Focus on Children and Noncommunicable Diseases". In addition Novo Nordisk references the IIF's work in two of its key documents:

- Access to Health: Our approach
- Diabetes: the Hidden Pandemic and its impact on sub-Saharan Africa

In looking at wider audiences the IIF's work has been referenced in the UN Chronicle in the special edition on "Achieving Global Health" and in id21 highlighting the link between this work and its impact not only on a "health" related agenda, but also a "development" one.

In addition in-country partners, the Health Policy Analysis Centre (Kyrgyzstan), Santé Diabète (Mali), Caring & Living As Neighbours (CLAN; Vietnam) and the Asociación de Padres de Niños y Jóvenes Diabéticos de Nicaragua (Nicaragua) all reference the respective RAPIA country reports in various documents and on their websites.

This Google search also identified news items from the BBC, Guardian, Financial Times, Asia Life and British Medical Journal, which referenced the RAPIA results or included interviews with people involved with the IIF. During this overall Google search it became apparent that Textbooks also referenced IIF publications, which presented results from the different RAPIAs. These textbooks are listed below in Table 4.

Table 4 – Textbooks referencing the IIF's work

Title	Authors/Editors
Epidemiology of Pediatric and Adolescent Diabetes	Dana Dabelea and Georgeanna J. Klingensmith
Global Health and Global Ethics	Solomon Benatar and Gillian Brock
"Good Health at Low Cost" 25 years on	Dina Balabanova, Martin McKee and Anne Mills
Handbook of Diabetes	Rudy Bilous and Richard Donnelly
Health Systems in Low- and Middle-Income Countries: An Economic and Policy Perspective	Richard D. Smith and Kara Hanson
Human Embryonic Stem Cells	Jon Odorico, Roger Pedersen and Su-Chun Zhang
Issues in Diabetes, Endocrinology, and Hepatology: 2011 Edition	Q. Ashton Acton
Manson's tropical diseases	Gordon Charles Cook and Alimuddin I. Zumla
Pancreatic Hormones: Advances in Research and Application: 2011 Edition	Q. Ashton Acton
Performance Measurement for Health System Improvement: Experiences, Challenges and Prospects	Peter C. Smith
Principles of Medicine in Africa	David Mabey, Geoffrey Gill, Eldryd Parry, Martin W. Weber and Christopher J. M. Whitty
Rights-based Approaches to Public Health	Dabney P. Evans
Sick Societies: Responding to the global challenge of chronic disease	David Stuckler and Karen Siegel
Textbook of Diabetes	Richard I. G. Holt, Clive Cockram, Allan Flyvbjerg and Barry J. Goldstein
The Evidence Base for Diabetes Care	William Herman, Ann Louise Kinmonth, Nick Wareham and Rhys Williams

In looking at policy and strategy documents the WHO African Region "Regional NCDs prevention and control strategic plan 2012-2016", Mozambique and Tanzania National NCD strategies reference material that uses the results from different RAPIA assessments.

Other policy documents possibly influenced by the implementation of the RAPIA and the IIF's subsequent work in Mozambique, include Mozambique's "Plano de Acção para a Redução da Pobreza Absoluta II" (PARPA, Poverty Reduction Plan) in that their burden is increasing and that Mozambique is facing a double burden of disease.[40] The Plano

Económico e Social (Economic and Social Plan) of Ministry of Health also includes NCDs and the activities that have been carried out with regards to all NCDs and diabetes.[41] This document is the annual plan for Ministry of Health based on the PARPA and sets the activities for the different areas of the Ministry. The European Parliament resolution on Major and Neglected Diseases in Developing Countries (2005/2047(INI)) adopted by the European Parliament in Strasbourg, under Point 41 includes the following: "Believes that health services able to diagnose, manage and treat conditions such as diabetes would save many lives and reduce disability and amputations; in particular access to insulin and Type 2 drugs needs to be expanded and made affordable".[42]

3.2. Meetings and conferences attended

One can argue that based on the results of this research and publications JSY and DB were invited on behalf of the IIF to present this work in a variety of forums. These are detailed in the table below.

Table 5 – Meetings attended by the IIF as of end of 2012

Name of conference/meeting	Organising institution	Title of presentation	Type of audience
International Society of Pediatric and Adolescent Diabetes	International Society of Pediatric and Adolescent Diabetes	Global Challenges for Integrated Pediatric Diabetes Care: Do we need to redefine the health system for Diabetes?	Academic/Clinical
African Diabetes Congress	International Diabetes Federation	Improving access to diabetes care: taking a health systems perspective	Academic/Clinical/Policy makers
Geneva Health Forum 2012	Geneva University Hospitals/University of Geneva	Health system assessments as a means to improve diabetes care in resource poor settings	Academic/Clinical/Policy makers
University of Insulindependence	Insulindependence	The case for Insulindependence	People with diabetes
Creating a healthier future for children and adolescents: A roadmap beyond the UN Summit on NCDs	NCD Child	Access to essential medicines	Academic/Clinical/Policy makers
21st World Diabetes Congress	International Diabetes Federation	Health system assessments as a means to improve diabetes care in resource poor settings	Academic/Clinical/Policy makers
Third International Conference for Improving Use of Medicines	INRUD	Irrational Use of Diabetes Medicines in Resource-Poor Settings	Academic/Policy makers
First Global Ministerial Conference on Healthy Lifestyles and Noncommunicable Disease Control	WHO	Statement on access to medicines for diabetes in resource poor settings	Policy makers

Name of conference/meeting	Organising institution	Title of presentation	Type of audience
International Conference on Realising the Rights to Health and Development for All	University of South Wales and Communist Party of Vietnam: Central Commission for Popularization and Education	"The right of everyone to the enjoyment of the highest attainable standard of physical and mental health" – the example of Type 1 diabetes and insulin	Academic/Policy makers
20th World Diabetes Congress	International Diabetes Federation	Access to insulin and diabetes care in developing countries – the experience of the International Insulin Foundation; Twinning and the Mozambique experience	Academic/Clinical/Policy makers
Geneva Health Forum 2008	Geneva University Hospitals/University of Geneva	Lessons from diabetes in sub-Saharan Africa: can they be applied to all countries	Academic/Clinical/Policy makers
Diabetes UK Annual Professional Conference	Diabetes UK	Diabetes in sub-Saharan Africa	Academic/Clinical
World Health Organization Consultative Meeting on the Direct Costs of Diabetes Treatment	WHO	Assessing access to diabetes care in resource poor countries	Academic/Policy makers
European Society of Paediatric Endocrinology Annual Conference	European Society of Paediatric Endocrinology	Diabetes Care in sub-Saharan Africa	Academic/Clinical
Oxford Health Alliance Annual Summit	Oxford Health Alliance	Access to insulin in sub-Saharan Africa	Academic/Policy makers
19th World Diabetes Congress	International Diabetes Federation	Rapid Assessment Protocol for Insulin Access and Managing Diabetes in sub-Saharan Africa	Academic/Clinical/Policy makers
International Diabetes Federation Africa Region and	International Diabetes Federation Africa Region and	Implementing National Diabetes Programmes in sub-Saharan Africa	Policy makers

Name of conference/meeting	Organising institution	Title of presentation	Type of audience
World Health Organization AFRO Region Workshop on National Diabetes Programmes in Bamako, Mali and Nairobi Kenya	World Health Organization AFRO Region	and Case studies from Mali, Mozambique and Zambia	
World Health Organization Planning Meeting on the Global Initiative for Treatment of Chronic Diseases	World Health Organization	Managing Insulin Dependent Diabetes Mellitus in sub-Saharan Africa	Policy makers

In addition JSY and DB through the links with the WHO and IDF participated in various meetings in the lead up to the United Nations High Level Meeting on NCDs and the follow-up and development of the NCD GAP.

3.3. Impact on funding

It is clear that the work of the IIF enabled funding to be allocated to this work in terms of research from the organisations funding the IIF, but also enabling projects by local partners to be funded. As shown in Table 6 the IIF's work was funded by the following organisations, which were more to do with diabetes than health systems research.

Table 6 – Organisations funding the IIF's work

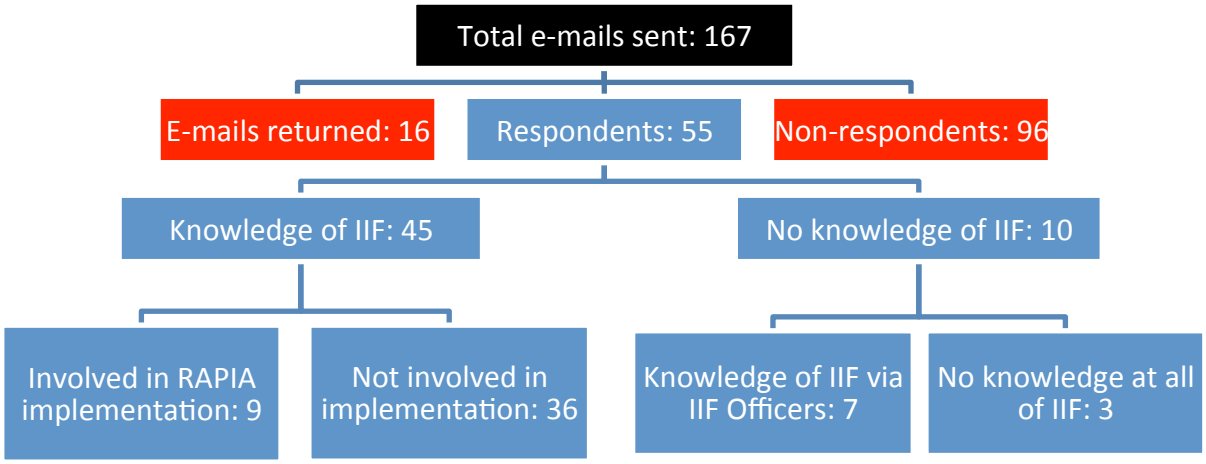
Funder	Country	Activity
World Diabetes Foundation	Mozambique	RAPIA
Diabetes Foundation	Zambia and Mali	RAPIA
Shine Foundation	Mozambique and Zambia	National diabetes plans
Diabetes Foundation	Mali, Mozambique and Zambia	Comparative report and report on implementing national policies for diabetes
Handicap International	Nicaragua	RAPIA
International Diabetes Federation	Kyrgyzstan and Vietnam	RAPIA
Diabetes UK	Mozambique	Diabetes Twinning Project

In Mali and Mozambique this initial assessment and funding for health systems research enabled further funding from the World Diabetes Foundation in both countries, as well as other donors in Mali. In Mozambique funding was made available by Diabetes UK for a Twinning project. A similar project was established in Zambia with no IIF support with the Norwegian Diabetes Association and the Norwegian Agency for Development Cooperation.

3.4. Online questionnaire

An online questionnaire was sent to a total of 167 individuals who had in some way collaborated with the IIF on the implementation of one or more Rapid Assessments. This list also included individuals who had used or referred to results from the different RAPIAs and/or IIF's work as detailed in the documentary analysis above or contacted the IIF about its work. Of the 167 individuals contacted 16 e-mails were returned as the e-mail addresses were no longer valid. Local partners represented 66 possible respondents with 85 individuals being international partners. Local partners were individuals from one of the countries where the RAPIA had been implemented, whereas international partners may have collaborated with the IIF, but were not directly involved in the assessment. In the returned e-mails unfortunately local partners represented 88% of this total. The diagram below details the response to the overall questionnaire.

Figure 3 – Details of responses to online questionnaire



Further details about the respondents are presented in Appendix 5.

Only 9 out of the 55 respondents were directly involved in the implementation of the RAPIA. Of these 9, 2 were from Kyrgyzstan, 1 from Mali, 3 from Mozambique, 0 from Nicaragua, 2 from Vietnam and 1 from Zambia. In rating the quality of different elements of the implementation of the RAPIA the answers from these 9 respondents are detailed in the table below.

Table 7 – Rating of different elements of RAPIA process by stakeholders involved in local assessments

Element of the RAPIA	Barely Acceptable	Good	Very Good	Score out of 5
Methods used in the RAPIA		1	8	4.9
Quality of the research team		1	8	4.9
Credibility of the research team		1	8	4.9
Involvement of local partners during the research process		2	7	4.8
Quality of the results from the RAPIA		1	8	4.9
Quality of the recommendations from the RAPIA		2	7	4.8
Quality of the dissemination of the RAPIA results	1	3	5	4.4

From this it is clear that in-country partners had a "Good" or "Very Good" view of most aspects of the RAPIA. The weakest of these elements was the dissemination of the RAPIA results. In highlighting a possible reason for the poor score received for the "Quality of the dissemination of the RAPIA" only 2 out of the 9 interviewees had participated in the in-

country priority setting exercise for the recommendations. The 9 respondents were then asked what influence the RAPIA had in the country where they were involved in the implementation. It is interesting to note that overall the influence of the RAPIA was most felt in the area of Policy implementation with this element of the policy process being scored highly for all elements. In terms of policy agenda setting less than half the respondents felt that the RAPIA influenced overall health, diabetes management and NCDs. For policy formulation the RAPIA's largest impact was for overall health and NCDs. Access to insulin, one of the IIF's key targets, was not highlighted as being influenced by the RAPIA at the levels of policy agenda setting or policy formulation, but that the RAPIA impacted policy implementation for this. This highlights the RAPIA's "research for action" perspective and that this may not help shape policy, but impact its implementation. Interestingly respondents also stated that the RAPIA influenced policy implementation for overall health. Again this may be because of the concrete recommendations given that could have a wider impact than just diabetes.

In looking at some of the open responses that interviewees completed in this section some of the responses regarding the impact of the RAPIA were:

- Elaboration and implementation of a National Strategic Plan for NCD
- NCDs introduced on the political Agenda
- Initiation of NCD advocacy movement
- Results were used in discussion held with Ministry of Health
- Recommendations written and presented to the Ministry of Health and other key leaders
- Discussion on how to address issues related to access to treatment
- The results were used to further push for a diabetes and NCD policy at Ministry of health and we had some success
- The very fact that the country was part of the survey raises the profile of the local players fighting for overall NCD recognition by the Government
- Collaboration with others working in the country around the same NCDs
- The IIF team were fantastic to work with, very inclusive and generous. Had a big bearing on things.
- It was very useful to Mozambique because of RAPIA and the publications, diabetes Mozambique situations was exposed to international communities and could find partners not only for diabetes but also for NCDs
- The assessment did help in the Ministry of Health finally accepting to have an NCD desk

However, these respondents also highlighted that:

- The RAPIA questionnaire is very long however it is not difficult to train the staff and implement.
- No feedback on the impact of the study
- A naive top down approach to disease management was taken

In looking at the overall impact of the RAPIA these 9 respondents answered a question asking them their level of agreement with the statements on the impact of the RAPIA with regards to different factors. The answers from these individuals shows that the impact of the IIF's work was mainly in the areas of access to insulin, diabetes management, NCD policies, government policies and programmes and the visibility of diabetes associations.

As was highlighted above the main impact of the RAPIA was with regards to insulin access, but this answer also highlights how the RAPIA impacted:

- Diabetes Management
- NCD Management
- NCD Policies
- Government policies and programmes
- Improved and increased the visibility of Diabetes Associations

Overall this highlights a relatively wide impact felt by those directly involved in the implementation of the RAPIAs in-country. Of course this sample of respondents, only 9 individuals, is too small to draw any overarching conclusions.

In looking at the answers from responders who were not directly involved in the implementation of an in-country assessment, representing 36 individuals, these people had heard about the IIF through Peer Reviewed publications (53%), seen a presentation about this work (53%), read about this work but not in a peer reviewed publication (33%) and 19% in an other way. These other ways included mainly meetings and being informed about this work through colleagues as well as the IIF's website. Their perceptions of the different elements of the RAPIA are detailed in Table 8.

Table 8 – Rating of different elements of RAPIA process by stakeholders not involved in local assessments

Element of the RAPIA	Barely Acceptable	Good	Very Good	N/A	Score out of 5
Methods used in the RAPIA	0	7	24	5	4.8
Quality of the research team	1	7	17	11	4.6
Credibility of the research team	0	7	20	9	4.7
Involvement of local partners during the research process	0	7	19	10	4.7
Quality of the results from the RAPIA	1	9	22	4	4.6
Quality of the recommendations from the RAPIA	0	10	22	4	4.7
Quality of the dissemination of the RAPIA	3	14	7	12	4.2

In comparing these results from people not directly involved in the implementation with those directly involved it is interesting to compare the score out of 5 for both groups.

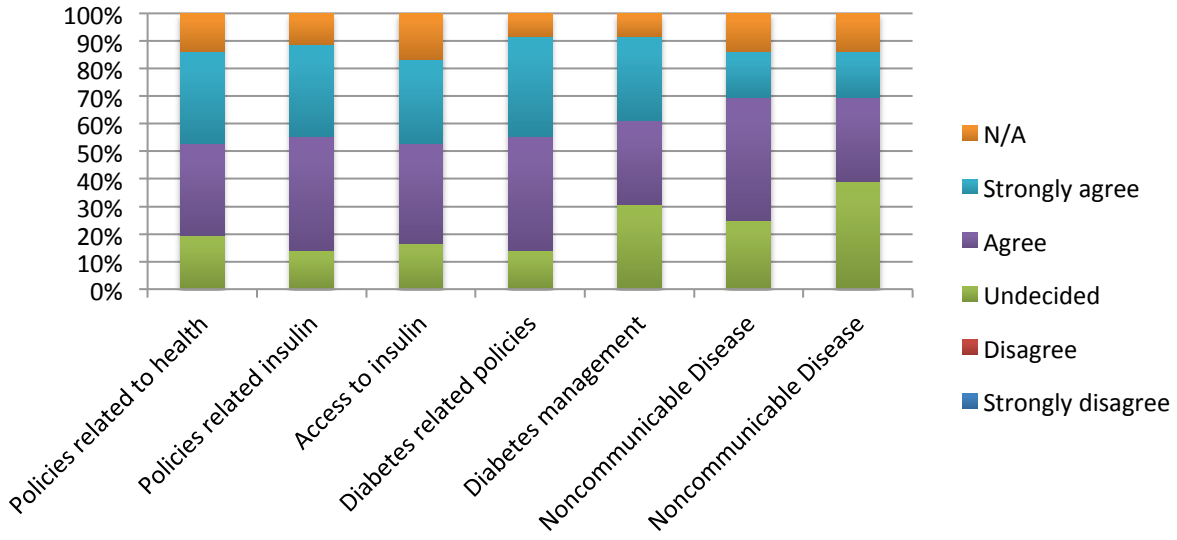
Table 9 – Comparison score out of 5 between responders involved in implementation of RAPIA and those who were not

Element of the RAPIA	Directly involved	Not directly involved
Methods used in the RAPIA	4.9	4.8
Quality of the research team	4.9	4.6
Credibility of the research team	4.9	4.7
Involvement of local partners during the research process	4.8	4.7
Quality of the results from the RAPIA	4.9	4.6
Quality of the recommendations from the RAPIA	4.8	4.7
Quality of the dissemination of the RAPIA	4.4	4.2

Overall those directly involved scored each of these elements higher than those not directly involved. For those not involved the quality of the research team and results seems to be questioned whereas this is scored highly by in-country partners. This may be linked to the high number of respondents from academic institutions. On the other hand dissemination is viewed as the weakest element by both groups. In looking deeper at this issues of dissemination raised by those not involved in the implementation their responses to open questions give some insight into this issue:

- The findings have been published, but I don't know to what extent the information has been disseminated in the target countries
- I follow the literature and I marked the 'dissemination" question as 'barely acceptable" as I do not think the results have been widely disseminated
- A lot of work behind each assessment for limited dissemination

Figure 4 – Impact of IIF's work for individuals with knowledge of the IIF



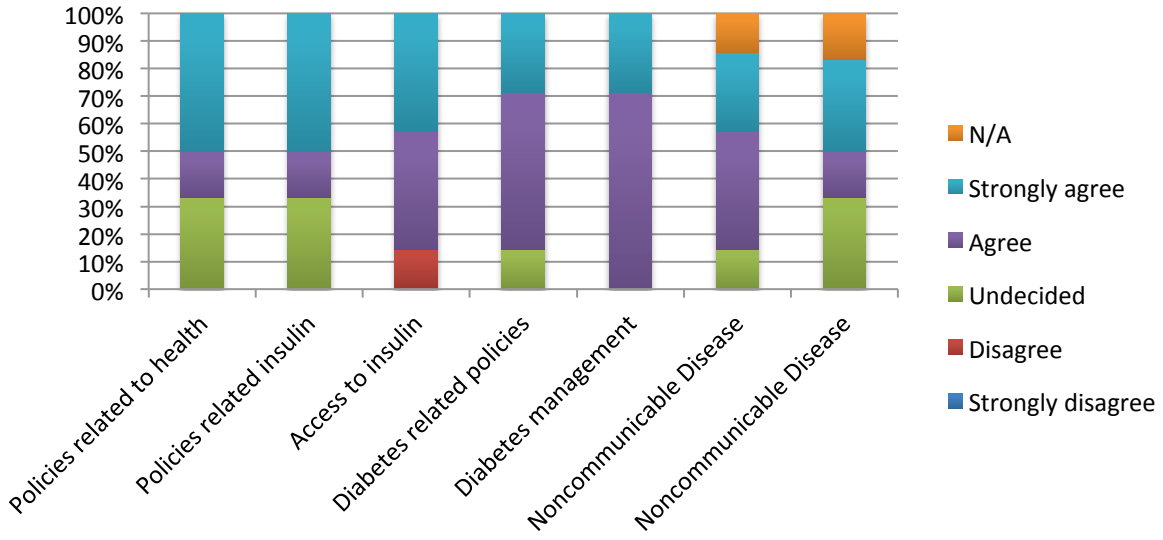
From Figure 4 three areas seem to be more important than the others, policies related to insulin, diabetes related policies and diabetes management. As with those directly involved the issue of insulin features highly in these individuals' responses.

In specifically asking what impact the IIF's work had this group of respondents mentioned:

- Diabetes and NCD policies
- Strengthening of the national diabetes associations
- Exposing dysfunctional drug procurement and insulin distribution systems in many developing countries and providing clear and practical guidance on how to address the challenges
- Raising global awareness
    - Lack of access to insulin
- To have facts as a basis for discussion
- Highly useful estimates of mortality rates
- Development of an assessment tool, but that this tool needs further validation and follow-up

For those who were unaware of the work of the IIF, they were asked if they knew about the work of the Trustees and Advisor to the Board of the IIF regarding access to insulin, 80% of these individuals responded positively. 86% of these individuals had heard about this work from a presentation given by 1 of these individuals. This highlights the importance of the results presented earlier on the range of forums where JSY and DB presented these results. When asked about the impact of this work on a variety of factors, which are described in Table 6.

Figure 5 – Impact of IIF's work for individuals knowing about this work through IIF Officers



Overall those having learnt about the IIF's work through one of the IIF Officers stated that the impact of this work was with regards to:

- Policies related to health
- Policies related insulin
- Access to insulin
- Diabetes related policies
- Diabetes management

In comparing Figure 4 (those with direct knowledge of the IIF) with Figure 5 (those with indirect knowledge of the IIF) both groups agreed that the IIF had an impact on "Diabetes related policies". Those with direct knowledge of the IIF's work also felt that this work had an impact on "Policies related to insulin". In comparison those with indirect knowledge felt that the IIF had impacted "Diabetes management" as well as "Access to insulin".

In looking at some of the quotes left in different parts of the online questionnaire by respondents these reflected positive aspects about the methods used in the RAPIA, with the following being said:

- I think that the RAPIA does well in that its rigorous and objective methodology gives very useful and robust information that people can then use within their own frameworks
- The RAPIA protocol works extremely well in practice.
- The Rapid assessment protocol is very good tool which in the right hands gives a good overview of the situation in a given country with regards to access to insulin.
- RAPIA is an essential tool - fast to implement and replicable in multiple settings. It is the only tool of its kind and should be employed in further settings to decrease barriers to access to insulin.
- From what I know of RAPIA, it is a positive tool that is much needed in the countries. The research is vital and a tool like this is much needed on a wider scale, so in my opinion what was carried out was all very good

Leading on from the quality of the tool itself others commented on the quality of the research team by saying:

- Globally the IIF is the leader on any research related to barriers to access to insulin in resource poor countries. It is a pioneer in the field.
- Research team combined high quality international researchers and motivated local policy makers. This led to both excellent research and an uptake into policy.
- The RAPIA is a useful tool that can help assess the micro, macro and mess level barriers to insulin (and other drugs for other NCDs) access in a country.

It was not only the quality of the research team that was mentioned, but also its credibility with a respondent stating:

- I had a chance to join the group of experts during presentation and discussion of results in one of the RAPIA countries. I also have experience in implementing various research projects in other countries. I can confirm all the listed above elements are extremely important for the RAPIA studies in all four fields of policy changing. The RAPIA group was very carefully listened by the local leaders, Minister of Health, physicians, diabetes society, because the team consisted of highly qualified experts, the methods used were high quality. The highest impact and importance of RAPIA methods and team had on the NCD management.

It could be argued that these elements influenced the quality of the results from the RAPIA and this element was highlighted by 2 respondents:

- With the RAPIA Mozambique we could have for the first time data about prevalence of Type 1 diabetes and data from access to treatment. The results was used by the Ministry of Health to introduce diabetes as a priority in our health policy and define strategic national plan for NCD. These results were also published in scientific journals.
- RAPIA has provided much needed evidence on issues affecting access to insulin. While I am unsure of the impact at the national level, I know it has bought the issue into focus at the international level.

In terms of recommendations the two quotes below highlight the impact both at a country level and international level in terms of the impact of the IIF:

- The recommendations were based on the results, regarding the country experience and really capacity, resources, etc. and because of that, most of the recommendations were implemented.
- While policies and access to insulin are hard to change and the insulin market is dominated by 3 western companies, this tool and work had a positive impact on communities that used it. Those that were able to take on the recommendations did, but sometimes politics prevented more from happening so there should be more funding allocated to follow-up these issues.

In looking at the overall impact of the RAPIA and the IIF's work the 4 quotes below summarise this quite well:

- The RAPIA for Diabetes and CAH have helped effect long-term, sustainable change for the communities of children and families living with Diabetes and CAH in

Vietnam. As an NGO we found the insights and clear reports that come from the RAPIA incredibly empowering in terms of understanding and explaining to others what the key challenges were. Inclusion of hydrocortisone and fludrocortisone in the WHO Essential Medicines List for Children became a direct focus as a result of the RAPIA for instance.

- This work produced information which enabled advocacy around diabetes and noncommunicable diseases, and led to new policies and priorities.
- Increased global awareness
- By engaging a range of different stakeholders (including people living with an NCD), the reporting phase of the RAPIA is incredibly powerful, as it can help clarify what needs to be addressed and motivate a range of actors (notably policy makers) to effect change.

Although these quotes highlight many positive aspects of the IIF's overall work in implementing the RAPIA other respondents raised important issues with regards to the actual methods and the need for "validation and follow up". Issues were again raised about the dissemination with one respondent stating "The key is how the results are disseminated and how the process is used to influence policy makers." This highlights the problem already mentioned above regarding the dissemination of the RAPIA results in-country, but another respondent highlighted this issue for dissemination of results at an international level saying that the "International Insulin Foundation has been preaching to the converts, i.e. the diabetes community." Another respondent stated that "The work of the IIF has an evidence-informed body of work that could be better leveraged to influence policy." Two respondents highlighted the challenge the IIF had focusing on Type 1 diabetes and insulin and that this was not the focus of the wider NCD community or necessarily the priority of policy makers in sub-Saharan Africa. Finally one criticism was raised that the IIF was "biased" in its assessments and the views it has.

Overall this small online questionnaire enabled some initial aspect of the impact of the RAPIA and the IIF's overall work to be investigated.

3.5. Interviews

Building on the information collected using the document review, involvement of the IIF in conferences and funding as well as the online questionnaire a more in-depth look at what some key stakeholders thought of the RAPIA and IIF's work was carried out. One of the main partners in each country where the RAPIA was carried out was contacted and ask if they were willing to participate in an interview. In Zambia two individuals were contacted, one a local partner and the other an international partner. After multiple attempts only the international partner in Zambia responded. In addition two WHO officers, one from Headquarters and the other from a country office were contacted and interviewed. One Global Diabetes Advocate active in the area of access to insulin was also interviewed. In total from 10 people contacted 9 individuals were interviewed using the discussion guide included in Appendix 6.

Individuals were informed about the project and told that their names would not be recorded. Interviews were carried out by DB and detailed notes were taken during each

interview. Interviews lasted on average of 46 minutes. Using answers from the online questionnaire the main areas the interviews focused on were:

- RAPIA Methods
- Research team and collaboration
- Results from the RAPIA implementations
- Dissemination of RAPIA results
- Recommendations from RAPIA reports
- Impact of the overall RAPIA process

The analysis of the interviews uses these headings.

3.5.1. RAPIA Methods

Colleagues in Kyrgyzstan, Mali and Mozambique stated that some aspects of the RAPIA were too long. In Nicaragua it was felt that additional information was needed on the social security system and the private sector. The WHO Country Officer interviewed stated that more was also needed on the supply chain. The Global Diabetes Advocate felt that the RAPIA provided "a formalised approach" to documenting the situation with regards to diabetes care and access to insulin. The Vietnamese partner added that the RAPIA provided a "scientific approach" and that the fact that the RAPIA used methods which were "pre-packaged" and that had already been used elsewhere were strengths. This aspect was also addressed by the Kyrgyz partner, as they stated, that "countries are not strong in the development of methods."

Another point highlighted by partners from Kyrgyzstan, Nicaragua and Zambia as well as a the WHO Country Officer was the RAPIA's comprehensive structure studying all levels of the health system. The Kyrgyz and Nicaraguan partners added that another of the RAPIA's strengths was its ability to adapt to the specific context and health system in different countries.

The WHO Country Officer in describing the methods and their use stated that the "methods are quite good as it not only provides availability and affordability information, but also health system barriers to diabetes care". This person went on to add that "prices and availability surveys do not include context – RAPIA does as it provides information about: the different levels of the health system; human resources; financial aspects and overall context. It gives an overview of diabetes treatment as a whole and not only medicines."

An interesting point raised by the Kyrgyz partner is that as the methods require site visits and interviews at different levels of the health system this created "noise about the study" and therefore got people interested in the study early on.

The experience and methods developed by the IIF "led the WHO to adapt this approach in a manual entitled "How to investigate access to care for chronic noncommunicable diseases in low- and middle-income countries" which is now being piloted in Peru." (WHO Officer from Headquarters)

3.5.2. Research team and collaboration

The partners in Kyrgyzstan, Mali, Mozambique and Vietnam highlighted that the close collaboration between the IIF and local partners was a strength of the research team. The WHO Country Officer stated that the IIF was able to build trust and a relationship with local partners and address sometimes difficult issues. The partner in Vietnam stated that "looking at access to medicines and insulin is complex" and that capacity to do this in LMICs is limited and that this is what the IIF brought. The contribution by the local partner was an understanding of the local situation and the right people to help. A detailed description of this collaboration was given by the Kyrgyz partner in that the local partner had:

- Good relations with the Ministry of Health
- Understanding of local context
- Knew the main stakeholders involved

That because of this the local partner was able to make suggestions on how to adapt the RAPIA to the local context with support from the IIF. This collaboration also helped with the data analysis and frame how to present the results and provide an external perspective on the challenge and solutions.

In Mali the partner also added that having an external person allowed for the RAPIA to be "critical", which may not have been possible for only an internal team. The Malian partner also added that throughout the process it was interesting to see "how local people learn about their health system."

In Zambia the partner felt that the research team and partner used there may not have been the best and that using a research institute may have been more advisable.

3.5.3. Results from the RAPIA implementations

All individuals interviewed highlighted that the RAPIA was the first study of its kind to be carried out in these different countries and all stakeholders involved valued it. The WHO Country Officer stated that the issue of affordability and access to medicines is a controversial issue, but an important one, and the scientific approach and involvement of local partners in the data collection helped with the ownership of the data and the use of this data locally. In Vietnam the partner stated that the results and report were read by many and this was useful to different people and not only policy makers as the wealth of results was useful for everyone.

Interviewees from Kyrgyzstan, Mozambique and Vietnam stated that the RAPIA results had an impact on policy. In Mozambique "data collected by the RAPIA showed that diabetes was a public health problem in Mozambique and was used in the best possible way as this was included in the Strategic Plan, NCD Health Policy, Government Plans and project proposals." The results from the RAPIA were included in a strategy on diabetes in Kyrgyzstan and were seen as "very important for policy development" in Vietnam.

In discussing the RAPIA results local partners highlighted that this research:

- Gave an overall analysis of the situation (Vietnam)
- Gave an overview of the situation with diabetes (Nicaragua, Vietnam and Zambia)
- Documented the situation (Kyrgyzstan and Mali)

- Brought a lot of attention to the problem (Kyrgyzstan)
- Provided a baseline (Kyrgyzstan, Mali, Nicaragua and Vietnam)
- Provided data from different sources (Global Diabetes Advocate)

The WHO Country Officer in describing why the RAPIA results had an impact on policy development stated that this was due to the specific data collected on the affordability of medicines, the high financial burden on individuals and especially that "prices for Essential Medicines were high and unaffordable." This aspect was also highlighted by the partner in Nicaragua in terms of medicines, but also globally for the issue of diabetes and provided "evidence of what was there and what was happening." The partner in Zambia also stated that it "showed people involved [in diabetes] the challenges." This person then went on to specify these issue specifically in terms of insulin access and healthcare worker training.

One piece of information highlighted by the partners in Mozambique and Vietnam as well as the Global Diabetes Advocate as having a large impact was the calculations the IIF made using the RAPIA on life expectancy for people with Type 1 diabetes. The Global Diabetes Advocate mentioned that this data was useful despite its serious assumptions. They also highlighted that the RAPIA was able to quantify issues that people knew about, but did not have data on for example travel costs. The Global Diabetes Advocate also added "information on particular countries reinforced what was already known, but not documented."

Another useful aspect of the results from the RAPIA that was discussed by the WHO Country Officer was that statistics on affordability exist, but that the RAPIA highlighted the issue and gave family stories and a personal perspective to the issue. They stated that these small factual stories made the difference and "for policy makers 5-10% are interested in the science, but practical examples have much more impact."

Partners in Mali, Mozambique, Nicaragua and Zambia highlighted how the results from the RAPIA were used in developing projects. For example, in Mozambique they were used for planning the national strategy not only for diabetes, but all NCDs, as well as medicine supplies. In Zambia this was a new area for the partner to develop and the report was used as a background document and the recommendations to guide their project.

In developing projects and being active in the area of diabetes partners in Mali, Nicaragua and Vietnam discussed how the results of the RAPIA were "credible" because of their quality and this "credibility" of the results led to the "credibility" of their organisation and/or projects. For Nicaragua the partner stated that "for the organisation the RAPIA created evidence and gave the organisation credibility to discuss diabetes." In Mali the partner stated that this credibility was also linked to being able to develop a targeted response to an identified problem on the ground with a clear understanding of the local context and problems.

It is interesting to note in terms of credibility the credibility of the data generated by the IIF through the RAPIAs, but also the credibility of the IIF as an organisation. From the perspective of the Global Diabetes Advocate some of the IIF's positions were detrimental to this with certain stakeholders, mainly on a global level. They stated that there was the need

to sometimes set aside “personal views versus larger picture” and the need to avoid being dogmatic. However, these same positions were what gave the partner in Vietnam the confidence and interest in working with the IIF as they viewed the IIF as an organisation with “integrity and objectivity”.

In terms of the quantity of data generated the partner in Mali stated that there was a need to address the issue of all the data collected versus the data presented in the report as it was felt that some data was lost. This balance was also felt to be needed in terms of addressing specific points or the overall picture.

3.5.4. Dissemination of RAPIA results

In looking at the dissemination the partners from Nicaragua and Mozambique felt that more “noise” could have been made and more people included in the formal dissemination of the report. This was echoed by the partner in Mali who said the dissemination went very well, but more could always be done. The partner in Vietnam added that it was also felt that more people should have been included in the dissemination as well as more time with beneficiaries, i.e. people with diabetes to explain the results to them.

The Kyrgyz partner was extremely positive about the dissemination in terms of the roundtable held and the discussion with policy makers. They mentioned that the initial reaction was not a positive one as local stakeholders felt that the results were negative, but after the dissemination and discussion they really appreciated the report and found the results very important. A suggestion based on this was maybe to take a softer approach in the way certain aspects were presented, but not hide the challenges. The WHO Country Representative also highlighted the importance of how the results are presented. Another positive comment from Kyrgyzstan was the holding of a closed door meeting with the Ministry of Health before the wider dissemination to address some issues and present initial findings. It was felt that this added importance to the results. Another factor that added importance to the results was the presence of international experts at the workshop where the RAPIA results were presented.

In the country where the WHO Country representative worked the dissemination continued beyond the formal presentation of the RAPIA results with the WHO and other local partners taking ownership of the results and using it in policy briefs, a presentation to the national assembly in 2010. This person highlighted that the formal dissemination helps in different stakeholders coming together, but that “one-off dissemination is not enough this needs to be sustained.” In Mozambique this was seen as possible the local partner was viewed as a “champion” for NCDs and was able to use the data to move their agenda forward. In Kyrgyzstan, Mali and Mozambique it was interesting to note the use of the term “we” referring to themselves and/or their organisation and the IIF when it came to describing the RAPIA process showing that they really had taken ownership of this. In terms of ownership it was also interesting to hear the example from Zambia where the partner felt that the diabetes association was not prepared to assume this ownership and take the lead in moving the process forward as in Kyrgyzstan, Mali and Mozambique for example.

From a global perspective the Global Diabetes Advocate and an Officer from WHO Headquarters highlighted that dissemination needed to be done locally and globally. The

Officer from WHO Headquarters stated that dissemination "needs to be planned in advance with a budget for printing and launch events". The Global Diabetes Advocate stated that from his perspective that dissemination was not a priority as the IIF was working with interested people and that in presenting results to these individuals "dissemination should not be viewed as preaching." From the perspective of the WHO Officer at Headquarters "together with HAI [Health Action International] the data from the IIF's work is widely quoted and used in looking at the issue of access to medicines for NCDs."

The interviewees mentioned the IIF's reports and publications in terms of dissemination of the results from the different RAPIAs. This dissemination also helped find new collaborations as the partner in Vietnam "found out about the IIF through the internet with the online material on insulin and RAPIA."

3.5.5. Recommendations from RAPIA reports

All partners stated that the recommendations proposed by the RAPIA reports were extremely useful to in-country partners. In Mozambique "the recommendations provided in the report of the assessment were simple and clear for the Ministry of Health and they felt that they could implement these recommendations." In Nicaragua "authorities responded positively to the recommendations." The partner in Vietnam stated that the recommendations were "clear, useful, helpful, offer new light" on a variety of inter-related issues regarding access to diabetes care. In Kyrgyzstan the recommendations served as a basis for a strategy and programme on diabetes. The WHO Officer at Headquarters asserted that " recommendations adapted to the local context were a strength of this process and allowed countries to make small, but significant changes as to how they approached the issue of diabetes".

From a global perspective the Global Diabetes Advocate stated that the recommendations were "straight forward and useful on a global level." They added though that the approach and views of the IIF sometimes hampered the implementation of these.

However, the impact of the recommendations in terms of implementation was seen as weak in Kyrgyzstan, Mozambique and Nicaragua as resources were not available for this and the governments had other priorities. The Global Diabetes Advocate affirmed that the recommendations were "not always achievable" because of "problems with financial resources to implement them." The partner in Mali addressed this issue in saying that this could be addressed by having more specific recommendations, also providing the Ministry of Health and other partners with the cost of the recommendations and framing the recommendations in terms of other national priorities and strategies. They added that having stratified recommendations like in Vietnam (Appendix 3) would have been useful for them to develop more targeted projects and also for other local stakeholders.

3.5.6. Impact of the overall RAPIA process

All the interviewees stated that it was hard to differentiate the impact of the RAPIA versus the impact of other work and changes in health systems. From the perspective of the Mozambican partner the "timing was right in Mozambique. There was advocacy in the WHO AFRO Region for countries around the issue of NCDs." From the global level, the Diabetes

Advocate stated, “It is hard to say which changes in diabetes were due to the RAPIA and which were due to changes in other diabetes initiatives.”

In looking at the impact of the RAPIA in Mozambique it was felt that “the biggest impact of the RAPIA was raising the profile of diabetes and showing that it was a public health problem and that these problems could be solved with a small amount of resources. For example informing people about a law that already exists[1].”

In Nicaragua it was said that although some of the problems identified by the RAPIA still exist there have been some improvements. In Kyrgyzstan, Mozambique and Zambia one impact mentioned was how the RAPIA helped the diabetes associations develop. Another impact in Zambia was that the issue of NCDs was being discussed by the Ministry of Health at the start of a project funded by international partners. How it helped get the issue on the agenda in Zambia is unclear, but the RAPIA showed that work had been done with regards to diabetes.

In Vietnam the partner said that some improvements in terms of insulin access had been seen, but that the issue remained complicated. The impact in Mali was helping shape the activities in terms of diabetes management of a local NGO which then helped address the recommendations at the Ministry of Health, Central Medical Stores and in facilities. One example the Malian partner mentioned was that from a policy perspective all aspects of care for Type 1 diabetes would be provided for free.

In Kyrgyzstan the developments were less tangible, with the Kyrgyz partner stating that the impact was the development of a diabetes programme meaning that this was an opportunity to get funds to address this in parallel to getting diabetes on the agenda linking it with CVD which was already a government priority. The RAPIA also helped document important health system functions and policy issues that were important for the government, e.g. laboratory capacity. This was also seen as relevant in the Vietnamese context with the RAPIA recommendations linking into issues of decentralisation, primary health care and universal health coverage.

The Mozambique partner stated that they felt “that the RAPIA enabled 50% of the activities with regards to NCDs to be developed in Mozambique.” In Mozambique the impact of the RAPIA was not diabetes specific, but for all NCDs as the results of the RAPIA work were integrated into the National NCD Plan. The data also helped the Ministry of Health for all NCD interventions and not only diabetes specific ones. In terms of the policy agenda the RAPIA was the first assessment to highlight diabetes and NCDs as a problem in Mozambique. The results not only highlighted the problems, but also gave the government solutions to address these. The value of this was recognised as a RAPIA reassessment was included in the National NCD Plan. The partner also added that they were unsure if this was an indirect impact of the RAPIA and all the work in NCDs, but there was now a large movement in the area of cancer in Mozambique.

[1] This is referring to a law on chronic diseases where individuals were entitled to subsidised medicines, but was found not to be implemented in the RAPIA assessment in 2003 because of lack of knowledge about this law

In Vietnam the RAPIA had a triple impact in that it helped improve certain aspects of diabetes care, impacted the management of CAH and also improved the work of an NGO. For CAH the Vietnamese partner was "in the dark about medicines for CAH and focused on donations. The RAPIA provided black and white situation and steps." These steps included getting the medicines for CAH on the Essential Medicines List, which the NGO was able to do. This then allowed the medicine to be registered in Vietnam and made available through the insurance scheme. Other impacts for CAH include:

- A Ministry of Health new born screening programme
- Increase in profile of CAH
- Increase in education
- Increase in family involvement

From the NGO's perspective the RAPIA helped them feel less "helpless and powerless", have "less of a sense of being in the dark" and feel empowered. In Kyrgyzstan, the Kyrgyz partner said that the RAPIA process also helped with capacity building f the local partner.

This impact on an organisation was also described by the partner in Mali with the RAPIA helping them gain credibility on the ground and help shape their activities. In looking at Mali as well the Global Diabetes Advocate described how the RAPIA enabled collaborations to be established between different partners and Mali and how this in turn enabled other partners in Burkina Faso to be included in these projects. The Global Diabetes Advocate also added that the Kyrgyz RAPIA was often quoted and that all the RAPIAs added to the knowledge of diabetes in LMICs. In Nicargaua this "adding to the knowledge" helped increase interest in NCDs as well as in Zambia.

Another impact of the RAPIA was the ownership of the data and outcomes of the RAPIA in all countries with local partners using data from the RAPIA in their own work or using the RAPIA recommendations to help develop their activities.

From a global perspective the Global Diabetes Advocate highlighted not only as mentioned before the impact that the RAPIA directly had, but also its impact on a global versus local level. They stated that when they started working in the area of diabetes with a focus on LMICs very few people were involved in the area and there was very little concrete information. Over the period of the IIF's work a critical mass came about and resulted in things happening on a global level. The IIF contributed to this with many others as well. "People started waking up" to the issue. The Global Diabetes Advocate stated it was unclear what made this happen, but that small advances have been seen in certain countries in terms of NCDs despite low capacity and competing priorities with Communicable diseases. "The impact of the RAPIA with regards to all of this was to show them [partners in the countries where the IIF worked] the way with recommendations and give them the response." On a global level the Global Diabetes Advocate also mentioned the inclusion of NCDs in children, including Type 1 diabetes in the GAP.

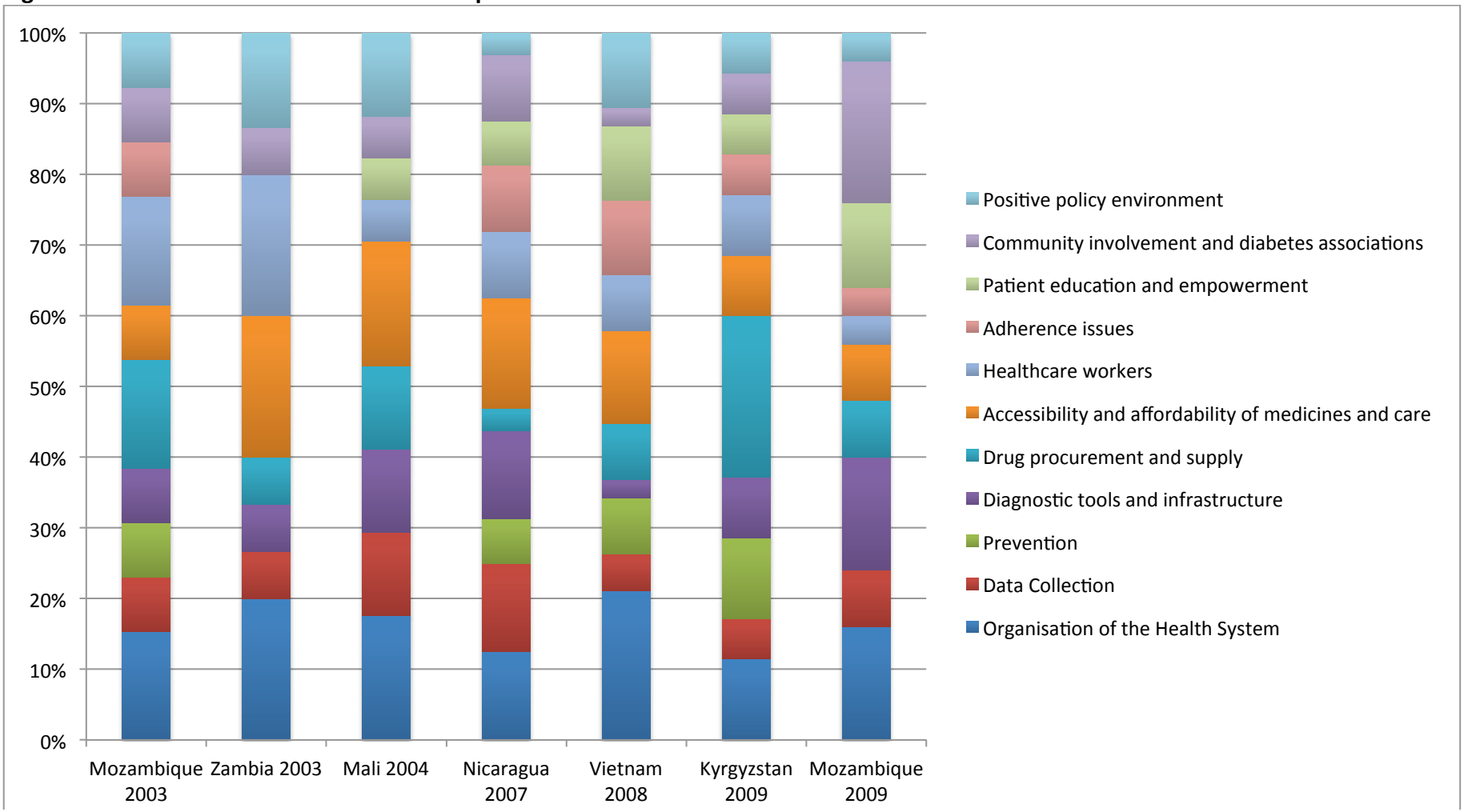
Getting the perspective from the Officer from the WHO Headquarters helps try to assess the impact of the RAPIA and IIF's work on these global policy changes. This person stated that "The material produced from the different implementations of the RAPIA have been

included in various WHO documents and helped develop Regional and Global Action plans on the issue of access to medicines for NCDs." This was possible according to this individual as the research and advocacy from the IIF informed WHO policy with regards to the issue of access to insulin and this material was also included in documents produced by the IDF and NCD Alliance in the run-up to the UN High Level Meeting in September 2011. This was also true from the perspective of the WHO Country Officer in the impact of the RAPIA and its results from a national and regional level with the government issuing a statement on access to medicines for NCDs and interest from the World Bank on this issue. The Officer from the WHO Headquarters added "as the IIF was able to substantively document the issue of the lack of access to medicines for NCDs it was able to influence WHO and other stakeholders on this issue, including discussions within WHO on the issue of access to insulin and NCD medicines; the UN High Level Meeting on NCDs; Global Action Plan on NCDs and the inclusion of the 80% target on availability." For the GAP the WHO Officer at Headquarters felt that the new manual developed based on the initial RAPIA by the WHO and IIF "will be an essential tool in the Monitoring and Evaluation of this target."

The Mozambican partner spoke of how the RAPIA had been used in Mozambique as a tool for monitoring and evaluation and how this had been useful to assess progress, but also identify continuing and new challenges. Partners in Mali and Vietnam also highlighted the use of the RAPIA as a tool for monitoring and evaluation.

In looking at the impact the partner in Mozambique stated that "policy implementation depends on politicians if they want to do something, something will happen" with the Nicaraguan partner adding that "NCDs are still not a real priority there are other factors in the environment that are on the agenda" and that budgetary issues need to be taken into account. For the Nicaraguan partner the impact was also not at the national level, but it influenced one of the areas where the RAPIA was carried out as health professionals saw the use of the results. A key element to improve impact from the Malian partner's perspective was to link the assessment with actual implementation of activities by the IIF. A summary of the main findings from the interviews is presented in Table 10.

Figure 9 – Recommendations from RAPIA reports



3.5.7. Limitations

This study has many limitations in that it was unable to assess the continued process, which are policy agenda setting, formulation and implementation. This research is really a snapshot and as mentioned by the interviews in the policy process it is often hard to disassociate what was impacted what and how this was done. For the document review any limits in the search strategy and also documents published, but unavailable freely on the internet may mean that key impacts of the RAPIA were missed.

Overall the low number of local respondents and low rate of response from local partners for the online questionnaire, the main people involved in the RAPIA process, limits the assessment of what truly happened on the ground. For example there were no respondents to online questionnaire from Nicaragua. The selection of interviewees for the in-depth interviewees was done using a convenience sample and as the respondents knew the main researcher this may have led to some bias.

As stated by Woelk et al.[39] in looking at translating research into policy this type of research is influenced by the respondents, their role at the time of the study and their relationship to the researcher. As many of the partners were self-selecting at the time of the study due to their interest in the topic, this already establishes a pre-exisitng bias. In addition as some of the collaborations were 10 years ago the issue of recall bias may also play a role as well as some countries there have been ongoing collaborations versus in others the RAPIA was the only joint project.

Chapter 4 – Discussion

The aim of this research was to assess the impact that a health systems assessment tool, the RAPIA, and therefore the impact of health systems research on policy. As described in the literature the policy process is not a linear one.[9] In addition the policy process and health systems are in a constant state of flux with many factors enabling or hampering change.[37, 43] It is therefore hard with research that took a snapshot of the situation to assess the impact and on-going impact of research on policy. This was even stated during the interviews by the Global Diabetes Advocate in that, “it is hard to say which changes in diabetes were due to the RAPIA and which were due to changes in other diabetes initiatives.”

That said the experience of the IIF using the RAPIA offers a unique perspective where a similar research approach has been take in 6 countries allowing for some insight to be gained into how health systems research can impact policy as this is very context specific.[39] Methods for policy analysis and impact are not standardised[44] and the approach taken here was to combine different methods used by others.[7, 8, 38, 39] Despite the limitations this project highlights a few interesting lessons in terms of getting research into policy.

Essential to any research are the **methods used**. In the online questionnaire these were viewed very highly. Although some changes were suggested overall the RAPIA provided “a formalised approach” to documenting the situation with regards to diabetes care and access to insulin and was viewed the first of its kind in terms of issue studied and also number of countries where this research had taken place. The strength of the methods were described as the RAPIA’s comprehensive structure in analysing all levels of the health system and

adding context to the issue of availability and affordability to medicines. Because of this the data collection phase also helped "create noise" about the actual project.

This **close collaboration** between local partners and the IIF was also highlighted as a strength of the overall process. Woelk et al.[39] mention the issues of trust, managing the political environment and using champions at different levels to influence change. Through its approach with the research team including international and local experts the IIF was able to do this. Results from the online questionnaire show that in-country partners scored the quality and credibility of the research team as good and very good (Table 8). In comparison those not directly involved viewed the research team slightly lower this may be because many of these respondents were from academic institutions.

The view of the **results** was similar, with the quality scored highly by in-country partners, but not by those not involved again this may have been because of their academic perspective on research. Specific results from the RAPIAs were viewed as important such as the calculations of life expectancies and also highlighting the issue from a story and personal perspective to the issue of access to diabetes care and insulin. Overall as described in this project by the interviewees and by Panisset et al.[45] in the literature the RAPIA helped to map the context, identify barriers and their determinants and propose practical solutions and recommendations.

In looking at the literature, **dissemination** can be improved by involving local partners and policy makers in the development of the research and if researchers take an active role in translating research into policy and that this is further enhanced if the topic is current, comes at the right time and is well funded.[46] The online questionnaire raised the issue of dissemination from both those directly involved in the RAPIA implementation as well as those not directly involved. Looking at the issues mentioned by Davis and Howden-Chapman[46], one could argue that the failings of the IIF in terms of dissemination were:

- Local partners could have been more involved
- Because of lack of funding the IIF could not always take an active role in the implementation side of things
- That the IIF's work in some contexts was before the issue of NCDs got on the agenda and that more funding for this issue was made available

The interviewees seemed to indicate that dissemination went as well as it could have. They highlighted though that dissemination happens at different levels, local, national and international, but also as Woelk et al.[39] describe within "policy communities" where the issue is already on the agenda or in other cases in environments where the issue is not on the agenda as was highlighted in the interview with the Mozambican partner. Because of the lack of funds the IIF should have focused on developing local ownership of the data as was described by the WHO Country Officer, identifying local champions as in Mozambique or organisations capable of continuing the IIF's work like in Kyrgyzstan or if necessary investing in capacity development to enable this to happen as was needed in Zambia.

Dissemination activities for the IIF besides presenting the results also included communicating and discussing **recommendations**. The recommendations prepared by the

IIF were scored highly by local partners and viewed as extremely useful by the people interviewed. The implementation of these recommendations would have been a good way to assess the impact of the RAPIA on policy. This was done in Mozambique with a reassessment of the RAPIA showing some progress in terms of initial recommendations.[26] Recommendations can have a variety of impacts some simply changing attitudes, garnering additional funding or even in some cases changing the situation dramatically.[46] In looking at change there is also the level or size of this recommendation in if its impact is "micro" or "macro".[47] In looking at different models of policy change one can argue that the RAPIA took an incrementailst[47] approach in proposing small changes linked to the recommendations rather than a complete overhaul of the system.

However, the impact of the recommendations in terms of implementation was seen as weak with some recommendations "not always achievable" because of "problems with financial resources to implement them." Walt[47] in looking at changing policy highlights that there needs to be legitimacy to do something, that this something needs to be feasible and that there needs to be support from the government to do this. The main barrier here was financial resources to enable this to happen as they were not available to the IIF or in-country, although some countries were able to implement some of the recommendations. It was suggested by one interviewee that this could have been addressed by costing the recommendations and framing the recommendations in terms of other national priorities and strategies and having stratified recommendations like in Vietnam (Appendix 3).

Although interviewees described the challenge in terms of framing recommendations and having resources for implementation the results from the online questionnaire show that one impact of the IIF's work was policy implementation in terms of insulin access. This may be due to the approach taken where the RAPIA is really viewed as a tool to get research into action. Also as it provides an overall situation analysis it is viewed as a tool that facilitates implementation as it gives a comprehensive overview of the situation. In addition the impact was also seen to be due to good timing and the involvement of the right people

In comparing Figure 4 (those with direct knowledge of the IIF) with Table 8 (those with indirect knowledge of the IIF) both groups agreed that the IIF had an **impact** on "Diabetes related policies". Those with direct knowledge of the IIF's work also felt that this work had an impact on "Policies related to insulin". In comparison those with indirect knowledge felt that the IIF had impacted "Diabetes management" as well as "Access to insulin".

More detailed impact given by the interviewees included:

- Showing diabetes was a public health problem
- Development of diabetes associations and NGO partners
- Improvements in terms of access to insulin
- Impacts on policy relevant to diabetes
- Development of projects, programmes and strategies following the RAPIA
- Ownership of IIF materials and data by local partners
- Impact on documents and strategies at a global level linked to the UN HLM

Stone et al.[48] state that the most common factors mentioned that enable research to be used in policy making are:

- Personal contact between researchers and policy makers
- Timeliness and relevance of the research
- Research that included a summary with clear recommendations
- Good quality research

One aspect highlighted in the online questionnaire and interviews was the **credibility of the research**. This element is viewed as important by Stone et al.[44] and they link this to "peer review" and that the individuals are linked to recognised institution and are viewed as experts. In terms of outputs the IIF was able to produce a wide range of materials including, presentations, peer reviewed publications and reports targeted at different audiences. As seen in the document review these were widely used and referred to in other documents and by other organisations, which allowed the IIF's research to be known beyond the countries where the RAPIA was implemented. It is important to note that the IIF although based at an academic institution and with a Board of Trustees made up of academics, was an NGO with a clear agenda to change the problem of access to insulin and diabetes care in resource poor settings. Some of the communities where the IIF presented its material shared the same beliefs, but the issue of what counts as evidence and how that evidence is shaped varies from individual to individual or within different organisations.[32] For example the use and perception of the IIF's research and position may have been very different between the IDF and WHO as well as in academic circles versus in-country policy makers. If these people shared the interest, ideology and values of the IIF they were probably more likely to take on the data and recommendations than if they did not. It is interesting to note in terms of credibility the credibility of the data generated by the IIF through the RAPIAs, but also the credibility of the IIF as an organisation. From the perspective of the Global Diabetes Advocate some of the IIF's positions were detrimental to this legitimacy with certain stakeholders, mainly on a global level. They stated that there was the need to sometimes set aside "personal views versus larger picture" and the need to avoid being dogmatic. However, these same positions were what gave the partner in Vietnam the confidence and interest in working with the IIF as they viewed the IIF as an organisation with "integrity and objectivity".

The IIF was also viewed as a **credible partner** and in developing projects and being active in the area of diabetes partners in Mali, Nicaragua and Vietnam discussed how the results of the RAPIA were also "credible" because of their quality and this "credibility" of the results led to the "credibility" of their organisation and/or projects. Davis and Howden-Chapman[46] discuss the issue of transmitting the results of research versus these results being received and then actively used. This highlight the issue of ownership of data and how in Vietnam the WHO and other local partners took ownership of the results using it in policy briefs and a presentation to the national assembly in 2010. In Mozambique a local partner was viewed as a "champion" for NCDs also took on this data as their own and used it for their purposes. In Kyrgyzstan, Mali and Mozambique it was interesting to note the use of the term "we" referring to themselves and/or their organisation and the IIF when it came to describing the RAPIA process showing that they really had taken ownership of this. In terms of ownership it was also interesting to hear the example from Zambia where the partner felt that the diabetes association was not prepared to assume this ownership and take the lead in moving the process forward as in Kyrgyzstan, Mali and Mozambique for example.

Box 1 – Key lessons

- Quality and comprehensive nature of the methods
- Close collaboration between local partners and IIF
- RAPIA helped to map the context, identify barriers and their determinants and propose practical solutions and recommendations
- Dissemination could be improved and is not a one-off presentation and workshop
- The recommendations were viewed as extremely useful
    - However, the impact of the recommendations in terms of implementation was seen as weak with some recommendations not always achievable
- Impact of RAPIA in each country linked to:
    - Personal contact between researchers and policy makers
    - Timeliness and relevance of the research
    - Research that included a summary with clear recommendations
    - Good quality research
- Credibility of the research
    - Methods and approach
    - Peer reviewed publications
    - Presentations
    - Reports
    - Reference of the research by others
- Credible partner
    - Credibility of research
    - Partners in each country

4.1. Conclusion

This research despite its limitations shows that the RAPIA helped to change policy in the countries where it was implemented, but also globally. That said and as highlighted by past studies looking at policy research methods and a quote from the Global Diabetes Advocate, "it is hard to say which changes in diabetes were due to the RAPIA and which were due to changes in other diabetes initiatives." The policy process and the use of research to inform it are constantly changing and therefore current methods that only enable a snapshot to be taken miss vital information. Methods to help gain a clearer overview need to include multiple data sources and approaches. This project attempted to do this using documentary reviews, an online questionnaire and in-depth interviews. It allowed for certain key lessons to be highlighted and show that the RAPIA had varying impacts in the countries where it was implemented and globally thanks to strong recognised methods, implemented in collaboration between the IIF and strong local colleagues, generating useful and credible results, that despite problems with dissemination allowed for targeted recommendations to be developed.

Based on the results presented the RAPIA process may help in achieving the goals set out in the GAP in both helping countries plan and implement some of the targets included especially the target on "80% availability of the affordable basic technologies and essential medicines, including generics, required to treat major NCDs in both public and private facilities."[6] The RAPIA would enable countries to identify the barriers, develop targeted responses and also monitor progress.

Appendices

Appendix 1 – The RAPIA: aim; approach; process and methods; results; and recommendations

The aim of 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 LMICs. It is structured as a multi-level assessment of the different elements that influence the access patients have to diabetes care in a given country through multiple data sources. The data collection process is expected to provide a situation analysis regarding the supply of medicines and diabetes care, which highlights the strengths and weaknesses of the health system and proposes concrete actions.[13, 49, 50]

Rapid Assessment Protocols (RAP) have been used extensively to assess services for communicable diseases, including malaria, tuberculosis and Sexually Transmitted Diseases, for the purpose of developing interventions.[51-57] The approach chosen here was to adapt existing protocols to suit the assessment of access to insulin. The main principles of the RAPs are:

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

Three components compose the RAPIA: macro-level, meso-level, and micro-level. The RAPIA built on the Innovative Care for Chronic Conditions Framework (ICCCF) by studying three levels of the health system, as detailed in the table below. This ensures that an issue is observed from different viewpoints. Fifteen kinds of semi-structured, open-ended questionnaires are used to target interviewees at these three levels as shown below.[13, 49, 50]

Figure 6 – Questionnaires that make up the RAPIA

Macro level	Ministry of Finance Ministry of Trade Ministry of Health Private sector Diabetes organizations Central medical stores Educators
Meso level	Regional health office Regional central medical stores Hospitals, clinics, health centres, etc. Laboratories Pharmacies
Micro level	Health workers Traditional healers Patients

For meso- and micro-level data collection, three sites are purposively selected: the capital city, one urban area and one rural area. Selection of facilities at meso-level (e.g. hospitals, laboratories, pharmacies) does not rely on random sampling but uses a convenience sample. Sampling facilities purposively includes both public and private sectors. Micro-level sampling is also purposive, and usually uses "snowball" sampling. The sample size is not fixed and recruiting respondents stops at "theoretical saturation". Data collected from different viewpoints are synthesised and analysed.

From these studies, eleven key elements for tackling problems linked to diabetes care have been identified and are used in reporting the findings.[28, 58] These elements are:

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

The table below details the primary partner with which the IIF collaborated with and any secondary partners that were involved with the research and its implementation.

Table 11 – Partners involved in the implementation of RAPIA

Country (Year)	Primary Partner	Other Partners
Mozambique (2003)	National Diabetes Association	Ministry of Health
Zambia (2004)	National Diabetes Association	Ministry of Health
Mali (2004)	International NGO	Ministry of Health/National Diabetes Association
Nicaragua (2007)	International NGO	Ministry of Health/Diabetes Association
Vietnam (2008)	Leading Clinicians (North)/Academia (South)	International NGO
Kyrgyzstan (2009)	Health Policy Analysis Centre (local NGO)	Ministry of Health/Clinicians/Diabetes Associations
Mozambique (2009)	Ministry of Health	National Diabetes Association

The process of implementing the RAPIA once key local stakeholders had been identified was:

1) Visit to country to establish contacts and introduce project
    a) Literature review
    b) Meetings with key informants and organizing survey teams
    c) Preliminary data collection at the national level, if possible
2) Preparation of logistics with Primary Partners and keeping Other Partners informed of process and seeking their input
    a) Development of sampling scheme including 3 areas of sampling in collaboration with local partners
3) Adapting standardised RAPIA tool to country
    a) Adaptation and development of necessary data collection tools
4) Preparation for field work
    a) Ethical and scientific reviews
    b) Fieldworker training
    c) Administrative arrangement to visit sites
5) Data collection and entry
    a) Interviews
    b) Secondary data
    c) Debriefings with local team
6) Data analysis
    a) Led by IIF, but input by local partners
7) Reporting and Dissemination
    a) Generation of reports
    b) In-country presentations
8) Follow on activities
    a) Funding proposals
    b) Training activities
    c) Development of diabetes or national NCD strategies

Using the 11 points identified through the implementation of the RAPIA in the 6 countries where the IIF worked, the section below details some of the key findings from the different implementations of the RAPIA.

Data collection

Information regarding the incidence and prevalence of diabetes in each country was often unavailable or difficult to obtain. Some national studies of prevalence had been carried out (Vietnam). These provided some data as to the overall burden of diabetes. In Kyrgyzstan the National Health Information System did collect information of diabetes, but many viewed this as unreliable. For Mali, Mozambique, Nicaragua and Zambia the RAPIA process enabled prevalence estimates to be made using data collected in registers in different hospitals and also with discussions with clinicians.

Prevention

The extent to which diabetes prevention was tackled varied greatly between countries. Very few, if any, countries had a primary prevention programme for diabetes. In Kyrgyzstan although the use of mass media to promote disease prevention is included within the National Health Programme no primary prevention programmes for diabetes were visible apart from some awareness activities organised around World Diabetes Day. This was the main activity that countries in sub-Saharan Africa held in terms of prevention.

The Ministry of Health in Nicaragua is mandated by health legislation to collaborate with the Ministry of Education on health education. It is required to promote a range of activities, lifestyles and research into NCDs to translate into policy or practice. Special attention is said to be given to NCDs through improving surveillance systems, inter-sectorial policy on food security and diet, and strengthening health promotion and rehabilitation services. A nutrition policy which was going to include aspects relevant to diabetes was in the process of being developed at the time of the RAPIA. Finally, the cadre of '*brigadistas*' were mentioned, who often play an active role in community prevention, but their role was seen as limited with respect to diabetes.

Vietnam was said to place a strong emphasis on prevention. However, preventative care services are not covered under the system of health insurance benefit packages, instead being paid for either by government budgets or out-of-pocket expenditure. Prevention of NCDs was identified as a troubling area for the country, as opposed to communicable diseases where the Vietnamese health system had shown experience and success. As with other countries, there was no primary prevention programme for diabetes underway in Vietnam.

Diagnostic tools and infrastructure

Laboratory tests and diagnostic tools are a vital prerequisite in the management of diabetes. Unfortunately, infrastructure to support this was often lacking, particularly outside major urban centres. Moreover, in cases where patients are required to pay, the costs of blood, urine and other tests present a challenge.

Table 12 – Availability of certain laboratory tests for diabetes

Country	Presence of urine glucose strips	Presence of ketone strips	Presence of a glucometer
Mozambique (2003)	18%	8%	21%
Zambia (2003)	61%	49%	54%
Mali (2004)	54%	13%	43%
Nicaragua (2006)	59%	54%	95%
Vietnam (2008)	80%	59%	96%
Kyrgyzstan (2009)	71%	38%	67%
Mozambique (2009)	73%	73%	87%

Drug procurement and supply

Following the RAPIA it was found that most of the countries used past consumption rates of insulin to guide the quantity of insulin required for the country. Individual health facilities or local units of the health system submit their needs based on these rates to higher levels before the rates are finally collated nationally and used to inform necessary orders.

Another issue highlighted was of the discrepancy between quantities of insulin ordered in each region. In each of the African countries surveyed, and Nicaragua it was evident that certain regions, often capital cities, were allocated a higher proportion of insulin when compared with their population. 77% of the country's insulin in Mozambique and 52% in Mali were supplied to health centres or institutions in the capital city. Interestingly in Nicaragua there was no discernible link between the quantity of insulin ordered and the number of reported people with diabetes. This apparent lack of a connection may be attributed to patients from other regions visiting the capital to acquire insulin, arranging for family members to purchase their insulin, or alternatively because of the failure to quantify the number of patients with diabetes in each region and adjust necessary insulin orders accordingly.

In Kyrgyzstan the main problem with insulin was not the overall supply, but the distribution throughout the country. It was often said that facilities got not what they ordered, but what was available. In some regions this meant that for example penfill insulin was used with a regular syringe and that often people with diabetes had to switch insulin regimens. Another factor was the large quantities of insulin stored at some facilities due to the irregular supply. However a significant problem was identified due possible over supply of insulin in contrast to a shortage of oral medicines, especially Metformin.

Mozambique and Zambia did not apply any taxes or customs duties on insulin. In Mali insulin and all other medicines were subject to a series of levies which amounted to a 2.5% duty, while in Vietnam insulin and oral medicines for diabetes were subject to 5% import duty and 5% VAT. Nicaragua applies a 6% customs duty on imported medical materials and medicines destined for the private sector. In Kyrgyzstan medicines are exempt of any VAT and import duties and no issues were reported with customs procedures for medicines which were registered in the country.

Most of the countries featured insulin on their Essential Drug Lists. Mozambique, Mali, Nicaragua and Zambia's lists all listed fast and slow acting insulin; Mozambique also listed

intermediate and mixed insulin. Vietnam's List contained rapid, intermediate and mixed insulin. In Kyrgyzstan a difference was identified between recommendations from the WHO Essential Medicines List and the National list.

In Mali, Mozambique and Zambia insulin is supposed to be available at hospitals and referral health centres. Findings from the RAPIA demonstrated it to be only available in a proportion of referral health centres in Zambia. Only the large referral level hospitals in the capital city of Mali had insulin during the RAPIA. Insulin was indicated for use in hospitals and health centres in Nicaragua, however difficulties were cited including some urban hospitals only supplying insulin to inpatients; disparities between regions in terms of insulin available or prescribed. No problems were reported in the supply of medicines in Vietnam. The RAPIA found 91% of facilities visited to have insulin stocked. The availability of insulin varied between districts in Kyrgyzstan. In Bishkek Family Medical Centres (FMCs) do not have insulin, this can only be found at the City Endocrinology Dispensary. In the Oblasts (regions) visited insulin was available at all FMCs. In Issyk-Kul and Osh Oblasts, insulin was not available at Rayon (district) and Oblast Hospitals. This was obtained on a case-by-case basis from the Oblast FMC or people brought their own insulin. Only one Rayon visited at the time of this study did not have insulin (92% availability of insulin).

Accessibility and affordability of medicines and care

At the time of each report, Mozambique and Zambia both benefited from unique pricing discounts from the LEAD initiative (Leadership for Education and Access to Diabetes care) established by the Danish company Novo Nordisk, a pharmaceutical company specialising in diabetes. Under this initiative public health systems in the 50 Least Developed Countries are offered insulin at prices not exceeding 20% of the average prices in North America, Europe and Japan.

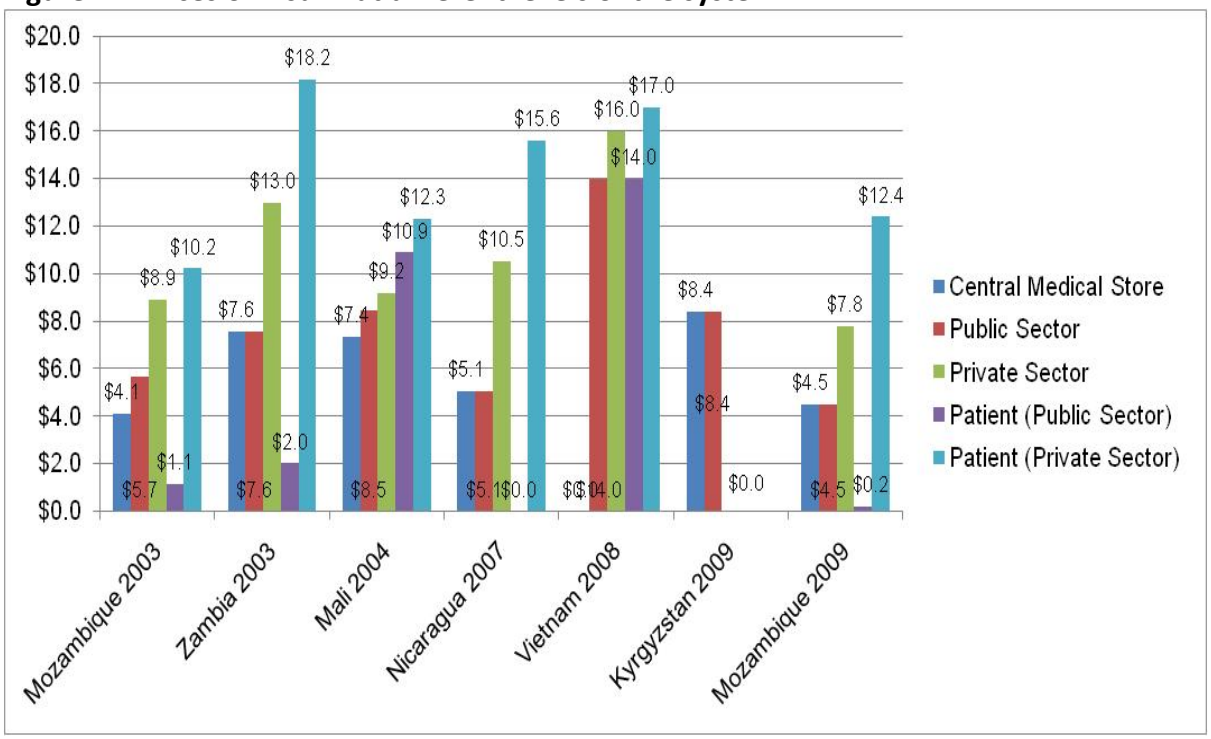
The consequence of this for example in Mozambique was a drop in price from US$9.00 per vial of insulin in 2001 to around half that price in 2002. While Mali should also have been entitled to benefit from the programme, at the time of the RAPIA it was paying prices of US$7.36 from a wholesaler in France. Findings from the RAPIA in Zambia showed cost improvements could have been made with improved quantification and tendering, since a miscalculation in quantities necessary meant an inappropriate number of vials were purchased locally, as opposed to through the LEAD initiative. An estimated US$38,000 or around 15% of total insulin costs would have been saved had the additional vials been purchased through the tender process. Findings from Nicaragua revealed insulin to cost between US$5.92 in 2005 and US$5.37 for a vial of rapid insulin, or US$5.06 for NPH insulin.

The Ministry of Health in Vietnam uses reference prices from Thailand, Malaysia, Cambodia and Laos to prepare a guide list for most medicines. The average price per 10ml of 100 IU insulin was US$12 ($6-17), which is higher than the price quoted on the International Drug Price Indicator. This disparity in price with international indicators was shared with most other diabetes medicines.

As mentioned earlier, a difference between the WHO Essential medicine list was identified in Kyrgyzstan. It is estimated that following WHO guidance would have lowered costs of insulin purchases by US$ 740,000 or around 40% of total insulin costs.

In all countries different prices of insulin were present at different levels of the health system. In some settings such as Mali cost-recovery at each level meant a constant increase in the price of insulin, whereas in Nicaragua insulin was provided for free to people needing it. This data is presented in Figure 7.

Figure 7 – Prices of insulin at different levels of the system



Given the necessity of a means by which to deliver insulin to patients, accessible and affordable syringes are essential for effective diabetes care. In each of the African countries and in Vietnam 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. Some patients opted to re-use their syringes in part due to this cost.

Cost was identified as a barrier to effective care in many of the countries assessed. In the African countries there were a particularly low number of diabetes specialists, with only 2 specialists and 5-10 healthcare workers with special training per area. Poor coordination between medical staff was reported in many of the countries, for example between inpatient and outpatient records or different hospitals and doctors. Lower levels of the health system often either failed or rarely managed diabetes leading to frequent referral to and inundation of the national Hospitals. Conversely, diabetes care in public facilities and facilities covered by the INSS in Nicaragua was free, including consultations and laboratory investigations.

Overall costs for diabetes care and their breakdown are presented in Table 13.

Table 13 – Cost of different aspects of diabetes care[25]

Country	Percentage of total cost					Total cost per year (US$)	%age of per capita income
	Insulin	Syringe	Testing	Consultation	Travel		
Mali	38%	34%	8%	7%	12%	339.4	61%
Mozambique	5%	24%	1%	9%	61%	273.6	75%
Nicaragua	0%	73%	0%	0%	27%	74.4	7%
Zambia	12%	63%	6%	6%	12%	199.1	21%
Vietnam	39%	8%	5%	3%	46%	427.0	51%

Healthcare workers

Doctors in the African countries often expressed anxiety around the treatment of diabetes. This was partly attributed to the poor training given to health workers in preparation for their care of patients with diabetes. In Zambia for instance, a mere 9% of healthcare workers interviewed had received any form of special training in diabetes and only 33% felt sufficiently trained to treat a patient with diabetes.

The mainstay of training regarding diabetes took place during physicians' university tenure. Healthcare workers in Zambia and had the opportunity to receive continuing training from the National Diabetes Association in addition to the training they received during university.

Lack of knowledge amongst healthcare staff was identified in many of the countries surveyed, leading to long lag time periods before a diagnosis of diabetes is established. In both Mali and Mozambique clinics by the Diabetes Associations could be only found in the capitals. Mali's Diabetes Association (Association Malienne de Lutte Contre le Diabète, AMLD) runs a full clinic employing their own staff which can prescribe medicines for the patients. 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 disease. In the Philippines Endocrinologists or diabetologists usually run their own private clinics raising questions regarding the broader availability of specialist care.

Similarly, endocrinology departments in Vietnam were based in the main cities. Diabetes made up a substantial 40% or more of adult endocrinology department patient cases. In Kyrgyzstan many regions and districts have an Endocrinologist, not necessarily a specialist in Diabetes care, but they serve as a focal point for diabetes and other endocrine disorders. It is noted that the Family General Practitioners were not able to treat diabetes, especially using insulin and nurses in Kyrgyzstan play no role in diabetes management.

Nicaragua's Ministry of Health reportedly organised annual training sessions for 2-3 people from lower levels of the health system to attend, however the programme had not been functioning in recent years. Instead, an 18-month postgraduate diploma course in diabetes was available from the university costing US$1,200, approximately 4 month's salary for a doctor. Nurses and other staff were entitled to a free 40-hour course on diabetes organised and funded by the Pan American Health Organisation, with approximately 30 attending the class each year.

In Kyrgyzstan different training programmes have been initiated, but almost all of them were not considered to provide healthcare workers with the practical tools they needed to manage diabetes. Some training for nurses has been organized but was not viewed as a success as once they returned to their facilities, they were not given the support needed to contribute in the patients' care.

Traditional healers in Mozambique, Mali and Zambia were found to be an integral part of the country's health system, to the extent that national associations were in existence, and health ministries featured divisions entrusted to work with them. Most healthcare workers in the allopathic systems in these countries stated that traditional healers never referred patients to them, whereas between 16-28% of traditional healers interviewed insisted they always referred to these physicians.

Traditional healers in several of the countries had some knowledge of diabetes and of the basic symptoms. In Vietnam the disease was referred amongst traditional healers as "Chung Tieu Khat" which literally translates to mean the syndrome when patients lose weight and feel thirsty. Interestingly, the healers stated in each of the African countries that they would welcome closer links with allopathic services and to learn more regarding diabetes.

Adherence issues

Adherence to treatment was identified as an issue in Vietnam and Nicaragua. In Vietnam the determining factor behind poor adherence was the prohibitive cost of treatment resulting in missed injections and incorrect dosages. In Kyrgyzstan the problem was mainly for people with Type 2 diabetes needing to purchase Metformin in the private sector, with treatment representing up to 7.4% of per capita GDP.

Very few patients in Nicaragua monitored their urine and blood glucose as recommended, again allegedly due to the great costs involved in paying for equipment or laboratory investigations. Some health workers cited a lack of family support to patients as another factor underlying the limited adherence to self-monitoring. Issue of discipline in the treatment were identified also in Kyrgyzstan which was intimately linked to poor knowledge and patient education. Adherence to diet instructions is poor as the traditional Kyrgyz diet is high fat and high carbohydrate.

Patient education and empowerment

Patient education was variable in each country assessed by the RAPIA. In Vietnam, a community education programme was established, comprising educational sessions on presentation of diabetes, complications, usage of medicines and diet. The success of this programme in the country was heavily dependent on the facility, a reflection of the importance placed on education by the staff. Written materials were available in the form of pamphlets or books, with the content being deemed by those interviewed as comprehensible and culturally relevant. The National Hospital of Paediatrics was able to provide an array of visual aids including dolls for the demonstration of injection sites and DVDs for patient information. In Kyrgyzstan Diabetes schools and education centres have been established in some facilities but in the majority of cases the doctor was responsible for delivering education. It was said that they were often too busy to do this and the available educational materials were not fully adapted to the Kyrgyz socio-economic

situation. Overall patient education for Type 1 diabetes was thought to be very well delivered, however education for Type 2 diabetes patients was extremely poor and not adapted to local socio-cultural factors, especially with regards to diet. Most of this education is delivered during the consultation and therefore there is little time to do this effectively.

Patient education in Mali was rather more limited, with weekly education sessions being arranged by an endocrinologist in the capital city Bamako once weekly for newly diagnosed patients and their families. Similarly, the situation in Zambia gave the impression of few educational materials or opportunities for patients, with the result that the general population and importantly, the government itself knew very little about diabetes.

The majority of clinics in Mozambique did not provide information or visual aids; the only materials evident in the study were at AMODIA. Finally, Nicaragua offered a variety of information sources regarding diabetes, ranging from pharmaceutical company pamphlets to foot care, exercise and diet leaflets prepared by the Ministry of Health. In addition, education and discussion sessions arranged by the Chronic Clubs at various health facilities provided 32% of patients interviewed the information they had been given about their condition. 12% of patients felt they had been given no information about their condition, a figure broadly similar in both urban and rural areas. Finally, 18% of people using insulin had received no indications regarding its use, whilst most of the education ostensibly focused on diet and lifestyle.

Community involvement and diabetes associations

Diabetes associations were present in each of the countries surveyed. Most had some links with the IDF, though the exact remit of their work varied between countries. Zambia's Diabetes Association is consisted of patients and healthcare workers. It provides a voice for people with diabetes by organising healthcare worker training, youth camps and national awareness days. Its funding currently comes from government or business donations, in addition to general fundraising.

Community involvement in Vietnam was undertaken through a series of different organisations each engaged at differing levels of the country's health system. The Vietnam Diabetes Association, related to the IDF and present in North and South Vietnam, provided a forum in which doctors could meet to discuss issues surrounding diabetes. Its workload again consisted of healthcare worker training in addition to patient education and diabetes research. Furthermore, the Diabetes Educators Association was described to be an open network to anybody with an interest in diabetes. This association provided support and education to patients; though it was commented that the efficacy of the network impinged upon the contribution of healthcare workers at the facility level since there was no official national patient organisation in the country. Finally, the Diabetes Network Vietnam was an online hub in which people with diabetes could receive information and news related to the condition.

In Mozambique in 2003, AMODIA was primarily based in Maputo with 323 members. Since then three branches of AMODIA now exist and the association now has a memorandum of understanding with MISAU. AMODIA Maputo held its first general assembly in early 2009

and continues to improve its management of diabetes both from a clinical and community aspect. There are about 2,600 members (2,000 at the end of 2008) and there are regularly 20-40 participants in the weekly education sessions run by a Psychologist and trained members of the association. The association has also held information sessions within the community (churches and women's groups) using their training. Members also visit inpatients with diabetes to provide education and moral support. AMODIA also has the advantage that education and support is given by people with diabetes and in local languages when needed.

Through WDD and other community outreach programmes many people will come directly to AMODIA for a random blood glucose test and be diagnosed at AMODIA. People come to AMODIA from all of Maputo and even Mozambique, but do not want to go back to their health facility due to quality of care and support. AMODIA Beira currently has 456 members (as of March 2009) and the AMODIA branch in Quelimane had 204 members.

The AMLD had 1,000 members in the capital city of Bamako, with two main areas of activity, namely World Diabetes Day arrangements and a diabetes clinic where members benefit from a reduced-price consultation. AMLD is a member of the IDF and receives funds mainly from consultation fees and the Lion's Club. Its aims were stated to be data collection, education and training, care and peer support. The AMLD also had helped to establish branches in Sikasso and Timbuktu.

Nicaragua featured a strong civil society engagement. The Ministry of Health having prepared a guide for community associations for NCD diseases with their proposed role the promotion of patient self-management of risk factors reducing the complications of the disease. These "NCD clubs" were supported by doctors at local facilities and funded by small monetary contributions from those patients who could afford to do so. Organisation of World Diabetes Day, World Children's Day and monthly discussion meetings were amongst the chief activities of the clubs, as well as general fundraising to support the needs of patients with financial difficulties for medicines or materials.

Finally in Kyrgyzstan Diabetes Association (IDF member association) was established in 1998, has about 500 members and is mainly based in Bishkek but is also developing activities in other regions of Kyrgyzstan. Its mission is to protect the rights of people with diabetes with a focus on ensuring the implementation and proper application of the government's law on diabetes. Activities include training of doctors and patients. Kyrgyzstan Diabetes Foundation was created by parents with children with Type 1 diabetes. Activities are focused on patient education. Besides establishing the school of diabetes at the National Children's Hospital it has also set-up a telephone hotline in coordination with a doctor.

Positive policy environment

The RAPIA also looked at the framework under which diabetes was considered by the Governments and policy actors in each country assessed. Policy is a vital component of the strategy of a health system and allows health actors to align their objectives to a common goal.

Vietnam approved a NCD programme in 2002, which was to operate until 2010. Following this, a preliminary National Plan for Diabetes was prepared for the years 2006-2010. Proposed areas of action were: (1) strengthening diabetes prevention; (2) developing education and advocacy; (3) promoting early detection and diagnosis; (4) building up a monitoring and controlling system; (5) patient rehabilitation; and (6) improving and expanding international cooperation. Targets were set with a view to reducing the rate of diabetes and related complications, with the eventual ambition of ensuring all patients had been diagnosed and were able to self-manage their condition. Policy was intended to facilitate funding, training, health system reorganisation and an enhanced set of preventative services whilst also maximising social participation in health.

The National Strategic Plan for the prevention and control of NCDs in Mozambique has as its aim to create a positive environment to minimise or eliminate the exposure to risk factors and guarantee access to care. The plan which was approved by the Minister of Health in October 2008 aims to both guide local action as well as making a case why NCDs should be dealt with in Mozambique, thereby being useful as a tool for advocacy as well as a providing a framework for action. In order to effectively implement this NCD plan throughout the country focal points have been nominated in all provinces. Their role will be to implement the plan in their provinces adapting the guiding principles of the plan to their local setting.

In Zambia, a high prevalence of communicable diseases was reported to have resulted in relatively little attention or resources being dedicated to diabetes or NCD diseases generally. At the time of assessment, the Ministry of Health was drafting a NCD policy; a policy whereby patients with NCD diseases should receive medication free of charge was in existence but ostensibly was often not applied.

A health policy document in Mali was proposed to include a section on NCD diseases. This included Diabetes, in addition to Hypertension and Sickle Cell Anaemia. Described as very ambitious, the document aimed to tackle the growing challenge of NCD through a wide range of actions. It did not however take into account the regional disparities in capacity in the country, for instance in terms of the material or human resources necessary to provide diabetes care at the local facility level, one action highlighted by the policy document.

The Ministry of Health in Nicaragua set national priorities on NCDs, subsequently implemented at each local healthcare system. One individual was reported to be responsible for NCDs in the Ministry of Health, with a focus on prevention, quality control, monitoring and health promotion. Theoretically this individual would then have a counterpart in each local region, entrusted with providing technical support, supervision, monitoring, training and implementation of policy protocols.

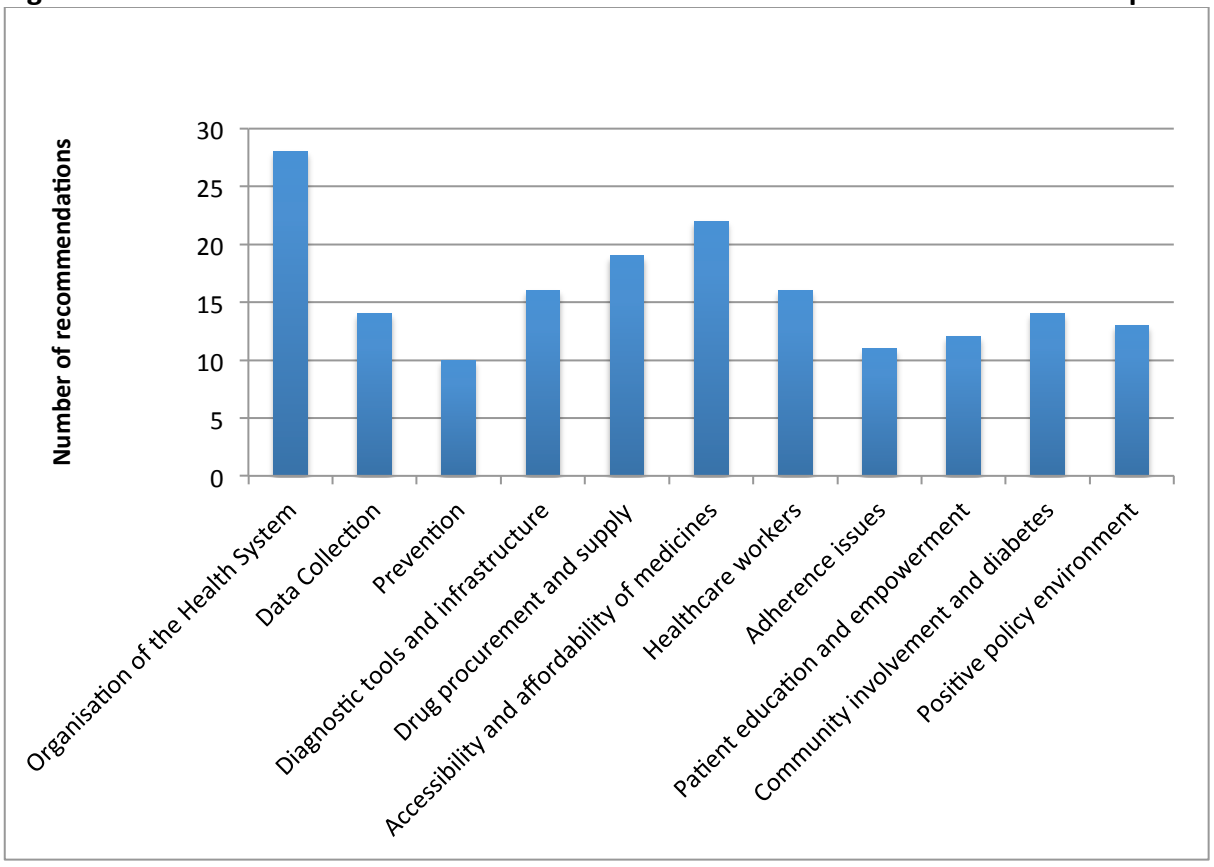
In Kyrgyzstan within the “Manas Taalimi” Health Programme, one of the priorities identified is the prevention and treatment of Cardiovascular Disease (CVD). Despite the fact of the close relationship and shared risk factors between CVD and diabetes, there is no inclusion of diabetes within this national strategy.[59] In 2006 a law on diabetes came into force although due to lack of resources not all of its elements have been implemented. The law includes a focus on primary prevention and healthy lifestyles, emphasising the need for social equity and fair access to prevention, treatment and rehabilitation services. The need for diabetes-

specific training of healthcare workers is recognized including improvement in diabetes education and counselling. The law states that treatment for people with diabetes should be free and that insulin, oral medicines and blood glucose monitoring should be available for free.

The findings of the implementation of the RAPIA in each country represent the evidence from research for action. The country reports helped not only identify the problems but also to propose viable solution to issues for people with diabetes. The in-country recommendations cover a full range of topics from the purchase and supply of insulin, medicines and other diabetes related supplies, the needed healthcare worker training and the development of diabetes associations to mobilize community resources appropriately.

In looking at the recommendations put forward by the different RAPIA reports similar areas of recommendations appear between countries. These are detailed in Figure 8 and

Figure 8 – Number of recommendations across countries from the different RAPIA reports



The main areas of recommendations were on the organisation of the health system; accessibility and affordability of medicines; drug procurement and supply and diagnostic tools and infrastructure.

Table 10 – Summary table of respondent comments from interviews

Main themes from interviews	Summary from interviews
RAPIA Methods	• Some elements missing/required further depth • RAPIA provided "a formalised approach"; "scientific approach" • Methods already developed • Comprehensive structure studying all levels of the health system
Research team and collaboration	• Close collaboration between the IIF and local partners • IIF was able to build trust and a relationship with local partners and address sometimes difficult issues

Results from the RAPIA implementations	• RAPIA was the first study of its kind to be carried out and all stakeholders involved valued it
	  ○ Gave an overall analysis and documented the situation
	  ○ Brought a lot of attention to the problem
	  ○ Provided a baseline
	  ○ Provided data from different sources
	  ○ "Information on particular countries reinforced what was already known, but not documented"
	  ○ Results from the RAPIA were used in developing projects
	• Credibility – the credibility of the data generated by the IIF through the RAPIAs, but also the credibility of the IIF as an organisation

Dissemination of RAPIA results	• More "noise" could have been made • Dissemination continued beyond the formal presentation of the RAPIA results with the WHO and other local partners taking ownership of the results • Dissemination needed to be done locally and globally
Recommendations from RAPIA reports	• Extremely useful to in-country partners • Recommendations were "straight forward and useful on a global level" • Approach and views of the IIF sometimes hampered the implementation of these
Impact of the overall	• Hard to differentiate the impact of the RAPIA versus the impact of other work and changes in health systems

Appendix 2 – List of publications resulting from RAPIA work

Publications (peer reviewed)

1. Beran D and Higuchi M. Delivering diabetes care in the Philippines and Viet and Practice issues. *Asia-Pacific Journal of Public Health*, 2013, 25(1):86-95.
2. Silva-Matos C and Beran D. Non-communicable diseases in Mozambique: burden, response and outcomes to date, *Globalization and Health*, 2012, 8(1 ahead of print.
3. Beran D, Basey M, Wirtz V, Kaplan W, Atkinson M and Yudkin JS. On the insulin centenary, *Lancet*, 2012, 380 (9854): 1648.
4. Beran D, Abdraimova A, Akkazieva B, McKee M, Balabanova D and Yudkin JS Kyrgyzstan: changes between 2002 and 2009, *International Journal of Hea and Management*, 2012, 5 November e-pub ahead of print.
5. Beran D. Health systems and the management of chronic diseases: lessons diabetes, *Diabetes Management*, 2012, 2(4):323–335.
6. Beran D and Yudkin JS. Letter. Apply criteria to improve health systems in countries, *BMJ*, 2012; 344:e546.
7. Beran D. Improving access to insulin: what can be done? *Diabetes Manage* 1(1):67-76.
8. Gill GV, Yudkin JS, Keen H and Beran D. The insulin dilemma in reso countries. A way forward? *Diabetologia*, 2011, 54(1): 19-24.
9. Beran D, Silva Matos C and Yudkin JS. The Diabetes UK Mozambiqu Programme. Results of improvements in diabetes care in Mozambique: a rea years later using the Rapid Assessment Protocol for Insulin Access. *Diabet* 2010, 27(8): 855-61.
10. Beran D and Yudkin JS. Looking beyond the issue of access to insulin: What is proper diabetes care in resource poor settings. *Diabetes Research in Clini* 2010, 88(3): 217-21.
11. Yudkin JS, Holt RIG, Silva-Matos C and Beran D. Twinning for better diab model for improving healthcare for non-communicable diseases in re countries. *Postgraduate Medical Journal*, 2009, 85(999): 1-2.
12. Beran D, McCabe A and Yudkin JS. Access to medicines versus access to tre case of type 1 diabetes. *Bulletin of the World Health Organization*, 2008; 86(8
13. Sidibé AT, Besançon S and Beran D. Le diabète : un nouvel enjeu de santé pu les pays en voie de développement : l'exemple du Mali. *Médecine d Métaboliques*, 2007; 1(1): 93-8.
14. Beran D and Yudkin JS. Diabetes Care in sub-Saharan Africa. *La* 368(9548):1689-95.
15. Beran D, Yudkin JS and de Courten M. Assessing health systems for type 1 sub-Saharan Africa: developing a 'Rapid Assessment Protocol for Insulin A *Health Serv Res*, 2006; 6(1):17.
16. **Beran D** and Yudkin JS. Letter. A theme issue by, for and about Africa: challenge of diabetes, ***BMJ***, 2005; 331:779-80.
17. **Beran D**, Yudkin JS and de Courten M. Access to care for patients with insu diabetes in developing countries: case studies of Mozambique and Zamb ***Care***, 2005; 28(9):2136-40.
18. Yudkin JS and **Beran D**. Letter. Prognosis of diabetes in the developing wo 2003; 362(9393): 1420-1.

Publications (not peer reviewed)

1. Gill GV, Yudkin JS, Keen H and Beran D. Ensuring universal access to insulin – The International Insulin Foundation Position Statement. *African Journal of Diabetes Medicine*, 2011, 19(2): 4-5.
2. Gill GV, Yudkin JS, Keen H and Beran D. Ensuring universal access to insulin – The International Insulin Foundation Position Statement. *Diabetes Voice*, 2011, 56(2): 29-31.
3. Beran D. Mission Mozambique. *African Journal of Diabetes Medicine*, 2011, 19(1): 9-11.
4. Beran D. The Rapid Assessment Protocol for Insulin Access (RAPIA): research for action on access to diabetes care. *MERA: Diabetes International*, 2009, 17(1): 4-8.
5. Beran D, Khue NT, Uoc HK, Toan, LQ and Deeb L. Access to insulin and barriers to care: results of the RAPIA in Vietnam. *Diabetes Voice*, 2009, 54(3): 19-21.
6. Silva Matos, C and Beran D. Improvements in care for people with diabetes in Mozambique. *Diabetes Voice*, 2008, 53(2): 15-7.
7. Beran D, Atlan-Corea C, Tapia B, Martinez AJ and Guadamuz De Castro A. Diabetes care in Nicaragua: results of the RAPIA study. *Diabetes Voice*, 2007, 52(4): 38-40.
8. Beran D, Besançon S and Bowis J. Le diabète, un problème majeur de santé publique pour l'Afrique. *Revue ReMed*. 2006; no. 33.
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12. Beran D. Fundacion Internacional de Insulina: buscando atencion. *Vivir Con Diabetes en Bolivia*, 2004; 5; August: 12-3.
13. Beran D. Rapid Assessment Protocol for Insulin Access: overcoming barriers to care. *Diabetes Voice*, 2004; 49(2): 20-2.
14. Beran D. Diabetes care in developing countries. *Diabetes Wellness News*, July 2004.

Reports

1. Report of the International Insulin Foundation on the Rapid Assessment Protocol for Insulin Access in Kyrgyzstan. London, International Insulin Foundation, 2009.
2. Report of the International Insulin Foundation on the Rapid Assessment Protocol for Insulin Access in Vietnam. London, International Insulin Foundation, 2008.
3. Report of the International Insulin Foundation on the Rapid Assessment Protocol for Insulin Access in Nicaragua. London, International Insulin Foundation, 2007.
4. The Diabetes Foundation Report on implementing national diabetes programmes in sub-Saharan Africa. London, International Insulin Foundation, 2006.
5. Diabetes Foundation Report on insulin-requiring diabetes in sub-Saharan Africa. London, International Insulin Foundation, 2005.
6. Report of the International Insulin Foundation on the Rapid Assessment Protocol for Insulin Access in Mali. London, International Insulin Foundation, 2004.
7. Report of the International Insulin Foundation on the Rapid Assessment Protocol for Insulin Access in Zambia. London, International Insulin Foundation, 2004.

8. Report of the International Insulin Foundation on the Rapid Assessment Protocol for Insulin Access in Mozambique. London, International Insulin Foundation, 2004.

Chapters and other publications

1. Beran D and Yudkin JS. (2009) Beyond Access to Insulin. International Diabetes Federation Diabetes Atlas 4th Edition. Brussels: International Diabetes Federation.
2. Beran D and Yudkin JS. (2006) Managing Insulin-Requiring Diabetes in Sub-Saharan Africa. International Diabetes Federation Diabetes Atlas 3rd Edition. Brussels: International Diabetes Federation.

Appendix 3 – Health system specific plans developed in Vietnam

National level action plan:

These recommendations should be taken into account when developing and implementing the recently approved Diabetes Strategic Target Programme.

One main recommendation is for the Ministry of Health to collaborate closely with the Health Insurance Scheme to adapt health insurance to the increasing burden of diabetes and other Non Communicable Diseases. This should lead to a collaborative approach in finding innovative ways of increasing prevention in order to avoid the future costs linked to an increasing burden of diabetes and its complications. The Health Insurance Scheme should move from being only involved in reimbursement to promoting prevention, therefore decreasing its present and future costs.

For diabetes and other Non Communicable Diseases any National Plan or Programme needs to include all 3 levels of prevention taking into account the changes in society at large that are impacting the increasing burden of diabetes. It also needs to address financial issues for both the individual and the health system.

In order to improve prevention socially and culturally adapted information campaigns to address the risk factors of diabetes need to be implemented (Primary Prevention) and the issue of adherence needs to be properly addressed (Secondary Prevention). To tackle the problem of adherence two key factors need to be dealt with:

- Patient education
- Cost of treatment

In looking at patient education, the following recommendations could help Vietnam address this:

- Increase role of nurses and improve nurse training to include more on the management of diabetes
- Develop specialised training for nurses especially in specialised hospitals and departments in diabetes especially in patient education
- Develop training for healthcare workers in patient education

With regards to the cost of treatment, different measures at different levels of the path of medicines could help lower the cost of medicines. These recommendations are presented below:

- Review prices of medicines
- Investigate ways of improving tenders in order to lower process (e.g. group tenders or centralised purchasing)
- Remove import duties and VAT on medicines
- Standardise all insulin to 100 IU
- Assess possibility of hospitals providing all medicines for all patients
- Investigate mark-ups in the private sector
- Ensure sustainable and regular supplies of insulin for Paediatric Hospitals for free or subsidised (development of an insurance scheme for children with chronic conditions)
- Develop a mechanism to ensure that patients are able to access all the medicines they are prescribed

- Regulate use of generic and branded versions
- Information campaigns on generic medicines being safe and effective for healthcare workers and patients

It is important to note that these measures benefit not only the person with diabetes, but also the Health System and Insurance Scheme by lowering the overall cost of treatment.

In looking at the current organisation of the Health System and its management of diabetes, this is focused on large hospitals in Vietnam's main urban areas. This increases the burden on the system (overburdened staff and facilities, etc.) and on the patient (travel costs, lost wages, etc.). Adherence is also impacted as healthcare professionals do not have enough time to carry out full patient examinations and education and people with diabetes face additional travel costs adding to the overall financial burden.

Based on the assessment in Vietnam the following recommendations could help address these problems:

- Devolve care to lower levels of the health system and to the provinces through training and providing necessary resources to facilities
- Develop chronic consultations for outpatients throughout the health system
- Have hospitals be the "sponsor" of different health centres in providing staff and resources for diabetes consultations in order to increase use of health centres by increasing the public's trust in these facilities
- Have a clear path developed for referrals and counter-referrals
- Improve training of healthcare workers, especially in large hospitals in the province, in the area of managing of Type 1 diabetes in both paediatric and department responsible for diabetes care

The final aspect is to ensure proper data collection and that this data collected should be used in assisting with decisions making and planning (e.g. for needs, medicines, facilities, healthcare workers, etc.)

Local action plan:

At a local level three main factors should be addressed in order to address the problem of patient adherence. These are healthcare worker training, patient education and the organisation of care.

In looking at healthcare worker training at specialised facilities doctors are extremely well trained and some nurses play a role in diabetes care. Existing training programmes should be expanded both in scale and scope and include training for nurses and also training in patient education. The role of nurses needs to be increased and all healthcare workers involved in diabetes care should receive training in patient education. In the first instance, before specialised courses can be developed for nurses, specialised training for nurses in hospitals can take place simply by involving nurses more in patient care and "shadowing" doctors.

In parallel to strengthening education in specialised centres in Vietnam's large urban areas, training of healthcare workers, especially in large hospitals in the provincial and district

hospitals including the management of Type 1 diabetes, should be developed. This is a necessary step in ensuring that diabetes care can be devolved to lower levels of the health system.

These trained healthcare workers will then need to address the issue of patient education by improving post diagnosis education. This needs to be done by developing socio-culturally adapted materials for patient education and information. As well as these materials a curriculum for in and out patients that can be delivered by nurses should be developed in order to ensure that a standard level of education is delivered to each patient.

This training needs to be included in a larger reorganisation of the health system to improve the management of diabetes from a clinical perspective in order to positively impact patient adherence and therefore decrease complications.

Reorganising the system needs to happen at a facility level, but also with regards to the relationship that different levels of the health system have with each other.

At each facility chronic consultations for outpatients should be developed. In some facilities these could be diseases specific, e.g. diabetes, but at others these may need to regroup several chronic conditions, e.g. diabetes, hypertension, etc.

Within this consultation education should play an important role and a team approach should be implemented. A diabetes team including nurses, nutritionists, psychologists, etc. should be created and they should actively be involved in diabetes care. In addition management guidelines for individual patients should be developed including screening programmes to be included by developing a list of tests and exams that should be provided at regular intervals. This should be linked to a unique patient record system which includes inpatient and outpatient details.

Care to should be devolved to lower levels of the health system and to the provinces through training and providing necessary resources to facilities. This could also be done by having hospitals be the “sponsor” of facilities at lower levels of the health system providing staff and resources for diabetes consultations in order to increase use of health centres by increasing the public’s trust in these facilities. In looking at facilities and their links a clear path should be developed for referrals and counter-referrals.

As foot complications seem to place a large burden on the health system the availability of tools for foot screening should be improved. This could be done by developing a tool kit for each level of the health system with regards to foot screening.

Facility action plan:
At a facility level three main factors should be addressed in order to address the problem of patient adherence. These are healthcare worker training, patient education and the organisation of care.

In looking at healthcare worker training at specialised facilities doctors are extremely well trained and some nurses play a role in diabetes care. Existing training programmes should

be expanded both in scale and scope and include training for nurses and also training in patient education. The role of nurses needs to be increased and all healthcare workers involved in diabetes care should receive training in patient education. In the first instance, before specialised courses can be developed for nurses, specialised training for nurses in hospitals can take place simply by involving nurses more in patient care and "shadowing" doctors.

These trained healthcare workers will then need to address the issue of patient education by improving post diagnosis education. This needs to be done by developing socio-culturally adapted materials for patient education and information. As well as these materials a curriculum for in and out patients that can be delivered by nurses should be developed in order to ensure that a standard level of education is delivered to each patient. This education should be delivered regularly.

Expert patients could also be trained and involved in delivering education. This could serve as the building block for the development of a diabetes club in facilities where they do not currently exist. Where they do exist the role of diabetes clubs could be increased to also have a patient representative involved in discussions with healthcare workers and administration.
At each facility chronic consultations for outpatients should be developed. In some facilities these could be diseases specific, e.g. diabetes, but at others these may need to regroup several chronic conditions, e.g. diabetes, hypertension, etc.

Within this consultation education should play an important role and a team approach should be implemented. A diabetes team including nurses, nutritionists, psychologists, etc. should be created and they should actively be involved in diabetes care. In addition management guidelines for individual patients should be developed including screening programmes to be included by developing a list of tests and exams that should be provided at regular intervals. This should be linked to a unique patient record system which includes inpatient and outpatient details. This data should then be used for monitoring and assisting with decisions making and planning (e.g. for needs, medicines, facilities, healthcare workers, etc.)

As foot complications seem to place a large burden on the health system the availability of tools for foot screening should be improved. This could be done by developing a tool kit for each level of the health system with regards to foot screening.

Paediatric facility action plan:
It is clear that the burden of Type 1 diabetes compared to all the conditions that paediatric facilities in Vietnam have to face is small. However, it is recommended that the management of Type 1 diabetes be included into the larger picture of management of chronic conditions at paediatric facilities. These conditions will not only represent a larger and larger burden, but also require special attention in order to avoid repeated admissions, which place an unnecessary burden on the hospital, its staff and the child with diabetes and their family.

The aim of any activity developed for Type 1 diabetes (and other chronic conditions) should be to prevent hospitalisation and long-term complications.

In looking at the present reasons for the high levels of readmissions and complications they are problems accessing insulin and low patient education both leading to poor adherence.

The cost of insulin and its availability need to seriously be addressed by paediatric facilities. At an overall cost of about US$ 130 per year, to guarantee insulin for a child, local solutions need to be found.

Patient education and support should be present both for in and out patients. For inpatients a specific post diagnosis curriculum should be developed using socio-culturally adapted materials. Nurses should play the leading role in delivering this education and providing the initial support to families after diagnosis. Nurses should also form part of an outpatient team including nutritionists, psychologists, etc.

This consultation should be a specialised “chronic” consultation where children with chronic conditions (diabetes, asthma, Congenital Adrenal Hyperplasia, kidney disease, etc.) have access to a doctor with more time for them, as well as a “team” to provide the child and his family with education and support.

A unique patient record system should be developed for Type 1 diabetes (and other chronic conditions) to include inpatient and outpatient information as the whole patient history is important in the management of paediatric chronic conditions.

The role of diabetes clubs and the frequency of their meetings should be increased if possible to add to the education and support provided by the hospital.

These plans were fed back to local stakeholders and included in the final report submitted to the Ministry of Health in Vietnam.

Appendix 4 – Online questionnaire

1. Do you work for:

- Ministry of Health
- International Organisation e.g. World Health Organization
- International NGO
- National NGO
- Academic Institution
- Healthcare provider
- Other (Please specify)

2. Other:

3. How would you describe the character of your work? (more than one option can be selected)

- Policy development
- Research
- Advocacy
- Healthcare delivery
- Teaching
- Other (please specify)

4. Other:

5. Do you know about the work of the International Insulin Foundation?

- Yes
- No

If No, skip to Question 7

6. Please describe in your own words what you know about the work of the International Insulin Foundation

7. Do you know about the Rapid Assessment Protocol for Insulin Access?

- Yes
- No

If No, skip to Question 18

8. Please describe in your own words what you know about the Rapid Assessment Protocol for Insulin Access

9. Were you directly involved in the implementation of one of the Rapid Assessments?

- Yes
- No

If No, skip to Question 22

10. Which Rapid Assessments were you directly involved with?

- Kyrgyzstan
- Mali
- Mozambique
- Nicaragua
- Vietnam
- Zambia

11. Please rate the quality of the:

	Very Poor	Barely Acceptable	Poor	Good	Very Good	N/A
Methods used in the Rapid Assessment Protocol for Insulin Access	O	O	O	O	O	O
Quality of the research team	O	O	O	O	O	O
Credibility of the research team	O	O	O	O	O	O
Quality of the results from the Rapid Assessment Protocol for Insulin Access	O	O	O	O	O	O
Involvement of local partners during the research process	O	O	O	O	O	O
Quality of the recommendations from the Rapid Assessment Protocol for Insulin Access	O	O	O	O	O	O
Quality of the dissemination of the Rapid Assessment Protocol for Insulin Access	O	O	O	O	O	O

Please describe your answers

12. Did you participate in a priority setting exercise of these recommendations?

- Yes
- No

If No, skip to Question 14

13. Please rate the quality of the:

	Very Poor	Barely Acceptable	Poor	Good	Very Good	N/A
Priority setting exercise	O	O	O	O	O	O

Please describe your answers

14. In the countries where you were involved did the Rapid Assessment Protocol for Insulin Access influence the following: (more than one option can be selected)

	Policy agenda setting	Policy formulation	Policy implementation	None of these
Overall health *How were the results used to influence this :*	O	O	O	O
Access to insulin *How were the results used to influence this :*	O	O	O	O
Diabetes management *How were the results used to influence this :*	O	O	O	O
Noncommunicable Diseases *How were the results used to influence this :*	O	O	O	O

15. Please state your level of agreement with the following statements:

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree	N/A
The Rapid Assessment Protocol for Insulin Access had an impact on access to insulin	O	O	O	O	O	O
The Rapid Assessment Protocol for Insulin Access had an impact on diabetes management	O	O	O	O	O	O
The Rapid Assessment Protocol for Insulin Access had an impact on Noncommunicable Disease management	O	O	O	O	O	O
The Rapid Assessment Protocol for Insulin Access had an impact on Noncommunicable disease policies	O	O	O	O	O	O
Recommendations from the Rapid Assessment Protocol for Insulin Access have influenced government policies and programmes	O	O	O	O	O	O
The Rapid Assessment Protocol for Insulin Access has improved and increased the visibility of Diabetes Associations	O	O	O	O	O	O
Recommendations from the Rapid Assessment Protocol for Insulin Access have have been included in projects and programmes of national NGOs	O	O	O	O	O	O
The Rapid Assessment Protocol for Insulin Access has helped in securing external funding and support for diabetes programmes	O	O	O	O	O	O
The Rapid Assessment Protocol for Insulin Access has been used for monitoring and evaluation	O	O	O	O	O	O

Please describe your answers

16. Were there any other contributions from the Rapid Assessment Protocol for Insulin Access?

17. What other conditions were present that facilitated the uptake of the RAPIA findings?

Skip to Question 26

18. Are you familiar with the work of any of the following individuals regarding access to insulin:

- ***Ayesha Motala***
- ***David Beran***
- ***Edwin Gale***
- ***Geoff Gill***
- ***Harry Keen***
- ***John S. Yudkin***
- ***Kaushik Ramaiya***
- ***Max de Courten***
- ***Nigel Unwin***
- ***Solomon Tesfaye***

- Yes
- No

If No, skip to Question 26

19. How did you gain knowledge of this work?

- Seen one of these individuals present this work
- Read a publication about this work in a peer reviewed journal
- Read about this work, but not in a peer reviewed journal
- Other

Other (please describe)

20. Do you feel that the work by these individuals has had an impact on:

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree	N/A
Policies related to health	O	O	O	O	O	O
Policies related insulin	O	O	O	O	O	O
Access to insulin	O	O	O	O	O	O
Diabetes related policies	O	O	O	O	O	O
Diabetes management	O	O	O	O	O	O
Noncommunicable Disease related policies	O	O	O	O	O	O
Noncommunicable Disease management	O	O	O	O	O	O

Please describe your answers

21. Please describe what aspect(s) you feel had the most impact from the work of these individuals.

Skip to Question 26

22. How did you gain knowledge of this work?

- Seen one of these individuals present this work
- Read a publication about this work in a peer reviewed journal
- Read about this work, but not in a peer reviewed journal
- Other

Other (please describe)

23. Please rate the quality of the:

	Very Poor	Barely Acceptable	Poor	Good	Very Good	N/A
Methods used in the Rapid Assessment Protocol for Insulin Access	O	O	O	O	O	O
Quality of the research team	O	O	O	O	O	O
Credibility of the research team	O	O	O	O	O	O
Quality of the results from the Rapid Assessment Protocol for Insulin Access	O	O	O	O	O	O
Involvement of local partners during the research process	O	O	O	O	O	O
Quality of the recommendations from the Rapid Assessment Protocol for Insulin Access	O	O	O	O	O	O
Quality of the dissemination of the Rapid Assessment Protocol for Insulin Access	O	O	O	O	O	O

Please describe your answers

24. Do you feel that the work by these individuals has had an impact on:

	Strongly disagree	Disagree	Undecided	Agree	Strongly agree	N/A
Policies related to health	O	O	O	O	O	O
Policies related insulin	O	O	O	O	O	O
Access to insulin	O	O	O	O	O	O
Diabetes related policies	O	O	O	O	O	O
Diabetes management	O	O	O	O	O	O
Noncommunicable Disease related policies	O	O	O	O	O	O
Noncommunicable Disease management	O	O	O	O	O	O

Please describe your answers

25. Please describe what aspect(s) you feel had the most impact from this work

26. Please include your e-mail address if you would be interested in speaking to the researcher in more detail about this project

27. Please include your e-mail address if you would be interested to receive a copy of the final report of this project

Appendix 5 – Background information on respondents to online questionnaire

In looking at the areas of activity these 167 possible respondents were in the table below details this.

Table 14 – Breakdown of people receiving online questionnaire

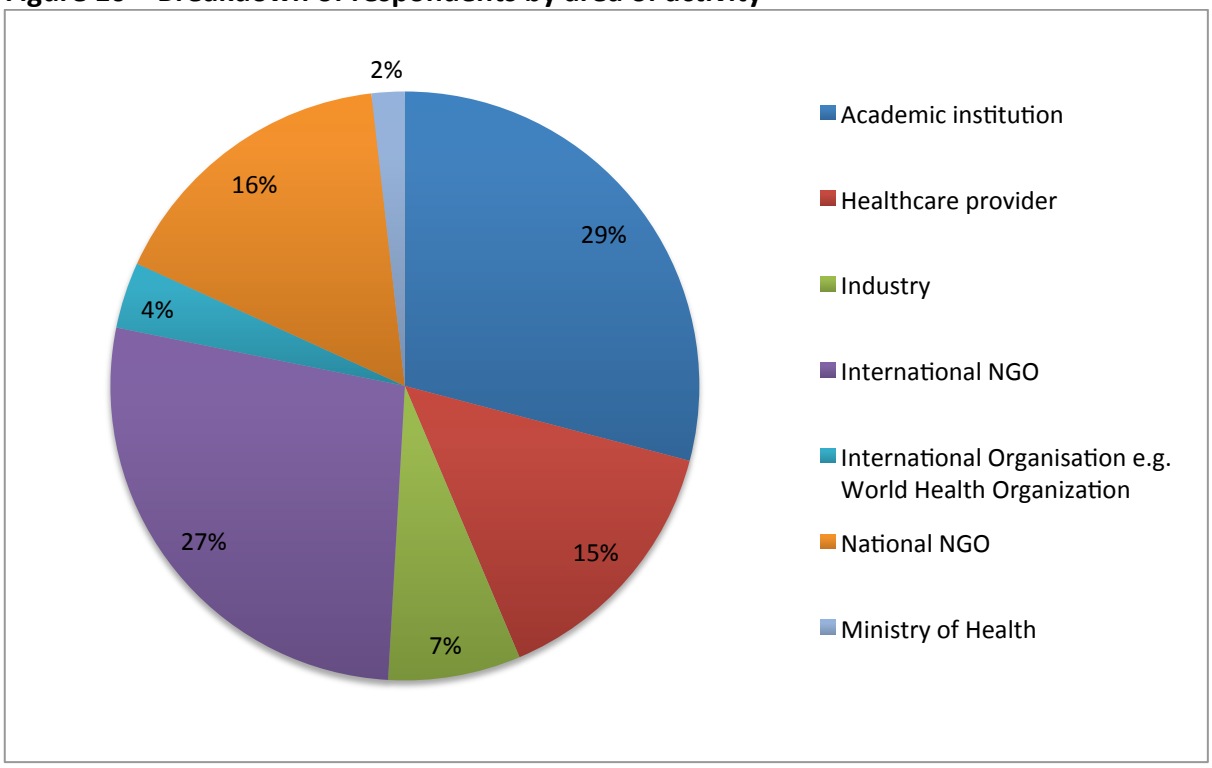
Type of partner	Area of activity							Country					
	Academic	International NGO	International Organisation	Journalist	Local NGO*	Ministry of Health	Private Sector	Kyrgyzstan	Mali	Mozambique	Nicaragua	Vietnam	Zambia
Local	5	5	8	0	25	23	0	16	5	7	13	20	5
International	18	43	10	3	3	1	7	N/A					

* - This includes diabetes associations

Of these 150 e-mails sent and received a total of 55 responses were received representing a 37% response rate. Internet based surveys usually have lower response rates than traditional questionnaires.[60, 61] Response rates are impacted by how the questionnaire is distributed, how the data is collected as well as issues of automated responses (out-of-office notifications), server rejection and spam filters. In reviewing response rates for online questionnaires from different studies Dobrow et al. found that they ranged from a minimum of 27.3% to maximum of 39.8% with a best estimate of 32.8%. Nulty[61] in a similar review found that online surveys achieved response rates that were much lower than the paper-based ones (on average, 33% compared with 56%). Therefore the response rate to this survey can be seen as high.

For the 55 respondents presented in Figure 3 the Figure below presents the breakdown by area of activity.

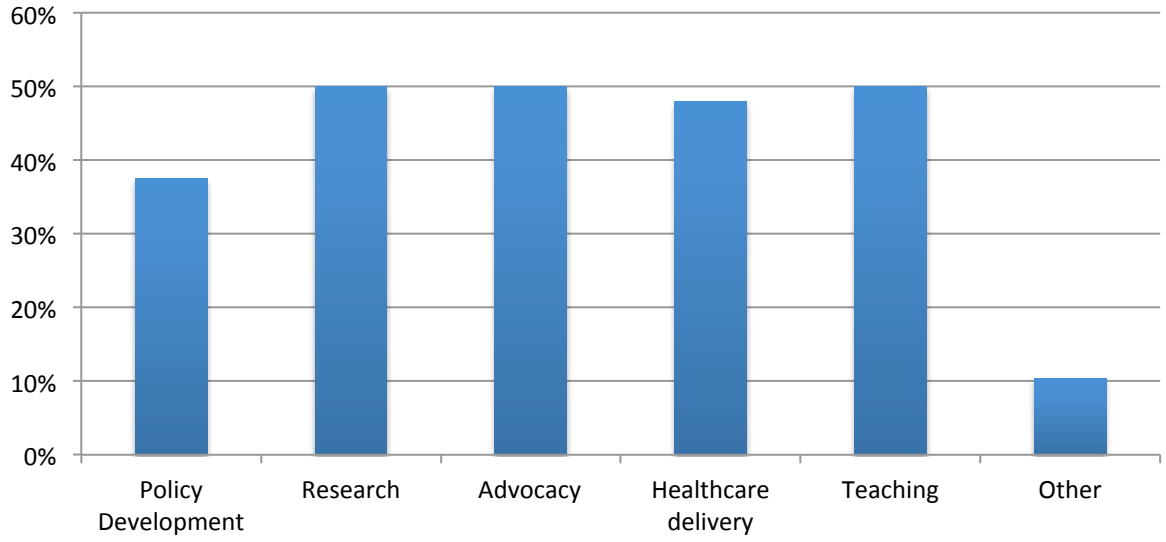
Figure 10 – Breakdown of respondents by area of activity



It should be noted that some clinicians responding to this were classified as "Ministry of Health" in the overall mailing as they are employed by the Ministry of Health. In looking at how the respondents described their work, as detailed in

Figure 11, it is interesting to note that 50% of respondents included "Research", "Advocacy" and/or "Teaching".

Figure 11 – Description of interviewees' area of work



Included in "Other" was technical assistance, grassroots advocacy, patient education and access to health.

Appendix 6 – Discussion guide **for interviews on impact of RAPIA**

- **Process**
  - Knowledge of IIF
  - Knowledge of RAPIA
    - Why collaborate
- **Methods**
- **Research team**
- **Results**
  - Use of data
    - Included in National Policies
      - NCDs
      - Diabetes
    - Impact on these
- **Dissemination**
- **Recommendations**
- **Impact**
  - Involvement in RAPIA process and how RAPIA was able to get on the policy agenda
  - People involved in the policy making process (identification of further interviewees)
    - What Policy exchange opportunities occurred during the RAPIA process
    - How and why were these successful/unsuccessful
  - What weight did the RAPIA have in influencing policy
  - What results or aspect of the presentation of results had the largest impact on the policy process
  - Did the RAPIA have any contribution to policy implementation
  - How were the results from the RAPIA used to change/implement policy
  - Any wider issues that the RAPIA process contributed to
  - What other conditions were present that facilitated the uptake of the RAPIA findings
  - What changes
  - Impact on UN HLM
  - Impact on Global Action Plan for NCDs
  - Involvement of local partners
  - Did it impact policy
    - Which
    - How
      - Policy agenda
      - Policy formulation
      - Policy implementation

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