

# A Guide to National Diabetes Programmes

**The mission of the International Diabetes Federation is to promote diabetes care, prevention and a cure worldwide**

© International Diabetes Federation, 2010

All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means without the written prior permission of the International Diabetes Federation (IDF).

ISBN: 2-930229-75-6

Requests to reproduce or translate IDF publications should be addressed to:  
IDF Communications,  
Chaussée de la Hulpe 166,  
B-1170 Brussels, Belgium,  
by e-mail to [communications@idf.org](mailto:communications@idf.org),  
or by fax to +32-2-5385114.

The first edition of the National Diabetes Programmes Toolbox was published in 2003.

This and other IDF publications are available from:  
International Diabetes Federation  
Chaussée de la Hulpe 166  
B-1170 Brussels  
Belgium  
Tel: +32-2-5385511  
Fax: +32-2-5385114  
[www.idf.org](http://www.idf.org)



# A Guide to National Diabetes Programmes

## PREPARED BY

Associate Professor Ruth Colagiuri  
IDF Task Force on Diabetes and Non-Communicable Disease Prevention, Policy and Practice  
Director, Health and Sustainability Unit – Menzies Centre for Health Policy  
The University of Sydney, Australia

## ACKNOWLEDGEMENTS

Assistance in preparing the Guide is gratefully acknowledged from

Maria Gomez, Robyn Short and Dr Alexandra Buckley  
Health and Sustainability Unit – University of Sydney

The members of the Task Force on on Diabetes and Non-Communicable Disease  
Prevention, Policy and Practice

Dr Jonathan Brown for his contribution to the module on Assessing the Cost of Diabetes

Mr Soren Skovlund for his contribution to the module on Psychological Issues

This Guide updates and replaces the National Diabetes Programmes Toolbox 2003  
its development was supported by an educational grant from Novo Nordisk Denmark

Eli Lilly is also acknowledged for its contribution to the work of the Task Force on  
National Diabetes Programmes



## Foreword

The long-feared diabetes epidemic is no longer predicted – it is here.

Diabetes strikes at people of all ages, in all walks of life, and in all countries. For people in countries where there is little or no social security, a diagnosis of diabetes can sentence a whole family to generations of financial and educational hardship and even poverty. In some low and middle income countries many children and young people who develop type 1 diabetes still die from lack of insulin. In high income countries, we know there is a social gradient to diabetes and its complications, with people of lower socio-economic status, indigenous and migrant communities being disproportionately affected.

Once thought of as a disease of the elderly, type 2 diabetes has become the scourge of the productive years of the life cycle, and is increasingly affecting people earlier and earlier, in some cases even in their teens and younger. Once thought of as a disease of affluence, new evidence suggests higher prevalence rates among slum dwellers in some countries and high, middle and low income countries alike are staggering under the impact of diabetes on health care costs, disability and productivity, early retirement, increased pensions and early death.

The impact of diabetes on families, communities and nations is not sustainable and it is little wonder that the 2006 UN Resolution on Diabetes called on world governments to 'develop national policies for the prevention, treatment and care of diabetes in line with the sustainable development of their healthcare systems'. Never before has there been such a need for a strong, systematic, co-ordinated and comprehensive response to prevent diabetes and reduce the personal hardship and societal costs caused by its complications.

I commend this Guide to National Diabetes Programmes to you to assist in your fight against diabetes.



**Professor Jean Claude Mbanya**

President, International Diabetes Federation



<b>WHAT IS A NATIONAL DIABETES PROGRAMME</b>	6
<b>WHO SHOULD BE INVOLVED?</b>	7
<b>PURPOSE AND SCOPE OF THE GUIDE</b>	8
<b>SECTION 1 - GETTING STARTED</b>	
Making the Advocacy Case for Diabetes	10
Developing a Framework for a National Diabetes Programme	13
Establishing a National Diabetes Organisation	17
<b>SECTION 2 - DETERMINING THE EXTENT OF THE PROBLEM</b>	
Conducting a Situation and Needs Analysis	22
Conducting a Baseline Prevalence Survey	25
Assessing the Cost of Diabetes	32
Assessing Community Awareness	36
<b>SECTION 3 - PREVENTING THE PROBLEM</b>	
Primary Prevention: The Individual / High Risk Approach	42
Primary Prevention: Environmental Approaches	46
<b>SECTION 4 - ADDRESSING THE PROBLEM</b>	
Developing a Community Awareness Campaign	50
Early Diagnosis of Type 2 Diabetes	54
Routine Care and Monitoring of Diabetes	59
Providing Patient Education	70
Psychological Issues in Diabetes	75
Developing and Implementing Guidelines	79
Developing the Diabetes Workforce and Services	85
<b>SECTION 5 - EVALUATING PROGRESS</b>	
Collecting Diabetes Data	90
Evaluating National Diabetes Programmes	94
<b>SECTION 6 - WHERE TO NEXT?</b>	
National Diabetes Programmes of the future	100
Standards for National Diabetes Programmes	103
<b>SECTION 7 - WHO CAN HELP?</b>	
IDF Global Infrastructure	106
IDF Regional Infrastructure	107
IDF Task Force on Diabetes and NCD Prevention, Policy and Practice	108
<b>SECTION 8 - ADDITIONAL INFORMATION</b>	
List of Suggested Readings	110
Useful Definitions	113

## WHAT IS A NATIONAL DIABETES PROGRAMME

A National Diabetes Programme is a *systematic and co-ordinated approach to improving the organisation, accessibility, and quality of diabetes prevention and care* which is usually manifest as a comprehensive policy, advocacy and action plan covering the:

- Main types of diabetes ie type 1 diabetes, type 2 diabetes and gestational diabetes
- Whole continuum of care from primary prevention to treatment and palliative care
- Resources, services and systems that support prevention and care

Where lack of resources or political support preclude the development of a comprehensive National Diabetes Programme, single component or 'stand alone' programmes can raise awareness of diabetes, bring worthwhile gains and may be helpful in paving the way for a more comprehensive programme. Single component programmes may focus on:

- One aspect of diabetes such as foot problems, visual impairment, kidney disease
- One aspect of care such as clinical management guidelines, data collection workforce training

Regardless of whether they are comprehensive or single component, *National Diabetes Programmes* can be defined as formal strategies for improving diabetes policy, services and outcomes that encompass structured and integrated or linked activities which are planned and co-ordinated nationally and conducted at the national, state or district, and local level.

*National Diabetes Programmes* must be documented and have stated goals and objectives, supported by a strategic plan, specified timeframes and milestones and dedicated funding, and a means of evaluation. Approval and endorsement of, and leadership from the Ministry of Health is vital.

The core elements of a comprehensive national diabetes programme are:

- Primary prevention ie preventing the development of risk factors
- Secondary prevention ie preventing the development of diabetes
- Tertiary prevention ie preventing the development of complications through early diagnosis and effective monitoring, treatment and care of people with diabetes
- The funding and systems that underpin prevention and care ie
  - workforce and services
  - medication, equipment and supplies
  - information and communication systems
  - monitoring and surveillance systems
  - clinical policy, guidelines and governance
  - resource allocation

## WHO SHOULD BE INVOLVED?

Diabetes impacts on everybody. It is a common, complex chronic and costly disease. It can affect all systems and all parts of the body. There is currently no cure. It affects people of both sexes from all walks of life and can occur at any age and stage of the life cycle. Even though there is an acknowledged social gradient associated with the development of diabetes, no one is immune.

People with diabetes, especially if they develop complications, need to use a wide range of health and support services from primary care physicians and nurses to acute hospital inpatient services and specialist outpatient services. And, it is now well documented that diabetes is associated with considerable cost to the community and to national economies as a result of lost productivity from early mortality and absenteeism, and increased dependency and use of pensions due to early retirement and growing claims on pensions and other forms of social security.

Diabetes does not occur in a vacuum. Nor do its causes occur in the health system. While genes play an important role, the trigger may often be environmental even for type 1 diabetes. For type 2 diabetes, the social, food and built environment in our communities and workplaces can play a vital role in determining our likelihood or otherwise of getting diabetes.

If we agree that diabetes is everybody's business, it follows that everyone should be involved in the battle to reduce its impact. Engaging or at least taking account of the impact of all sections and levels of society in planning and implementing *National Diabetes Programmes* is vital to achieving optimal support, penetration and impact. Consequently, it is worth undertaking a national stakeholder mapping exercise to identify key players and groups who are in a position to exert a positive influence on the process. In addition to the usual professional and consumer diabetes groups, pharmaceutical companies and health agencies such as WHO, these might include:

- Government departments for finance, central planning, housing, employment and business, transport, fisheries, agriculture, environment, energy, climate change
- Food manufacturers and retailers
- Employers, manufacturers and business/industry organisations
- Property developers
- Major banks
- Private health insurers and insurers more generally
- Employees unions
- Academic institutions and groups eg public health law, architecture, economics
- International and national philanthropic organisations
- International aid organisations
- Church groups and charitable organisations
- Non-diabetes NGOs such as heart, stroke, lung, kidney and cancer.

So, when reading through this Guide to *National Diabetes Programmes* be prepared to think strategically and laterally about who diabetes impacts on and who might be in position to help turn the tide.

## PURPOSE AND SCOPE OF THE GUIDE

The *Guide to National Diabetes Programmes* presents a set of practical generic frameworks and considerations covering aspects of primary prevention and diabetes care which are integral to developing and conducting comprehensive and effective responses to the crippling burden imposed by diabetes on individuals, families, communities and national governments.

### What is its purpose?

Due to the wide variation in health care systems internationally, the Guide suggests 'what to think about' rather than prescribing 'how to do it'. Its purpose is twofold:

#### INFORMATIVE

Each module presents considerations for the development and implementation of various components of *national diabetes programmes* and highlights issues which need to be thought through and addressed in order to optimise the potential success of each initiative.

#### SUPPORTIVE

The Guide aims to encourage and support the development of national diabetes activities, assisting and making the task of countries newly embarking on such initiatives easier while, simultaneously providing a benchmark for countries where national diabetes programmes are already underway. The Guide presents a summary of the results of collective experience in aspects of national diabetes programmes from around the world and from the literature. According to the stage and extent of the development of national diabetes activities and their relevance to the country's health care system, these frameworks can be used to consider choices about suitable approaches for the circumstances prevailing in a particular country at a particular time.

### What is its scope?

The *Guide to National Diabetes Programmes* concentrates on selected topic areas relevant to national diabetes programmes. It provides a menu of templates which can be adapted or expanded for application in a variety of health system and health service contexts for a range of different activities. The scope is comprehensive but is not exhaustive. Nor is it meant to be prescriptive. Rather, the Guide seeks to help the reader think through the issues involved and predict, plan and prepare for the likely consequences of particular courses of action. The modules are designed to link with each other but could be used on an individual, stand-alone basis if it is not feasible to undertake a comprehensive national diabetes programme.

### Who is it designed for?

The Guide can be used by anyone but was designed with the needs and circumstances of middle to lower income countries in mind. It can be used by diabetes clinicians, national diabetes organisations, ministries of health and public health authorities to assist them in developing and carrying forward plans for various elements of national diabetes programmes. It is also anticipated, that the Guide will be useful as an advocacy tool to assist in explaining the rationale, requirements and potential benefits of investing to address various aspects of diabetes prevention and care. Possible targets for this may be health authorities and authorities from other government departments (eg treasury, agriculture, transport) and agencies, other disciplines (eg law, energy, economics, architecture and urban planning, environment), industry and business (eg food industry, property developers, employers).

# GETTING STARTED

- 10** Making the Advocacy Case for Diabetes
- 13** Developing a Framework for a National Diabetes Programme
- 17** Establishing a National Diabetes Organisation

## MODULE:

# MAKING THE ADVOCACY CASE FOR DIABETES

### Rationale:

As the result of efforts by the International Diabetes Federation (IDF), its network of national diabetes associations in some 200 countries around the world, and the World Health Organization (WHO), there is now considerable awareness of diabetes globally. Nonetheless, politicians and policy makers, funders, community and business leaders, and philanthropic organisations are constantly bombarded with requests and proposals to fund good causes and specific disease areas. We are gradually getting better at putting the argument for governments and other health funders, and business and industry to invest in preventing and managing diabetes but we continue to make common mistakes. For example, we often tend to:

- provide too much information
- make it sound too complicated and too hard
- focus on the enormity of the problem without offering solutions
- forget to frame our argument in ways that make sense to those we are trying to convince
- fail to take account of the knowledge base and needs of those we are trying to convince
- forget to emphasize the benefits of intervening
- concentrate on the health system and neglect to reach out to other stakeholders

### Purpose:

This module aims to raise awareness of the need to prepare and present a concise, compelling advocacy case for investing in diabetes and to provide some tips on how to do this effectively.

### Potential Application:

This module is mindful of the needs of:

- National diabetes organisations
- Professional diabetes organisations

It may also be useful to public health practitioners and health bureaucrats who are trying to convince their own Ministers or Ministers from other portfolios to invest in diabetes.

### Links:

Links with “*Who should be involved?*” and all modules in the Guide.

### Suggested Reading:

**IDF.** *Diabetes Atlas. 2009*, International Diabetes Federation: Brussels. 2009.

**IDF.** *World Diabetes Media Kit: Every 10 seconds 1 person dies of diabetes.* International Diabetes Federation: Brussels. 2007.

**WHO.** *Preventing Chronic Diseases: A vital investment.*

Available at: [http://www.who.int/chp/chronic\\_disease\\_report/en/index.html](http://www.who.int/chp/chronic_disease_report/en/index.html)

**CDC.** *Preventing diabetes and its complications.* Centres for Disease Control and Prevention

Available at: <http://www.cdc.gov/nccdphp/publications/factsheets/prevention/diabetes.htm>

**Colagiuri, R. (2010).** “*Diabetes: a pandemic, a development issue or both?*” *Journal of Expert Reviews Cardiovascular Therapy.* 8(3):305-309.

## CONSIDERATIONS FOR:

### MAKING THE ADVOCACY CASE FOR DIABETES

It is said that nobody in government really likes the health system because it uses up so much money and doesn't contribute anything. This is an important point to deal with in advocacy approaches and can be handled by:

- whenever you describe the problem also offer a solution
- emphasise that the solutions are cost effective and relatively simple
- assure your target audience that the evidence for preventing and treating diabetes effectively is strong, consistent and widely agreed.

In order to frame your advocacy case in the most appealing way possible, it is helpful to understand know what matters to your target audience, and what are their needs and imperatives. Everyone is under pressure from somewhere so it helps if you can find a way to convince your target audience that doing what you want them to do will bring them benefits to eg votes, savings, an enhanced community reputation and profile.

#### The Message

The message needs to be short, crystal clear and easily understandable. It should specify what the issue is and what you want your target audience to do about it.

Be very clear about the interventions and course of action you want them to take. Make sure it is feasible, cost effective and founded on evidence. It is helpful if you can cite precedents eg other countries that have intervened successfully. Remember that your target audience may not know or understand the many facts about diabetes that we take for granted.

#### The Evidence

Base your advocacy on solid evidence eg the cost of illness attributable to diabetes, but do not expect busy politicians, bureaucrats or CEOs to read long and detailed reports populated by large volumes of complex data. Instead, summarize the evidence into short, sharp meaningful statements written in plain language with clear headings that lead the reader to the key points you want them to take note of and remember. Reference and provide, or offer to provide, research and technical reports on which your messages and summaries are based.

Don't over interpret the evidence or make false claims. Sticking to the facts and presenting them in key points is far more powerful. The IDF and WHO references in this module are both excellent examples of this approach

#### Bad News - Good News

Nobody likes to hear bad news all the time - least of all politicians who have a steady stream of people coming to them every day with problems and asking for money to resolve them.

The evidence about the terrible and growing toll of diabetes on individuals and society is overwhelming. There is no point in making the people and organisations you want to invest in diabetes feel that the problem is so big nothing can be done about and it is vital to offer solutions. So, a good approach might be to state the bad news first and finish with the good news eg "every 10 seconds two people develop diabetes" or "diabetes costs our country \$20 (cite appropriate figure) billion each year in lost productivity" BUT "80% of diabetes can be prevented with simple cost effective measures".

## **Match the advocacy angle to your target**

Not everyone is motivated or moved by human pain and suffering so you will need to think about what is important to your target audience so you can mount an irresistible case for them investing in diabetes. For example, big business needs a healthy workforce. Illness and absenteeism leads to loss of productivity and increased production costs. There is ample evidence now that workplace health strategies and programmes are effective in raising productivity and bring an excellent return on investment. So if you are targeting employers, this is a good angle to take.

## **Speak with one voice**

Ensure a cohesive approach ie consult widely with relevant stakeholder group to negotiate an agreed position and present a united front when putting the advocacy case to politicians and funders. Open disagreement between stakeholder groups will lead to confusion and contradictory advocacy messages and no-one will benefit. Politicians are afraid of making themselves unpopular and losing votes and will not back any cause where there is a hint of internal fighting and disagreement. Failure to present a united front gives them a perfect excuse for not providing support.

## **Emphasise return on investment**

Any investment in diabetes will bring returns in other areas. There are any number of ways in which the benefits of investing in diabetes can be framed eg:

- Preventing diabetes will also prevent a substantial proportion of heart disease
- Improving access to recommended standards of care will reduce complications and reduce dependency on hospital services and pensions - and reduce foregone national income lost productivity
- Investing in diabetes prevention brings returns in other areas such as lifestyle risks for a myriad of diseases and reducing obesity, heart disease, hypertension and even, depression.

## MODULE:

# DEVELOPING A FRAMEWORK FOR A NATIONAL DIABETES PROGRAMMES

### Rationale:

The diabetes epidemic is no longer approaching, it is here. The huge personal and public cost of diabetes is threatening the security of families and the economic stability of nations. Mounting an effective fight to reduce the personal and economic burden of diabetes requires a co-ordinated approach which can only be fully achieved through strategic national and regional diabetes plans. This is emphasized in the 2006 UN Resolution on Diabetes which encourages UN Member States to develop national policies to combat diabetes.

### Purpose:

This module is designed to assist in the development of robust frameworks for planning national diabetes programmes in countries where these have not already been developed and implemented.

### Potential Application:

The primary target for this module is:

- Health authorities eg public health planners, chronic disease units
- National diabetes organisations
- Professional diabetes organisations

### Links:

Links with all modules in the Guide.

### Suggested Reading:

United Nations (2006). UN Resolution on Diabetes. Signed 20 December 2006 (UN Resolution 61/225). Available at: <http://www.worlddiabetesday.org/en/the-campaign/unite-for-diabetes/the-un-resolution-on-diabetes>

IDF (2006). Diabetes Declaration and Strategy for Africa: a call to action and plan of action to prevent and control diabetes and related chronic diseases. Available at: [http://www.idf.org/webdata/docs/Diabetes\\_Declaration\\_&\\_Strategy\\_for\\_Africa\\_full.pdf](http://www.idf.org/webdata/docs/Diabetes_Declaration_&_Strategy_for_Africa_full.pdf)

IDF (2008) The Kathmandu Declaration – The “Life-Circle” of prevention in diabetes. International Diabetes Federation. Available at: <http://www.idf.org/webdata/docs/IDF-SEA-kathmandu-declaration.pdf>

## CONSIDERATIONS FOR:

# DEVELOPING A FRAMEWORK FOR A NATIONAL DIABETES PROGRAMME

The content, scope and timelines of national diabetes programmes will vary from country to country. The nature and extent of activities will depend on many factors including available resources, the political, socio-economic and cultural context, and whether or not leaders in government, the health professions, consumer organisations and the community are aware of the severity of diabetes as a public health problem. Gaining political support, designating leadership and establishing an administrative structure are the first pre-requisites for developing a successful National Diabetes Programme. In developing a framework for your country's National Diabetes Programme it may be useful to consider the following:

## 1. What will be its focus and scope?

Who will the National Diabetes Programme target?

- people at risk of diabetes
- particular types of diabetes eg type 1 diabetes, type 2 diabetes, gestational diabetes
- all types of diabetes

What will be included in its scope?

- community awareness
- primary prevention
- early diagnosis
- routine care and services
- patient education
- psychological issues in diabetes
- cultural diversity
- workforce issues
- guidelines, protocols for standards of care
- information systems
- medications and equipment
- research
- all of these

## 2. Mission

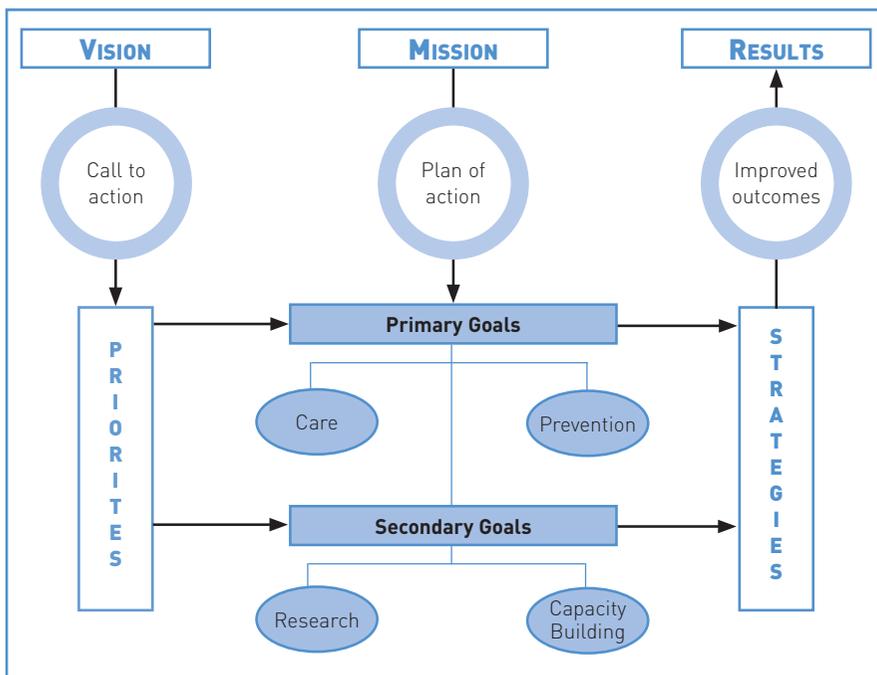
State in a few words what is the fundamental issue being addressed. Some possible examples are 'equal access to diabetes care for all who need it' or 'fight diabetes and win' or 'reduce diabetes risk factors, halve diabetes complications' or 'building better diabetes care'. Whichever way the Mission is phrased it should signal what the National Diabetes Programme hopes to achieve. That is, what is its core business, what is the bottom line?

## 3. Vision

What would the diabetes situation in your country look like if your National Diabetes Programme achieved its mission? This is a 'wish' list of how you visualise diabetes care and services in an ideal world. For example, in an ideal world all people with diabetes would have access to high quality diabetes care and essential medications and supplies would be available and affordable. The Vision does not have to be fully achievable as its purpose is to paint a picture of what could be in order to inspire and motivate a cohesive approach to addressing the problem.

## 4. Conceptual Framework

The framework below is designed to show how a vision and mission can inform the identification of priorities and strategies, and guide efforts to operationalise the goals in order to achieve the desired results of better access and improved health outcomes for all people with, or at risk of diabetes and emphasises the interconnectedness of the various components.



Source: Diabetes Strategy for Sub-Saharan Africa: International Diabetes Federation – Africa, 2006.

## 5. Action Plan

National diabetes programmes should be underpinned by a detailed strategic plan which specifies:

### GOALS AND TARGETS

Goals should be potentially achievable in whole or part within the specified time frame of the *National Diabetes Programme*. They should be reasonable, feasible, simple and should be kept to a minimum. Goals should specify what it is you are trying to achieve and in a comprehensive *National Diabetes Programme* should cover primary prevention, care of the diagnosed and address infrastructure issues. Targets are usually numerical and are applied to the whole population of people with diabetes eg 'reduce blindness by 30% in 5 years'.

Alternatively, 'expected outcomes' or 'expected results' which define general parameters of success rather than specific epidemiological targets can be specified.

## OBJECTIVES

Objectives are a useful way of breaking broad goals down into more manageable components. In reality they are 'mini' goals and should be clear, concise, achievable and measurable within a specified time frame. Two or three objectives relating to each goal can be effective in documenting and demonstrating what is required to achieve the goals

## STRATEGIES

Strategies are the 'game plan' for your *National Diabetes Programme*. They should define broad approaches to the problem which are capable of making a tangible contribution to achieving the goals. For example, if one of the goals is to improve the quality of diabetes care, important strategies for achieving this would be health professional training and clinical guidelines and protocols.

## PRIORITIES

The tasks encompassed in developing and implementing a National Diabetes Programme are enormous and resources are likely to be limited. It is vital to prioritise action in order to make the task manageable and to ensure appropriate use of available resources.

A sound framework for identifying priorities should include:

- the extent of the problem (in terms of human suffering and health care costs)
- the availability and affordability of effective interventions
- the likely benefits of intervening ie the health and cost gains

## EVALUATION PLAN

A mechanism for evaluating the impact and effectiveness of a National Diabetes Programme should be included in the framework and plan at the development stage and should include the identification of process and outcome indicators eg an outcome indicator for a goal of preventing blindness would be a reduction in the incidence of new blindness.

## PARTNERS

Partners may be drawn from among stakeholder groups and organisations such as the national diabetes organisation and professional diabetes organisations. It is also worth looking at engaging organisations and agencies outside the diabetes community. Think about involving non-government organisations and the various government sectors other than health eg education, agriculture, transport, environment. Diabetes related NGOs (such as heart, kidney, stroke etc) and agencies such as WHO are all important potential partners.

## 6. Organisational structure and oversight

A peak committee should be established, preferably under the auspices of the government health authority, and given responsibility for co-ordinating, guiding, monitoring and reporting on the overall development and implementation of the *National Diabetes Programme*. The peak co-ordinating committee must:

- have specific terms of reference detailing their responsibilities, budget, timeframes, reporting requirements and the expected outcomes
- work to clear lines of accountability and communication,
- include representation from among senior specialist clinicians, primary care, public health, policy makers, funders and people with diabetes and should include expertise in research, financial planning, strategic planning, and evaluation methods.

## MODULE:

# ESTABLISHING A NATIONAL DIABETES ORGANISATION

## Rationale:

By identifying the needs of consumers/patients and diabetes health care professionals and providing a collective voice for expressing those needs, National Diabetes Organisations can play a key role in lobbying for, initiating, supporting and/or conducting many aspects of National Diabetes Programmes. National Diabetes Organisations can apply for membership of the International Diabetes Federation (IDF). This can provide your country with a voice in diabetes affairs in your Region; place it in the global Diabetes Federation communication loop; and broaden avenues of support for your country's 'fight' against diabetes.

## Purpose:

This module is designed to assist with the establishment of National Diabetes Organisations in countries where they do not currently exist.

## Potential Application:

National diabetes organisations are by definition non-government organisations, as a result, this module targets:

- Consumer/patient groups and/or leaders
- Community groups which may have an interest in diabetes
- Non-government and charitable organisations which may have an interest in diabetes
- Senior diabetes clinicians

## Links:

This tool stands alone but it is useful to note that a strong National Diabetes Organisation representing a combination of professional and consumer (patient) organisations can be a powerful force in lobbying for and driving improvements to the organisation, delivery and quality of diabetes care and prevention.

## Suggested Reading:

International Diabetes Federation. Available at: <http://www.idf.org/idf-membership>

## CONSIDERATIONS FOR:

### ESTABLISHING A NATIONAL DIABETES ORGANISATION

Having a national diabetes organisation enables a country to become a member of the IDF. Membership of IDF provides the country member association with:

- a voice in diabetes affairs at both regional and global levels
- access to the IDF network of member associations, resources, and information
- an international diabetes journal, *Diabetes Voice*

National diabetes organisations began to appear in the first half of the 20<sup>th</sup> Century and have flourished and spread throughout the world. Their success is largely due to their ability to articulate the needs of people with diabetes and diabetes care providers by providing a collective voice to articulate and lobby for these needs.

To clarify your thinking about this so you can start convincing others of the need to establish a National Diabetes Organisation, you may wish to consider the following issues:

#### **1. What purpose would a National Diabetes Organisation serve?**

What function would it fulfill, what could it do for people with diabetes that is not currently being done and that is not part of anyone else's brief to do?

#### **2. Potential Benefits**

What could a National Diabetes Organisation achieve? How would it benefit:

- people with diabetes
- diabetes health professionals
- existing diabetes organisation/s
- the country

#### **3. Who should be involved?**

Are there existing diabetes organisations or endocrine, general medicine or research societies which could be used as a starting point?

Are there any informal diabetes (or chronic disease) consumer groups, or community organisations which could be invited to become involved? Are there any business, professional or community leaders who have an interest in diabetes who could be approached to help initiate and lead this movement?

#### **4. Scope**

How broad should the scope of the National Diabetes Organisation be? Will it combine and represent the interests of health professionals, researchers and consumers or will it be limited to one or two of these interest groups?

A truly national 'umbrella' organisation should combine, and be capable of representing all relevant interest groups. However, this benefit may be offset by the accompanying diversity of interests and expectation of the National Diabetes Organisation.

## 5. Focus

What functions will the National Diabetes Organisation focus on:

- identifying the needs of people with diabetes
- lobbying
- fundraising
- support for research
- consumer rights
- providing services
- subsidising or providing supplies
- other

## 6. Mission / Goals

What will be the primary purpose and core business of the National Diabetes Organisation? Once this is agreed, some broad goals can be defined to guide the early activities of the Organisation.

## 7. Potential sources of support

What individuals or groups in the government, non-government organisations, industry, business, the professions and/or the community have the power, leadership, financial resources, time, or expertise to assist in the establishment and maintenance of the National Diabetes Organisation? How can they be involved?

## 8. Legal and financial accountability

Even where the management or 'owners' are voluntary and there are no profits made, all organisations which handle money and employ people must be legally constituted to do so under the laws and regulations in place in their country. People seeking to establish National Diabetes Organisations carry a responsibility to find out and observe the requirements for legal and financial accountability governing such organisations.

## 9. Organisational and Operational Structure

Appropriate organisational and operational structures, procedures and processes need to be put in place from the outset to ensure the proper and smooth running of the organisation. These should include voting procedures and terms of reference for office bearers, meeting schedules, lines of accountability and communication, delegation of authority, budgetary processes, protocols for the handling of money and many others.



# DETERMINING THE EXTENT OF THE PROBLEM

- 22** Conducting a Situation and Needs Analysis
- 25** Conducting a Baseline Prevalence Survey
- 32** Assessing the Cost of Diabetes
- 36** Assessing Community Awareness

## MODULE:

# CONDUCTING A SITUATION AND NEEDS ANALYSIS

### Rationale:

The term situation and needs analysis simply means analysing or determining what is happening now and establishing what needs to happen in order to improve diabetes prevention and care.

In order to determine what needs to be achieved through the National Diabetes Programme and where to place the greatest effort and resources, it is important to identify the current status of diabetes policy, practice, workforce, services and supplies. How easy or difficult is it for people with diabetes to obtain essential medications and access services? Are the current policies and infrastructure adequate for the goals and objectives of the NDP to be met.

By comparing 'what is happening now' to 'what should be happening' (based on the international standards of recommended care), a needs analysis can identify where the gaps lie and guide future direction for closing the gaps. This will help achieve the best possible health care and outcomes for people with diabetes within the constraints of your country's resource limitations and provide a baseline against which service development and health service delivery programmes can be later evaluated

### Purpose:

This tool seeks to assist the development of national (or local) profiles on the current status of diabetes care and services and the identification of deficiencies in order to provide a rationale basis for establishing priorities for action.

### Potential Application:

*Conducting a Situation and Needs Analysis* is primarily designed for application at a national level. However, this tool can be simplified or expanded to suit a range of situations and could be used by:

- Health authorities - policy and planning personnel
- Diabetes organisations (professional, consumer/patient)
- Diabetes specialist staff at the local level (eg medical, nursing, dietetic etc)
- Primary care staff

### Links:

Links with *Developing a Framework for a National Diabetes Programme* as a method of identifying priorities and '*Evaluating Progress*', in as far as a baseline situation analysis may be a useful benchmark against which changes can be assessed.

### Suggested Reading:

IDF (2010) Rapid Assessment Protocol for Insulin Access (RAPIA). International Diabetes Federation.

Available at: [http://www.idf.org/webdata/docs/IIF-RAPIA\\_plan.pdf](http://www.idf.org/webdata/docs/IIF-RAPIA_plan.pdf)

## CONSIDERATIONS FOR:

### CONDUCTING A SITUATION AND NEEDS ANALYSIS

Situation and needs analyses can be multi-dimensional or uni-dimensional. It may be a comprehensive assessment of what is happening or a simple inventory of available services and equipment, and then an analysis of what needs to be happening to achieve a standard of diabetes care as close as possible to internationally recognised standards. There may be a variety of reasons for conducting a situation and needs analysis and there is a range of different ways to obtain this information. As always, available resources will influence the focus, scope and choice of methods.

Situation and needs analyses may collect quantitative data, be of a more qualitative nature, or a mixture of both. It is difficult to find reports of diabetes specific situation analyses in the literature. Situation analyses may be based on survey questionnaires; audits of hospital or community health centre patient records, admissions, staffing and equipment; reviews of policies; the level availability and distribution of health workers. Needs analyses will be based on these methods too but also require extensive consultation with those who work close to the problem, and who may be able to suggest workable solutions. Some issues for consideration in planning a situation and needs analysis are:

#### 1. Purpose

Be clear about why you are conducting a situation and needs analysis. What questions do you expect it to answer? Why do you need this information? Is there a more appropriate way of obtaining the information, a prevalence or costing study for example? What will you do with the information? How will it be disseminated and used? How will it help to improve diabetes care in the future?

#### 2. Focus

What aspects of diabetes will the situation and needs analysis focus on:

- services (type and scope, number, distribution, quality, accessibility)
- availability of medications, supplies
- costs
- workforce numbers and distribution
- information and research deficiencies

#### 3. Scope

Will the situation and needs analysis be conducted nationally or will it be applied selectively to particular geographic areas ie urban/rural, or particular community groups eg ethnic groups. Will it examine what is happening in primary care, specialist services or both?

#### 4. Specific Aim/s

What are the explicit aims of the situation and needs analysis? List precisely what it will achieve ie what information will it provide?

## **5. Parameters to be assessed**

What will be measured, assessed, counted, audited or analysed in order to achieve the aims of the situation and needs analysis?

## **6. Methods**

What strategies and techniques will be employed to collect the required information? Options include, but are not limited to quantitative or qualitative surveys, focus groups, interviews with key personnel, audit of existing records, supplies, equipment or facilities.

## **7. Use of results**

Deciding how and to whom the results will be disseminated and how they can best be used will help determine what to focus on, what to assess and which methods are best suited to answer the questions being asked.

## MODULE:

# CONDUCTING A BASELINE PREVALENCE SURVEY

## Rationale:

The rationale for conducting a baseline prevalence study of diabetes is similar to the rationale for conducting a situation and needs analysis. Baseline prevalence data are needed to:

- determine the extent of the diabetes problem
- determine the prevalence of diabetes/NCD risk factors which can be used to predict the magnitude of future diabetes and related health problems
- estimate the need for services
- provide a sound rationale for a national effort to reduce the burden of diabetes
- as a baseline for future comparisons

Type 2 diabetes is a major underlying cause of cardiovascular disease and shares many common risk factors with cardiovascular disease eg obesity, lack of physical activity, and inappropriate nutrition. These factors make it critical to include parameters of cardiovascular risks in the design of diabetes prevalence surveys.

## Purpose:

This module aims to assist countries which do not have current diabetes data, or data on the prevalence of associated risk factors, to explore the practical considerations involved and examine the options, feasibility and practicalities of conducting a prevalence survey.

## Potential Application:

- Health authorities
- Senior diabetes medical clinicians and clinical epidemiologists
- National diabetes organisations

## Links:

*Conducting a Baseline Prevalence Survey* links with *Early Diagnosis* in that a prevalence study will invariably diagnose many people earlier than they would normally have been diagnosed. This in turn has implications for *Routine Care* and the adequacy of the diabetes workforce and services to cope with an increased load. Not least, it links with *Preventing the Problem: the High Risk Approach* as people with identifiable risk factors for diabetes but who have not yet progressed to diabetes will require counseling about their risk status and how to improve it.

## Suggested Reading:

WHO (2001). Noncommunicable Diseases and Mental Health Surveillance: The WHO STEPwise Approach to Surveillance (STEPS) of NCD Risk Factors. World Health Organization, Geneva.

WHO (2010) STEPwise approach to chronic disease risk factor surveillance (STEPS). World Health Organization, Geneva. Available at: <http://www.who.int/chp/steps/riskfactor/en/index.html>

WHO and IDF (2006). Definition and diagnosis of diabetes mellitus and intermediate hyperglycemia: report of a WHO/IDF consultation. World Health Organization Geneva. Available at: [http://www.who.int/diabetes/publications/Definition\\_and\\_diagnosis\\_of\\_diabetes\\_new.pdf](http://www.who.int/diabetes/publications/Definition_and_diagnosis_of_diabetes_new.pdf)

## CONSIDERATIONS FOR:

### CONDUCTING A BASELINE PREVALENCE SURVEY

Although the advantages associated with having accurate and up to date prevalence data on diabetes are widely agreed, many countries do not have such data. Collecting, analysing and managing large volumes of clinical data is labour intensive and costly. Processing, storing and transporting samples may be logistically difficult. Procedures must be standardised. Epidemiological expertise is required to ensure adequate sample sizes and appropriate sampling procedures to ensure that those tested represent the gender and age distribution and other relevant demographic and social parameters of the population. Confidentiality issues need to be addressed and survey staff need to be trained to consistent protocols.

In discussing the logistics of conducting a baseline prevalence survey, it may be useful to consider the following:

#### 1. Rationale for conducting the survey

Develop a brief but clear and convincing rationale in collaboration with other key stakeholders. Include some background data on the burden of diabetes, this may be derived from the diabetes literature, from existing local data or from information obtained from local expert consensus. Once documented, this can be used for:

- guiding the direction and development of the project
- convincing other stakeholders of the need
- approaching potential funding sources to assist in financing the project

#### 2. Scope

What other parameters will the survey assess in addition to basic demographics and diagnosis of diabetes and intermediate hyperglycaemia (impaired glucose tolerance and impaired fasting glucose). Height and weight are important to measure but will blood pressure and other physical and laboratory assessments be included as well? What, if any, lifestyle factors will be examined? Will provision be made to include the collection of data on nutrition habits, tobacco use, alcohol consumption and exercise?

A prevalence study is a wonderful opportunity to collect a wealth of diabetes and related data but remember that collecting, collating, managing and disseminating data is expensive and time consuming. So, before broadening the scope of the project, ask yourself and your collaborators, if and how the information you want to collect will be used.

#### 3. Focus

Who will be surveyed? Inclusion/exclusion criteria must be established and should include an upper and lower age limit. The sample should be representative of the whole community and it should be noted that if the prevalence survey focusses on particular subgroups in the community, the results can only be applied to similar groups and cannot be extrapolated to the whole community.

#### 4. Aim

Agree on and clearly state and document the aim of the survey. This should specify the focus of the survey and give an indication of its scope.

## 5. Sampling

Sampling is about getting the appropriate number of people, and a balance across gender and age groups, rural and urban dwellers, socio-economic levels and ethnic backgrounds to accurately represent the overall composition of the population. For example, if 30% of the total population is aged between 35 and 55 years then 30% of the survey sample should be aged between 35 and 55 years.

If sampling is not done properly, the results will be skewed and will not accurately reflect the true prevalence of diabetes. There are recognised statistical sampling methods and models for this purpose. Their application requires specialised expertise. Most governments have a Bureau of Statistics which collects and manages their country's data on population demographics, distribution and characteristics and which may agree to be involved.

*Note: A home visit to prospective participants prior to the survey may be useful in raising participation rates from the households or individuals selected by the random sampling method.*

## 6. Data collection and management

### DESIGNING DATA COLLECTION FORMS

Data collection forms should be kept as simple as possible. Items of data to be collected will be determined by the scope, focus and aim of the project with specific data fields being negotiated among stakeholders.

### ORDERING OF DATA FIELDS

In designing the data collection form/s, it is vital to consider the logistical flow of the data collection at the survey site. For example, a person attending for assessment will first have to register their presence at the survey site and give their personal details for identification purposes. Therefore, the demographics will come first on the survey form. The following fields on the data collection form should be in the same sequence as the survey subject's progress through the assessments ie height and weight measurement, blood pressure, blood collection etc. Attention to this level of detail will enhance the efficiency of collecting and recording the data and will help minimise the number of data fields not completed. An example of a data collection form can be found at the end of this module on page 24.

*Note: The statistical programme for entering and analysing the data should also follow the same sequence for the same reasons.*

### DATA MANAGEMENT

Who will collect the data? Where will it be held? Who will analyse it, and perhaps even more importantly, who will decide what should be analysed and in what way? Who will be able to access the data and for what purpose? How will the results be reported and to whom? Who will finance the data management and what ethical issues must be considered and resolved?

## 7. Assessment Issues

Explicit protocols to guide the manner in which assessment procedures are carried out, must specify the steps involved and the correct technique to use. These should be based on sound evidence and should give thorough consideration to issues such as:

- what test/s will be used? For a prevalence survey, the gold standard for diagnosing diabetes is still the oral glucose tolerance test (OGTT). However, unequivocally elevated fasting blood glucose levels can be used, and glycated haemoglobin (HbA1c) is now being recommended as an option for diagnosing diabetes.

- will all survey participants have this test or will some pre-screening such as capillary blood glucose and HbA1c be used to identify those who obviously have diabetes leaving only those in whom the diagnosis is doubtful to have an OGTT.
- what diagnostic criteria will be used to diagnose diabetes?
- if blood pressure is to be assessed, will it be taken lying or sitting, after a period of rest?

## 8. Laboratory Issues

Many practicalities have to be thought through with regard to laboratory issues. For example:

- the supply, storage, and transport of reagents
- identification of samples
- transportation and storage of blood and urine samples
- standardisation of laboratory assays
- reporting results

Storage and transport of reagents and samples usually requires refrigeration and may require centrifuging and then freezing. Adequate storage space and transportation must be arranged to comply with the specified conditions well in advance of the survey.

Laboratory assays and reference ranges must be standardised and if possible all samples should be analysed in the same laboratory. Consideration of mechanisms to ensure accurate sample identification and verification is essential to ensure minimal error and avoid misdiagnoses and to maintain the highest possible integrity of data for statistical analysis.

## 9. Location and set up of survey venue

The location of the survey venue/s must be accessible to the people expected to attend for assessment. If it is within the resources of the project, providing free transport from central locations from which the survey participants are drawn may help increase attendance and reduce the number of defaulters.

The survey venue must be clean, safe, large enough to allow a series of data collection 'stations' to be set up and for people to move freely between them. It must have adequate provision for privacy and for segregation of the sexes where this is required to satisfy local custom and community values. Seating must be provided for people who are waiting for long periods. Likewise toilet facilities must be provided if there are none close by.

For the sake of efficiency and smooth flow of people through the steps of the survey, the survey data collection stations need to be arranged in a logical sequence. That is, the same sequence as the assessments eg demographics, height/weight, blood pressure, blood collection. An example of a survey venue set up is included on page 25 at the end of this module.

## 10. Training of survey staff

Survey staff must be specifically and systematically trained according to survey protocols and procedures which set out consistent and documented standards and criteria. Each member of the survey team should have a role description which specifies the specific tasks they are to perform and other general areas of responsibility. In addition to the mix of clinical skills required for performing the various assessments and handling of samples and data. Survey staff training should include:

- crowd management and general safety
- data recording
- infection control
- identification of survey participants and labelling of samples

Ideally, the training of survey staff should be conducted in a group, preferably at the survey site with staff being given an opportunity to 'rehearse' their roles.

## 11. Ethical and safety considerations

A number of ethical considerations have already been touched upon including

- data ownership
- infection control
- informing participants of results

### ■ **Informed consent**

The need to obtain informed consent from survey participants must be considered. Ethical requirements relating to this will no doubt vary from country to country.

### ■ **Informing survey participants of the results of their investigations**

People participating in the survey must be told their results as soon as possible. Those who have diabetes or any other abnormalities will need treatment, advice or referral. Those who are not found to have any abnormalities may be worrying about their health status and also need to be informed of their results as soon as possible. Protocols as to how this will be handled are essential to ensure accurate and speedy delivery of results and should specify who will be responsible and need to be developed and agreed upon well in advance of the prevalence survey taking place.

### ■ **Putting mechanisms in place to care for people found to have a problem**

A major ethical consideration in conducting a prevalence survey is that it will invariably find substantial numbers of people who have diabetes but had not been diagnosed prior to the survey. Prior consideration and arrangements are essential to determine:

- how these people will be managed?
- are there sufficient diabetes services to provide them with medical treatment and self-care education?
- are there adequate supplies of oral agents and insulin available to treat them?

## 12. WHO STEPS surveys

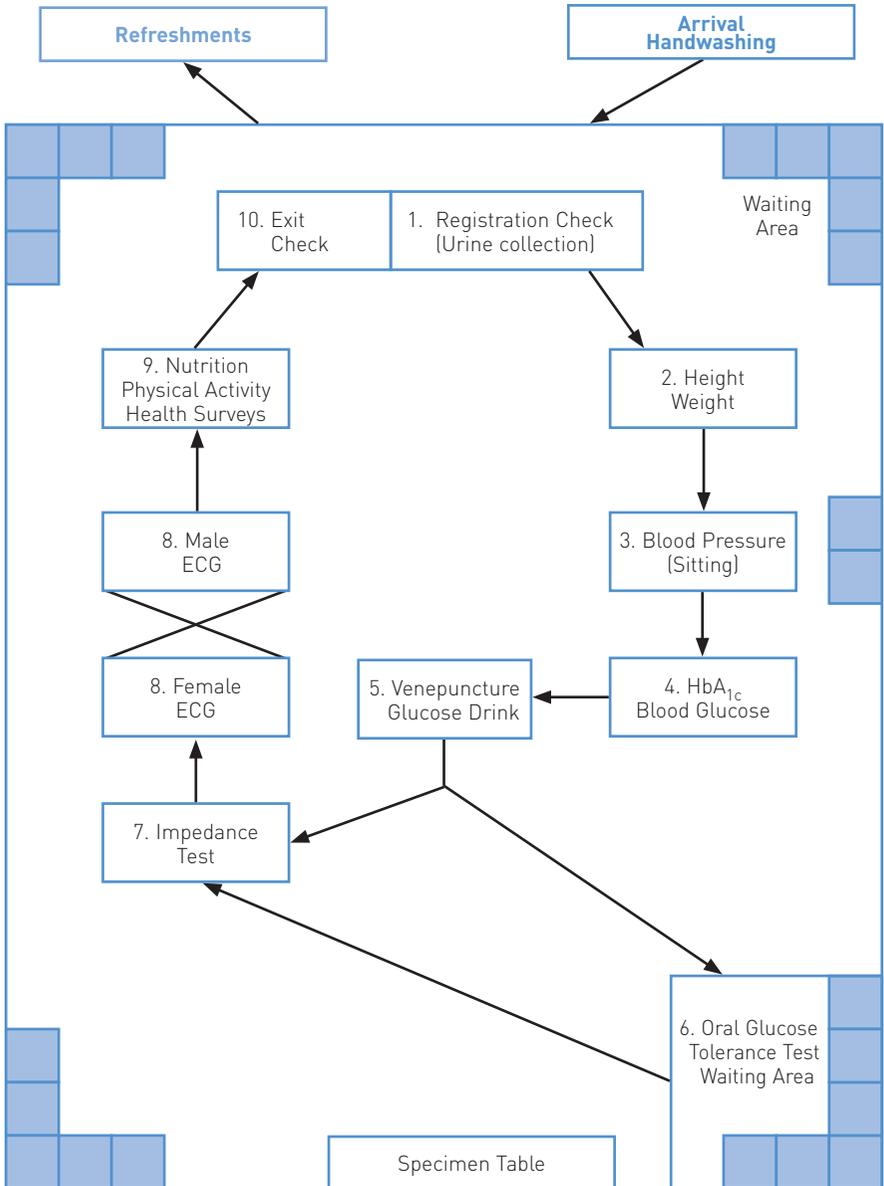
Another option for carrying out a prevalence survey is the WHO STEPS program. This details different ways of obtaining data on the prevalence of diabetes and its risk factors ranging from:

- Step 1: questionnaires on demographics and lifestyle habits
- Step 2: questionnaires plus anthropometric measures such as height, weight, BMI
- Step 3: questionnaires, anthropometric measures and finally blood tests to assess biomedical parameters of risk such as cholesterol, blood glucose etc

WHO STEPS Surveys have been conducted in a number of countries including in Africa, Europe and the Western Pacific Region.



# EXAMPLE OF A PREVALENCE SURVEY PROCEDURE



## MODULE:

# ASSESSING THE COST OF DIABETES

### Rationale:

As governments all over the world are struggling to provide affordable health care in the face of rising costs, more and more focus is concentrated on containing health care expenditure and eliminating low-value services. In low and middle-income countries, where the expenditure of donors and governments favour communicable diseases, data about the prevalence and costs of diabetes are vital to bringing about reform. Government leaders need solid economic data from their own or similar countries to justify investing in diabetes care and prevention. At the highest levels of many governments, the ability of investment in diabetes to accelerate economic growth may be more influential than data on the impact on health expenditures or the effects on mortality and quality of life.

### Purpose:

This module aims to assist those considering economic studies by reviewing the methods and resources that are available to them.

### Potential Application:

- Health authorities
- Private funding organisations
- General Practitioners, Diabetes Specialists, Clinics/Hospitals, Diabetes Centres
- Ministries of Finance and Development
- Advocates and advocacy organisations
- Donor agencies and organisations
- Policy analysts and researchers

### Links:

*Costing Diabetes* can be used in conjunction with or applied to data obtained from clinical data collection, see *Collecting Diabetes Data*. Assessing the cost of diabetes is also an important component of *Evaluating National Diabetes Programmes*.

### Suggested Reading/References:

IDF, 2010, Diabetes Impact Study.

Available at: <http://www.idf.org/economics/diabetes-impact-studies>

IDF, Diabetes Atlas. 2009, International Diabetes Federation: Brussels. 2009.

Available at: <http://www.diabetesatlas.org/>

Suhrke, M. Nugent, R.A. Stuckler, D. Rocco, L. (2006) Chronic disease : An economic perspective. Oxford Health Alliance, London. Available at:

<http://www.oxha.org/knowledge/publications/oxha-chronic-disease-an-economic-perspective.pdf>

## CONSIDERATIONS FOR:

# ASSESSING THE COST OF DIABETES

Cost of illness studies are useful in describing the magnitude of a health problem such as diabetes in economic terms. They have been used effectively to build the case for why governments should invest in reducing the impact of diabetes and its complications.

Costs can be calculated in different ways and focus on different aspects of health care. A cost of illness study is a descriptive study that will give an indication of the cost of diabetes at a particular point in time. When a study assessing costs in relation to outcomes compares costs between two treatment regimens over time, it is called a 'cost-consequence', cost-effectiveness, cost-utility or cost benefit study, depending on which outcome measures are collected and how they are analysed.

## 1. Focus / viewpoint of the analysis

Usually, analyses take the perspective of the medical care system, the economy or society as a whole. When presenting data from a cost of illness study it is essential to make clear from the outset whose viewpoint the analysis will take. The different viewpoints which can be considered include:

- Society as a whole
- Government bodies such as ministries of health or finance
- Government in general
- Employers
- The person with the illness
- Private insurers, and service providers or carers, including hospitals.

It is important to understand that, from the societal or whole-government perspectives, costs such as the loss of ability to work due to a diabetes complication like an amputation or a stroke, might well be small or non-existent. After all, if one person loses his or her job, an unemployed person in the society will benefit by taking over the job. A loss to one person is a gain to another. This is especially true in places where governments and employers pay no disability insurance or old-age pensions, and where unemployment is high.

In low and middle income countries, where most medical care is paid out of pocket by patients and their families - and where medical services can be difficult to access - an institutional or Ministry of Health (MOH) perspective will miss expenditures for necessities such as costs of travel and purchases from private pharmacies, which can be very large for families, but not recorded in hospital records. A Ministry of Finance perspective might differ from a MOH perspective because the cost of medicines to the MOH that buys them may look like a benefit to the company that makes the medicines, and like a 'wash' to the finance ministry that sees drug manufacturing as just another industry that creates jobs and generates taxes. Consequently it is better, when taking a societal perspective, to conceptualise the impact of diabetes as a drag on economic growth eg:

- The extra taxes and health insurance premiums required to treat preventable diabetes complications

- The extra costs to employers of avoidable medical care and less productive workers
- The inability of families to feed, cloth, and educate their children, especially girls, because of medical expenses
- The social disruption caused by family destitution and its sequellae such as crime, sexually transmitted disease, and social unrest.

The economics literature shows that chronic diseases like diabetes retard economic growth substantially. However, the studies necessary to estimate an effect on economic growth require data from a large number of countries and are technically quite difficult. In a single country or area, it is therefore better to document the social and financial effects described above, which can be quantitatively linked to economic growth through equations derived from multi-national data.

Please note that, for most welfare economists most of the time, the term, “cost,” has a special meaning ie a net loss of overall social utility. Cost in this theoretical sense is a “shadow cost” that is not directly observable in the real world. Payments for medical services are better described as “expenditures” than as costs. Note also that the prices charged for medical services can be much different than the expenditures required to produce them. Finally, in low and middle income countries, a dollar or a euro often buys more services than it does in the USA or France. Therefore, to facilitate comparisons among countries, expenditures are often recalculated into “international dollars,” which attempt to correct for this. However, internationally traded products like drugs and medical devices can be more rather than less expensive in poorer countries, so the conversion to international dollars can be misleading.

## **2. Timeframe and study size**

Expenditures are usually measured retrospectively so you will need to decide how far back you want to dig for data, and how many subjects to include. Expenditures are usually expressed as annual rates. It is possible to collect data over a 3 month period and then multiply by 4 to estimate an annual expenditure rate. However, the most expensive major medical events like heart attacks and amputations are relatively infrequent, so several years of data may be required to obtain statistically stable estimates. This is particularly true in wealthy countries, where a small minority of hospitalizations and patients can accumulate enormous expenditures: if these high-expenditure cases are missed, mean expenditures will be underestimated; if one or two are included by chance within a small sample, expenditure estimates will be unstable and overestimated. When data on the utilisation of services are collected by interviewing patients - often the best approach when written records are limited and/or subjects receive medical care from many sources—most patients will not be able to remember the details of ambulatory medical care longer than about 3 months, or remember major events and hospitalizations longer than about 1 year. In these cases, larger study samples should be considered. IDF’s experience in low-income countries suggests that a sample of 500 cases and 500 non-diabetic controls should be adequate. In wealthy settings, ten thousand or more cases may be required to achieve statistical separation for inpatient expenditures.

### 3. Study Designs

It can be relatively easy to identify medical expenditures for people who have diabetes, but harder to estimate the portion of these expenditures that were actually caused by diabetes. For example, although the cardiovascular complications of diabetes are by far the largest generator of expenditures among Europeans living in wealthy countries, cardiovascular disease is quite common in older persons who do not have diabetes, and therefore could have occurred anyway in persons who happen to have diabetes.

One approach to estimating medical expenditures caused by diabetes is to identify all the payments for medical care made by person living with diabetes and trying to decide which were “for” diabetes and which were for other diseases. However, it is very difficult to decide whether, say, a heart attack or stroke was caused by diabetes or would have happened anyway. On the other hand, the expense of caring for many non-diabetic conditions (eg tuberculosis or influenza) is higher when diabetes is present. Therefore, it is easier and more accurate to identify expenditures for diabetes indirectly, by comparing total expenditures for persons diagnosed with diabetes to total expenditures for persons without diabetes, controlling for age and sex. The easiest way to do this is to select a sample of people with diabetes and then identify a control group matched to the cases with diabetes by age (+/- a few years) and sex. Studies using this design are usually much more accurate than direct assessments of diabetes costs.

Case-control designs are especially easy when there is a registry of people with diabetes. In the absence of a comprehensive database, one can start by identifying the cases with diabetes from, say, clinic records, and then find controls by asking the cases to identify the persons living nearest them of the same sex who are about the same age. Do NOT attempt to find controls from among other clinic visitors because these persons will be sicker than the general population, which will cause expenditures for diabetes to be underestimated.

The IDF has developed a standard protocol and tool-box for case-control studies of the economic impact of diabetes in low and middle-income countries, based on personal interviews. The IDF design does not require access to medical records. Resources in variety of languages will be posted on the IDF website at <http://www.idfecon.org/> as they become available.

The IDF methodology ascertains the use of ambulatory, inpatient and emergency medical services; out-of-pocket payments for services, drugs, tests, travel, and home care; impact of ill health on employment, ability to work, education, nutrition and family wealth; sources of funds to pay for medical care; health utility (quality of life); the quality and efficiency of medical care received; access to and availability of medical care, including essential drugs and testing; self-care including blood glucose monitoring; adherence to medical advice; and use of traditional healers and remedies. Disease impacts are measured in the subject’s family as well as on the subject, including impacts on the nutrition and education of the children. Because interviews cannot assess the full cost of producing the services that subjects used, external estimates of institutional costs must be added to the interview results.

## MODULE:

# ASSESSING COMMUNITY AWARENESS

### Rationale:

Without knowledge of diabetes and the lifestyle risks associated with it, it is difficult indeed for individuals within the general community to self-assess their risk and/or to seek professional assessment and advice about their risk status and strategies for reducing their chance of getting diabetes.

Raising community awareness is a vital strategy for identifying people at risk of diabetes and achieving earlier diagnosis of diabetes but it is impossible to know how best to address this issue without first knowing what are the community's perceptions and misconceptions about diabetes and its antecedent risks regardless of whether these risks are modifiable or non-modifiable. In order to develop and implement truly effective community awareness raising campaigns it is important to first determine the current status of community knowledge and perceptions about diabetes.

### Purpose:

This module presents a simple generic tool to assist in assessing community awareness as a basis for developing targeted community awareness raising messages.

### Potential Application:

- Health authorities - public health planners
- National diabetes organisations
- Health promotion/health education staff
- Health care providers

### Links:

Links with and underpins Developing a Community Awareness Campaign.

### Suggested Reading:

Coulson FR, Ypinazar VA, Margolis SA. (2006). Awareness of risks of overweight among rural Australians. *Rural Remote Health*. 6:514

Murugesan N, Snehalatha C, Schobhana R, Roglic G, Ramachandran A. (2007). Awareness about diabetes and its complications in the general and diabetic population in a city in southern India. *Diabetes Research and Clinical Practice*. 77: 433-437.

## CONSIDERATIONS FOR:

### ASSESSING COMMUNITY AWARENESS

It is not necessary to conduct a full scale costly scientific study to obtain general information about community knowledge of diabetes. For the purpose of gaining a sense of community perceptions, possible misconceptions and significant knowledge gaps it is sufficient to conduct focus groups or basic paper based surveys. However, it is important to note the results will be skewed, and therefore not representative of the whole population, unless care is taken to ensure a balance of participant representation from different age groups, socio-economic and educational status and geographical location. Alternatively, if certain community groups or age bands within the total population are to be targeted, it is reasonable to choose a survey or focus group sample from within that group.

Survey instruments and focus group guides do not need to be complex. An example of a tool for assessing community awareness and an example of a tool for determining sources of health information are included at the end of this module. Other considerations include:

#### 1. Purpose

Why does this need to be done? How will the information be used to the best advantage?

#### 2. Who should be involved?

Are there diabetes consumer or professional organisations, government health promotion services or others who should be involved? Are there community organisations, community health care providers such as primary care professionals who could assist in developing and/or recruiting community members and administering surveys for the assessment.

#### 3. Scope

Will the scope be comprehensive? Or will it be limited to sub-sections of the population eg adults, children, women, men, rural or urban dwellers, labourers, or office workers, particular ethnic or cultural groups? This decision will be influenced by the scope of the proposed community awareness campaign and may be limited by available resources and/or particular community groups already identified for targeted action because of their high risk status.

#### 4. Focus

Are there particular aspects of community knowledge and awareness that need to be targeted specifically eg knowledge of symptoms, knowledge of risk factors.

#### 5. Specific Aims

To ensure that there are agreed and common goals for assessing community awareness which can be communicated widely, discuss and document specific aims in collaboration with key stakeholders.

## 6. What to ask?

Invariably the quality and usefulness of the answers to survey or focus group questions are only as good as the questions that are asked. Carefully design your questions to tell you what you need to know. To assess community awareness, questions about perceptions of what causes diabetes, knowledge of symptoms, risk factors, and possible consequences of diabetes eg amputation etc will yield important information about public perceptions and misconceptions about diabetes. To obtain further information, it may also be useful to include questions about where people obtain their information about health generally. Surveys or focus groups of this nature can be anonymous but consideration needs to be given to whether or not it would be useful to collect demographic information which may influence people's beliefs, such as:

- geographic location by region or postcode or urban/metropolitan
- ethnic origin or mother language
- religion

## 7. Methods

Select methods which are capable of achieving the aims of the project and which will allow you to be confident that you are obtaining reasonably accurate and reliable information which:

- is feasible to collect within the available resources allocated to this project
- will produce data which are easily analysed statistically or easily grouped according to recurring themes

Paper based surveys are more suited to collecting quantitative data and not so suited to the collection of qualitative information which may need interpretation and which is not as readily adaptable to entering directly into a database. Focus groups are useful for obtaining qualitative information and can assist with the identification of key issues and recurring themes. Focus groups are particularly useful when attempting to canvass the knowledge or needs of diverse cultural groups. However, to optimise the reliability of the information being gathered, it is essential to:

- ensure that focus group participants appropriately represent the population to be targeted in the community awareness campaign.
- pilot test and refine the survey questionnaire based on feedback from the pilot prior to using widely.

## 8. Analysing the results

Look for recurring themes and group them into like categories. Compare differences in beliefs on the basis of age, urban vs rural location, ethnic groups etc as you may need to vary your approach to developing community awareness messages depending on these factors. In multicultural societies, language and religious beliefs may need to be taken into account in order to properly inform planning for a community awareness campaign

## EXAMPLE OF A TOOL FOR ASSESSING COMMUNITY AWARENESS OF DIABETES

1. Have you ever been told that you had diabetes or a high blood sugar level?	Yes/No
2. Year of birth or age (in years)	_____
3. Gender	Male                      Female
4. Do any of your relatives have diabetes?	Mother                  Yes/No Father                   Yes/No Sister                    Yes/No Brother                   Yes/No Child                     Yes/No
5. Please list 3 possible causes of diabetes	1) _____ 2) _____ 3) _____
6. Do you smoke tobacco everyday?	Yes/No
7. Do you exercise or play sport regularly (eg. at least once per week)?	Yes/No
8. Please name 3 symptoms of diabetes	1) _____ 2) _____ 3) _____
9. What health problems can diabetes cause?	_____ _____
10. Please list 3 risk factors for diabetes	1) _____ 2) _____ 3) _____

# EXAMPLE OF A TOOL FOR IDENTIFYING SOURCES OF HEALTH INFORMATION

## HEALTH INFORMATION SURVEY

1. Have you heard anything about diabetes? Yes    No
2. If yes, where did you hear it?
- |                          |                     |                      |
|--------------------------|---------------------|----------------------|
| radio                    | doctor              | other hospital staff |
| teacher                  | television          | internet             |
| health education officer | church/church group | newspaper            |
| nurse                    | pamphlet            | relative/friend      |
| magazine                 | dietitian           | drama                |
- social club, please specify: \_\_\_\_\_
- other, please specify: \_\_\_\_\_
3. Where would you like to learn about diabetes from?
- |                          |                     |                      |
|--------------------------|---------------------|----------------------|
| radio                    | doctor              | other hospital staff |
| teacher                  | television          | health officer       |
| health education officer | church/church group | newspaper            |
| nurse                    | pamphlet            | relative/friend      |
| magazine                 | dietitian           | drama                |
- social club, please state: \_\_\_\_\_
- other, please state: \_\_\_\_\_
4. Do you think there is anything you can do to reduce your chances of getting diabetes? Yes    No
5. If yes, please state: \_\_\_\_\_

# PREVENTING THE PROBLEM

- 42** Primary Prevention:  
The Individual /High Risk Approach
- 46** Primary Prevention:  
Environmental Approaches

## MODULE:

# PRIMARY PREVENTION: THE INDIVIDUAL / HIGH RISK APPROACH

### Rationale:

Over the past 10 years or so a substantial body of good quality evidence from randomised controlled trials in a number of countries has demonstrated conclusively that the onset of type 2 diabetes can be significantly prevented or delayed in people with impaired glucose tolerance (IGT). Successful interventions promoting good nutrition, increased physical activity and weight reduction through individual and groups programmes have been shown to be cost effective. Certain medications have also been shown to work in preventing type 2 diabetes.

Diabetes and cardiovascular disease share many common risk factors and investing in preventative activities that bring returns in more than one disease is likely to have more appeal for Ministries of Health. Therefore, designing primary prevention activities that adopt an integrated approach which includes a focus on both diseases is advisable.

Unfortunately, although intensive international research is focusing on preventing type 1 diabetes, there is currently no feasible way to identify early signs of type 1 diabetes and no widely available prevention interventions for this type of diabetes.

### Purpose:

To assist in considering imperatives and options for reducing diabetes and cardiovascular risk factors in individuals and susceptible community groups who already have these risk factors.

### Potential Application:

- Health Authorities eg public health, health promotion and NCD prevention
- Diabetes organisations

### Links:

Links with *Community Awareness and Early Diagnosis*

### Suggested Reading:

Li G, Zhang P, Wang J, et al (2008). The long-term effect of lifestyle interventions to prevent diabetes in the China Da Qing Diabetes Prevention Study: a 20-year follow-up study. *Lancet* 371(9626):1783-1789.

Lindstrom J, Ilanne-Parikka P, Peltonen M, et al. (2006). Sustained reduction in the incidence of type 2 diabetes by lifestyle intervention: follow-up of the Finnish Diabetes Prevention Study. *Lancet* 368(9548):1673-1679.

Crandall JP, Knowler WC, Kahn SE, et al (2008). The prevention of type 2 diabetes. *Nat Clin Pract Endocrinol Metab* 4:382-93.

Ramachandran A, Snehalatha C, Yamuna A, et al (2007). Cost-effectiveness of the interventions in the primary prevention of diabetes among Asian Indians: within-trial results of the Indian Diabetes Prevention Programme (IDPP). *Diabetes Care* 30(10):2548-2552.

## CONSIDERATIONS FOR:

### PRIMARY PREVENTION: THE INDIVIDUAL / HIGH RISK APPROACH

The evidence that diabetes can be prevented or significantly delayed in high risk individuals through cost effective lifestyle interventions (and to a lesser extent medication) is irrefutable.

The question is not so much what to do but how to do it – how to find people with the relevant risk factors and how to translate the lifestyle interventions that have been so effective in the controlled trial setting into everyday practice.

Improving dietary habits, reducing weight and increasing physical activity are all vital factors. The salient research evidence is around intensive programs of counseling and education of at risk individuals to achieve a modest weight loss of around 5-7% through appropriate nutrition and exercise /physical activity. Other approaches targeting particular community settings such as schools, workplaces and women's groups have been found to have some benefits. Community education programmes such as social marketing have limited effectiveness and are very expensive.

The individual/high risk approach to diabetes prevention is very complex. To clarify what needs to be done and what can be done through a diabetes prevention programme, it may be useful to consider:

#### 1. Rationale

What is the purpose and the potential benefits of preventing type 2 diabetes. A good case can be made from the literature and it is worth documenting the rationale and evidence in a summary form for use as an advocacy tool and business case. This should be predicated on the fact that:

- it is possible to prevent or delay the onset of type 2 diabetes
- the cost of not intervening will be far greater than the cost of intervening

#### 2. Focus

It will be important to decide on the scope of the prevention programme at an early stage because this will determine who needs to be involved and how the programme will be conducted. For example, will the programme target high risk individuals or high risk community groups? If it targets high risk individuals, how will they be identified without the need for expensive risk factor screening of the whole population? If it targets high risk community groups, what is the best way of reaching them?

#### 3. Finding individuals at risk of diabetes

Identifying practical and feasible ways of finding people in the community who may be at high risk of developing type 2 diabetes has been a pressing problem ever since the emergence of the prevention evidence for type 2 diabetes. The best method we currently have is using risk scores which have been developed based on evidence from the prevention trials combined with population demographic data. A number of risk scores including the original Finnish risk assessment tool (FINDRISC) are available internationally.

Multimedia campaigns based on information about diabetes risks may be useful in supporting efforts to encourage individuals to check their risk status against a suitable risk score. But, if resources are limited, a multi-media prevention awareness campaign will not be affordable.

In this case, consider targeting people who may be in a position to *influence* people who are at risk of diabetes eg:

- health care providers in the community such as primary care physicians, community nurses, maternal and child health nurses, community pharmacists
- people who already have diabetes and may be able to influence their family members and friends who are at risk of diabetes
- religious and community leaders
- royalty, political leaders, celebrities eg sports stars.

#### **4. Targetting at risk groups**

A lead agency needs to be identified to take overall responsibility for developing, monitoring, evaluating and reporting on the campaign or programme and liaising with other stakeholders to gain their support and involvement. This could be the Ministry of Health. Alternatively, it could be led by a national diabetes organisation. Either way, decisions need to be made about which group or groups to target. This will be based on a number of factors including, the group's susceptibility to diabetes and/or other unifying factors such as ethnicity, social disadvantage or age. Whatever group is to be targeted, regardless of whether it is an indigenous or ethnic minority or a socially disadvantaged community, there are principles which need to be taken into account when developing the prevention programme. These include understanding and tailoring the programme to:

- cultural, ethical, moral values and norms of the target group
- educational, language and learning capabilities
- the work, physical and social environment most commonly encountered by the group

Another key consideration is thinking about and targeting those who may be able to influence the group's behavior eg community leaders, church leaders, local heroes, employers.

#### **5. Workplaces as setting for preventative action**

Most people work for around 40 hours per week (equivalent to almost 40% of their waking hours) for around forty years of their life making workplaces make an excellent setting for risk reduction programmes. Further, the workplace may be the vector that causes or exacerbates chronic diseases risks.

Due to the rising economic costs of lost productivity from absenteeism, 'presenteeism' (being at work but not able to perform well due to stress or illness), staff turnover and early retirement, employers are showing an increasingly keen interest in workplace health programmes. As a result, there is a growing body of literature about the benefits of these initiatives and it is timely to encourage employers to focus on a risk factor (smoking, nutrition, physical activity and stress) approach to reducing the impact of diabetes and related conditions on the workforce. This should include both a risk assessment and risk reduction component

#### **6. Who else should be involved**

The short answer to this is everyone but in reality this will depend on the scope and focus of the programme, on how much support can be generated for it, and on how strong are the interests which may oppose it. Either way, for success of the programme the involvement of the following is desirable:

- the government health department (non-communicable disease unit)
- individual key leaders and experts in health promotion/prevention
- public health units outside government health departments ie in universities
- national diabetes associations / organisations
- professional diabetes organisations
- key expert diabetes clinicians and centres
- where available IDF and WHO contacts and in-country officers
- key primary care centres and personnel
- national heart and/or stroke organisation
- specialty groups eg obesity organisations
- intersectoral government departments ie education, agriculture
- food industry

An often overlooked resource for community awareness, early diagnosis and prevention activities are people who already have diabetes. People with type 2 diabetes can be trained to give risk reduction messages to their immediate relatives who are automatically at higher risk than others in the community who do not have a close relative with diabetes.

There may also be non-government and charitable organisations operating in the community which can be highly influential in lobbying, fundraising, and practical implementation of prevention programmes. These include Lions and Rotary Clubs and local women's groups. Various industries, large corporations and large and small businesses may also be approached for support.

## 7. Implementation

A staged implementation plan needs to be developed to guide the programme. This should include specification of aims or goals, principles, strategies, monitoring and evaluation processes and mechanisms and should also specify which agency, organisation, or group is responsible for the various aspects and components of the programme.

## 8. Evaluation

A practical evaluation strategy should be developed along with the implementation plan and should specify both process and outcome indicators.

Process indicators may include the number of health practitioners (eg primary care physicians) and/or community health centres, schools, clubs, or workplaces participating in the programme. The ideal endpoint indicator of a diabetes prevention programme would be a reduction in the annual incidence of type 2 diabetes and diabetes-related complications. As this would take several years to achieve it is acceptable to measure surrogate endpoints such self reporting of increased physical activity, or weight reduction and reductions in the purchase and consumption of alcohol and tobacco. In the case of primary care physicians or community workers providing individual counseling and support for improved nutrition and increased physical activity, the provider should endeavour to ensure that the individual's progress is monitored and measured.

## MODULE:

# PRIMARY PREVENTION - ENVIRONMENTAL APPROACHES

### Rationale:

Since World War II, and particularly in the last 20 years or so, massive secular changes and technological advances have altered the way we live, eat, work and play. Although the rate of change may vary from country to country, globalisation has ensured that no country is exempt from the impact of urbanisation, cars, high density - low nutrient foods and sedentary work and leisure practices. The net result has been an explosion of obesity, heart disease, diabetes, cancer and chronic lung diseases which, when combined, currently account for 60 % of the world's deaths; countless years of disability and suffering; everything from minor family hardship to extreme poverty and transgenerational loss of 'life chances'; an unsustainable drain on national health systems, and loss of national income resulting from lost productivity. There are solutions if we are prepared to act on them by engaging with new stakeholders and partners –remembering that:

- 80% of diabetes and heart disease can be prevented
- these diseases were generated in our societies not in our health systems and can only be resolved by a comprehensive community and societal approach
- diabetes and other chronic diseases share common causes with climate change eg car dependency and are an important input to economic sustainability

### Purpose:

To raise awareness and a sense of urgency of the imperative need to address diabetes and chronic disease 'vectors' in our physical, food, work and social environment and some of the ways in which this might successfully be done.

### Potential Application:

- Health Authorities eg public health, health promotion and NCD prevention
- Other governments sectors such as Transport, Urban Planning, Local Government
- Diabetes organisations
- Employers eg big business, business councils and associations

### Links:

Links with *Community Awareness and Who* should be involved. It is important to note that an 'environmental' approach to primary prevention of chronic diseases will also be beneficial in assisting people who already have diabetes and other chronic diseases to lead healthier lifestyles and avoid or delay the onset of complications.

### Suggested Reading:

The Sydney Resolution. The Oxford Health Alliance.

Available at: [http://www.oxha.org/knowledge/publications/Sydney\\_Resolution\\_FINAL\\_27.02.08.pdf](http://www.oxha.org/knowledge/publications/Sydney_Resolution_FINAL_27.02.08.pdf)

WHO Health impact assessment. Available at: <http://www.who.int/hia/en/>

South Australian Government Health in all policies.

Available at: <http://www.health.sa.gov.au/pehs/HiAP.htm>

## CONSIDERATIONS FOR:

### PRIMARY PREVENTION - ENVIRONMENTAL APPROACHES

Governments everywhere are alarmed at the burgeoning cost of obesity and chronic diseases such as diabetes. They are also concerned about the need for increased infrastructure of all kinds to support rapid urbanisation and population growth. Above all they are concerned about sustainability - environmental sustainability and economic sustainability.

There is an inarguable physical and psychological link between human health and well being and nature. Our physical environment has a significant influence of the way we get around, how we spend our leisure time, if and how we exercise, and what we eat. While the international research evidence illustrates the benefits of the individual approach to diabetes prevention, the food and physical activity environment in most countries does not support this approach. Therefore a two-pronged approach is required and it is increasingly clear that attention to leveling the environmental gradient is essential if we are to protect and promote health and reduce current burden of so-called lifestyle or chronic diseases.

The current high level of concern about climate change and environmental and economic sustainability makes this an excellent time to launch an environmental approach to diabetes and chronic disease prevention. Such an approach might focus on:

#### 1. Healthy Urbanisation

As of 2007 more people live in cities than not. Consequently, it is vitally important to ensure that cities and towns promote rather than inhibit health. This means:

- retaining open spaces ie parks and gardens where people can walk, play and meet incidentally
- promoting active transport eg walking and cycling
- having joined up public transport systems that minimize the need for cars
- local employment opportunities
- minimal use of non-renewable energy and optimal use of renewable energy
- locating domestic dwellings within walking distance from public facilities such as schools, shops

#### 2. Healthy Food

Access to healthy food may relate to cost, or to physical/geopgraphical availability. It may also be about how food is produced (pesticides, chemical additives, excessive salt, sugar and fat content), stored and transported. So-called 'fresh food' is being produced at increasingly greater distances from the point of consumption often requiring picking before its peak ripening and long term cold storage. The issue we face now is not so much one of 'making healthy choices easy choices' but is more an issue of ensuring that healthy food choices are available and affordable. This means:

- protecting our food growing areas from environmental degradation so that fresh food is available
- working with the food manufacturers to reduce the proportion of salt, sugar and fat in processed food
- working with urban planners to ensure that food distribution points promote access to healthy foods
- working with producers, manufacturers, and food policy makers to optimise the quality and appropriate pricing of healthy food.

### **3. Healthy Business**

Workplace health programs can play a vital part in promoting health by focusing on reducing risk factors such as stress, smoking, physical inactivity, and over or inappropriate nutrition. They can also provide incentives for people to adopt healthy lifestyles outside of the workplace and successful programs have been said to improve the health of employees' families and communities as well as that of individual employees.

There are also other parameters of healthy business. These include the impact of business on the communities in which they operate ie their social and environmental impact. Most important of all is the influence of business, through marketing, on our lifestyle choices and on over-consumption (and subsequent waste) which are among the factors which have led to the current levels of obesity and associated chronic diseases, and environmental damage. In recent years many corporations have become acutely conscious of their environmental impact and have reduced their water and energy consumption. Some are acting on their responsibility for healthy people and healthy societies but many corporations are yet to be convinced that true corporate social responsibility (CSR) means attention to preserving health as well as social well being and the environment.

### **4. Healthy public policy**

In all societies from the most developed to the least developed countries, industrialisation and urbanisation are causing people to lead more sedentary lifestyles, eat less healthy food, and have a more consistently plentiful supply of unhealthy food. Approaches to remedying this situation cannot be truly effective unless they include creating an environment where, for example, it is possible and safe to exercise, and where healthy foods are as available and affordable as unhealthy foods. Achieving this requires major changes to socio-political structures like the taxes on foods and agriculture and food retailing regulations, and involving a variety of stakeholders including food industry and government sectors such as fisheries, agriculture, education, local government and councils, and others dealing with the public environment.

The health impact of all policies should be carefully considered before the policy is introduced in order to avoid unintended adverse consequences. An obvious example of the need for a 'health-in-all-policies' approach is the readiness of governments in some developing countries to allow cigarette companies to establish factories (in order to boost employment) without considering the impact of smoking on the health of the population.

### **5. Who should take the lead?**

The Ministry of Health is responsible for public health and preventative services and has a mandate to make and implement health policy, and has the power to negotiate with other government departments which need to be brought on side. However, here is no reason why a national diabetes organisation, professional society, an academic group or NGO could not take the lead in demonstrating the environmental approach with a view to the government ultimately taking it up.

# ADDRESSING THE PROBLEM

- 50** Developing a Community Awareness Campaign
- 54** Early Diagnosis of Type 2 Diabetes
- 59** Routine Care and Monitoring of Diabetes
- 70** Providing Patient Education
- 75** Psychological Issues in Diabetes
- 79** Developing and Implementing Guidelines
- 85** Developing the Diabetes Workforce and Services

## MODULE:

# DEVELOPING A COMMUNITY AWARENESS CAMPAIGN

### Rationale:

Type 2 diabetes may develop over many years and may be asymptomatic. In many countries it is not uncommon for diabetes to be diagnosed as a direct result of an individual presenting with an existing complication (eg a foot ulcer, visual impairment) even though they are completely unaware they have diabetes. Growing proportions of the population in all countries are at greater risk of diabetes than ever before by virtue of increasingly sedentary lifestyles, inappropriate and/or over-nutrition, overweight and obesity. Raising community awareness of easily identifiable risk factors for diabetes (and associated cardiovascular disease risks) and recognised strategies for reducing personal risks is an important fundamental strategy for:

- informing, educating and motivating people who do not have diabetes but who may be at risk to recognise their diabetes risk status and adopt preventive actions to reduce their modifiable risks
- encourage people who already have diabetes but do not yet know it to seek early diagnostic testing and treatment

Type 2 diabetes and vascular disease share many common risk factors and ideally, approaches to community awareness about type 2 diabetes should be integrated with a focus on cardiovascular disease. Community awareness programmes for type 1 diabetes are not recommended as there is currently no generally available, cost effective means of identifying people at risk of type 1 diabetes.

### Purpose:

To raise awareness of risk factors and symptoms of diabetes and encourage preventative action, early diagnosis and timely initial treatment of type 2 diabetes.

### Potential Application:

- National diabetes organisations
- Health authorities eg health promotion and planning staff
- Senior diabetes clinicians and diabetes centres

### Links:

Links with *Assessing Community Awareness* and *Case Detection and Diagnosis*

### Suggested Reading/References:

Unwin N and Marlin A (2004). Diabetes Action Now: WHO and IDF working together to raise awareness worldwide. *Diabetes Voice* 49(2):27-31. Available at:

[http://www.who.int/diabetes/actionnow/DAN\\_diabetesvoice\\_article.pdf](http://www.who.int/diabetes/actionnow/DAN_diabetesvoice_article.pdf)

The National Diabetes Education Program (NDEP) awareness campaigns.

Available at: <http://ndep.nih.gov/partners-community-organisation/campaigns/index.aspx>

IDF (2010) Materials for World Diabetes Day.

Available at: <http://www.worlddiabetesday.org/materials>

## CONSIDERATIONS FOR:

### DEVELOPING A COMMUNITY AWARENESS CAMPAIGN

There are a multitude of complex issues to consider when contemplating conducting a community awareness campaign. Careful planning and communication of these plans to all who may potentially be affected by the campaign, and the assignment of responsibilities, are essential. Equally important is the need to set limits to the scope of the campaign in order to establish where community awareness ceases and where care of the diagnosed begins. The management and follow up of people who present for diagnostic testing as a result of the campaign and are found not to have diabetes but have identified risk factors for diabetes is an important consideration which should not be overlooked.

Due to the complex nature of type 2 diabetes and its close association with heart disease, hypertension and dyslipidaemia it may be advisable to combine with other relevant health NGOs to run a “know your risks” campaign that includes a broader approach than diabetes alone. This may be more appealing to Ministries of Health and/or other potential funders than a focus on a single disease such as diabetes. In either case, it is worth thinking about:

#### 1. Rationale

What is the purpose and the potential benefits of conducting a community awareness campaign. Your rationale could include evidence that:

- type 2 diabetes has a long preclinical phase and may take many years before the individual notices symptoms
- many people with type 2 diabetes have established complications at the time of diagnosis eg visual impairment, foot ulcers, cardiovascular disease
- making people aware of diabetes and vascular disease risk factors may lead to earlier diagnosis
- the cost of not intervening will be far greater than the cost of intervening

#### 2. Scope

Will the campaign target the whole community or be limited to high risk groups within the community. Will it target all adults in the community or concentrate on community groups known to be at high risk of diabetes, for example by virtue of their age or ethnic background? Will it be time limited or continuing?

Raising awareness of diabetes leads to the identification of people at risk of diabetes and diagnosis of new cases of diabetes. Will responsibility for reducing risk factors rest with the community awareness campaign or should there be a separate prevention programme which has responsibility for this? Are there sufficient service providers and adequate services and supplies to treat the newly diagnosed? If not, it may be better to delay the community awareness campaign until these issues have been addressed.

#### 3. Aim

Will the campaign aim to inform and educate the community about possible strategies for reducing their risk of diabetes? Will it concentrate on trying to achieve earlier diagnosis?

## 4. Preparing the workforce

Plans need to be made to prepare the workforce to participate and assist with disseminating the campaign messages, identify people with risk factors who should be tested, and to cope with the effects of the campaign.

If the campaign is successful there will be a substantial workload increase for health service providers, firstly in increased requests to screen and, secondly in managing new cases of diabetes. Communication with, and involvement of health service provider groups from the commencement of planning and throughout the development of the program is essential.

### PROTOCOLS

Before commencing a community awareness campaign certain protocols must be in place to define consistent, agreed, and preferably evidence based standards for:

- the identification of risk factors for people with diabetes ie who should be tested?
- procedures for testing
- diagnostic criteria
- referral of those diagnosed

## 5. The Message

There is not a great deal of evidence in the diabetes literature about what is the most effective awareness message/s. However, there is a solid body of theory accompanied by evidence about health beliefs and health behaviours to underpin efforts at effective community health education. And, there are five essential questions individual people in the community needs to know about diabetes:

- what is it?
- is it serious?
- is there a cure?
- am I at risk?
- do I have it?

These questions make intuitively good sense as the basis of a diabetes community awareness campaign. However, collective experience tells us that community awareness messages must include a 'call to action'. That is, they must tell people what to do, including where to go for further advice or testing.

## 6. Who the lead organisation/s

A lead agency needs to be identified to take overall responsibility for:

- developing, monitoring and reporting on the campaign
- liaising with other stakeholders to gain their support and involvement

This could be the national diabetes organisation or a government sub-department such as the Ministry of Health NCD Unit; a Diabetes Team within the Ministry of Health; the Public Health Unit or Department; the national diabetes organisation or a professional diabetes organisation.

## 7. Who else should be involved

Community awareness campaigns can be greatly enhanced by the involvement of networks that are in daily touch with people in the community who can deliver awareness messages in the course of their routine practice eg primary care workers and community pharmacists. It is also useful look at community dynamics, where people congregate and who they listen to. For example:

- In some countries and cultures, involving church or community leaders is vital. In others it may be important to use social and sporting clubs, sports stars or other celebrities to attract attention to the message.
- Most people spend about 40 hours per week for 40 years at work, making workplaces an ideal place for risk reduction programs so employers and employee unions are important groups to consider engaging in community awareness campaigns.
- In the context of community awareness, people with diabetes are an under utilised source of 'people power' in raising awareness of diabetes. Family members often share common risks for diabetes either because of their genetic similarities or because they share common lifestyle risks. People with type 2 diabetes can be educated to encourage their non-diabetic relatives to be aware of their diabetes risk factors, to present for testing and adopt preventive actions.

## 8. Key Strategy

Selecting the key strategy for the awareness campaign will be heavily influenced by the extent of the resources available to conduct it. A comprehensive multi-media campaign has more impact because it reaches more people but if resources are limited, a multi-media prevention campaign will not be affordable. In this case, consider:

- a) restricting the scope of the programme to targeting people who can influence those at risk of diabetes and vascular disease eg:
  - health care providers in the community such as primary care physicians, community nurses, maternal and child health nurses, community pharmacists
  - people who already have diabetes (to influence their family members)
  - churches and religious groups
- b) conducting an opportunistic rolling media campaign. This involves developing media contacts and taking advantage of any news stories about diabetes to procure additional media coverage and/or generating human interest or research stories in the popular press.

## 9. Evaluation

A practical evaluation strategy should be developed in parallel with the implementation plan and should specify both process and outcome indicators. This should be based on:

- Process indicators which may measure the extent to which the awareness messages penetrated the community ie how many advertisements were in the press, how many people heard / saw and could recall the messages.
- Outcome indicators which may include the number of people attending for diagnostic testing and the number of new diagnoses over and above the usual rate of diagnosis.

## MODULE:

# EARLY DIAGNOSIS OF TYPE 2 DIABETES

### Rationale:

Type 2 diabetes has a long pre-clinical phase and may be asymptomatic until well after long term microvascular and macrovascular complications have occurred. Type 2 diabetes can be detected before the onset of symptoms and clinical signs by identifying people who are at risk, and performing diagnostic testing. The potential benefits of early diagnosis of type 2 diabetes include:

- less complications at diagnosis
- better longer term diabetes control
- less treatment requirements
- lower rates of developing complications
- lower premature mortality

### Purpose:

To assist and motivate countries to put national mechanisms in place for the early detection of type 2 diabetes.

### Potential Application:

- Health authorities
- National diabetes organisations (professional and/or consumer)
- Diabetes specialist services
- Primary care physicians and community health and health promotion personnel

### Links:

Links with Developing a *Community Awareness Campaign and Preventing Type 2 Diabetes*. In addition, *Routine Care and Monitoring* needs to be considered as part of the planning for early diagnosis.

### Suggested Reading:

WHO and IDF (2006). Definition and diagnosis of diabetes mellitus and intermediate hyperglycemia. Report of a WHO/IDF consultation. World Health Organization, Geneva.

International Expert Committee report on the role of the A1C assay in the diagnosis of diabetes. *Diabetes Care*. 2009; 32:1327-34.

Roglic G, Williams R, Colagiuri S. Screening for Diabetes – the World Health Organisation Perspective. In *Prevention of Type 2 Diabetes*. M Ganz (ed). John Wiley & Sons Ltd: England, 2004.

## CONSIDERATIONS FOR:

### EARLY DIAGNOSIS OF TYPE 2 DIABETES

Screening the general population is not recommended but targeted screening of people with risk factors is and there is emerging evidence indicating that the early detection of type 2 diabetes reduces complications and hence treatment costs. There is currently no generally available, cost effective method of screening for the early detection of type 1 diabetes but there are readily identifiable risks for having undiagnosed type 2 diabetes. These include:

- having a first degree relative with diabetes
- being overweight and obese
- having had gestational diabetes
- increasing age (age ranges are population specific)
- having had a heart attack
- having hypertension
- having migrated to another country

When planning a campaign for the early detection of type 2 diabetes consider the following:

#### 1. Identify risk factors

Ensure that protocols are based on evidence which, where possible, is specific to the population in question, is standardised and available to health professionals in the community or those who may be in a position to inform the community and/or influence people with risk factors to attend for screening and diagnostic testing.

#### 2. Decide Strategies

Will the early detection campaign be supported with community education about risk factors and/or a comprehensive community awareness campaign or will it rely on opportunistic identification of risk factors eg screening people attending general practitioners for other health problems?

Who will be involved in developing and implementing the campaign? What groups of health professionals need to be informed about the programme and/or trained to participate in it?

#### 3. Standardise diagnostic criteria

The diagnostic procedure should be based on evidence, standardised into easy to use protocols and communicated to health care professional, hospital staff and private pathology laboratories. Additional care should be taken to ensure that health professionals who will not necessarily participate directly in the early diagnosis of diabetes but who may be asked about diagnostic processes and criteria are appropriately informed.

Together the WHO and IDF have produced a report on defining and diagnosing diabetes and intermediate hyperglycemia (listed above in the Suggested Readings) which should be used as the internationally recognised standard for case detection and diagnosis.

## 4. Identify screening services

Determine who should assess people for risk factors and where people identified as having risk factors should be referred to for further testing. Will these locations be community based, hospital based, provided by primary care or by specialist services? Cost and accessibility will be key factors in these decisions.

## 5. Inform and train staff

Ensure that health professionals who are expected to look for people with risk factors and perform further testing are informed and trained to the identified standards and protocols. To do this effectively, it will be necessary to develop and implement training protocols for relevant staff which:

- specify risk factors and referral criteria for those who should be tested
- describe the steps required for referral and testing
- identify locations where testing is available
- specify testing methods and diagnostic criteria
- indicate referral pathways for people who are newly diagnosed with diabetes
- indicate referral pathways for people who are found to have diabetes risk factors and develop recommendations for retesting individuals who have diabetes risk factors but are found not to have diabetes on this occasion

## 6. Management of newly diagnosed diabetes

Are services, medications and supplies available to treat people who are newly diagnosed? Have primary care and specialist diabetes staff and services been informed and prepared to expect and deal with increased cases of diabetes? If not, consider delaying the programme until these deficiencies are addressed.

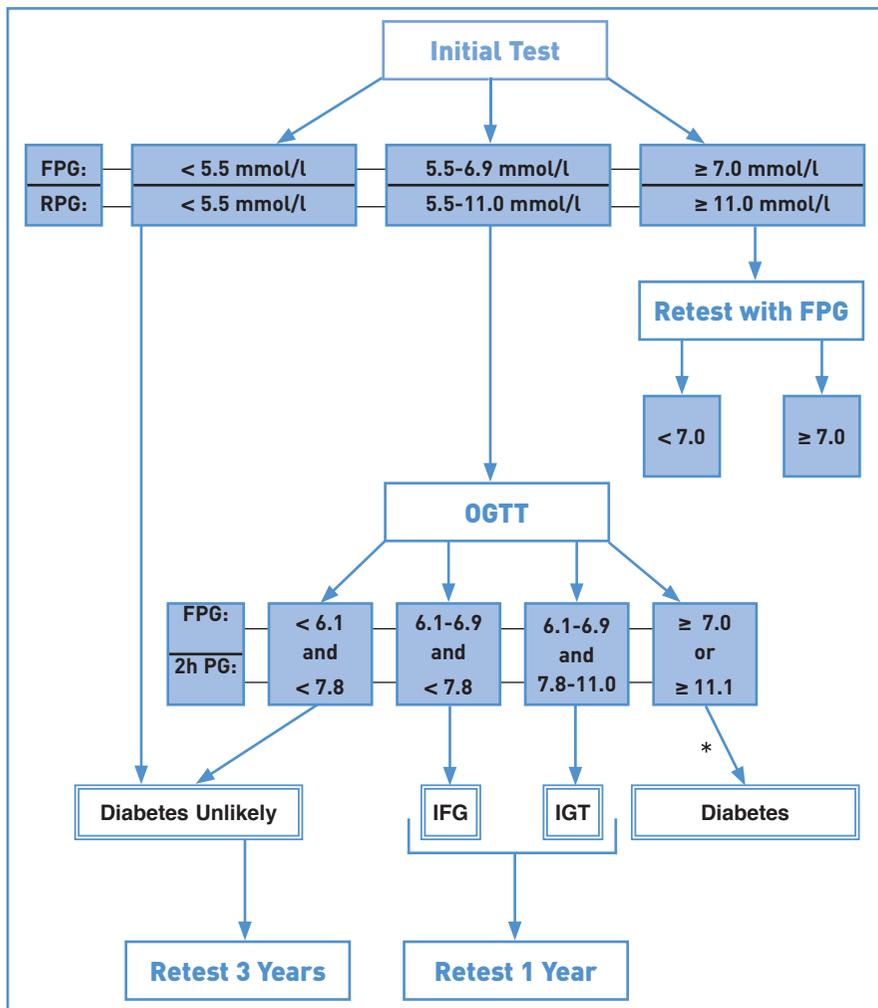
## 7. Diagnostic criteria and protocols

The following pages present two examples of diagnostic criteria and protocols. The first example represents a comprehensive evidence base and reflects the WHO position on the diagnosis of diabetes. However, it is recognised that the routine application of such a comprehensive protocol may not be feasible in many countries. Consequently, the second example presents a simplified protocol. When modifying such protocols to suit local circumstances full consultation with local public health and clinical leaders is recommended. This can be based on the comprehensive protocol, with local experts amending and simplifying the protocol by balancing what must be done to achieve optimal sensitivity and specificity of the testing against how this can be done within the limitation of available material resources and expertise

The current diagnostic criteria are based on glucose testing but the use of HbA1c as a diagnostic test is currently under consideration by WHO. However, due to the cost, the lack of availability in many countries, the lack of standardization of assays, and the prevalence of conditions which interfere with the accuracy of its measurement, in most countries around the world, HbA1c is unlikely to replace glucose measurement for diagnosing diabetes.

# COMPREHENSIVE DIAGNOSTIC PROTOCOL

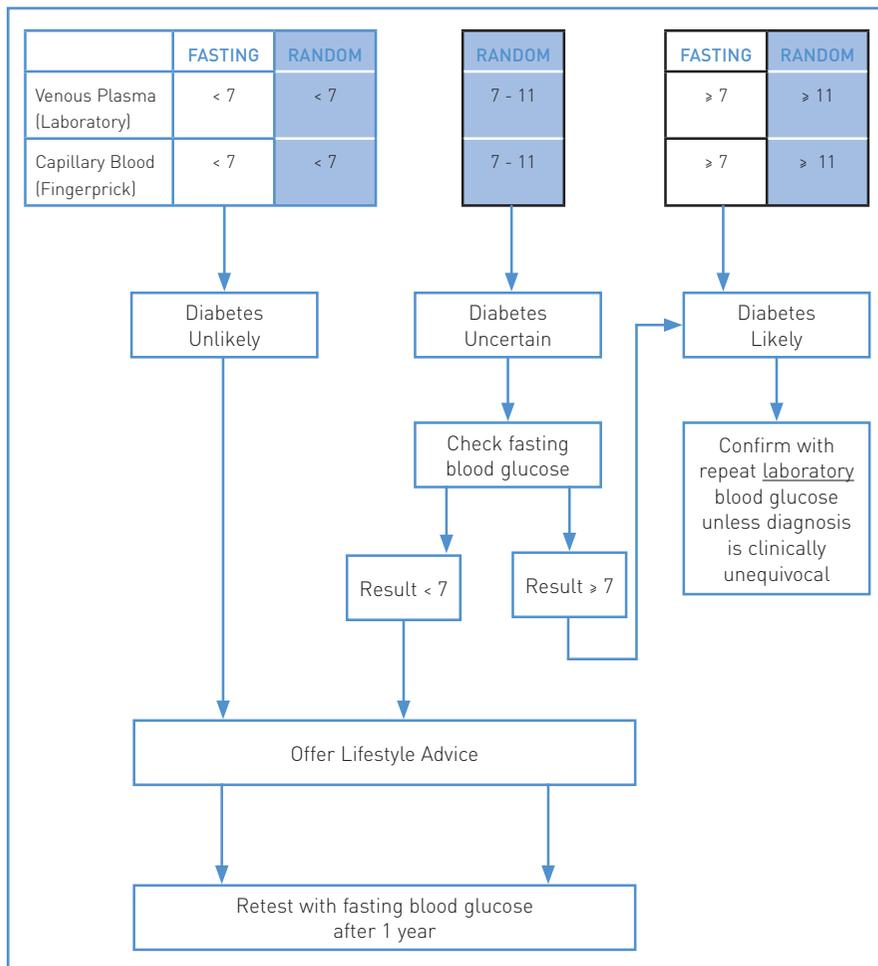
Source: Evidence Based Guidelines for Type 2 Diabetes:  
Case Detection and Diagnosis. Diabetes Australia & NHMRC:2009



FPG – fasting plasma glucose      RPG – random plasma glucose      OGTT – oral glucose tolerance test  
IFG – impaired fasting glucose      IGT – impaired glucose tolerance  
\* diagnosis must be confirmed by further testing if initial FPG 5.5-6.9mmol/L or RPG 5.5-11.0mmol/L.  
# people with an initial plasma glucose consistent with a diagnosis of diabetes or IGT/IFG which is not confirmed on subsequent testing should be retested after 1 year and subsequent testing interval determined according to the 1 year result

## SIMPLIFIED DIAGNOSTIC PROTOCOL

Source: Guidelines for the Prevention and Management of Diabetes in Tonga. A National Consensus Position. Tonga Ministry of Health and Australian Centre for Diabetes Strategies.



## MODULE:

# ROUTINE CARE AND MONITORING OF DIABETES

### Rationale:

There is a wealth of evidence illustrating that the course of diabetes is highly amenable to intervention and that effective interventions are available. Two landmark trials, one in Type 1 diabetes (DCCT, 1993), and the other in type 2 diabetes (UKPDS, 1998) conclusively demonstrated that the health outcomes of diabetes can be significantly improved by intensifying care.

These and the myriad of studies testifying to the benefits of certain clinical processes, practices and therapies in optimising surrogate outcomes such as HbA1c, dyslipidaemia and reducing endpoint complication such as blindness and kidney disease have formed the basis of international standards of care for diabetes. It is this evidence that guides the routine monitoring and treatment of diabetes and the IDF Clinical Task Force has been active in translating this evidence into guidelines which can be adapted internationally to support improved management and care of diabetes around the world.

### Purpose:

This module aims to demonstrate what is required for a comprehensive and systematic approach to managing diabetes and monitoring diabetic status for signs of complications.

### Potential Application:

- Health authorities
- Diabetes medical specialists
- Primary care physicians
- Other health professionals

### Links:

Links with and provides a flow on from *Early Detection* and links with *Developing and Implementing Guidelines*.

### Suggested Reading:

IDF Global Guidelines for Type 2 Diabetes (2005).

Available at: [http://www.idf.org/Global\\_guideline](http://www.idf.org/Global_guideline)

Mukhtar Q, Jack L, Jr., Martin M, Murphy D, Rivera M (2006). Evaluating progress toward Healthy People 2010 national diabetes objectives. *Preventing Chronic Disease* 3(1):A11.

## CONSIDERATIONS FOR:

### ROUTINE CARE AND MONITORING OF DIABETES

Routine care of diabetes is not complicated or even expensive in comparison to many other diseases. There is conclusive evidence that diabetes-specific complications can be delayed or prevented by good quality care and any well trained health professional can deliver most aspects of this care. There are many evidence and consensus based guidelines which provide clear direction on recommended clinical processes of care. Therefore, the issue is not so much knowing what to do but is more a matter of putting mechanisms in place to make sure it is done. Table 2 illustrates key intervention points in the progression of the diabetes disease process across the continuum of care. This module deals with one aspect only of the key intervention points ie routine care. This is not to say that the care of complications and palliative care are not equally important. However, they may require more individualised management, and approaches to their management may vary widely depending on the nature of the health system, as well as the degree of specialisation in available medical services such as laser therapy and renal dialysis facilities.

Considerations of the routine monitoring of diabetes raise a number of issues not least of which is the need to remember that collecting clinical data is a tool not a solution and can only contribute to solutions when it is used appropriately eg:

- as a quality improvement tool
- to link clinical processes to effective outcomes
- to provide clinicians with feedback on the quality of care they provide
- to identify problem areas for action

It is also vital to remember that optimal diabetes care is built on a 'package' of management strategies that includes patient education and dietary modification as well as treatment, and that these three pillars of diabetes care are best delivered in an integrated manner by a multidisciplinary team.

#### 1. Self-care Education

The importance of patient education for people with diabetes cannot be over estimated. Patient education is central to understanding the nature of diabetes and how to self manage it, and the importance of following treatment recommendations. Consequently an entire module is devoted to considerations for patient education (see next module).

#### 2. Dietary Modification

All people with diabetes should have access to dietary advice at diagnosis and periodically thereafter. This should ideally be provided by a dietitian but can be given by any health professional trained in the principles of nutrition and dietary recommendations for diabetes.

Depending on locally available foods, general eating and lifestyle norms and clinical custom, dietary recommendations may vary from country to country. However, the guiding principles should be consistent eg:

- a balanced diet that meets the nutritional needs of the individual
- achieving and/or maintaining ideal body weight
- the distribution of carbohydrate foods
- encouraging a high fibre, low fat, low salt diet
- limiting alcohol intake

## TABLE 2: KEY INTERVENTION POINTS AND ASSOCIATED ACTION REQUIRED

Adapted from the (Australian) National Diabetes Strategy and Implementation Plan, 1998

KEY INTERVENTION POINTS	ACTION - KEY TASKS
<b>No diabetes*</b>	<ul style="list-style-type: none"> <li>■ Prevent the healthy population from developing risk factors</li> <li>■ Increase public awareness of risk factors, the significance of risk factors, and risk reduction strategies</li> </ul>
<b>Pre diabetes</b>	<ul style="list-style-type: none"> <li>■ Reduce risk factors in the 'at risk' population *</li> <li>■ Support goal directed preventative interventions</li> </ul>
<b>Undiagnosed diabetes*</b>	<ul style="list-style-type: none"> <li>■ Increase public awareness of symptoms, risk factors and how to be screened for undiagnosed diabetes</li> <li>■ Implement programs for:               <ul style="list-style-type: none"> <li>- active identification and screening of people with risk factors</li> <li>- opportunistic screening of people with risk factors</li> <li>- population screening for high risk groups</li> </ul> </li> </ul>
<b>Known diabetes</b> <ul style="list-style-type: none"> <li>■ At diagnosis</li> <li>■ Established uncomplicated diabetes</li> <li>■ Diabetes with complications</li> </ul>	<ul style="list-style-type: none"> <li>■ Provide services for:               <ul style="list-style-type: none"> <li>- clinical care according to guidelines</li> <li>- education in self-care</li> <li>- information about recommendations for clinical care</li> </ul> </li> <li>■ Provide services for:               <ul style="list-style-type: none"> <li>- routine monitoring of diabetic and general health status</li> <li>- regular screening for complications</li> <li>- management of problems as they arise</li> <li>- reinforcement of self-care education</li> <li>- affordable therapies and supplies</li> </ul> </li> <li>■ Implement programs for:               <ul style="list-style-type: none"> <li>- identification and reduction of risks for diabetes</li> <li>- complications</li> <li>- self-care education and psychosocial support</li> </ul> </li> <li>■ Provide services for:               <ul style="list-style-type: none"> <li>- prevention of the progression of complications</li> <li>- self-care education and psychosocial support</li> <li>- rehabilitation of people with disabilities</li> <li>- palliation for people with end stage complications</li> </ul> </li> <li>■ Support goal directed research aimed at the reversal of complications</li> </ul>

\* Until modifiable risk factors are identifiable and effective interventions available, these interventions cannot be applied to Type 1 diabetes

### 3. Self-care Education

The importance of patient education for people with diabetes cannot be over estimated. Patient education is vital to understanding the nature of diabetes and how to self manage it, and the importance of following treatment recommendations. Consequently an entire module is devoted to considerations for patient education (see pages 60 to 64).

### 4. Dietary Modification

All people with diabetes should have access to dietary advice at diagnosis and periodically thereafter. This should ideally be provided by a dietitian but can be given by any health professional trained in the principles of good nutrition and dietary recommendations for diabetes.

Depending on locally available foods, general eating and lifestyle norms and clinical custom, dietary recommendations may vary from country to country. However, the guiding principles should be consistent eg:

- a balanced diet that meets the nutritional needs of the individual
- achieving and/or maintaining ideal body weight
- the distribution of carbohydrate foods
- encouraging a high fibre, low fat, low salt diet
- limiting alcohol intake

### 5. Physical Activity

Because of its widely acknowledged benefits for general health and well being, physical activity (exercise) is recommended for everyone. For people with type 2 diabetes regular physical activity has additional benefits with regard to decreasing insulin resistance. Unless there is a medical contraindication, all people with diabetes should be encouraged to exercise regularly and play sports if they so chose. If embarking on a new exercise routine, people who are older, unfit, overweight, or have a history of heart disease should seek medical advice about the type of exercise which is safe and suitable for them.

A regular exercise routine can be recommended along with dietary advice by the doctor or diabetes educator and does not have to be strenuous or prolonged. There is now evidence that walking for an accumulated 30 minutes per day is beneficial. The benefits of including resistance exercises are increasingly recognized, especially in people with type 2 diabetes.

*Note: Specific education on the avoidance of hypoglycaemia in relation to exercise is essential for people with type 1 diabetes and for people with type 2 diabetes who are taking insulin or oral diabetes medications which may predispose them to hypoglycaemia.*

### 6. Complications screening at diagnosis

Because type 2 diabetes may have a long preclinical phase and may be asymptomatic until after complications have occurred, all people with type 2 diabetes should be screened for both macrovascular and microvascular complications at the time of diagnosis.

*Note: provision needs to be made for clinical management of complications identified at diagnosis so that they are regularly monitored in order to prevent or delay their progression and to provide palliative care for people with end-stage complications.*

## 7. Medications

Where indicated after clinical assessment, oral antidiabetic agents, insulin and other medications such as blood pressure lowering and lipid lowering agents should be prescribed by a qualified medical practitioner, and the effects monitored.

### AVAILABILITY OF MEDICATIONS

Many developing countries do not have the financial capacity to provide freely available medications and many fully industrialised countries are struggling to keep escalating pharmaceutical costs down. Nonetheless, governments have a clear responsibility to provide essential medications to those who need them at an affordable price. There are a number of strategies which can help achieve this:

- group purchasing
- rationalisation of the use of interchangeable or equivalent medications
- co-ordinating the input of donors in developing countries
- efficiency measures to prevent 'loss' of medications
- efficiency measures to enhance processing/dispensing and reduce handling costs
- training and or providing incentives for doctors to reduce the prescribing of excessive and unnecessary medications

## 8. Clinical monitoring for the early detection of diabetes complications

All people with diabetes should be monitored regularly to assess the status of their metabolic control, the possible need for treatment changes, and to detect the onset of complications at an early stage where interventions can then slow or prevent their progression. Physical and laboratory assessments should be regular and should include:

- measurement of glycated haemoglobin ( HbA<sub>1c</sub> )
- assessment of lipids
- measurement of blood pressure
- measurement of kidney function (ideally by albuminuria)
- retinal examination through dilated pupils
- foot examination (including testing sensation perception with a10g monofilament)
- weight assessment

## 9. Setting standards of care

An essential component of providing an appropriate standard of routine diabetes care is setting and disseminating standards of care. These should specify clinical and service standards including frequency of assessments and specifications for patient recall. These standards can take the form of evidence based guidelines, consensus guidelines, national position statements or national standards of care and should include recommendations and/ standards for:

- primary prevention ie of risk factors for type 2 diabetes
- case detection and diagnosis of diabetes
- the clinical management of all aspects of diabetes
- prevention of diabetes-related complications
- referral pathways and criteria
- patient education

## 10. Services

Health care services for people with diabetes should be staffed and equipped to meet the recommended standards of care and provide affordable essential medications and self-care supplies. Services should be geographically distributed in a manner that enhances their accessibility and consideration must also be given to the availability of support services.

In countries where available resources do not allow for all standards to be fully met, a national consensus should be developed under government auspices to determine service priorities and rationalise what is the 'next best thing to do within the resource constraints' when a standard cannot be met.

## 11. Monitoring the processes and outcomes of care

Monitoring the processes and outcomes of diabetes care is an essential tool for linking and replicating processes that lead to good outcomes and for ongoing quality assurance and improvement.

Ideally, monitoring should be carried out by means of interactive electronic databases that record patient demographics, occasions of service, clinical treatments, assessment care processes, surrogate outcomes such as HbA1c, blood pressure etc and endpoints such as blindness, amputation etc. Where possible, electronic patient databases will be constructed to reflect the recommended standards of care and have the capacity for patient recall and prompts for the clinician.

If electronic databases are not affordable paper based databases are a sound alternative but are less efficient. Databases for monitoring the processes and outcomes do not have to be complex and extensive and their scope will depend very much on local resources. As discussed in the module on Collecting Diabetes Data in Section 4, careful consideration needs to be given to constructing meaningful and consistent data fields and data definitions and to how the data will be collected and used. An example of an electronic patient database is shown on the following pages.

## EXAMPLE OF A PATIENT REGISTRATION FORM AND CLINICAL DATABASE

Registration Date:	<input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> / <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> / <input style="width: 40px; height: 20px; border: 1px solid black;" type="text"/>		
Health Professional:	<input style="width: 280px; height: 20px; border: 1px solid black;" type="text"/>		<input style="width: 210px; height: 20px; border: 1px solid black;" type="text"/>
	Surname	First Name	
<b>Demographic Information</b>			
MRN:	<input style="width: 180px; height: 20px; border: 1px solid black;" type="text"/>		
Name:	<input style="width: 280px; height: 20px; border: 1px solid black;" type="text"/>		<input style="width: 210px; height: 20px; border: 1px solid black;" type="text"/>
	Surname	First Name	
Address:	<input style="width: 180px; height: 20px; border: 1px solid black;" type="text"/>		<input style="width: 420px; height: 20px; border: 1px solid black;" type="text"/>
	House/Unit no	Street Name	
	<input style="width: 320px; height: 20px; border: 1px solid black;" type="text"/>		<input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>
	Suburb	State	Postcode
Day Time Phone:	<input style="width: 220px; height: 20px; border: 1px solid black;" type="text"/>		Home Phone: <input style="width: 140px; height: 20px; border: 1px solid black;" type="text"/>
Date of Birth:	<input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> / <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> / <input style="width: 40px; height: 20px; border: 1px solid black;" type="text"/>		
Sex:	<input type="checkbox"/> Male <input type="checkbox"/> Female		
Marital Status:	<input type="checkbox"/> Single <input type="checkbox"/> Married <input type="checkbox"/> Widow/er <input type="checkbox"/> Separated <input type="checkbox"/> De facto <input type="checkbox"/> Divorced		
Country of Birth:	<input style="width: 440px; height: 20px; border: 1px solid black;" type="text"/>		
	<i>If Australia</i> ⇒ <input type="checkbox"/> Aboriginal <input type="checkbox"/> Torres Strait Islander		
Language at home:	<input style="width: 440px; height: 20px; border: 1px solid black;" type="text"/>		
	<i>If not English</i> ⇒ <input type="checkbox"/> Interpreter needed: <input type="checkbox"/> Yes <input type="checkbox"/> No		
<b>GP Information:</b>			
Practice Name:	<input style="width: 620px; height: 20px; border: 1px solid black;" type="text"/>		
Name:	<input style="width: 280px; height: 20px; border: 1px solid black;" type="text"/>		<input style="width: 210px; height: 20px; border: 1px solid black;" type="text"/>
	Surname	First Name	
Address:	<input style="width: 180px; height: 20px; border: 1px solid black;" type="text"/>		<input style="width: 420px; height: 20px; border: 1px solid black;" type="text"/>
	House/Unit no	Street Name	
	<input style="width: 320px; height: 20px; border: 1px solid black;" type="text"/>		<input style="width: 60px; height: 20px; border: 1px solid black;" type="text"/>
	Suburb	State	Postcode
Phone:	<input style="width: 220px; height: 20px; border: 1px solid black;" type="text"/>		Provider No: <input style="width: 140px; height: 20px; border: 1px solid black;" type="text"/>
<b>Duration and Type of Diabetes:</b>			
Year of Diagnosis:	<input style="width: 80px; height: 20px; border: 1px solid black;" type="text"/>		
Type of Diabetes:	<input type="checkbox"/> Type 1 <input type="checkbox"/> Type 2 <input type="checkbox"/> GDM <input type="checkbox"/> Don't know		

**Family History of Diabetes and Life Style Characteristics:**

**Family History Diabetes:**      Yes      No      Don't know

*If yes =>*      Mother      Father      Siblings:       Children:

**Smoking:**      Yes      No      =>      Cigarettes/day:

**Alcohol:**      Yes      No      =>      gm/day:

**Self-care Practice:**

**Self Monitoring:**      Blood Glucose Testing:      Yes      No

Urine Glucose Testing:      Yes      No

**Attendance at (last 12 months):**

Podiatrist:	Yes	No	Number of Visits: <input type="text"/>
Dietitian:	Yes	No	Number of Visits: <input type="text"/>
Diabetes Educator:	Yes	No	Number of Visits: <input type="text"/>
GP:	Yes	No	Number of Visits: <input type="text"/>

**Other Self-care Practices:**

Carrying Identification:	Yes	No	
Carrying Simple Carbohydrates:	Yes	No	N/A
Keeps Glucagon at home:	Yes	No	N/A

**Management:**

**Method:**      Diet Only      Tablet      Insulin      Insulin and Tablet      Nil

---

**Tablets:**      Tablet Since:

Tablet Name (1): <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> (ma) mane	<input type="text"/> <input type="text"/> <input type="text"/> (ma) midi	<input type="text"/> <input type="text"/> <input type="text"/> (ma) nocte
Tablet Name (2): <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> (ma) mane	<input type="text"/> <input type="text"/> <input type="text"/> (ma) midi	<input type="text"/> <input type="text"/> <input type="text"/> (ma) nocte
Tablet Name (3): <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> (ma) mane	<input type="text"/> <input type="text"/> <input type="text"/> (ma) midi	<input type="text"/> <input type="text"/> <input type="text"/> (ma) nocte

**Insulin:**      Insulin Since:

Insulin was commenced as:      Inpatient      Ambulatory      At home      Don't know

Insulin Name (1):

<input type="text"/> <input type="text"/> <input type="text"/> (U) mane	<input type="text"/> <input type="text"/> <input type="text"/> (U) Prelunch	<input type="text"/> <input type="text"/> <input type="text"/> (U) Predinner	<input type="text"/> <input type="text"/> <input type="text"/> (U) Prebed
--	--	---	--

Insulin Name (2):

<input type="text"/> <input type="text"/> <input type="text"/> (U) mane	<input type="text"/> <input type="text"/> <input type="text"/> (U) Prelunch	<input type="text"/> <input type="text"/> <input type="text"/> (U) Predinner	<input type="text"/> <input type="text"/> <input type="text"/> (U) Prebed
--	--	---	--

**Also on Treatment For:**

Ischaemic Heart Disease	Neuropathy	Cardiac Failure
Nephropathy	Hypertension	

<b>Medications:</b>							
<b>Medications:</b>	Yes	No					
<b>Ace Inhibitors:</b>	Yes	No					
			<input type="text"/>				
			(ma) mane	(ma) midi	(ma) nocte		
<b>Calcium Antagonists:</b>	Yes	No					
			<input type="text"/>				
			(ma) mane	(ma) midi	(ma) nocte		
<b>Angiotensin 2 Inhibitors:</b>	Yes	No					
			<input type="text"/>				
			(ma) mane	(ma) midi	(ma) nocte		
<b>Beta Blockers:</b>	Yes	No					
			<input type="text"/>				
			(ma) mane	(ma) midi	(ma) nocte		
<b>Alpha Blockers:</b>	Yes	No					
			<input type="text"/>				
			(ma) mane	(ma) midi	(ma) nocte		
<b>Diuretics:</b>	Yes	No					
			<input type="text"/>				
			(ma) mane	(ma) midi	(ma) nocte		
<b>Other Anti-Hypertensive:</b>	Yes	No					
			<input type="text"/>				
			(ma) mane	(ma) midi	(ma) nocte		
<b>Dyslipidaemia Medication:</b>	Yes	No					
			<input type="text"/>				
			(mg) mane	(mg) midi	(mg) nocte		
			<input type="text"/>				
			(ma) mane	(ma) midi	(ma) nocte		
<b>Other Medication:</b>	Corticosteroids	Aspirin					
<b>Specific Relevant History:</b>							
<b>Angina Pectoris:</b>	Yes	No					
<b>Myocardial Infarction:</b>	<i>Last 12 months:</i>	Yes	No	<i>Previously:</i>	Yes	No	
<b>CABG/Angioplasty:</b>	<i>Last 12 months:</i>	Yes	No	<i>Previously:</i>	Yes	No	
<b>Cerebral Stroke:</b>	<i>Last 12 months:</i>	Yes	No	<i>Previously:</i>	Yes	No	
<b>Claudication:</b>	Yes	No					
<b>Peripheral Bypass /Angioplasty:</b>	<i>Last 12 months:</i>	Yes	No	<i>Previously:</i>	Yes	No	
<b>Lower Limb Amputation:</b>	<i>Last 12 months:</i>	Yes	No	<i>Previously:</i>	Yes	No	
<b>End Stage Renal Failure:</b>	Yes	No					
<b>Renal Dialysis/Transplant:</b>	<i>Last 12 months:</i>	Yes	No	<i>Previously:</i>	Yes	No	
<b>Erectile Dysfunction:</b>	Yes	No					
<b>Cataract Extraction:</b>	<i>Last 12 months:</i>	Yes	No	<i>Previously:</i>	Yes	No	
<b>Hypoglycaemia requiring assistance (last 3 months):</b>	Nil	1	2	3	4	5	>5 episodes
<b>Hyperglycaemic emergency (last 3 months):</b>	Nil	1	2	3	4	5	>5 episodes

Hospitalisations, diabetes related (last 12 months): Yes No **Days in Hospital:**

- **If yes** Peripheral Vascular Disease Stabilisation Cerebro Vascular Disease  
 Cardio Vascular Disease Infection Foot Problem Eye Problem

**Anthropometric and Clinical Examination Details:**

**Height:** . Metre **Blood Pressure:** **Sitting** / mmHg  
**Weight:**  Kg **Lying:** / mmHg  
**Body Mass Index:** . **Standing:** / mmHg

**Right:**

**Left:**

**Biothesiometer:**

**Monofilament (10g):** Normal Abnormal Normal Abnormal

**Peripheral Sensation:** Normal Abnormal Normal Abnormal

**Distal Foot Pulses:** Normal Abnormal Normal Abnormal

**Gangrene:** Absent Present Absent Present

**Foot Infection (bacterial or fungal):** Absent Present Absent Present

**Ulceration:** Absent Present Absent Present

**If present => Ulcer Type:**

Neuropathic Ischaemic	Neuro Ischaemic Other	Neuropathic Ischaemic	Neuro Ischaemic Other
--------------------------	--------------------------	--------------------------	--------------------------

**Osteomyelitis:**

No Probable	Definite Don't know	No Probable	Definite Don't know
----------------	------------------------	----------------	------------------------

**Lower Limb Amputation:** Yes No Yes No

**If yes => Amputation Type:**

Toe Forefoot	BKA AKA	Toe Forefoot	BKA AKA
-----------------	------------	-----------------	------------

**Eye Examination:**

**Fundus Examination:** Yes No Don't know **Date:** //

**If yes =>** Ophthalmologist Optometrist GP  
 Diabetes Specialist Non mydriatic Camera

**Visual Acuity:** **Right Eye:** **Left Eye:**

6/5	6/18	Count Fingers	6/5	6/18	Count Fingers
6/6	6/24	Hand Movement	6/6	6/24	Hand Movement
6/7.5	6/36	Perceive Light	6/7.5	6/36	Perceive Light
6/9	6/60	Blind	6/9	6/60	Blind
6/12			6/12		

**Eye Examination:** **Right Eye** **Left Eye** **Right Eye** **Left Eye**

Cataract Extraction: Severe NPDR:  
 Cataract: Proliferative Retinopathy:  
 Retinae Not Visualised: Maculopathy:

Normal:  
 Minimal NPDR:  
 Mild NPDR:  
 Moderate NPDR:

Clinically Significant Macular Oedema:  
 Photocoagulation (laser):  
 Non Diabetic Abnormalities:  
 Photograph:

<i>Laboratory Investigation (within last 12 months):</i>					
<b>Lipids:</b>	<b>Date:</b>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	<b>Fasting:</b>	Yes	No		
	<b>Cholesterol:</b>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>
	<b>Triglycerides:</b>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>
	<b>HDL Cholesterol:</b>	<input type="text"/>	.	<input type="text"/>	<input type="text"/>
	<b>LDL Cholesterol:</b>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>
<hr/>					
<b>Creatinine:</b>	<b>Date:</b>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	<b>Result:</b>	<input type="text"/>	<input type="text"/>	<input type="text"/>	$\mu\text{mol/L}$
<b>Glycated Hb:</b>	<b>Date:</b>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	<b>Result:</b>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>
	<b>Normal Range:</b>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>
		<input type="text"/>	.	<input type="text"/>	<input type="text"/>
<hr/>					
<b>Urine Collection:</b>	Yes	No	<b>Date:</b>	<input type="text"/>	<input type="text"/>
			<b>Micro Albumin:</b>	<input type="text"/>	<input type="text"/>
			<b>Units:</b>	<input type="text"/>	<input type="text"/>
				mg/	$\mu\text{g}/\text{mi}$
				$\mu\text{g}/24 \text{ hr}$	ratio
			<b>Normal Range:</b>	<input type="text"/>	<input type="text"/>
				To	<input type="text"/>
				<input type="text"/>	<input type="text"/>
			<b>Proteinuria:</b>	<input type="text"/>	<input type="text"/>
				mg/day	
			<b>Creatinine Clearance:</b>	<input type="text"/>	<input type="text"/>
				ml/sec	

## MODULE:

# PROVIDING PATIENT EDUCATION

### Rationale:

Self-care education for people with diabetes has long been cited as one of the pillars of diabetes care. In addition to the fundamental right of individuals to be informed about i) their health status and ii) the requirements of the management of their condition, diabetes patient education has been shown to have multiple benefits. These include better knowledge and self-care practices, better coping skills, better quality of life and reduced utilisation and cost of health services. Despite this, actual investment in and support for patient education has not always reflected the rhetoric and patient education remains the poor relation of medical treatment. Consequently, millions of people never experience the benefits of education about their diabetes or receive only very superficial education.

### Purpose:

To assist in the development and implementation of effective education services and in making patient education for diabetes more focused, systematic and accountable

### Potential Application:

- Health authorities
- Diabetes educators associations
- Senior diabetes clinicians and diabetes centres
- National diabetes organisations

### Links:

Links with Routine Care and Monitoring and Psychological and Behavioural Issues

### Suggested Reading/References

Majumdar SR, Johnson JA, Bowker SL, Booth GL. A Canadian consensus for the standardized evaluation of quality improvement interventions in type 2 Diabetes. *Can J Diabetes*. 29, 220-229 (2005).

American Association of Diabetes Educators. Standards for outcomes measurements of diabetes self-management education. Position Statement. *Diabetes Educator*. 29, 804-816 (2003).

Colagiuri R and Eigenmann CA. A national consensus on outcomes and indicators for diabetes patient education. *Diabetic Medicine*. 26, 442-446 (2009).

IDF (2008) International Curriculum for Diabetes Health Professional Education. International Diabetes Federation.

Available at: [http://www.idf.org/webdata/docs/IDF\\_Curriculum\\_Introduction\\_EN.pdf](http://www.idf.org/webdata/docs/IDF_Curriculum_Introduction_EN.pdf)

IDF (2010) Diabetes Education Modules. International Diabetes Federation. Available at: <http://www.idf.org/node/1348?unode=A513C97A-F08C-4F97-9358-D406CDF4FEC1>

## CONSIDERATIONS FOR:

### PROVIDING PATIENT EDUCATION

All people with diabetes should have access to self-care education to optimise the management and outcomes of their diabetes care and to assist and empower them to participate actively in decisions about their diabetes treatment. Where possible this should be done by a health professional with specific training in the recognised principles, techniques and strategies of adult education. Education should include information about:

- The causes, effects and management of diabetes
- Self-care recommendations specific to the person's type of diabetes and treatment
- Strategies for avoiding short and long term diabetes complications
- Principles and recommendations for nutrition and exercise
- The administration of diabetes and related medications where applicable
- Self blood glucose monitoring if available to the patient
- Where and when to seek professional help for assistance with diabetes care
- Where and how to obtain the required diabetes medications and supplies.

The question is no longer whether or not people with diabetes need self care education but, rather, how best to structure and deliver education and education services - especially in low resource settings. When considering this, the following points may be useful.

#### 1. Who needs education?

Everyone who has diabetes needs self care education in order to understand and manage their diabetes optimally. The content of the educational messages and material will vary depending on patient factors such as the:

- type of diabetes eg type 1, type 2 or gestational diabetes
- stage of the diabetes eg newly diagnosed, established, complicated diabetes
- stage of the person's life cycle eg childhood, adolescence, reproductive/mature. elderly
- nature of the person's lifestyle eg level of physically active or sedentariness
- level of the person's education and capacity to understand the information provided

#### 2. How should it be provided?

The areas of health education and health behaviour have a well developed body of theory and evidence and much of the theory and practice of diabetes education is derived from this. There are a number of models of health behaviour such as the health belief model and the stages of change model which are well worth studying if you are serious about diabetes education. There is also much written about the two main models of education ie the pedagogical or teacher centred approach versus androgogy which favours a more learner centred approach.

##### ■ Models of education

The pedagogical or didactic approach, where the teacher 'lectures' the learner and the learner is expected to simply do what they are told is not favoured in diabetes education and has not been found to be very useful in helping people with diabetes to self manage their condition optimally.

A number of health education models used in diabetes spring from humanistic theory and are essentially variations on the person-centred or empowerment approach. It is worth noting that the word educate is derived from the old Latin language and literally means to lead out (e-ducate). Consequently, these models adopt an approach that seeks to build on what the individual already knows and their life experience as well as what he or she needs to know. In these models the educator is more of a coach than a teacher, and supports the learner to set and meet his/her self care goals and participate actively in treatment decision by providing accurate and timely information and learning opportunities.

Regardless of whether education providers use one model or a mixture of the main models, it is clear that people learn best when they are:

- safe from fear of failure or embarrassment
- are supported to learn rather than just told what to do
- encouraged to ask questions and experiment
- the information provided is clear and relevant to their needs
- provided with a range of learning opportunities eg visual, experiential
- given the opportunity to practice what they learn in a safe environment.

#### ■ **Individual or group education**

A key issue in thinking about how diabetes education should be provided is the question of whether it should be delivered in groups or individually. There has been very little research dedicated to comparing the relative effectiveness of individual versus group delivery of diabetes education. While most experts agree that people with diabetes need individual education that is tailored to their particular individual needs and circumstances, resources may dictate that group education is the main option available. If this is the case it is important to ensure that groups are not too large, and that the groups are as homogeneous as possible in terms of their needs eg type of diabetes, type of treatments, age group or stage of the life cycle.

### **3. Who should provide diabetes education?**

There is often debate about who should provide diabetes education - the doctor, nurse, dietitian, pharmacist, or less qualified health workers and/or peer-educators. All are important and have a role to play but it is essential to understand that the quality and extent of the education will depend on how well the education provider has been trained for the job and what quality controls are built into the care systems within which the education provider operates in. In reality, the choice will often boil down to who is available to provide education.

#### ■ **Health professionals**

Any health professional with a sound knowledge of the pathophysiology and management of diabetes and training in education theory and techniques can provide diabetes education. However, diabetes educators are usually the best equipped to provide comprehensive diabetes patient education as they have training in education as well as diabetes. Diabetes educators are usually nurses or dietitians who specialise in diabetes care and education.

#### ■ Peer educators

In some countries dietitians provide most of the education, in others it may be nurses, and occasionally it is doctors. Unfortunately, in many low resource settings there are simply not enough health professionals to provide health care AND health education and, in many countries, there are no diabetes educators at all. This raises the question of whether or not peer education is appropriate and beneficial.

Peer educators are people with diabetes, or other community members, who volunteer to provide education to people with diabetes. Clearly they do not have professional training in a health discipline and therefore cannot provide detailed and comprehensive patient education. There is also a danger that they may have misconceptions - for example about the causes and consequences of diabetes or how to manage it - and may pass these on to the people they are educating.

The current status of research evidence about the efficacy of using peer health educators and peer community health workers is inconclusive but this, nor the concerns outlined above, mean we should abandon the idea of peer educators. Rather it means that we need to develop agreed core competencies, appropriate generic training programmes and systems for ongoing support and supervision by suitably qualified and experienced health professionals.

### 4. When should it be provided?

Ideally diabetes education should be provided whenever the person with diabetes needs and/or is ready for it. This may vary from person to person but will include:

- any substantial change of treatment eg changing from oral medications to insulin
- at major lifecycle or lifestyle changes eg puberty, menopause, marriage, parenthood, widowhood, significant changes in physical activity
- at diagnosis
- at in the event of acute episodes of intercurrent illness eg 'flu or surgery
- at the onset of comorbidities and as needed thereafter
- at the onset of complications and as needed thereafter

An assessment of the person's knowledge of diabetes and self care requirements should be included in their annual complications screening and treatment review.

### 5. Where should it be provided?

Hospitalisation is often a good opportunity to find people with diabetes who need education. However, it is not necessarily the best place for education to take place. Most people who are in hospital are sick and are often stressed and may not be able to absorb the information provided so, apart from teaching the patient essential self care skills, it may be better to wait until he or she is discharged from hospital before starting comprehensive education.

Aside from ensuring that the venue is as comfortable as possible, appropriately private, and free from intrusive distractions, there really is no right or wrong place to conduct diabetes education. Some of the venues that are often used are:

- Diabetes Centres
- a separate room in the outpatients department of a hospital
- Community Health Centres
- church or community halls

Diabetes education can also be undertaken in the homes of people with diabetes or even out of doors. What is important is the not so much where the venue is but to make sure that the venue is not intimidating, the atmosphere is relaxed and not too formal and is set up in a way that encourages interaction. For example, when educating groups, it is preferable to set up the chairs in a circle or semi-circle rather than in straight rows which tend to be more formal.

## **6. How can it be made more systematic and accountable?**

It is not sufficient to provide education without evaluating its outcomes. Nor is it appropriate or productive to provide education without a clear idea of what the education is trying to achieve. Consequently diabetes teams need to spend time considering and agreeing on what are the goals of education. What are the objectives? How will the team know if the objectives are met or not?

Ideally, each team should document (in general terms) the goals, objectives, and processes of education they will provide and indicators by which they can measure the success of the education. An obvious indicator is changes in patient knowledge, but changes in lifestyle habits (smoking, diet and exercise) are also important as are indicators like the avoidance and or management of sick days, hypos or foot problems.

These outcomes should be reviewed by the diabetes team on a regular basis eg at least annually. Measuring the outcomes of patient education will assist the team in determining and refining educational inputs and addressing deficiencies as a matter of routine practice. It is also helpful for the team to develop a list of core education topics based on essential aspects of self care knowledge and skills in order to assist in ensuring that important topics are not overlooked.

## MODULE:

# PSYCHOLOGICAL ISSUES IN DIABETES

### Rationale:

Given the serious nature of diabetes it is not surprising that chronic diseases carry a heavy burden of stress, anxiety and depression.

Diabetes has been described as the most “do-it-yourself” disease of all because the person with diabetes has to take so much responsibility for the care and outcomes of their diabetes and make multiple daily decisions about energy intake and expenditure, and self medication and monitoring. People with diabetes have to juggle self care, medical appointments and the cost of care with their responsibilities to their families and their employers. Diabetes is an all day every day responsibility. Having diabetes or a dependent child with diabetes has been shown to reduce employment and/or career progression/promotion opportunities. In some cultures it can also significantly reduce marriage opportunities.

The quantity, variety and complexity of daily self care requirements imposed by diabetes is indeed onerous. And there is the ever present threat of short and long term complications and it is little wonder that people with diabetes are often deeply concerned about their future health and capacity to work and live a normal life. Especially in developing countries, diabetes and its complications can have a major impact on gender roles and socioeconomic hardship – and even transgenerational poverty. For example, countries where there is no social protection, the loss of life or a limb for the family bread winner has the potential to plunge the whole family into poverty.

### Purpose:

To assist in raising awareness of the need to recognise and address psychological issues in diabetes.

### Potential Application:

- Health care professionals
- Health authorities - planners and funders
- National diabetes organisations
- Professional organisations

### Links:

This module links with Patient Education and Routine Care and Monitoring.

### Suggested Reading/References:

Peyrot M, Rubin RR, Lutaritzen T, Snoek FJ, Matthews DR, Skovlund SE. Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabet. Med.* 22, 1379-1385 (2005).

Mezuk B, Albrecht S, Eaton WW, Hill Golden S. Depression and Type 2 Diabetes Over the Lifespan. A Meta-analysis. *Diabetes Care.* 31: 2383-2390 (2008).

## CONSIDERATIONS FOR:

### PSYCHOLOGICAL ISSUES IN DIABETES

Depression and anxiety are common issues in diabetes and can pose a considerable barrier to effective self care and adherence to treatment recommendations. These conditions are now well documented in a international diabetes studies along with their significant burden of 'intangible' costs to people with diabetes, their families and carers. Psychological issues need to be recognised and addressed alongside clinical care and education. There is good evidence about the benefits of counselling and psychological / behavioural therapies but these are grossly under-utilised in diabetes care – mainly due to the shortage of psychologists / mental health workers. However, there are strategies which can help to address these deficits, and the integration of psychosocial care within a national diabetes programs framework is both desirable and possible. For practical purposes, as shown in Figure 1 it can be useful to divide mental health problems in diabetes into three broad categories according to their level of complexity ie:

- Psychiatric disorders
- Psychological disorders or problems
- Adaptation problems

#### 1. Psychiatric Disorders

It is not really possible to deal with psychiatric disorders within a National Diabetes Programme, except to acknowledge that these conditions exist and are complex, difficult to manage, and often highly stressful, emotional and disruptive to the individual and his or her family. They can also be dangerous in terms of (either or both) self-harm and harm to others. As with physical disorders, there are specific international diagnostic categories and criteria.

It is extremely unlikely that psychiatric problems are caused by diabetes. Nonetheless, a small proportion of people with diabetes will inevitably develop psychiatric disorders and a small proportion of people with psychiatric disorders will inevitably develop diabetes. As a result diabetes care providers will undoubtedly be faced with providing care to people with psychiatric disorders at some stage. Few diabetes care providers are qualified to treat psychiatric problems and, aside from taking account of and tailoring diabetes management to the individual's specific needs and functional capability, should refer the person to a psychiatrist or other suitably trained mental health worker - working closely with them on the person's diabetes management.

#### 2. Psychological Problems

Rates of depression and anxiety are two to three times higher in people with diabetes than in the background population. Psychological and personality disorders may pre-exist in people who get diabetes may sometimes be serious and /or have acute phases that can complicate and compromise the management of diabetes. Many people, regardless of their health status, suffer acute bouts of depression, stress and anxiety either caused or exacerbated by adverse life events. For people with diabetes, various stages along the continuum of the disease process from diagnosis to the onset and end stage of complications are a prime time for the manifestation of psychological problems. Whether mild or severe, these problems are

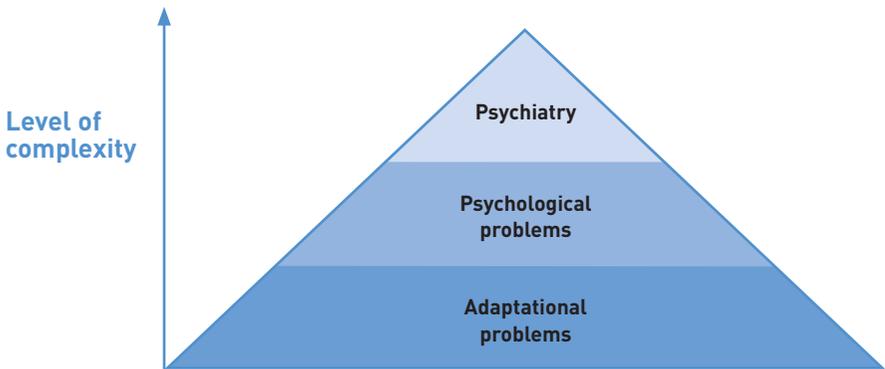
common, cause untold suffering and anguish and present significant barriers to optimal self care. For all these reasons, psychological problems should be addressed within the context of National Diabetes Programmes. For example:

- **Identifying and monitoring the problem**

Internationally validated survey tools, including those from the Novo Nordisk's DAWN Programme are available to facilitate the gathering of data on psychological needs and mental health co-morbidities in the population.

Assessment of psychological problems should routine included in the annual cycle of diabetes care along with complications screening and assessment of metabolic control. Validated tools are available which can be used in this situation. One such tool is the WHO-5 Well-being Index, an integral part of the DAWN MIND Programmes which can be used to monitor the well-being of people with diabetes. The Problem Areas in Diabetes (PAID) scale is widely also used as is the Appraisal of Diabetes Scale (ADS). Care providers who are responsible for interpreting and acting on the results need to have specific training in how to analyse and use the information obtained.

**Figure 1: Levels of mental health problems**



- **Expert professional management**

People with diabetes who have serious and complex psychological disorders should be referred to a psychologist or suitably qualified health professional with training in counselling and the management of psychological disorders. Health professionals who specifically trained in counselling can also help with motivational strategies to improve self care.

In countries that do not have psychologists or specially trained mental health workers or where psychologists / mental health workers are in short supply, it is important to train diabetes care providers in the identification and management of psychological problems. There are a number of available resources to support this including a section in the IDF Clinical Management Guidelines on psychological issues. Also, under the international DAWN Programme, organisations such as Psychosocial Aspects of Diabetes Study Group (PSAD) of the European Association for the Study of Diabetes (EASD) have contributed to developing curricula and tools for training health professionals in managing psychosocial aspects of diabetes as an integral part of diabetes care.

National standards for psychological care should be incorporated into clinical management and/or patient education guidelines and a few countries now have separate national guidelines for the management and care of psychological problems in diabetes.

#### ■ **Delivering psychosocial support as part of diabetes education**

The most cost effective and sustainable model of delivering psychological and adaptation support to people with diabetes may be to integrate it within the framework of existing patient education programmes. Some approaches include:

- integration of psychosocial topics in core patient education curricula
- designing educational programs to elicit participants' concerns, worries and needs
- ensuring that at least part of the education is guided by patient's priorities
- use of group sessions to facilitate peer and emotional support
- integrated use of motivational and psychoeducational self-help strategies
- providing training in coping skills and problem-solving
- involvement of family members and friends
- involving relevant psychosocial disciplines in designing and providing education programmes

### **3. Adaptation Problems**

The majority of people with diabetes do not have either psychiatric or psychological problems but may have considerable difficulty adjusting to a diagnosis of diabetes; living with it; and managing acute episodes and/or complications. The demands of self care of diabetes, the prospect of both short and long term complications, and the potential cost and employment implications of diabetes are so overwhelming that it would almost be abnormal for an individual not to have problems adapting to it. For some people diabetes limits life chances (job, education, marriage). For others who already have serious health, or social problems such as a disabled child, living with violence, being a single parent, living in poverty, diabetes can create a massive personal and family burden.

Most of the strategies and tools listed above under Point 2 (Psychological problems) can also be applied to adaptation problems. It is also worth noting that adaptation problems and concerns can often be resolved or alleviated by the provision of education and information tailored to the individual's needs and circumstances. This must include sensitive communication by health care providers with an emphasis on reflective listening to elicit myths and misconceptions that need to be dealt with. Practical assistance such as referral to support services can also be helpful. Health care providers, family members and community workers treating or supporting people with diabetes can all assist in alleviating the psychosocial burden of diabetes. In some cases peers can play a key role in helping people with adjustment problems to accept and adapt.

Awareness campaigns targeting the myths, misperceptions and psychosocial issues that prevent people with diabetes from living full productive lives can be integrated into National Diabetes Programmes. Active involvement of people with diabetes or their family members in communicating about diabetes can help reduce stigma and provide an improved sense of support to people with diabetes who often feel socially isolated or feel that the community around them is insensitive to their struggles and needs. Awareness campaigns of this nature should reach family, friends, local communities, patient associations, health professionals and policy-makers in order to stimulate dialogue, understanding and acceptance of diabetes in the wider community.

## MODULE:

# DEVELOPING AND IMPLEMENTING GUIDELINES

## Rationale:

Increasing health care costs have created a growing imperative for the development of methods and mechanisms to assist governments and consumers to get the best possible value for money from the health services they provide or use. Perhaps the most important trend in this area has been the emergence of evidence based health care and specifically, evidence based clinical management guidelines which can effectively decrease unwarranted variations in clinical practice, reduce harms arising from treatments, improve clinical performance and patient outcomes. Evidence based guidelines seek to synthesise and summarise research evidence and make it available to clinicians, consumers, and health care funders and administrators in order to:

- maximise effectiveness and minimise harm by identifying safe, effective treatments
- inform decisions about resource allocation

## Purpose:

This module aims to explore the benefits and limitations of evidence based guidelines and present some options for their development and implementation.

## Potential Application:

Guidelines developed and auspiced by global non-government organisations such as the IDF Global Guideline are increasingly influential. On an individual country basis they are most commonly led by:

- Health authorities
- Professional diabetes organisations
- National diabetes organisations

## Links:

Links with *Early Diagnosis and Routine Care and Monitoring* and is relevant to all aspects of diabetes prevention and care

## Suggested Reading/References:

The ADAPTE Collaboration. Resource toolkit for guideline adaptation Version 1.0. 2007. Available at: [www.adapte.org](http://www.adapte.org)

IDF (2003). Guide for Guidelines. A guide for clinical guideline development. International Diabetes Federation, Brussels.

SIGN (2008) Scottish Intercollegiate Guidelines Network. SIGN 50: A Guideline Developer's Handbook. Available at: <http://www.sign.ac.uk/guidelines/fulltext/50/index.html>

NICE (2009) National Institute for Health and Clinical Excellence. The Guidelines Manual 2009. Available at: <http://www.nice.org.uk/aboutnice/howwework/developingniceclinicalguidelines/clinicalguideline-developmentmethods/GuidelinesManual2009.jsp>

NHMRC (2007). Standards and procedures for externally developed guidelines. National Health and Medical Research Council. Canberra, Australia. Available at: <http://www.nhmrc.gov.au/publications/synopses/nh56syn.htm>

## CONSIDERATIONS FOR:

### DEVELOPING AND IMPLEMENTING GUIDELINES

Over the past five to ten years, methods for developing evidence based guidelines have become increasingly complex and sophisticated. Nonetheless, there are still some issues which remain to be addressed. Current systems for grading the strength of the evidence are designed to evaluate strictly scientific, quantitative, research studies of interventions eg randomised controlled trials. However, many systems do not have an equivalent capacity to take account of less scientifically rigorous research such as observational or qualitative evidence.

It has been suggested that the processes for guideline development and evaluation should be outcome focused. The methods and processes used to synthesise the available evidence into guideline recommendations are very rigorous and objective. Consequently, they are labour intensive and costly and, with new evidence emerging almost daily, keeping guidelines up to date is a major challenge. Nonetheless, there is good evidence in diabetes about which clinical practices and processes are effective in improving health and cost outcomes and clinical management guidelines are the best method available for informing clinicians and consumers about the recommended standards of care. It is important, however, that guidelines are developed, disseminated and implemented with resource constraints in mind and that they are sufficiently flexible to adapt to variations in local conditions.

Recently increasing attention has been directed to simplifying the guideline development process by adapting existing relevant guidelines rather than necessarily starting from scratch to develop a guideline. This has been referred to as “derived guidelines” by the IDF and similar process known as the ADAPTE process has been proposed by others.

The considerations and options for generating and implementing national diabetes guidelines which are outlined below should be considered in relation to available expertise, financial and other resources.

#### 1. The complexity of guidelines for diabetes

Diabetes is a complex condition which can affect virtually all systems in the body and its management must include attention not only to glycaemic control but also to blood pressure, weight, and lipids. Therefore, a diabetes guideline is not just one guideline for blood glucose management but must also cover areas such as:

- hypertension
- macrovascular diseases
- dyslipidaemia
- foot problems
- case detection and diagnosis
- primary prevention
- retinopathy
- microvascular diseases
- renal disease
- patient education
- psychological care

#### 2. Expertise required for developing evidence based guidelines

Expert clinicians, professionals and academics with high level expertise and experience in guideline development methodology are essential to the process of developing guidelines for diabetes prevention and care. The process should also involve a multidisciplinary approach and include representation of people with diabetes who need to be involved to provide a patient perspective.

### 3. Lead agency or group

The guideline development process should be under the umbrella of an agency or group with widely acknowledged expertise and credibility either in the field of diabetes or in guideline development eg professional or combined professional/consumer national diabetes organisation, a government or academic centre whose brief is guideline or evidence methods and generation.

### 4. Endorsement of guidelines

Guidelines introduced for national use must have undergone an extensive consultation process and have the endorsement of a national health authority, preferably a government auspiced body.

### 5. Options for generating guidelines

#### OPTION 1: STEPS FOR DEVELOPING NEW EVIDENCE BASED GUIDELINES

##### This requires:

- Defining clinically relevant questions to guide the literature searches
- Searching the literature using a systematic approach for each identified question
- Sorting and culling the search yield using pre-defined inclusion and exclusion criteria
- Critically reviewing and grading the evidence using a standardised appraisal approach
- Synthesising and summarising the evidence and formulate recommendations

##### Defining clinically relevant questions

To guide the literature searches in order to generate evidence for diabetes guidelines, questions should consider issues such as:

- what needs to be assessed?
- what are the key treatment/management issues?
- should everyone with diabetes be assessed for this or are there identifiable risks which indicate selective assessment?
- what assessment methods are the most reliable and appropriate?
- how should the results be interpreted - normal ranges, clinical targets?
- what, if any action should be initiated on the basis of the results?
- what are the overall costs of intervening?
- what are the socioeconomic considerations ?

Each question should be framed using the 'PICO' approach:

- **P**opulation or **P**roblem
- **I**ntervention (for a treatment/intervention question)
- **I**ndicator (for a prognosis/aetiology question)
- **I**ndex test (for a diagnostic accuracy question)
- **C**omparator
- **O**utcome

### ***Searching the literature***

A systematic literature search using recognised search strategies should be conducted for each of the identified questions by a person experienced in health related literature searching and should at least include Medline, Embase, Cochrane, and CINAHL data bases. Other sources such as the internet, resources from experts and hand-searching of reference lists should also be used in the search for relevant evidence. It is important to document the search question and its yield.

### ***Sorting and culling the search yield***

Articles, or initially abstracts, should be sorted according to their relevance to the identified question and their scientific rigour into the following categories:

- meta-analysis, or systematic review
- randomised control trial
- cohort studies
- case control studies
- case series
- observational/descriptive studies

Whether an article is included as part of the evidence for the guideline needs to be decided using pre-defined inclusion and exclusion criteria with the most important criterion being .... "does the article address one or more of the identified research questions". For transparency and replicability of the guideline, it is essential to document the reasons behind the decision for including/excluding articles.

### ***Critically reviewing and grading the evidence***

This should be done by a person with specific training in critical appraisal methods and sufficient content knowledge of the subject matter to recognise possible confounders and to discriminate between clinically relevant and clinically irrelevant issues. Criteria for grading the evidence in a systematic and standardised way will usually be prescribed by the peak national government research body.

### ***Synthesising and summarising the evidence into recommendations***

Guideline recommendations must be based on the best available evidence of safety, clinical effectiveness, availability of interventions, cost effectiveness and community values. The framework for expressing guideline recommendations can be based on the same framework for identifying clinically relevant questions to guide the literature searches. For each clinical question, recommendations should be based on the assessment of all of the included studies (body of evidence). In judging the body of evidence the following five components should be considered:

- the evidence base in terms of the number of studies, level of evidence and quality of studies (risk of bias)
- the consistency of the study results
- the potential clinical impact of the proposed recommendation
- the generalisability of the body of evidence to the target population for the guideline
- the applicability of the body of evidence to the healthcare context in which the guideline is to be used.

## OPTION 2: ADAPTING EXISTING GUIDELINES TO THE LOCAL CONTEXT

Given the high cost, intensive labour and highly specialised expertise required for searching, grading and synthesising the evidence, it may not be possible or practical for every country to go through the entire process of developing their own guidelines. Particularly in the event of limited health resources, it may be wiser to adapt existing evidence based guidelines to the local circumstances and allocate the resources saved to other aspects of care. Precedents show that this process can be equally effective, is relatively uncomplicated and consumes significantly less resources. The IDF Guidelines Task Force has developed a guide for adapting guidelines to local needs and/or the following steps can be followed:

- **Establish an Expert Committee or Steering Group**

This should be a small group of key clinical and public health experts who will drive the process.

- **Select suitable existing evidence based guidelines**

The Expert Committee should review major existing evidence based guidelines for relevance to national needs and the health system context in consultation with other experts and key interest groups.

- **Convene a workshop of key experts, opinion leaders and key stakeholders**

Hold a workshop of key diabetes specialists, primary care physicians, public health physicians and relevant health authorities. Include discrete representation from consumer and professionals diabetes associations.

- **Adapt the existing guidelines to local needs and circumstances**

Use the workshop to examine the recommendations from the existing guidelines and compare them to what is possible and feasible to do in the local country context. For example, where the existing guidelines recommend an assessment or treatment that is not locally available, negotiate a consensus from the workshop participants about what is the next best thing that can be done within local resources. In this way the guidelines can be modified to the resource and health system context of the individual country.

- **Circulate the adapted guidelines for confirmation**

Circulate the adapted guidelines to workshop participants or at least to a reference group which represents the workshop participants for confirmation of the agreed changes.

- **Obtain national endorsement for the guidelines**

Obtain endorsement from government and or national diabetes professional and/or consumer associations.

The IDF Clinical Guidelines Task Force has developed a number of evidence or evidence-and-consensus-based guidelines which are available internationally and which are suitable to be adapted for optimal; local relevance.

## 6. Implementing Guidelines

Developing guidelines is not in itself sufficient to change clinical practice. Nor is just disseminating them to clinicians, for example by mail. For optimal uptake of guidelines into everyday practice, a proactive systematic approach is needed. Approaches can incorporate 'high tech' mechanisms such as electronic decision support systems but where resources do not allow this, there are a number of less resource intensive methods which can be equally successful. A useful framework for thinking about approaches is to look at what is already available in the health system and utilise it eg:

- **People**

People who will use the guidelines and recipients of treatments and interventions covered in the guidelines including consumers, allied health workers, non-government organisations

- **Providers**

Primary care physicians, diabetes and other medical specialists, and other health professionals who may be involved in treating people with diabetes

- **Provider organisations and funders/insurers**

Publicise the guidelines to their members and incorporate the guidelines into their policies and protocols

- **Policy makers**

To create systems, incentive and disincentives to promote uptake of the guidelines throughout all aspects of the health system

- **Programmes**

Refocus existing programmes and/or base planned diabetes programmes on the guidelines

- **Other influences**

Those in a position to indirectly promote use of the guidelines eg pharmaceutical industry, undergraduate and continuing education training schools, professional and consumer organisations.

## MODULE:

# DEVELOPING THE DIABETES WORKFORCE AND SERVICES

### Rationale:

Technological advances and increasing expectations on the part of consumers mean that, for some considerable time now, governments all over the world, whether from fully industrialised or developing countries, have been struggling to contain health care costs and make effective health care available to their populations. In view of the 2008/2009 global financial crisis, this is more of a problem than ever. In addition to applying the principles of evidence based health care in order to maximise health care effectiveness, an important mechanism for obtaining best value for money in diabetes care is to ensure that:

- the health workforce is trained and focussed on knowing what their job is, knowing how to do it well, and knowing when and where a patient should be referred if required.
- health services for diabetes are appropriately distributed, equipped and follow established referral pathways and networks designated to deliver the required levels of care

### Purpose:

To ensure an appropriate level and mix of health care provider skills and services that are equipped to deliver the timely and effective care to people with diabetes across the continuum including early diagnosis, routine care, management of complications and co-morbidities through to palliative care.

### Potential Application:

This module applies most notably to local health authorities. However, it is increasingly common for professional medical and diabetes educators associations to take responsibility for accrediting training programs and credentiaing mechanisms for their members. In any case, it will require broad support from:

- Health authorities
- Professional diabetes organisations
- Key specialist medical and non-medical clinicians
- Diabetes Centres
- Primary care

### Links:

This module links with all modules in Section 4 of the Guide.

### Suggested Reading:

WHO (2005) Preparing a Health Care Workforce for the 21st Century: The Challenge of Chronic Conditions. World Health Organisation.

Available at: [http://www.who.int/chp/knowledge/publications/workforce\\_report.pdf](http://www.who.int/chp/knowledge/publications/workforce_report.pdf)

## CONSIDERATIONS FOR:

# DEVELOPING THE DIABETES WORKFORCE AND SERVICES

While diabetes is undoubtedly a complex condition, unlike many other diseases, diabetes care does not require a lot of high tech expensive equipment to achieve good results. Also unlike many other disease areas, diabetes has good quality evidence from the literature and strong expert consensus about which care processes produce consistently and significantly improved outcomes. If diabetes is such a serious public health issue, is not so costly to treat compared to other diseases, and we know how to treat it, then what is the problem?

The problem is not so much about knowing what to do, it is about getting it done. This requires creating systems and work environments which make it relatively easy to do the recommended thing. That is, having systems and work cultures in place which encourage, promote and reward doing the 'right thing in the right way'. Having a knowledgeable and well trained workforce and well equipped services that are balanced across primary care and specialist services is arguably the single most important factor in achieving optimal diabetes. Developing an appropriately skilled and motivated workforce and streamlining health services comes under the heading of capacity building. Capacity building is about 'making what is there work better' or, put another way, it is about strengthening the capacity of health care providers and health services to perform to the best of their ability. Workforce capacity and the effectiveness can be enhanced by the use of multiple strategies:

## 1. Identify Needs

Consult about the current situation with consumers and providers. Conduct a situation analysis of the status of services available to people with diabetes on the basis of quality and accessibility. Determine whether or not the recommended standards of care are being provided to people with diabetes and if the nature of the services and mix of primary versus specialist services is appropriate to the identified needs.

## 2. Delineate Roles

Determine what kind of services is required and who should provide them. Thinking in terms of routine care, semi-specialised care and highly specialised or tertiary care is useful but must include consideration of where services and health professionals are located and what types and levels of services are affordable. In addition to the clinical workforce and services consider needs for services such as prevention and health promotion and support services such as laboratories, information services and so on.

## 3. Models of care

Diabetes has traditionally led the way in developing models of care for chronic diseases. Some of these models are patient empowerment, chronic disease self management, multidisciplinary care, shared care programmes, and service integration between disease areas. Exploring these and other models may help decisions about what is most appropriate to your country's social, political, cultural and health system context.

## 4. Develop and implement clinical management guidelines and protocols

Based on the role delineations and models of care identified as the most suitable to the operating context, develop or adapt and implement protocols and guidelines for the referral and management of the various types of diabetes and the stages of the diabetes disease

process. Such guidelines and protocols should contain recommendations which are feasible, affordable and acceptable to clinicians and consumers alike and should become:

- the national benchmark for diabetes care and treatment targets
- the basis of health professional undergraduate and continuing education
- the basis of clinical information, recall and data collection services data collection systems

## 5. Train and equip staff

Use the guidelines and protocols as a basis for continuing education for staff and to help determine what types of services are required and how they will need to be equipped. Staff will need to be trained not only in the clinical skills required but in systems, mechanisms and structures that underpin the health care they provide eg:

- how to use and maintain equipment
- understanding information systems and documentation requirements
- requirements for accountability and reporting
- interpreting and applying policy and guidelines
- continuous monitoring and quality improvement of the services provided

Train staff and equip health facilities to put these protocols and guidelines into practice according to their designated level of services delineation. For example:

- staff designated to provide routine care will require a good, sound level of broad basic training in diabetes clinical care and education and the facilities they staff will require general basic equipment
- to provide intermediate or semi-specialised care staff will need a more detailed level of diabetes specific knowledge and skills training and will need access to more sophisticated equipment
- staff designated to provide highly specialised services will need advanced training and access to a selection of specialised equipment and laboratory tests

## 6. Governance

Identify appropriate organisational structures and communication and accountability structures and mechanisms to ensure that clinical governance is observed.

## 7. Horizontal Integration

Horizontal integration refers to integration between different disease areas (Figure 2). Type 2 diabetes and cardiovascular disease have many common primary and secondary risk factors and, many common secondary risk factors. For optimal results, both conditions require patient education and behavioural counselling as well as medical treatment. Lifestyle modification is important in the management of both conditions. Even with medical treatment, although there are marked differences in the nature of treatment for these conditions, there are also notable commonalities such as the need to normalise blood pressure and lipids. Given this and that diabetes is an important risk for heart disease and stroke, it makes sense to integrate or combine diabetes and cardiovascular disease services. There are obvious economies of scale and, at least in theory, it should be easier to provide more holistic or 'seamless' care especially if attention is given to training staff and designating services as combined diabetes and cardiovascular disease centres. However, this does not mean that diabetes should be subsumed into cardiovascular disease because of its much higher profile at both the community and government levels. The role of diabetes as an independent risk factor for heart disease should be a central focus for promoting government and public attention to diabetes.

Figure 2: 'Horizontal' integration



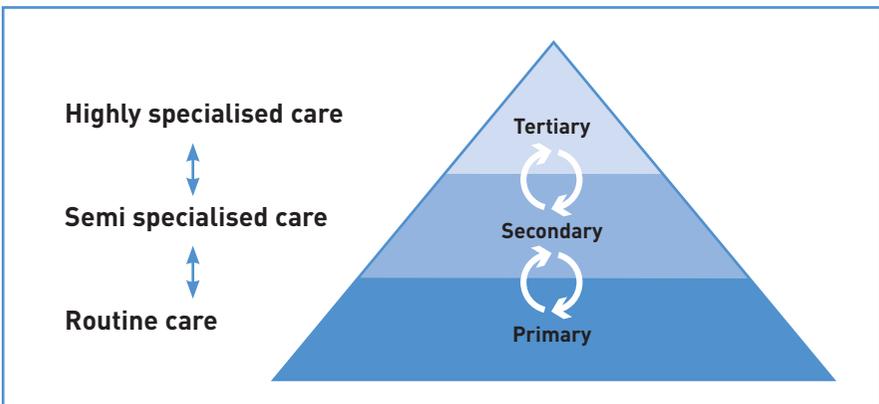
## 8. Vertical Integration

Vertical integration refers to integration between different levels of care within a specified disease area. Integrating primary and specialist diabetes care is vital in promoting continuity of care and reducing duplication of services between the two. For optimal success, the integration of primary and specialist diabetes services requires:

- a designated case manager ie the general practitioner, specialist diabetes nurse, or the patient
- clearly defined roles, functions and responsibilities
- clearly defined referral pathways
- formal mechanisms for communication about the planning, delivery and results of care

Figure 3 illustrates the potential use of the vertical integration model as a framework for delineating service roles.

Figure 3: 'Vertical' integration



# EVALUATING PROGRESS

**90** Collecting Diabetes Data

**94** Evaluating National Diabetes Programmes

## MODULE:

# COLLECTING DIABETES DATA

## Rationale:

Monitoring diabetes care processes and outcomes is essential in identifying which processes and models of care lead to the best health and cost outcomes. It provides feedback on the effectiveness or otherwise of interventions and helps determine where best to invest scarce resources. Data collection, and its yield, forms an important central platform for clinical and economic research and statistical modeling to advance our knowledge and understanding of diabetes. Nonetheless, data collection and management is labour intensive and costly, therefore careful consideration needs to be given to the most appropriate and meaningful data that can be collected and managed within the available financial resources and technical capacity of each country.

In the current climate of cost rationalisation in health care and the push for health care practices to be based on evidence of effectiveness, the collection and dissemination of clinical outcomes data has become pivotal to the management of health care and is an essential tool for:

- measuring the health burden of diabetes
- monitoring changes to the health status of the diabetic population
- generating information about the quality of diabetes care
- assessing the effectiveness of interventions
- estimating the economic burden of diabetes to the Government, the community, and the family/individual
- providing a basis for planning diabetes services and predicting future needs

## Purpose:

This module aims to assist in promoting the development of optimally appropriate and consistent data collection for diabetes.

## Potential Application:

While assessing and reporting on the health of the population is ultimately the responsibility of Ministries of Health, it is not uncommon for national diabetes organisations, professional diabetes organisations or groups of senior clinicians to initiate and conduct large scale data collection on diabetes. This module should be useful for:

- Health authorities – departments with a responsibility for health surveillance
- Key diabetes clinicians
- Professional diabetes organisations

## Links:

Links with *Routine Care and Monitoring, Conducting a Baseline Prevalence Survey, Assessing the Cost of Diabetes and Evaluating National Diabetes Programmes*

## Suggested Reading:

WHO (2010) STEPwise approach to chronic disease risk factor surveillance (STEPS). World Health Organization, Geneva. Available at: <http://www.who.int/chp/steps/riskfactor/en/index.html>

## CONSIDERATIONS FOR:

### COLLECTING DIABETES DATA

There are numerous issues to consider when planning data collection for any disease area. For example, what data are required and why? How will the data be collected and by whom? How will it be disseminated and used? How will consistency and comparability of data be assured? How will patient confidentiality be protected? Although there will be diabetes specific issues to consider, the same broad principles should be applied to the collection of clinical information for any disease area and should include answers to two key questions ie what should be assessed and how should the data be collected and used?

#### 1. What should be assessed?

While measuring endpoint outcomes is always desirable, given that there is good evidence about the effectiveness of certain clinical practices and processes in reducing diabetes complications, it is not essential to always measure outcome endpoints, and the use of surrogate outcomes such as HbA1c are good indicators of these endpoints. Ultimately, deciding what to assess to evaluate quality of care is reduced to three choices:

- Endpoint outcomes such as blindness, end stage kidney failure, amputation rates, heart attack and stroke, death
- Surrogate outcomes eg meeting agreed targets for HbA1c, microalbuminuria, blood pressure and lipids. Other surrogate outcomes may be measured by hospital admissions or use of other health care services.
- Process indicators include the proportion of people with diabetes appropriately accessing services and receiving care eg the annual cycle of care and complications screening or clinicians adhering to clinical management guidelines

Whatever is being assessed, it is vital that indicators are agreed nationally, are valid (ie actually do measure what they are designed to measure), are reliable and realistic (ie collecting the required information is feasible).

#### EXAMPLES OF PROCESS INDICATORS

- Primary prevention
  - number of weight loss or physical activity programmes
- Quality of diabetes care
  - proportion of people with diabetes having their HbA1c assessed according to the recommended frequency

#### EXAMPLES OF SURROGATE OUTCOME INDICATORS

- Primary prevention
  - Risk factors data such as proportion of people in the healthy weight range
- Quality of diabetes care
  - frequency and duration of hospital admissions
  - labour force participation – time off work
  - glycaemic control, blood pressure, lipids

## EXAMPLES OF OUTCOME (ENDPOINT) INDICATORS

- Primary prevention
  - incidence and prevalence of diabetes
- Quality of diabetes care
  - incidence and prevalence rates for complications
  - health status (functional status, quality of life, well being)
  - morbidity and mortality rates

## 2. How should the data be collected and used?

A common reason for collecting clinical diabetes data is to evaluate the effectiveness of care. This requires identifying and tracking people with diabetes to determine what happens to them. This, in turn requires record linkage, financial resources and available local expertise. To clarify the issues involved, think about who needs it and why? What and how will it contribute to improving diabetes care and outcomes? What information needs to be collected to achieve the identified purpose?

### WHAT INFORMATION IS AVAILABLE IN THE COUNTRY?

What information is already available in the country? How will this be utilised?

### HOW WILL IT BE COLLECTED AND BY WHOM?

It is important to consider who is in the best position to collect the data. Are they willing to do it? Do they understand what is required? Are they skilled to do the job properly? How will they be funded? What assistance will they require? Is the necessary hardware available for the data collection project?

### DATA FIELDS REQUIRE DEFINITIONS

Data definition is vital to ensure that the information which is intended to be collected is what is actually being collected. There should be no room for ambiguity to ensure that everyone is measuring the same things in the same way.

### DATA COLLECTORS REQUIRE TRAINING IN DEFINITIONS OF DATA FIELDS

Who will train the data collectors? What mechanisms will be put in place to assure the quality of the data collection process?

### HOW WILL DATA BE ENTERED INTO A DATABASE?

Who will enter the data and by what means? How will the data enterers be trained? Will it be entered locally and then pooled at a central site or would it be more efficient to send all data to a centralised data entry site? This will vary depending on needs and resources.

### WHO WILL OWN AND MANAGE THE DATA?

What format will the reports be in? How will they be disseminated and by whom? Who will own and manage the data? Who will have access to it? How will this be funded?

### HOW WILL CONFIDENTIALITY OF INDIVIDUAL PATIENT DATA BE MAINTAINED?

Are there national regulations in force about the use of data and confidentiality? What steps will need to be taken to ensure that the privacy of the patient is protected? Will the data need to be de-identified? If so, are mechanisms available for doing this eg a unique identifier such as a social security number, or does a system need to be developed?



## MODULE:

# EVALUATING NATIONAL DIABETES PROGRAMMES

### Rationale:

National Diabetes Programmes (NDP) require a large investment of resources. For Ministries of Health in many countries, they are not just about diabetes but are an experiment in a comprehensive, outcomes focused approach to health problems more generally. Above all they are a 'test case' for demonstrating that improving policy, governance, access, quality of care, and reducing risk factors for diabetes brings a worthwhile return on investment. Whether they work at all or how well they work must be assessed to justify the investment and to determine if the interventions and strategies used in the National Diabetes Programme are effective or if they need to be re- thought and modified.

The impact and effectiveness of an NDP can be evaluated using indicators ie a set of qualitative and/or quantitative measures for determining the extent to which the goals and objectives of the NDP have been achieved.

### Purpose:

Evaluation mechanisms which take account of a range of both quantitative and qualitative measures are required. This module presents some of the issues and options for deciding how to assess NDPs.

### Potential Application:

Ministries of Health will be the main authority leading the evaluation of NDPs but will need to involve and consult closely with:

- Key diabetes clinicians
- Professional diabetes organisations
- National diabetes organisations

### Links:

Links with *Developing a Framework for a National Diabetes Programme* and *Collecting Diabetes Data*.

### Suggested Reading:

Gallivan J, Greenberg R, Brown C. (2008) The National Diabetes Education Program evaluation framework: how to design an evaluation of a multifaceted public health education program. *Prev Chronic Dis* 5(4). [http://www.cdc.gov/pcd/issues/2008/oct/07\\_0191.htm](http://www.cdc.gov/pcd/issues/2008/oct/07_0191.htm).

Standards for National Diabetes Programs. Available at: (Add IDF Task Force Policy & Prevention Website).

## CONSIDERATIONS FOR:

### EVALUATING NATIONAL DIABETES PROGRAMMES

Deciding what to assess in order to evaluate progress and assess the impact of national diabetes programmes is no easy task. Clearly, the evaluation of NDPs must be linked to their goals and objectives – what did they set out to achieve, have they achieved it? However, the magnitude of what could be assessed is enormous. Resources may be limited and consideration must be given to what proportion of available funding should be spent on evaluation as opposed to prevention and the care of people already diagnosed with diabetes. In some countries and in some circumstances it may be more manageable to assess individual components of the NDP sequentially rather than attempt to undertake a comprehensive evaluation of all aspects at one time.

The ultimate purpose of a comprehensive NDP is to improve and/or maintain the health of people with diabetes, prevent or reduce new cases of diabetes from occurring, and reduce the cost burden of diabetes. Achieving this requires improving the ability of the health system and the people who work in to deliver more effective services. Early evaluations of NDP concentrated heavily on the collection of quantitative data to measure progress towards specified numerical clinical outcomes. While these indicators are of vital importance, developing and measuring indicators of other benefits associated with the NDP such as policy changes, availability of essential medications and supplies, service development and increased community awareness should not be overlooked.

Some of the ways in which the effectiveness of a National Diabetes Programme can be evaluated are through the use of one or a combination of the following:

- data collection on clinical indicators of health care processes and health outcomes as
- outlined in the previous module *Collecting Diabetes Data*
- repeating baseline prevalence surveys after a specified time period eg a minimum of 5yrs
- conducting baseline costing studies and repeating after a specified time period
- developing indicators to assess progress against the specified goals and objectives of the
- NDP
- measuring implementation processes

National Diabetes Programmes are essentially a policy process. The three stages of policy are development, implementation and evaluation. This module deals primarily with implementation processes and focusses on reviewing the overall status (and measurable changes to the status) of the NDP.

#### 1. Does a National Diabetes Programme exist?

Key questions for reviewing progress are:

- is there a National Diabetes Programme?
- is it documented and publicly available?
- does it set out specific goals and priorities for reducing the burden of diabetes?
- is it endorsed and led by the Government?
- does it have dedicated funding?

## **2. Is it a comprehensive or single component programme?**

- does it cover the main types of diabetes eg type 1 diabetes, type 2 diabetes, diabetes in pregnancy or focus on only one of these?
- does it include primary prevention, secondary prevention and tertiary prevention?
- does it focus on all clinical areas of diabetes or on one single aspect such as reducing blindness, preventing amputation or other single component approaches?
- does it include patient education?
- does it cover psychological and behavioral issues?

It is also important to determine if the NDP addresses the all-important range of systems that underpin the provision of good quality diabetes. These include:

- information and communication systems
- workforce training and development
- clinical guidelines, protocols and targets
- service delineation and referral systems
- policies and systems for resource allocation

To assess the status of prevention efforts it is necessary to ask if steps are being taken to prevent diabetes and reduce risk factors in the general community and/or in high risk groups within the general community? If 'yes' – what are they and are they working. If not, are there plans and partnerships being developed to address this issue?

## **3. Who is responsible?**

Who has overall responsibility in leading and driving the National Diabetes Programme? Unless the Ministry of Health has major responsibility for leading the NDP it is unlikely to be sustainable in the long term.

## **4. Who is involved?**

Are the key stakeholders actively involved in the development, implementation and evaluation of the NDP? Are the national diabetes organisation, diabetes professional organisations, senior clinicians and researchers involved? Are other stakeholders such as industry and government sectors (other than health) co-operating and engaged in the activities of the NDP?

## **5. Are goals and priorities being actioned?**

Have goals, priorities key strategies and associated indicators been developed in association with key stakeholders and communicated widely to all concerned? What progress has been made towards achieving the Programme's stated goals and objectives?

## **6. What is known about diabetes nationally?**

Does the NDP involve monitoring and surveillance of the diabetes burden? Is the incidence and prevalence of diabetes known? Are complication rates known? Is the cost of diabetes known? How is diabetes care funded? What is the proportion of costs borne by the government, private health insurers, the individual or family with diabetes? How accessible are the necessary services and essential medications and supplies for people with diabetes? Are mechanisms in place to enable the collection and management of data to monitor and measure the outcomes of diabetes prevention and care?

## **7. Is appropriate diabetes care available to people with diabetes?**

Is the diabetes workforce adequately trained to provide the required levels of diabetes care eg primary or routine care, semi-specialised care and tertiary care? Are there mechanisms for planning and communicating about diabetes care between primary and specialist care? Are diabetes services available and accessible to those who require them? Are essential medications and supplies for diabetes care available and affordable to those who require them? Are guidelines and protocols describing recommended standards of diabetes prevention and care in place? If the answer to the above questions is “no”, are strategies being put in place to address the identified deficiencies?

## **8. General implementation and evaluation strategy?**

Is there an implementation strategy and evaluation plan in place which outlines agreed indicators and timeframes for assessing the overall Programme?

## **9. Key Question**

Has anything changed as a result of introducing the National Diabetes Programme? If so, what has changed?



# WHERE TO NEXT?

- 100** National Diabetes Programmes of the future
- 103** Standards for National Diabetes Programmes

# NATIONAL DIABETES PROGRAMMES OF THE FUTURE

Over time, what constitutes 'best practice' and best treatment may vary in response to new research evidence about the effectiveness of treatments and/or models of service delivery. And, there is no doubt that while there are people with diabetes, National Diabetes Programmes will continue to have a strong focus on improving and maintaining the best possible access to the best possible quality of care and support services. However, it is already clear that there will be significant changes in other areas. These will include:

- a much broader approach to primary prevention
- attention to the management of previously under-recognised co-morbidities
- new partnerships and advocacy efforts
- increased awareness of the social and economic impact of diabetes / chronic diseases
- an improved global policy response to chronic diseases.

Some possible changes in the focus of national diabetes programs of the future might include concentration on:

## 1. Diabetes and the environment - from silos to synergies

The original diabetes action plans and programmes of 20 years ago were almost entirely concerned with the care of diabetes and with the health system. Now, with the benefit of a substantial body of evidence about preventing diabetes in people at identifiable risk, and an emerging body of evidence about the benefits of health promoting food and physical activity environments, prevention is very much at the forefront of National Diabetes Programmes thinking and activity. Moreover, the focus on prevention itself is increasingly taking the next step up from targeting 'at risk' individuals and is expanding to include a focus on making the environment more health-friendly (eg urban planning and design, workplace design, promoting active transport and reducing car dependency).

We now better understand that illness is a by product of the way we live - not a by product of the health system - and cannot be solved by the health system alone. We are also beginning to understand that protecting and maintaining health requires a whole-of- government and whole-of-society effort. This has opened the way to promote diabetes programmes in synergy with other chronic diseases and advocate that an investment reducing the burden of type 2 diabetes, for example, is also an investment in reducing heart disease, stroke, hypertension and obesity. There is only a small step between linking these conditions to each other; and linking their current proliferation to the same causes that are exacerbating climate change eg overconsumption, over-urbanisation, inactive transport, sedentary automated workplaces, over-dependence on non- renewable energy; and the marketing of unhealthy food that is also 'carbon-costly' to produce.

This is not just about primary prevention. A healthier environment helps to reduce risk and assists people who already have diabetes to adopt healthier lifestyles that are consistent with international recommendations for the avoidance of long term complications. National Diabetes Programmes of the future would be well advised to take account of these issues and use them as advocacy arguments.

## 2. Diabetes and the link with communicable diseases

Our knowledge and understanding of the interaction between diabetes and the major communicable diseases such as TB, malaria, HIV/AIDS, and newer infections like SARS and Avian flu is gradually improving. The body of research evidence about the link between diabetes and communicable diseases is growing both in volume and quality. This evidence will undoubtedly inform and influence the direction and focus of National Diabetes Programmes. This will be particularly important in developing countries where infectious diseases remain prevalent, and where resources do not permit parallel workforces and infrastructure for non-communicable and communicable diseases but demand a more holistic and integrated approach to both.

## 3. Diabetes as a development issue

Recognition of the massive human and economic cost of diabetes, and chronic disease more broadly, has finally reached a tipping point. Not only is the cost of treatments and services unsustainable but WHO has estimated hundreds of billions of international dollars worth of forgone income due to lost productivity resulting from diabetes heart disease and stroke in countries like China. This problem is not confined to developing nations. For example, in 2007, the American Diabetes Association reported that one third (USD58 billion) of the total cost of diabetes in the US was attributable to foregone income resulting from the impact of diabetes on national productivity.

There is growing awareness at all levels of national and global governance and policy that these diseases are not confined to the health system but are significant barrier to human development and economic sustainability. The myth of diabetes being a disease of old age and affluence has finally been put to rest. This is largely due to i) the data collated into successive editions of Diabetes Atlas demonstrating that diabetes is now mostly affecting working age people in developing countries and ii) greater understanding of the two way relationship between poverty and chronic diseases ie the cost and complications of diabetes causing individual and family financial hardship and the social gradient associated with developing diabetes.

Following on from the 2006 UN Resolution on Diabetes, the decision taken by the UN General Assembly in May 2010 to hold a Summit on chronic diseases in September 2011 heralds a new era of global attention and better governance for chronic diseases. Voted for by 140 UN member countries, the Summit has the potential to crystallise attention on both the plight of people who already have diabetes and the urgent need to prevent its development. Although not explicit in the push for the UN Summit on chronic diseases, the IDF is heavily involved in leadership, advocacy and action aimed at getting diabetes and related chronic diseases represented among the indicators for the Millennium Development Goals (MDGs).

The UN's public global recognition of the importance of chronic disease as a development issue will have a flow on effect to UN agencies, international donor agencies and global philanthropic organizations. Future National Diabetes Programmes will undoubtedly reflect this and will seek to magnify and amplify an approach that is built on good global governance and public policy that support the protection of good health, and better health care of those who experience chronic illnesses.

## **4. New horizons – new partners**

Even since the launch of the original National Diabetes Programmes Toolbox at the 18th IDF Congress in Paris 2003, attitudes and understanding of the problems the world faces have changed dramatically. Environmental issues are on everyone's lips; chronic diseases are at last receiving the recognition they deserve; and the boom years of prosperity (for developed countries) and unprecedented economic growth (for developing countries) has been slowed by the "great financial crises" and its aftermath.

Managing the triple crises of chronic diseases, climate change and the financial downturn successfully requires new thinking and new partnerships. New horizons require new partnerships and IDF's global body is taking a strong strategic focus and decisive leadership in this regard. For example, IDF recently formed an alliance with the World Heart Federation, the International Union Against Cancer, the International Union Against Tuberculosis and Lung Disease to jointly lobby the UN for a UN Summit for chronic diseases and works towards the inclusion of the major chronic diseases into the MDGs. Information about the alliance can be viewed at its website: <http://www.ncdalliance.org/>. In addition to working closely with WHO its new chronic disease initiative NCDNet, IDF is also 'looking outside the box' to liaise and collaborate with others with whom it has not previously been engaged. And, this too should be replicated at the national level via National Diabetes Programmes.

# STANDARDS FOR NATIONAL DIABETES PROGRAMMES

In the interests of developing a common understanding and language around National Diabetes Programmes at the global level, the IDF Task Force on Diabetes and NCD Prevention, Policy and Practice has developed an initial set of 10 core standards for National Diabetes Programmes. Over time it is intended to refine and expand the standards and add measurable indicators by which national programmes can be assessed meaningfully and compared.

1. A National Diabetes Programme exists and is publicly available
2. The goals and objectives of the National Diabetes Programmes are clearly documented
3. The National Diabetes Programme is endorsed and led or auspiced by the Ministry of Health
4. The National Diabetes Programme has been allocated dedicated funding by the Government
5. The National Diabetes Programme includes:
  - type 1 diabetes (this may not be applicable in, say, Pacific Island countries)
  - type 2 diabetes
  - gestational diabetes
6. The National Diabetes Programme covers specific areas eg:
  - ensuring equitable access to prevention and care services for all who need them
  - workforce development
  - the provision of adequate services, equipment and supplies
  - information systems
  - clinical governance/ guidelines and protocols
7. There is a documented implementation plan for the National Diabetes Programme
8. An appropriately constituted steering committee or group is tasked with overseeing the implementation of the National Diabetes Programme. This should include a range of stakeholders eg:
  - government authorities/officials
  - specialists and Primary Health Care Workers
  - business leaders
  - community leaders
  - diabetes association, professional societies or, action groups
  - relevant national/international health Organisations/agencies
9. The National Diabetes Programme takes a Patient Centred Approach ie:
  - people with diabetes are consulted about their needs
  - people with diabetes are represented on the committee responsible for the NDP implementation
  - the NDP takes account of individual differences and preferences and cultural diversity
  - the NDP includes a focus on ensuring equal access to health care regardless of geographic location, socio-economic status, language, culture or indigenous status
10. The National Diabetes Programme involves monitoring and surveillance of:
  - prevalence and incidence
  - access to and outcomes of routine clinical care and services
  - availability of essential medications and supplies
  - cost of diabetes to the health system/government
  - cost of diabetes to individuals/families or carers
  - community awareness
  - workforce: distribution, skills, numbers



# WHO CAN HELP?

- 106** IDF Global Infrastructure
- 107** IDF Regional Infrastructure
- 108** IDF Task Force on Diabetes and NCD Prevention, Policy and Practice

## IDF GLOBAL INFRASTRUCTURE

IDF has come of age. Over the past few years it has moved from an almost solely volunteer organisation with minimal infrastructure to support it, into a well organised, professionally run machine with the capacity to compete for attention and funding at a high level in the global health arena. This transition has been enabled largely by a previous decision by the IDF Executive Board to run the IDF Global Diabetes Congresses itself rather than outsourcing them to professional Congress organisers. The income from this has enabled IDF to build a solid infrastructure in the global office in Geneva to support the work of the Board and the Task Forces and Consultative Sections. In addition to the Chief Executive Officer, financial and development staff, administrative, IT, publicity and policy staff this includes an:

- epidemiologist
- economist
- education specialist

This infrastructure positions IDF well to optimise the effectiveness of its Task Forces and Consultative Sections. The Task Forces and Consultative Sections for the 2009- 2012 IDF Triennium can be viewed by visiting the IDF website at <http://www.idf.org/activities-0> and are listed below:

- **Consultative Section on Diabetes Education**  
Chair: Ann Belton
- **Task Force on Global Advocacy**  
Chair: Anne-Marie Felton
- **Task Force on Clinical Practice Guidelines**  
Chair: Stephen Colagiuri
- **Task Force on Science**  
Chair: Massimo Massi Benedetti
- **Task Force on Sustainable Diabetes and NCDs Policy and Practice**  
Chair: Ruth Colagiuri
- **Task Force on Epidemiology and Prevention**  
Chairs: George Alberti and Paul Zimmet
- **Task Force on Insulin and Other Essential Diabetes Medicines and Technologies**  
Chair: Larry Deeb
- **Task Force on Health Economics**  
Chair: Jonathan Brown
- **Task Force on Childhood and Youth**  
Chair: Johnny Ludvigsson

## IDF REGIONAL INFRASTRUCTURE

The IDF Regions are its backbone. The member organisations on which IDF is built form the Regional Councils. Each Regional Council elects a chair person - who forms part of the IDF Executive Board along with the elected vice presidents – a deputy chair and an executive to run its business. Each Region employs a Regional Manager. A list of the chairs, deputies and regional managers for each of the seven IDF Regions is listed below.

### AFRICAN REGION

**Chair:** Silver Bahendeka, Uganda

**Vice-Chair:** Evarist Bouenizabila,  
Republic of Congo

**Regional Manager:** Nancy Njje

Regional Office:

E-mail: idfafrica@mail.gm

Tel: +220-4224174

### EUROPEAN REGION

**President:** Chris J Delicata, Malta

**Vice-President:** João Nabais, Portugal

**Regional Manager:** Lex Herrebrugh

Regional Office:

IDF EUR Region

Chaussée de La Hulpe 166

B-1170 Brussels, Belgium

Tel: +32 2 5371889

Fax: +32 2 5371981

e-mail: lex@idf-europe.org

### MIDDLE EAST AND NORTH AFRICA REGION

**Chair:** Amir Kamran Nikosikhan, Iran

**Vice-Chair:** Adel El-Sayed, Egypt

**Regional Manager:** Aly El Sherif

Regional Office:

IDF MENA Region

c/o Egyptian Diabetes Association

40 Safia Zaghloul Street

Alexandria, Egypt

Tel: +203-5433505

Fax: +203-5431698

e-mail: alyshrf@hotmail.com

Website: www.idf-mena.org

### NORTH AMERICA AND CARIBBEAN REGION

**Chair:** Lurline Less, Jamaica

**Vice-Chair:** Serge Langlois, Canada

**Regional Manager:** Linda Cann

Regional Office:

IDF NAC Region

c/o American Diabetes Association

1701 N. Beauregard Street

Alexandria VA 22311, USA

Tel: 1-703-5491500 ext 2148

or 1-703-3795066

Fax: 1-703-5491715

E-mail: lcann@diabetes.org

### SOUTH AND CENTRAL AMERICA REGION

**Chair:** Manuel Vera Gonzales, Cuba

**Vice-Chair:** Edwin Jimenez, Costa Rica

**Regional Manager:** Vasco Campanella Lemes

Regional Office:

IDF SACA Region

José Benito Lamas 2980

11.300 Montevideo, Uruguay

Téléfono: +598 2 709 5457

Fax: +598 2 707 2963

E-mail: susanafe@adinet.com.uy

## SOUTH-EAST ASIAN REGION

**Chair:** Dhruba Lall Singh, Nepal  
**Vice-Chair:** Veenoo Basant Rai, Mauritius  
**Regional Manager:** Farzana Hameed

Regional Office:  
IDF SEA Region  
c/o Diabetes Association of Sri Lanka  
National Diabetes Centre  
50 Sarana Mawatha  
Rajagiriya, Sri Lanka  
Tel: +94-1-2883318  
Fax: +94-1-2872952  
E-mail: farzana@idf.org

## WESTERN PACIFIC REGION

**Chair:** Yutaka Seino, Japan  
**Vice-Chair:** Nam Han Cho, South Korea  
**Regional Manager:** Esther Ng

Regional Office:  
IDF WPR Region  
Blk 680A Jurong West Central 1 #16-38  
Singapore 641680  
Tel/Fax: (65) 6790-1252  
Mobile: (65) 9623-2119  
e-mail: esther@idf.org

## TASK FORCE ON DIABETES AND NCD PREVENTION POLICY AND PRACTICE

- Associate Professor Ruth Colagiuri (Chair) - Western Pacific Region
- Dr Kaushik Ramaiya (Deputy Chair) - Africa Region
- Professor Juan José Gagliardino - South and Central American Region
- Mr Lex Herrebrugh - Europe Region
- Dr Abdullah Ben Nakhi - Middle East and North Africa Region
- Professor Ambady Ramachandran - South-East Asia Region
- Professor Gayle Reiber - North America and Caribbean Region
- Dr Gojka Roglic - WHO Geneva

# ADDITIONAL INFORMATION

- 110** List of Suggested Readings
- 113** Useful Definitions

## LIST OF SUGGESTED READINGS

American Association of Diabetes Educators. Standards for outcomes measurements of diabetes self-management education. Position Statement. *Diabetes Educator*. 29, 804-816 (2003).

CDC. Preventing diabetes and its complications. Centres for Disease Control and Prevention Available at: <http://www.cdc.gov/nccdphp/publications/factsheets/prevention/diabetes.htm>

Colagiuri, R. (2010). "Diabetes: a pandemic, a development issue or both?" *Journal of Expert Reviews Cardiovascular Therapy*. 8(3):305-309.

Colagiuri R and Eigenmann CA. A national consensus on outcomes and indicators for diabetes patient education. *Diabetic Medicine*. 26, 442-446 (2009).

Coulson FR, Ypinazar VA, Margolis SA. (2006). Awareness of risks of overweight among rural Australians. *Rural Remote Health*. 6:514

Crandall JP, Knowler WC, Kahn SE, et al (2008). The prevention of type 2 diabetes. *Nat Clin Pract Endocrinol Metab* 4:382-93.

Gallivan J, Greenberg R, Brown C. (2008) The National Diabetes Education Program evaluation framework: how to design an evaluation of a multifaceted public health education program. *Prev Chronic Dis* 5(4). [http://www.cdc.gov/pcd/issues/2008/oct/07\\_0191.htm](http://www.cdc.gov/pcd/issues/2008/oct/07_0191.htm).

International Diabetes Federation. Available at: <http://www.idf.org/idf-membership>

IDF (2010) Rapid Assessment Protocol for Insulin Access (RAPIA). International Diabetes Federation. Available at: [http://www.idf.org/webdata/docs/IIF-RAPIA\\_plan.pdf](http://www.idf.org/webdata/docs/IIF-RAPIA_plan.pdf)

IDF, 2010, Diabetes Impact Study.

Available at: <http://www.idf.org/economics/diabetes-impact-studies>

IDF (2010) Diabetes Education Modules. International Diabetes Federation. Available at: <http://www.idf.org/node/1348?unode=A513C97A-F08C-4F97-9358-D406CDF4FEC1>

IDF (2010) Materials for World Diabetes Day.

Available at: <http://www.worlddiabetesday.org/materials>

IDF, Diabetes Atlas. 2009, International Diabetes Federation: Brussels. 2009.

Available at: <http://www.diabetesatlas.org/>

IDF (2008) The Kathmandu Declaration – The "Life-Circle" of prevention in diabetes. International Diabetes Federation.

Available at: <http://www.idf.org/webdata/docs/IDF-SEA-kathmandu-declaration.pdf>

IDF (2008) International Curriculum for Diabetes Health Professional Education. International Diabetes Federation.

Available at: [http://www.idf.org/webdata/docs/IDF\\_Curriculum\\_Introduction\\_EN.pdf](http://www.idf.org/webdata/docs/IDF_Curriculum_Introduction_EN.pdf)

IDF, *World Diabetes Media Kit: Every 10 seconds 1 person dies of diabetes*. International Diabetes Federation: Brussels. 2007.

IDF (2006). Diabetes Declaration and Strategy for Africa: a call to action and plan of action to prevent and control diabetes and related chronic diseases. Available at:

[http://www.idf.org/webdata/docs/Diabetes\\_Declaration\\_&\\_Strategy\\_for\\_Africa\\_full.pdf](http://www.idf.org/webdata/docs/Diabetes_Declaration_&_Strategy_for_Africa_full.pdf)

IDF Global Guidelines for Type 2 Diabetes (2005).

Available at: [http://www.idf.org/Global\\_guideline](http://www.idf.org/Global_guideline)

IDF (2003). Guide for Guidelines. A guide for clinical guideline development. International Diabetes Federation, Brussels.

International Expert Committee report on the role of the A1C assay in the diagnosis of diabetes. *Diabetes Care*. 2009; 32:1327-34.

Li G, Zhang P, Wang J, et al (2008). The long-term effect of lifestyle interventions to prevent diabetes in the China Da Qing Diabetes Prevention Study: a 20-year follow-up study. *Lancet* 371(9626):1783-1789.

Lindstrom J, Ilanne-Parikka P, Peltonen M, et al. (2006). Sustained reduction in the incidence of type 2 diabetes by lifestyle intervention: follow-up of the Finnish Diabetes Prevention Study. *Lancet* 368(9548):1673-1679.

Majumdar SR, Johnson JA, Bowker SL, Booth GL. A Canadian consensus for the standardized evaluation of quality improvement interventions in type 2 Diabetes. *Can J Diabetes*. 29, 220-229 (2005).

Mezuk B, Albrecht S, Eaton WW, Hill Golden S. Depression and Type 2 Diabetes Over the Lifespan. A Meta-analysis. *Diabetes Care*. 31: 2383-2390 (2008).

Mukhtar Q, Jack L, Jr., Martin M, Murphy D, Rivera M (2006). Evaluating progress toward Healthy People 2010 national diabetes objectives. *Preventing Chronic Disease* 3(1):A11.

Murugesan N, Snehalatha C, Schobhana R, Roglic G, Ramachandran A. (2007). Awareness about diabetes and its complications in the general and diabetic population in a city in southern India. *Diabetes Research and Clinical Practice*. 77: 433-437.

NICE (2009) National Institute for Health and Clinical Excellence. The Guidelines Manual 2009. Available at: <http://www.nice.org.uk/aboutnice/howwework/developingniceclinicalguidelines/clinicalguideline-developmentmethods/GuidelinesManual2009.jsp>

NHMRC (2007). Standards and procedures for externally developed guidelines. National Health and Medical Research Council. Canberra, Australia.

Available at: <http://www.nhmrc.gov.au/publications/synopses/nh56syn.htm>

Peyrot M, Rubin RR, Lutaritzen T, Snoek FJ, Matthews DR, Skovlund SE. Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. *Diabet. Med*. 22, 1379-1385 (2005).

Ramachandran A, Snehalatha C, Yamuna A, et al (2007). Cost-effectiveness of the interventions in the primary prevention of diabetes among Asian Indians: within-trial results of the Indian Diabetes Prevention Programme (IDPP). *Diabetes Care* 30(10):2548-2552.

Roglic G, Williams R, Colagiuri S. Screening for Diabetes – the World Health Organisation Perspective. In *Prevention of Type 2 Diabetes*. M Ganz (ed). John Wiley & Sons Ltd: England, 2004.

South Australian Government -Health in All Policies

Available at: <http://www.health.sa.gov.au/pehs/HiAP.htm>

SIGN [2008] Scottish Intercollegiate Guidelines Network. SIGN 50: A Guideline Developer's Handbook. Available at: <http://www.sign.ac.uk/guidelines/fulltext/50/index.html>

Standards for National Diabetes Programs. Available at: [Add IDF Task Force Policy & Prevention Website.

Suhrke, M. Nugent, R.A. Stuckler, D. Rocco, L. (2006) Chronic disease : An economic perspective. Oxford Health Alliance, London. Available at: <http://www.oxha.org/knowledge/publications/oxha-chronic-disease-an-economic-perspective.pdf>

The ADAPTE Collaboration. Resource toolkit for guideline adaptation Version 1.0. 2007. Available at: [www.adapte.org](http://www.adapte.org)

The National Diabetes Education Program (NDEP) awareness campaigns. Available at: <http://ndep.nih.gov/partners-community-organisation/campaigns/index.aspx>

The Sydney Resolution. The Oxford Health Alliance. Available at: [http://www.oxha.org/knowledge/publications/Sydney\\_Resolution\\_FINAL\\_27.02.08.pdf](http://www.oxha.org/knowledge/publications/Sydney_Resolution_FINAL_27.02.08.pdf)

United Nations (2006). UN Resolution on Diabetes. Signed 20 December 2006 (UN Resolution 61/225). Available at: <http://www.worlddiabetesday.org/en/the-campaign/unite-for-diabetes/the-un-resolution-on-diabetes>

Unwin N and Martin A (2004). Diabetes Action Now: WHO and IDF working together to raise awareness worldwide. *Diabetes Voice* 49(2):27-31. Available at: [http://www.who.int/diabetes/actionnow/DAN\\_diabetesvoice\\_article.pdf](http://www.who.int/diabetes/actionnow/DAN_diabetesvoice_article.pdf)

WHO. *Preventing Chronic Diseases: A vital investment*. Available at: [http://www.who.int/chp/chronic\\_disease\\_report/en/index.html](http://www.who.int/chp/chronic_disease_report/en/index.html)

WHO Health impact assessment. Available at: <http://www.who.int/hia/en/>

WHO (2010) STEPwise approach to chronic disease risk factor surveillance (STEPS). World Health Organization, Geneva. Available at: <http://www.who.int/chp/steps/riskfactor/en/index.html>

WHO (2010) STEPwise approach to chronic disease risk factor surveillance (STEPS). World Health Organization, Geneva. Available at: <http://www.who.int/chp/steps/riskfactor/en/index.html>

WHO and IDF (2006). Definition and diagnosis of diabetes mellitus and intermediate hyperglycemia: report of a WHO/IDF consultation. World Health Organization Geneva. Available at: [http://www.who.int/diabetes/publications/Definition\\_and\\_diagnosis\\_of\\_diabetes\\_new.pdf](http://www.who.int/diabetes/publications/Definition_and_diagnosis_of_diabetes_new.pdf)

WHO and IDF (2006). Definition and diagnosis of diabetes mellitus and intermediate hyperglycemia. Report of a WHO/IDF consultation. World Health Organization, Geneva.

WHO (2005) Preparing a Health Care Workforce for the 21st Century: The Challenge of Chronic Conditions. World Health Organisation. Available at: [http://www.who.int/chp/knowledge/publications/workforce\\_report.pdf](http://www.who.int/chp/knowledge/publications/workforce_report.pdf)

WHO (2001). Noncommunicable Diseases and Mental Health Surveillance: The WHO STEPwise Approach to Surveillance (STEPS) of NCD Risk Factors. World Health Organization, Geneva.

## USEFUL DEFINITIONS

For the purpose of this document, the following definitions and terms have been developed, adopted or adapted:

### **Ambulatory care**

Care provided in a non inpatient setting, either through a diabetes specialist service (Diabetes Centre) or hospital outpatient department, or in the community).

### **Best practice**

The best possible standard of performance in delivering safe, high quality care, as determined on the basis of available evidence and by comparison among health care providers.

### **Capacity building**

Capacity building means increasing and enhancing the ability of services, service providers and/or health systems to improve the quality of their services and perform more effectively.

### **Clinical guidelines**

Systematically developed statements that summarise the best available evidence and clinical consensus to assist providers and users of health services to make decisions about appropriate health care for specific circumstances.

### **Clinical protocols**

Practice guides designed to assist health practitioners make optimal decisions about health care interventions for specific circumstances. Protocols often take the form of checklists, flow charts or algorithms which set out particular process steps, treatment choices, and/or referrals pathways for particular circumstances.

### **Consumer**

A person who uses the health care system. For the purpose of this document the term consumer should be taken to mean a person with diabetes who uses the health care system.

### **Diabetes Centre**

A Diabetes Centre is a discrete unit comprising a multidisciplinary or interdisciplinary team of health professionals dedicated to diabetes. Its key functions are to provide:

- patient clinical care and education
- clinical leadership and quality improvement
- a focus for continuing health professional education in diabetes
- shared care and other programs to support local primary care professionals
- a research function, where possible

## **Diabetes educator**

A non-medical health professional who specialises, and has advanced training in the clinical management of diabetes and patient education. Diabetes educators are usually nurses or dietitians.

## **Early detection**

Early detection refers to diagnosing a disease at an early stage in the disease process, usually before it has become manifest in symptoms and/or clinical signs.

## **Evidence based**

Based on systematic review and synthesis of the results of peer reviewed publications classified according to the rigour of the research methods used.

## **Goal**

A goal is a general statement of intent and aspiration. A goal describes outcomes which might reasonably be achieved in light of current knowledge and resources. Goals usually apply to the broad population.

## **Health intervention**

A health intervention is a program, procedure, service or activity which is carried out to improve or maintain health, health behaviours or other factors associated with health.

## **Health outcome**

A health outcome is a change in the health of individuals, groups of individuals or populations, as a result of a variety of factors such as health services, health promotion programs, aging, the environment, lifestyle factors or programs unrelated to health.

## **Incidence**

The number of new cases of a disease in a specified population during a given period of time.

## **Indicator**

A health indicator is a unit of information that reflects, directly or indirectly, the performance of an intervention or health service.

## **Multidisciplinary team**

In diabetes care the multidisciplinary team usually includes, as a minimum, a medical specialist (endocrinologist, diabetologist, specialist general physician), a diabetes nurse, and a dietitian. There may be variations depending on health systems settings and if available, the team should include a podiatrist, and a psychologist or social worker.

## **Objective**

A specific, measurable statement of an action required to make progress toward achievement of a particular goal or outcome. For example, a goal of preventing type 2 diabetes and cardiovascular disease would have an objective of reducing modifiable risk factors in the population as an objective.

## **Palliative care**

Management of and promoting the person's adjustment to irreversible adverse health impairment. This includes medical treatment - usually centred on the alleviation of symptoms and/or pain, counseling and the provision of support services.

## **Patient**

A person with a health problem who is receiving treatment for that problem. In this document we have used the terms patient and consumer interchangeably. However, it should be noted that many people with diabetes do not wish to be called a patient except when they are actually in hospital or visiting the doctor. They argue that, even though they have a chronic health problem, they function in society just as others do and would prefer to be known as a 'person with diabetes' rather than a 'patient'.

## **Population Health**

This means considering health promotion and health interventions on a broad scale ie the whole population. Population health strategies include prevention initiatives such as reducing cardiovascular and diabetes risk factors in the general community by encouraging increased physical activity.

## **Prevalence**

The number of instances of a given disease in a particular population at a particular point in time.

## **Primary prevention**

Interventions aimed at reducing and minimising risk factors for the development of health problems. For diabetes and cardiovascular disease this means attention to preserving good nutritional status, physical fitness, and supportive environments.

## **Provider**

An individual health practitioner or an organisation or institution that provides preventative services, health care services and/or support services.

## **Public health**

Public health is a combination of sciences, skills, and beliefs directed to the maintenance and improvement of the health of all people through collective or social actions. The aim of public health is to protect, promote and restore the health of people using a population rather than an individual approach. Essentially, public health is about the health of the public.

## **Quality of care**

The term quality of care includes efficiency, effectiveness, accessibility, patient satisfaction, appropriateness of care and patient safety.

## **Screening**

Screening is an initial or preliminary examination only. Strictly speaking, a screening test is not

aimed at diagnosis but seeks to identify people who require definitive diagnostic testing.

- population screening focuses on the general population or community and is not considered cost effective for type 2 diabetes
- targeted screening is based on identifying and selecting people at high risk for diagnostic testing and is the recommended approach to 'screening' for type 2 diabetes

## **Secondary prevention**

Secondary prevention is about preventing the development of diabetes. The Finnish, American, Chinese, Indian and Japanese trials which involved working with people at identifiable risk of diabetes to reduce their risks and prevent or delay the onset of diabetes are good examples of secondary prevention.

## **Stakeholder**

Individuals or groups with a direct interest in a particular area ie those who are affected by decisions, activities and outcomes relating to an area and who therefore wish to influence or at least have a voice in its affairs. There are many stakeholders in diabetes eg people with diabetes, health professionals who look after diabetes, government departments and pharmaceutical companies.

## **Sustainable development**

Sustainable development meets the needs of the present without detracting from the capacity of future generations to meet their own needs.

## **Tertiary prevention**

Interventions aimed at achieving early detection and prompt and effective interventions/ treatments to cure or (as in the case of diabetes) control the health problem. This includes preventing or reducing long term irreversible health problems.







**International  
Diabetes  
Federation**

**International Diabetes Federation (IDF)**

166 Chaussée de la Hulpe

B-1170 Brussels

Belgium

tel +32-2-538 5511

Fax +32-2-538 5114

[info@idf.org](mailto:info@idf.org)

[www.idf.org](http://www.idf.org)