



# Diabetes Care

Securing the Future

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● Report of the Diabetes Service Development Group 2002



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**Report compiled by Ms. Anna Clarke**

Edited by:

Dr. John Barragry, Ms. Rita Forde, Dr. Emer Shelley, Professor T.J. McKenna and Mr. Ronan Quirke.



# Diabetes Care: Securing the Future

## Action plan for implementation of The St. Vincent Declaration

*Diabetes Service Development Group - Facilitated by Diabetes Federation of Ireland  
on behalf of 200,000 Irish people with diabetes*

### **Summary**

The new health strategy launched by the Government in 2001 clearly states that quality and fairness are the objectives of our national health policy. The document states the reasons why there is a need for change and the goals that are necessary to achieve quality and fairness. Diabetes is a chronic, and to a large extent preventable condition which at present utilises about 10% of the total health budget. Much of this money goes towards treating the complications of diabetes. These complications are preventable if patients with the condition have access to expert healthcare.

Each year the state spends €350 million on diabetes care, 59% of which is spent treating the costly complications of the disease. Clinical trials and economic analyses have demonstrated that services aimed at preventing or delaying the onset of complications are both effective and cost-effective.

In Ireland, there are approximately 200,000 people with diabetes. Persons with diabetes have a five fold increased incidence of heart disease and a three fold increased incidence of stroke. Diabetes is the leading cause of blindness in the working population and end-stage kidney failure in the general population. Studies have shown a prolonged prediagnosis state of on average 7 years before clinical diagnosis is made (Type 2), and hence a significant proportion of patients have complications of the condition at diagnosis. There is unequivocal evidence that early detection, management and treatment of diabetes can reduce morbidity and costs.

The Department of Health together with more than 50 other countries signed, and in so doing endorsed, the St. Vincent Declaration in 1989 and agreed to the implementation of measures to:

- Reduce new blindness due to diabetes by one third or more
- Reduce the numbers of people entering end-stage kidney failure by at least a third
- Reduce the rate of limb amputations for diabetic gangrene by half
- Cut morbidity and mortality from coronary heart disease in the person with diabetes by vigorous programmness of risk factor reduction
- Achieve pregnancy outcome in the woman with diabetes that approximates to that of the non-diabetic population.

In order to achieve equity of access to modern care for the person with diabetes, all geographical areas must be serviced by an adequately staffed and resourced primary care service that is integrated with a well developed hospital unit. The Diabetes Service Development Group was initiated by the Diabetes Federation of Ireland and sought to design a framework, with costing, for diabetes service development over a four-year timeframe.

More than 12 years after the signing of the declaration it is time that people with diabetes obtain a service that is geographically accessible in an evenly distributed way throughout the country. This document sets out what needs to be done to reduce the human burden of diabetes. The implementation of strategies set out in this document will result in considerable savings to our overburdened and underfunded health service.

Population should be used as a basis for allocation of facilities and manpower. International agreed levels for a diabetes team per 80,000 – 100,000 persons is as outlined below with appropriate space, resources and access to other specialist services as warranted.

Per 80,000 – 100,000 target population	Consultant /specialist in diabetes	2
	Diabetes Nurse Specialists	4
	Dietician	2
	Chiropodist / podiatrist	2
	Ophthalmologist	2 sessions / week
	Social Worker	1
	Access to psychologist	
	Secretarial Staff	

This report outlines region by region staffing and other requirements. In particular the report highlights the importance of building up specialist units in each region, specialist units being led by a physician trained in diabetes and includes training junior doctors who will be necessary to support the service: nurse specialists, dieticians, social workers, psychologists and podiatrists. The document stresses the importance of setting up foot clinics and effective treatment centres to prevent blindness. The report highlights the inequality of services for pregnant women with diabetes and the lack of expert paediatric services for young children with diabetes. The report identifies region by region the services that are necessary and the costing of these services.

Summary of capital investment and Maintenance costs for the delivery of a health system for patients with diabetes within the Health Strategy, which defines quality and fairness.

## REGIONAL SERVICES

### Midland Region

*Capital cost*

**€939,824**

*Maintenance/year*

**€2,801,594**

RECOMMENDED MANPOWER LEVELS IN THE MIDLAND HEALTH BOARD			
Staff	Number Employed	Recommended Number	Deficit
Consultant physician/diabetes/endocrinology	1	4	3
Retinal surgeon	2 Part-time	1 Designated Post	1
Paediatrician with an interest in diabetes	0	1	1
Diabetes co-ordinator	1	1	-
Diabetes nurse specialist	3	8	5
Paediatrician diabetes nurse specialist	0	1	1
Dieticians	Equivalent of 1	4	3
Paediatric dietician	0	1	1
Podiatrist	Part-time	4	4
Social worker	Referral	2	2
Social worker (paediatric)	0	0.5	0.5
Psychologist	Referral	1	1
Child psychologist	0	0.5	0.5

Services to be Developed in the Midland Health Board
Foot clinic
Retinopathy centre
Mobile retinopathy screening unit
Paediatric and adolescent clinic
Theatre for retinal surgery

**Mid Western Region**

**Capital cost**  
**Maintenance/year**

**€1,490,890**  
**€4,181,791**

<b>RECOMMENDED MANPOWER LEVELS IN THE MID-WESTERN HEALTH BOARD</b>			
Staff	Number Employed	Recommended Number	Deficit
Consultant physician/diabetes/endocrinology	1	6	5
Paediatrician with an interest in diabetes	0	1	1
Retinal surgeon		1 Designated Post	1
Diabetes co-ordinator	0	1	1
Diabetes nurse specialist	3	12	9
Paediatrician diabetes nurse specialist	0	1	1
Diabetes midwife	0	1	1
Dieticians	No protected time for diabetes	6	6
Paediatric dietician	0	1	1
Dietician for maternity services	0	0.5	0.5
Podiatrist	Part-time	6	6
Social worker		3	3
Social worker (paediatric)	0	0.5	0.5
Psychologist		1	1
Child psychologist	0	0.5	0.5

<b>Services to be Developed in the Mid-Western Health Board</b>
Foot clinic
Retinopathy centre
Mobile retinopathy screening unit
Retinal theatre
Paediatric and adolescent clinic
Maternity clinic

**Eastern Region**

**Capital cost**  
**Maintenance/year**

**€149,890**  
**€4,181,791**

<b>RECOMMENDED MANPOWER IN THE ERHA</b>			
Staff	Number Employed	Recommended Number	Deficit
Consultant physician/diabetes/endocrinology	15	32	17
Retinal surgeon.	3	3	-
Diabetes co-ordinator	1	12	11
Diabetes nurse specialist	32	52	20
Paediatrician diabetes nurse specialist	4	10	6
Diabetes midwife	1.5	3	1.5
Dieticians	Equivalent of 6.2	26	19.8
Paediatric dietician	Equivalent of 1.75	7	5.25
Dietician for maternity services	0.4	1.5	1.1
Podiatrist	3	26	23
Social worker	2	10	8
Social worker (paediatric)	0.5	7	6.5
Psychologist	0	9	9
Child psychologist	Part time	5	5

<b>Recommended Services to be developed in the ERHA</b>
Foot clinic (6 required)
Retinopathy centre (8 required)
Mobile retinopathy screening unit

**North Eastern Region****Capital €970,134****Maintenance/year €4,017,408**

RECOMMENDED MANPOWER LEVELS IN NORTH-EASTERN HEALTH BOARD			
Staff	Number Employed	Recommended Number	Deficit
Consultant physician/diabetes/endocrinology	1	6	5
Retinal surgeon	1	1 Designated Post	1
Paediatrician with an interest in diabetes	0	1	1
Diabetes co-ordinator	0	1	1
Diabetes nurse specialist	2.5	12	9.5
Paediatrician diabetes nurse specialist	0	1	1
Dieticians	Equivalent of 1.5	6	4.5
Paediatric dietician	0	1	1
Podiatrist	0	6	6
Social worker	0	3	3
Social worker (paediatric)	0	0.5	0.5
Psychologist	Referral only	1	1
Child psychologist	0	0.5	0.5

Services to be Developed in the North Eastern Health Board
Foot clinic ( 2 needed)
Retinopathy centre
Mobile retinopathy screening unit
Retinal theatre
Paediatric and adolescent clinic

**North Western Region****Capital €1,013,345****Maintenance/year €3,539,347**

RECOMMENDED MANPOWER LEVELS IN THE NORTH WESTERN HEALTH BOARD			
Staff	Number Employed	Recommended Number	Deficit
Consultant physician/diabetes/endocrinology	0	5	5
Retinal surgeon	0	1 Designated Post	1
Paediatrician with an interest in diabetes	0	1	1
Diabetes co-ordinator	0	1	1
Diabetes nurse specialist	4	8	4
Paediatrician diabetes nurse specialist	0	1	1
Dieticians	Equivalent of 1.75	4	2.25
Paediatric dietician	0.2	1	0.8
Podiatrist	0	4	4
Social worker	0	2	2
Social worker (paediatric)	0	0.5	0.5
Psychologist	Referral only	1	1
Child psychologist	0	0.5	0.5

Services to be developed in the North Western Health Board
Foot clinic ( 2 needed)
Retinopathy centre
Mobile retinopathy screening unit
Retinal theatre
Paediatric and adolescent clinic

**South Eastern Region****Capital €680,174****Maintenance/year €4,438,071**

RECOMMENDED MANPOWER LEVELS IN THE SOUTH EASTERN HEALTH BOARD			
Staff	Number Employed	Recommended Number	Deficit
Consultant physician/diabetes/endocrinology	1 physician 2 posts approved	8	6
Retinal surgeon	2	2	2
Paediatrician with training in diabetes	0	1	1
Diabetes co-ordinator	0	2	2
Diabetes nurse specialist	4.5	16	11.5
Paediatrician diabetes nurse specialist	0	1	1
Dieticians	Equivalent of 2	8	6
Paediatric dietician	0	1	1
Podiatrist	Sessional	8	7
Social worker	0	4	4
Social worker (paediatric)	0	0.5	0.5
Psychologist	0	1.5	1.5
Child psychologist	0	0.5	0.5

Services to be Developed in the South Eastern Health Board
Foot clinic (2 extra needed)
Retinopathy centre
Mobile retinopathy screening unit
Paediatric and adolescent clinic

**Southern Region****Capital €1,625,111****Maintenance/year €7,304,295**

<b>RECOMMENDED MANPOWER LEVELS IN THE SOUTHERN HEALTH BOARD</b>			
Staff	Number Employed	Recommended Number	Deficit
Consultant physician/diabetes/endocrinology	3	13	10
Retinal surgeon	1	2	1
Paediatrician endocrinologist	0	1	1
Diabetes co-ordinator	0	5	5
Diabetes nurse specialist	7	22	15
Paediatrician diabetes nurse specialist	0	2	2
Diabetes midwife	0	1	1
Dieticians	Equivalent of 2.75	13	10.25
Paediatric dietician	0.2	1.5	1.3
Dietician for maternity services	0	0.5	0.5
Podiatrist	1	13	12
Social worker	1	6	5
Social worker (paediatric)	0	1	1
Psychologist	1	2	1
Child psychologist	0	1	1

<b>Services to be Developed in the Southern Health Board</b>
Foot clinic (4 extra needed)
Retinopathy centre (3 needed)
Mobile retinopathy screening unit
Retinal theatre
Paediatric and adolescent clinic
Maternity clinic

**Western Region****Capital €1,508,419****Maintenance/year €4,884,389**

<b>RECOMMENDED MANPOWER LEVELS IN THE WESTERN HEALTH BOARD</b>			
Staff	Number Employed	Recommended Number	Deficit
Consultant physician/diabetes/endocrinology	1	7	6
Retinal surgeon	1	2	1
Paediatrician endocrinologist	0	1	1
Diabetes co-ordinator	0	1	1
Diabetes nurse specialist	2.5	14	11.5
Paediatrician diabetes nurse specialist	0	2	2
Diabetes midwife	0	1	1
Dieticians	Equivalent of 1	7	6
Paediatric dietician	Equivalent of 0.1	1.5	1.4
Dietician for maternity services	0	0.5	0.5
Podiatrist	1	7	6
Social worker	0	3.5	3.5
Social worker (paediatric)	0	1	1
Psychologist	0	1	1
Child psychologist	0	1	1

<b>Services to be Developed in the Western Health Board</b>
Foot clinic ( 3 extra needed)
Retinopathy centre
Mobile retinopathy screening unit
Retinal theatre
Paediatric and adolescent clinic
Maternity clinic



## National Services

*National Centre for retinopathy screening programme to prevent blindness*

Capital	€653,915
Maintenance	€1,205,087

*Pancreas and islet cell transplant centre and National Research unit*

Maintenance	€743,295
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*National patient support programme to include prevention of diabetes through education and public awareness*

Capital	€146,020
Maintenance	€2,187,758

*To support the above expert services it will be necessary to invest in primary care diabetes services*

Capital	€3,142,600
Maintenance	€7,123,230

## Conclusion

The introduction of a screening programme has the potential to substantially reduce the impact of diabetes related complications, particularly ophthalmic and cardiovascular. The development of a properly integrated primary and secondary care service is necessary to achieve better outcomes, better health status for persons with diabetes and better cost-effectiveness. The appointment of additional manpower and service development to internationally recognised ratios as detailed above, will ensure an accessible and equitable service to persons with diabetes regardless of geographical location.

Each year the health service spends €350 million on diabetes care, 59% of which is spent treating the complications of diabetes. These complications are preventable. The report justifies the increase in expenditure both in terms of human suffering and in economic terms. People with diabetes deserve a quality health system that is distributed fairly throughout the country.

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# Preface

Diabetes is a significant and growing public health issue, with serious implications both for the health status of individual patients and for the resources needed by the health services. Diabetes mellitus is a lifetime condition with important clinical complications. However, appropriate diagnosis and care can significantly improve the health outcomes and wellbeing of affected patients.

The Diabetes Service Development Group supports the involvement of people from all relevant disciplines, as appropriate, in ensuring that the necessary screening programmes are implemented to detect the many undiagnosed people with diabetes known to be in the community, and to ensure that all people at risk of developing diabetes are identified early, so that they can receive suitable care.

The reason for early diagnosis and intervention is based on clinical evidence which confirms that the complications of diabetes are preventable thus improving the quality of life for the patient but also reducing the financial burden on the community. Diabetes at present accounts for almost 10% of the total health budget, with most due to the cost of treating the complications of diabetes.

Persons with diabetes and its pathophysiological sequelae have the right to universal and consistent access to the highest quality healthcare. There is a growing armamentarium of modern medicines available to prevent and control many of the complications of diabetes, and it is the responsibility of healthcare professionals to ensure that all patients receive optimal therapy. Patients, healthcare professionals and government must work together to ensure that such universal access is achieved.

There is a wide body of evidence that shows the extent to which people with diabetes are at risk of cardiovascular disease, leading frequently to premature death. However, it is argued that in general, the attention paid to the management of cardiovascular risk factors in this population is disproportionately low. The management of cardiovascular risk factors in persons with diabetes in Ireland must be raised to the level of international best practice.

Diabetes is the leading cause of blindness in people of working age. Early detection of diabetes in at risk patients and early treatment is cost effective due to the cost offsets achieved from prevention of visual impairment accompanied by long-term health gain. Selective screening to detect those at high risk of diabetes will pre-empt the development of complications since a high proportion (up to 50%) of those diagnosed with Type 2 diabetes in the absence of screening will already have retinopathy.

Every person with diabetes should be managed according to international best practice with effective clinical audits in place. The introduction of schemes to accredit diabetes care services will ensure uniformly high standards of care.

There is a need to mobilise resources at a national level to ensure that the burden of diabetes is effectively addressed. To this end, it is essential that it be brought to the wide attention of the public and policymakers, that diabetes can legitimately be described as the next major public health epidemic facing this country, and that the necessary resources must be devoted to confronting it.

Empowered and well-informed patients will have greater expectations, both of the level of personal care they receive, and of the level of resources available to deal with their condition. Accordingly, well-informed patients can contribute to the effectiveness of advocacy in support of improved services. Furthermore, informed patients will have improved health outcomes, and to this end all activities that contribute to patient education and knowledge must be supported.

Finally, effective management of diabetes at a national level requires the implementation of a long-term national programme, sponsored, endorsed and funded by the government through the Department of Health and Children.



# Background

The Diabetes Service Development Group is an independent group consisting of healthcare representatives currently providing diabetes care in Ireland and relevant patient interest groups. The group met five times between March and October 2001 and this report was agreed with the group in December 2001.

# chapter one

## 1.1 Terms of Reference

In May 2001, the following terms of reference were agreed:

To design a framework plan for service development at national level over a four year time frame, which meets the requirements of desirable standards of care, but is also flexible enough to allow effective implementation at local level by each health board.

To achieve the above the group agreed to review the following sub-terms:

1. The group will consider the recent report of the St. Vincent Task Group, and other information such as Health Board reports of current diabetes services.
2. The group will assess the impact of current research into delivery of care.
3. The group will make formal statements on standards of modern diabetes care, and on the rights and responsibilities of people with diabetes and their families.
4. The group will identify locations, regions or groups whose needs are not adequately met, and recommend effective changes (including changes in manpower, infrastructure, or service delivery).
5. The group will recommend areas requiring further research, setting a research agenda for the coming years, from which projects should be preferentially funded.
6. The group will make general recommendations on strategies for health promotion, patient education, quality assurance and the use of IT solutions.

## 1.2 Group Members

The group convened in March 2001 comprised of :

<u>Chairperson</u>	Dr. John Barragry Diabetes Section, Irish Endocrine Society
<u>Vice-chairperson</u>	Dr. Tony O'Sullivan Representing patients with diabetes
Dr. John Nolan	Diabetes Specialist
Dr. Richard Firth	Diabetes Specialist
Dr. Donal O'Halloran	Diabetes Specialist
Dr. Daphne Owens	Diabetes Federation of Ireland
Ms. Kate Fleck	Diabetes UK (Northern Ireland)
Ms. Rachel Devlin	Institute of Public Health Nurses
Dr. Sam Kingston	Irish Association of Internal Medicine
Ms. Tara Power	Irish Association of Social Workers
Dr. Paul Grassby	Irish Centre for Continuing Pharmacy Education
Mr. Robert Acheson	Irish College of Ophthalmologists
Mr. David Mooney	Irish College of Ophthalmologists
Dr. Patricia Carmody	Irish College of General Practitioners
Dr. Susan Smith	Irish College of General Practitioners
Ms. Mary Coffey	Irish Diabetes Nurse Specialist Association
Ms. Rita Forde	Irish Diabetes Nurse Specialist Association
Prof. Gerald Tomkin	Irish Endocrine Society (Past President)
Prof. T.J. McKenna.	Irish Endocrine Society (Past President)
Dr. Colm Costigan	Irish Paediatric Association
Mr. Ronan Quirke	Pharmaceutical Society of Ireland
Ms. Linda Latham	Irish Practice Nurses Association
Ms. Sarah McEvoy	Irish Nutrition and Dietetic Institute
Dr. Neville deSouza	Irish Society of Public Health Medicine
Ms. Aine Cunningham	Representing Children with Diabetes
Ms. Teresa Shanahan	Senior Dietician in Diabetes
Mr. Joe Kelly	Society of Chiropodists and Podiatrists of Ireland
Dr. Emer Shelley	Specialist in Public Health Medicine
Ms. Deirdre Hayes	Paediatric Social Worker
Dr. Jean Holohan	Pharmaceutical Industry
Mr. Nicky Barry	Pharmaceutical Industry
Mr. Fred Doherty	Pharmaceutical Industry
Ms. Patricia White	Psychological Society of Ireland

### **1.3 Consultative Process**

The consultative process which informed this report took place between March 2001 and October 2001.

Patients' perceptions of current services and views on how they considered that their interests would be best served were sought. Health Boards were asked to submit relevant studies. Patients' views were sought through organised weekends, focus groups and through direct submission. The consultative process was twofold, involving written submissions from all healthcare disciplines and patient interest groups, and participative workshops.

The written submissions permitted each discipline to communicate their views among the group. The aim of the workshops was to permit disciplines involved in community and hospital care to determine their own professional needs in providing optimal care for all persons with or at risk of diabetes.

Joint sessions focused on the integration of primary, secondary and tertiary diabetes care.

### **1.3.1 Submissions**

Public submissions were invited through *Identity*, the quarterly publication of the Diabetes Federation of Ireland. Submissions were invited from the group members and resulted in submissions from:

Association of Internal Medicine  
Diabetes Federation of Ireland  
Diabetes shared care in Ireland from Dr. Susan Smith  
Pharmaceutical Society of Ireland  
Hospital based structures for diabetes care from Dr. John Nolan  
Irish Association of Social Workers  
Irish College of Ophthalmologists  
Irish College of General Practitioners Diabetes Task Force  
Irish Diabetes Nurse Specialist Association  
Irish Nutrition and Dietetic Institute  
Irish Endocrine Society  
Irish Paediatric Association  
Irish Practice Nurses Association  
Institute of Community Health Nursing  
National Transplant Program from Mr. David Hickey  
Pharmaceutical Industry  
Psychological Society of Ireland  
Screening for diabetes in primary care from Dr. Susan Smith/  
Dr. Colin Bradley  
Screening for diabetes mellitus from Prof. T.J. McKenna /  
Dr. Tony O'Sullivan  
Shared care in the management of diabetes mellitus from  
Dr. Brendan Kinsley  
Society of Chiropractors and Podiatrists of Ireland.  
The impact of Diabetes from Ms. Jenny Hughes (Health Economist)  
Research paper from Professor Gerald Tomkin

Therefore, this document represents the views of patients, healthcare professionals, patient support groups and others that participated in the consultative process.

### **1.4 Outline of Report**

The first chapter looks at the group that compiled this report and the means used to reach agreement. Chapter 2 provides an overview of diabetes and its complications. It outlines clearly the need for and the financial savings that can be made by investment in diabetes care. Chapter 3 gives an overview of screening for diabetes. Chapter 4 looks at the structures of diabetes care in Ireland. Chapter 5 gives an overview of the role of members of the diabetes team, the difficulties they face and the future development of delivering care to persons with diabetes. Chapter 6, 7, 8 and 9 looks at specialist areas of diabetes care. Chapter 10 looks at the Diabetes Federation of Ireland and its role in supporting persons with diabetes. Chapter 11 outlines the recommendations of the Group. Chapter 12 looks at the costing of recommendations in each health board area and nationally. Chapter 13 reviews the impact of diabetes on the individual and the state.

# Introduction

# chapter two

Diabetes is a chronic, multisystem condition, which has a high risk of serious complications, is expensive to treat, and has profound effects on patients' daily lives. However, there is unequivocal scientific evidence that early detection, management and treatment of diabetes can reduce morbidity and costs.

To manage diabetes optimally it is necessary to establish a platform for collaboration based on equality and the mutual respect of all parties involved. The interests of all people concerned with diabetes, whether they live or work with the condition, are best served by joining together, thus ensuring a uniform structure to fight this growing concern. The recent publication of the National Health Strategy provides an opportunity for all parties to work together to combat this growing concern.

## 2.1 Description

Diabetes mellitus is now one of the most common non-communicable diseases globally and is considered endemic in many developed countries<sup>1</sup>. Environmental factors that fuel the current epidemic include an ageing population, dietary changes, industrialisation, improved transport, social changes, economic factors that feed into lifestyle changes, reduced physical activity, obesity and other unhealthy lifestyle and behavioural patterns. Epidemiological data supports the role of obesity, fat intake and physical inactivity as risk factors for diabetes and have led to successful trials to prevent/delay the onset of Type 2 diabetes by lifestyle interventions<sup>2</sup>.

Diabetes mellitus is a chronic metabolic disorder in which the body's capacity to utilise sugar, fat and protein is disturbed due to absolute or relative insulin deficiency or insulin resistance which leads to high blood glucose levels (hyperglycaemia). Type 1 diabetes affects mainly young people, with a sudden, often life-threatening onset of symptoms and requires life long treatment with insulin. This type of diabetes is caused by a combination of genetic and autoimmune processes. Type 2 diabetes has a more gradual onset and affects mainly middle-aged and elderly persons. It tends to be hereditary and is associated with lifestyle factors<sup>3</sup>. In many cases, there is an absence of noticeable symptoms, or symptoms are attributed to the ageing process, which leads to a delay in diagnosis. Epidemiological studies have shown that there is a prolonged prediabetic state of on average 7 years duration before the clinical diagnosis of diabetes is made. The United Kingdom Prospective Diabetes Study (UKPDS) found that half of the subjects in their study had evidence of complications of diabetes at diagnosis. It has also been shown that dyslipidaemia, hyperinsulinaemia, hypertension and obesity (which are also cardiovascular

risk factors) may predate the emergence of hyperglycaemia by many years<sup>4</sup>.

## 2.2 Complications

The complications of diabetes may be acute or chronic. Acute complications are more common in Type 1 and are due to low blood sugar (hypoglycaemia) or high blood sugar that can lead to ketoacidosis (accumulation of waste products of abnormal metabolism) – both conditions causing death if untreated. Chronic complications are due to vascular changes:

- Macrovascular complications, where large blood vessels are damaged resulting in heart disease, cerebrovascular disease, and peripheral vascular disease.
- Microvascular complications, where the small blood vessels are damaged resulting in:
  - Diabetic kidney disease (nephropathy) takes about 5 to 15 years to develop and can lead to end stage renal failure (ESRF) which is the most common reason for kidney transplantation in western Europe<sup>5</sup>.
  - Diabetic eye disease (retinopathy) is present in up to 50% of persons at diagnosis with Type 2 diabetes and in 40 to 50% of persons with Type 1 at 10 years after diagnosis. Diabetes is also associated with cataract formation at an earlier age and with less favourable outcome of treatment than in people without diabetes.
  - Diabetic nerve disease (neuropathy) refers to damage to the nerves and is directly related to glycaemic control and duration of diabetes. Peripheral neuropathy contributes to the development of foot ulcers, gangrene and amputation.

It is generally accepted that the degenerative changes associated with diabetes mellitus are to a large extent preventable through blood glucose control<sup>6,7</sup>. The Diabetes Clinical Control Trial (DCCT) provided convincing scientific evidence about the benefits of glycaemic control in the management of Type 1 diabetes.

The UKPDS suggested that improvements in glycaemic control are associated with reductions in microvascular complications in patients with Type 2 diabetes and tight blood pressure control reduced both microvascular and macrovascular endpoints. From an economic perspective, it is the prevention of cardiovascular disease that is the key, as cardiovascular disease accounts for a large proportion of the excess medical care costs attributed to diabetes. For Type 2 diabetes, cardiovascular disease is



known to be the most costly single class of complications<sup>8</sup>.

Early detection and intensive interventions will delay or prevent complications, reduce the burden in terms of cost and improve quality of life for the patient. This strategy will reduce the personal and economic burden of diabetes.

### 2.3 Burden of Diabetes

Diabetes mellitus and the complications from diabetes are major causes of ill health and premature death. It is the leading cause of blindness in adults of working age in developed countries. Atherosclerotic cardiovascular disease, including coronary artery disease, strokes and diseases of blood vessels, are 2 to 5 times more common in people with diabetes. People with diabetes are 17 times more prone to kidney disease. The high cost of diabetes is caused largely by the treatment of complications of the disease, as they increase spending for the affected patient more than fivefold<sup>9</sup>. Medical costs for a person with Type 2 diabetes are on average 1.5 times greater than those of a person without diabetes. The presence of microvascular complications doubles the costs. The presence of macrovascular complications trebles the costs incurred, whilst the presence of both micro and macrovascular complications increases costs by more than 5 times. The costs impact on the lives of individuals, their families, the healthcare sector, government and society.

The CODE-2 (Cost of Diabetes in Europe – Type 2)<sup>10</sup> study indicated that 30 to 65% (on average 53%) of the total costs incurred by national health services on the care of persons with diabetes are due to hospitalisation; 18 to 39% are due to ambulatory care; 2 to 7% on oral antidiabetic medication and 11 to 31% on other medication. This study also showed that the presence of both microvascular and macrovascular complications increased patient management costs more than 3.5 fold. Therefore, to reduce direct and indirect costs of diabetes, it is recommended to try and reduce inpatient length of stay (LoS) and prevent or delay the onset of complications.

The T<sup>2</sup>ARDIS<sup>11</sup> report states that Type 2 diabetes costs Britain's NHS £2 billion a year, almost 5% of the total NHS expenditure and an additional £36 million is spent on related social services. This report found that people with diabetes are 2 to 3 times more likely to be admitted to hospital than their demographic peers and that on average they stay four times as long.

A recent UK study using hospital record linkage estimated that the cost of diabetes is more realistically approaching 9% of the NHS budget. Although this figure includes the costs for both Type 1 and Type 2 diabetes, it is well in excess of that estimated in the T<sup>2</sup>ARDIS report.

Research from an as yet unpublished Irish study confirms that diabetes care costs €350.5 million per year, which is about 10% of the total healthcare budget. Of this, 59% is spent on managing expensive and preventable complications, and only 16% on the management of diabetes. The remaining 25% is spent on ambulatory care.

There is now no doubt that the onset of the complications of diabetes can be prevented and delayed by intensive treatment and education<sup>2,6,7</sup>. By effective early intervention the total cost of diabetes care can be reduced.

Reducing the costs of diabetes may be achieved through:

- Primary prevention
- Prevention of complications
- Earlier treatment of complications.

### 2.4 The Declarations

The World Health Organisation and International Diabetes Federation foresaw the rise in diabetes prevalence and have collaborated to bring about strategic action. In Europe, the St. Vincent Declaration was agreed in October 1989. The Declaration, endorsed by all European countries, set out goals for the future planning of diabetes care and the implementation of effective measures over a five-year framework for the reduction of complications from diabetes (see Appendix 1). At the conclusion of the meeting, all those in attendance formally agreed to seek implementation of the recommendations on their return home. In countries where diabetes programmes existed, the representatives strove to work through all available channels to have the programme implemented. In countries such as Ireland, where no structured programme that included diabetes existed, representatives were urged to give priority towards having one drafted and endorsed.

The Declaration underlines the need for co-operation among all groups concerned with diabetes, healthcare professionals, governments, diabetes associations, and the pharmaceutical industry and emphasises the role of primary care. The Declaration emphasises the involvement of patients in their own management - such as home monitoring of blood sugar levels - thereby permitting the concentration of medical care on education and prevention of complications. The Declaration acknowledged the need for the development of local programmes to oversee this and to set local targets, whilst still ensuring action was taken at national level.

Similarly, the Declaration of the Americas on Diabetes (DOTA) signed in 1996 focused on crucial areas such as diabetes education, training, research, quality of care, mobilisation of resources and the development of policies, plans and norms. Likewise, the Western Pacific Declaration on Diabetes signed in 2000, identified the

specific issues of that region and provided the outline of strategies similar to the earlier declarations.

### **2.5 The St. Vincent Declaration in the U.K.**

In the United Kingdom, the St. Vincent initiative began in 1992 with the setting up of the Joint Task Force in Diabetes. In 1993, the first recommendations were made and accepted by the Department of Health. Specialist subgroups assisted the task force in implementing the St. Vincent recommendations. Diabetes care strategies are in place aimed at achieving the St. Vincent objectives. These will be further endorsed with the publication later this year of the National Service Framework, a government-led national plan for diabetes formulated jointly by the Department of Health, Diabetes UK and invited experts.

### **2.6 The St. Vincent Declaration in Northern Ireland**

In Northern Ireland, the U.K Task Force recommendations were supported, with the Clinical Resource Efficiency Support Team (CREST) Taskforce underlining the issues specifically relevant to Northern Ireland. CREST is made up of medical doctors under the auspices of the Medical Advisory Committee. Priority was set for the following areas - local strategies, patient registers, guidelines for referral of patients, research and education. Much has been achieved over the past four years. Regional guidelines have been drawn up for the diabetic foot, mobile diabetic retinopathy screening units and the management of diabetes in pregnancy. Some areas have also developed local guidelines. Training courses are available for both local initiatives and multiprofessional training. The introduction of computerised registers in the hospital sector - DIAMOND for adults and TWINKLE for children - may be expanded and offer an opportunity for total registration of all persons with diabetes. The recommendations are currently under review.

### **2.7 The St. Vincent Declaration in Ireland**

In the Republic of Ireland, the Irish St. Vincent Group came together in the early 1990s as a voluntary group, under the auspices of the Diabetes Section of the Irish Endocrine Society. Over a four year period it compiled a report of current diabetes services and made recommendations that a national diabetes programme be instigated. This report was published in 2000 and formally presented to the Minister for Health and Children in March 2001. The report highlights the striking variation of diabetes patient services in this country and shows the considerable savings that could be made by improving diabetes care and demonstrated the benefits for patients in terms of better health through the prevention of complications. It also showed that considerable savings could be made by improving diabetes care, most evidently in reducing acute hospitalisation and amputations in the short term, and nephropathy and retinopathy in the long term<sup>12</sup>.

### **2.8 Diabetes Service Development Group**

The Diabetes Service Development Group, initiated by the Diabetes Federation of Ireland (the national diabetes patient support organisation) continues the work of the Irish St. Vincent Group by making recommendations for the future planning and implementation of comprehensive diabetes care in Ireland for everyone with diabetes regardless of age or location. Equity has been a recurring theme in national health strategies for the last few years. "Shaping a Healthier Future"<sup>13</sup> emphasised that access to health care should be based on actual need rather than ability to pay. In order to achieve equity of access to good quality care for all persons with diabetes, it is essential that every area in the country is serviced by an adequately staffed and resourced primary care service that is integrated with a well developed hospital unit. The level of services required in a particular area to ensure equal access to comprehensive care of high quality will vary. All persons with diabetes should have access to specialist diabetes care as required or desired.

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# chapter three

## Screening for Diabetes Mellitus

Diabetes mellitus presents an ideal condition for screening and provides the optimum goal, the opportunity to prevent serious common medical disorders e.g. cardiovascular disease, renal failure, eye disease. There is international consensus on the importance of early detection and diagnosis although there is variation in guidelines of how screening should be conducted. Earlier this year, Diabetes UK published a position paper on screening, recommending that in the absence of a national diabetes screening programme, screening should take place in primary care with identification and testing of high risk individuals every three years<sup>1</sup>.

Diabetes is a high prevalence condition with approximately 50% of persons with Type 2 diabetes undiagnosed at any given time. Persons newly diagnosed with diabetes have had the condition on average seven years previously with many already having developed complications<sup>2</sup>. The complications of diabetes are preventable but to do so diagnosis must be made first. Screening tests for diabetes are sensitive and cheap and effective treatment is readily available.

### 3.1 Screening

Population screening would require a national co-ordinated programme. When compared to focused screening, it will require greater resources and be less efficient i.e. lower ratio of diagnosed to screened. However, focused screening is not comprehensive. On balance, focused screening should be initiated immediately with a long-term plan for population screening.

#### 3.1.1 At Risk Groups

The risk factors for the development of Type 2 diabetes are known and high risk individuals are identifiable. They include the following groups:

- a) The individual may be asymptomatic but should be screened for diabetes when two of following three conditions are present:
  - i) Over 40 years
  - ii) Overweight, and
  - iii) With parent, brother or sister diagnosed as having diabetes.
- a) An individual should be screened for diabetes if their history is suggestive :
  - i) Over 50 years
  - ii) Those with unusual thirst, increased urination, genital infection
  - iii) History of gestational diabetes
  - iv) History of having a baby over 4 kgs
  - v) Hypertension
  - vi) Hyperlipidaemia
  - vii) Existing cardiovascular, cerebrovascular or peripheral vascular disease
  - viii) Skin infections, urinary tract infections
  - ix) Incidental glycosuria or random glucose over 6 mmol/L.

### 3.2 Initiation

Improved public awareness of diabetes is necessary as the symptoms of diabetes are often not known by the general public. Therefore, there is a need to:

- Promote target groups to attend for screening through national and local media
- Increase awareness in secondary care wards/clinics and identify at risk patients
- Arrange an annual Diabetes Awareness Week

### 3.3 Test Options

Identification of whom to screen leads on to the best method of screening. This is a complex issue, which is outside the scope of the Diabetes Service Development Group. However, the group in cognisance of the need to establish some guidelines offers the following as an initial starting point.

- Fasting blood glucose (New diagnostic criteria have increased sensitivity and are diagnostic but require subjects to be fasting)
- Random blood glucose (more readily applicable, but non-specific and requires fasting blood glucose or glucose tolerance test follow-up)

**Location** Primary care is the optimum setting for screening

**Outcome** Management of those diagnosed through the screening procedure should be arranged locally as recommended in an integrated primary care and hospital based care programme.

### 3.4 Resource Implications

The cost of diagnosis of one individual with diabetes will be in the region of €152. A screening programme will generate additional resource requirements proportional to its success. It is emphasised that screening has the potential to substantially reduce the impact of diabetic complications, especially retinopathy and cardiovascular, by facilitating early detection and treatment.

### 3.5 Gestational Diabetes

Gestational diabetes is diabetes which first presents in pregnancy, commonly in the middle of the second trimester. Gestational diabetes is rarely symptomatic and can only be detected by screening. Though there is no consensus, screening at 28 weeks detects the majority of gestational diabetes. It is important that women at risk of developing gestational diabetes are identified, because the condition is associated with an increased incidence of perinatal morbidity and the development of diabetes by the mother in later life.

Certain women are at risk of developing diabetes during pregnancy and may be identified when the history reveals one or more of the following:

- Family history of diabetes
- Previous baby weighing > 4.5 kgs or large for gestational age
- Previous unexplained intrauterine death or stillbirth
- Obesity (>100kgs)
- Hydramnious.

Identification of the at risk individual warrants a random blood glucose and suspected cases should have a 100 gr. glucose tolerance test.

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## Structures

Each person with diabetes is entitled to comprehensive specialist diabetes care of high quality in whatever setting that individual chooses. Comprehensive means the availability of all services which will meet the broad aim of the health services in Ireland i.e. “to promote the enjoyment by all of the highest possible levels of health”<sup>1</sup>. Availability should be on the basis of actual need rather than ability to pay or geographical location. The care of people with diabetes requires a collaborative effort between a number of different healthcare professionals. The appropriate setting for various elements of this care will vary according to the needs of the particular person and the skills and interest of their local healthcare teams.

Currently, there are three different levels of care for persons with diabetes, i.e. primary, secondary and tertiary.

### 4.1 Primary Diabetes Care

Primary care has been defined as “first contact, continuous, comprehensive, and co-ordinated care provided to populations undifferentiated by gender, disease or organ system”<sup>2</sup>. Many general practitioners have initiated the management of diabetes on their own or in conjunction with secondary care – shared care schemes. Many persons with diabetes choose to have part or all of their diabetes care in their local general practice. This is in keeping with the general model for management of chronic disease in primary care settings. This trend needs to be supported and developed, as with the increasing prevalence of diabetes, hospital based diabetes management will not be sustainable. A recent study showed that in primary care, individualised goals with educational and surveillance support achieves the same level of risk factors as large intervention studies from secondary care<sup>3</sup>. The only aspect of routine diabetes management that may cause particular difficulty within the primary care setting is the detection of diabetic retinopathy and this issue is dealt with elsewhere in the report.

#### 4.1.1 Current Difficulties in Primary Diabetes Care

The majority of primary diabetes care with the exception of those taking part in shared care schemes are unsupported and unstructured. There is limited access to many community resources – public health nurses, podiatrists, dieticians, and practice nurses. While some improvements have taken place, there are still disincentives to effective prescribing to people with or at risk from diabetes. The infrastructure of general practice mitigates against good quality diabetes care with funding available for curative rather than preventative care within the General Medical Services (GMS). In addition, patients who are not GMS eligible have to pay to see the general practitioner for preventative care. Furthermore, approximately 50% of general practitioners operate singly with the potential for isolation from other professional colleagues. At present only 40% of GPs are working with a practice nurse, though this figure is rising.

#### 4.1.2 Prerequisites for Primary Diabetes Care

There are approximately 2,200 general practitioners distributed throughout the country. Many practices have demonstrated their ability to deliver quality care. The Irish College of General Practitioners has facilitated the development of primary diabetes care through its guideline documents and educational initiatives. There are currently many general practices with the necessary commitment to provide structured diabetes care. The core members of the primary care diabetes team are the general practitioner and the practice nurse. They must be supported with adequate facilities and administrative resources and have access to diabetes nurse specialist, dietician, chiropodist, ophthalmologist and laboratory facilities.

# chapter four

Ability to refer patients or to seek guidance from the secondary care diabetes team is necessary.

### 4.1.3 Benefits of Primary Care

The benefits of general practitioner care include continuity, convenience, integration with other health concerns, care in the context of the patient’s psychosocial environment, and unrivalled accessibility. Many patients cannot access hospital services and many more drop out of services that are inconvenient or unsuitable. Around 15% of Type 1 and 20 to 30% with known Type 2 diabetes receive care entirely from their general practitioner or not at all. Many studies have shown that loss to follow-up and non-attendance rates are lower in primary care<sup>4,5</sup>. The willingness of the patient to comply with the prescribed regime is one of the requisites for successful diabetes care and it appears that the setting for care delivery influences attendance for care<sup>6</sup>.

### 4.2 Shared Care

Shared care involves a complementary service to augment hospital and general practice based care. Primary Care – A New Direction<sup>7</sup> will facilitate the integration of primary and secondary care. The commitment and skills of the individuals involved with the care of the patients will determine the success or failure of shared care irrespective of the resources available. Success of the shared care concept necessitates spending time at the outset, defining objectives, assessing the needs of the target population, evaluating the facilities, staffing levels, commitment and expertise available in each practice and tailoring the shared care package to the needs and resources identified<sup>8</sup>. This can only be done locally with inclusion of all interested parties. General practitioners should be involved in standard setting and strategic planning of the shared care scheme at the outset<sup>9</sup>.

### 4.2.1 Service Delivery

The structured diabetes shared care service will have the following components, though adaptations and variations can be made depending on local needs.

1. Patient eligibility: patients with Type 2 diabetes agreeing to participate in the service
2. Practice eligibility: commitment to providing structured diabetes care in terms of preparedness to undertake preparatory education course and availability of a practice nurse with protected time or at a minimum practice accommodation that can be used by the community diabetes nurse specialist or visiting practice nurse
3. Community based diabetes nurse specialist: to provide ongoing support to participating practices, education of practice nurses and facilitate communication across sectors. Other roles will include participation in service planning and research/audit roles
4. Access to community dietetic services with protected time for diabetes care. The patient should have a follow-up appointment in the community 3 months after the hospital visit and 3 monthly for the first year after diagnosis
5. Access to community podiatry
6. Access to diabetes eye screening and responsibility within the service to ensure that this is taking place
7. Local agreement on combined record keeping
8. Shared communication between hospital/community through a formal relationship. There is a need for good liaison between the hospital team and primary care team with healthcare professionals working in partnership and with strong links between hospital based and community based personnel
9. Access to review/discuss cases both formally and informally
10. Locally agreed clinical care and referral protocols
11. Patients will be offered an annual medical review in the hospital setting and three to six monthly reviews in general practice
12. Access to community pharmacy services including medicine management and pharmaceutical care.

Much discussion centres on the suitability of patients for primary diabetes care. The initial stabilisation of newly diagnosed Type 2 diabetes or the re-stabilisation of diabetes that has drifted out of control is a very interactive and labour-intensive process. Often, this requires weekly or more frequent contact over a 3-6 month period. In some cases this process may be best conducted by an endocrinologist and be completed prior to the setting up of routine reviews in primary care.

### 4.2.2 Shared Care Guidelines

The following guidelines are broadly agreed by the relevant bodies:

- The participation of persons with diabetes in the shared care programme is optional but should be encouraged for all persons with Type 2 diabetes in the absence of major complications
- The integration of primary and secondary care is a complex process. Therefore, the specialist team remains the hub of any shared care programme not only for clinical care but also for leadership and organisation
- Agreed treatment targets and management protocols must be in place before commencing any shared care programme. For instance, the person with Type 2 diabetes and without complications could make three visits to the general practitioner and one visit for annual review at the hospital clinic. The frequency of visits is discretionary with deviations closely monitored and accounted for
- Communication and educational meetings to be held regularly (at agreed intervals) as a core component of supported shared care
- All relevant information to be recorded on a joint record held by the patient and an e-technology diabetes register that has formal means of recall, a system for identifying non-attendees and facilitates clinical audit. Where possible, the system should be linked to all points of care delivery
- The general practitioner should have access to immediate consultation with hospital staff.

### 4.3 Integration of Primary and Secondary Diabetes Care

As the quantity and quality of diabetes care provided within primary care increases, more patients may be able to receive routine follow-up in this setting. However, this will not reduce the need for, or importance of, adequately staffed and resourced secondary care teams. As interest in diabetes by primary care teams increases, more new cases and more clinical problems will be detected and the demands on the secondary care team will increase. Audits and evaluations will result in more stringent targets to reduce mortality and morbidity, thereby, further increasing the demand on hospital services.

Shared care involves the joint participation of primary and secondary care in the planned delivery of care for patients and necessitates enhanced information exchange. Enhanced exchange of information over and above routine discharge and referral letters between primary and secondary carers is essential. Shared records will go some way to achieving this. Care is not shifted from one to the other but shared with both parties maintaining responsibility. The "hub and spoke" model is proposed for integration of primary and secondary care with local adaptations as appropriate to suit population density and local resources.

- Each diabetes centre would serve as the nucleus for integration with a network of GPs in the catchment area of the centre.
- Ideally, a standard core database could serve the whole country, incorporating a core minimum dataset relevant to diabetes treatment (demographics, diagnosis, duration, glycosylated haemoglobin, blood pressure, lipids, and urine albumin as well as current therapy according to agreed codes).

- Each centre and primary care network could further develop their local database, beyond the minimum dataset, according to local preference – and build in local administrative and audit functions.

#### 4.3.1 Co-ordination of Shared Care

The appointment of a co-ordinator /data manager is essential to prevent fragmentation of any shared care scheme. The co-ordinator would have responsibility for global planning within their region and address operational issues of diabetes services. They could also be involved with the Department of Health and Children for national planning. This officer should monitor and advise on the local services that should be commissioned and provided in order to improve the health of local people with diabetes.

Initially, the co-ordinator should:

- Develop and co-ordinate local services to meet the needs of all people within the locality
- Maintain adequate community and hospital based staffing levels
- Monitor the level, range and quality of services provided locally against agreed local and national standards
- Prepare and maintain a register of all persons with diabetes
- Facilitate audit and evaluation of local diabetes services alongside specialist staff.

#### 4.4 Diabetes Centres

Historically, the role of the diabetes centre in Ireland was to provide diabetes education. Later diabetes centres began to provide outpatient clinical management of issues such as commencing insulin therapy, which traditionally warranted hospital admission. With appropriate infrastructure, diabetes centres have the potential to support general practitioners in the community, decompress the hospital outpatients clinics and allow a more structured review of patients by the most appropriate member of the diabetes team. The diabetes centre would augment the diabetes clinic (both primary and secondary) and should become the focus of diabetes care in the hospital and community. To achieve this, there is need for committal of resources to the expansion of diabetes centres in all county hospitals with the commitment of a named consultant in each centre to oversee care.

An expansion in specialist numbers will not solve critical problems in clinical practice without a similar expansion in numbers of nursing, paramedical, administrative and IT staff. International diabetes organisations such as the International Diabetes Federation (IDF), the European Association for the Study of Diabetes (ESAD) and the American Diabetes Association (ADA) have all supported the model of the diabetes team, a multidisciplinary group of professionals with specialised training in the care of people with diabetes. The major emphasis of this team care is on education of the patient in self-care and prevention of problems. The ADA has a formal accreditation system for the monitoring of such diabetes teams.

#### 4.4.1 Recommended Staffing Levels

Each general hospital throughout the country should have at least one named physician with a special interest in diabetes and the support of a diabetes team. The number of consultants required will depend on the availability of individual consultant's sessions devoted to diabetes care, the availability of support staff and the overall structure of the local service. It is recommended that the diabetes teams have a designated area and be staffed according to international agreed levels i.e.

##### Per 80,000 – 100,000 target population

Consultant /specialist in diabetes	2
Diabetes nurse specialists	4
Dietician	2
Podiatrist	2
Ophthalmologist	2 sessions/week
Social worker	1
Access to psychologist	
Secretarial staff	

Each centre should have

- education facilities with dedicated space, equipment and protected time for education of patients, carers and health professionals
- Appropriate facilities for the systematic review of patients supported by laboratory services
- Each centre could serve as the fulcrum for integration with primary care groups in the region, networked for data exchange and for ease of referral and communication generally.

#### 4.5 Regional Centres

Regional diabetes centres will be required to support sub-speciality interventional needs for patients with diabetes. Currently, such centres are confined to the large teaching hospitals. The current geographic distribution of these services makes access difficult for many patients. Staffing and equipment for regional centres would include the same list as for the standard centres.

The additional complement would be as follows:

1. Additional diabetes nurse specialist (s)
2. Additional dietician (s)
3. Consultant ophthalmologist with facilities for laser photocoagulation
4. Access to consultant vascular surgeon
5. Access to consultant nephrologist
6. Access to consultant paediatrician
7. Access to consultant obstetrician
8. Registrars in all specialities, in training positions.

Which centres should be developed as regional diabetes centres is a matter for discussion and consultation in each health board region and could be assessed in light of current developments or plans in the related sub-specialities.



#### 4.5.1 Cost Implications

Building: New office space may be required to accommodate these activities depending on existing facilities. Costs will vary between centres, depending on available re-usable space.

Commissioning: IT services and retinal photography equipment will be a major cost in each centre.

**Table 1. RECOMMENDED MANPOWER REQUIRED IN REGIONAL CENTRES**

Manpower	Minimum Number Required per Regional Centre
Consultant endocrinologist	2.5
Diabetes co-ordinator	1
Diabetes nurse specialist	10
Dietician	5
Social worker	1.5
Podiatrist	2
Ophthalmologist	1
Psychologist	1
Paediatrician with a special interest in the management of children with diabetes supported by paediatric trained specialist nursing, dietetic and psychology services.	
Obstetrician with a special interest in the management of the pregnant woman with diabetes, supported by a diabetes midwife specialist.	
Access to cardiovascular, nephrology and neurology services.	

#### 4.5.2 Development Plan

To progress with new regional and local diabetes centres, the following plan is suggested:

Audit in each centre of the following:

- 1 Current staffing, accommodation, equipment and materials for diabetes care.
- 2 Calculation of costs in each centre to augment the services to the standard complement drafted above.

#### 4.6 Tertiary Referral Centres

Tertiary centres will need to be developed strategically around the country and headed by a diabetologist. These will be affiliated to universities. These centres will augment the regional centres and undertake formal research.

#### 4.7 Structures to be addressed

Each health board should establish a group to monitor and advise on the services which should be commissioned and provided in their area in order to improve the health of local people with diabetes. The group should consist of professional and managerial representatives from both the hospital and community health services and patient representation.

##### 4.7.1 Local Diabetes Service Development Group (LSDSG)

The composition of the group and method of working is likely to vary to meet local needs but suggested makeup is as follows:

- Local specialist endocrinologist/ physician involved in diabetes care provision
- Local hospital based diabetes nurse specialist

- Hospital based dietician
- 3 general practitioners, including 1 without a practice nurse, and one who is a General Practice Unit doctor
- Diabetes Federation of Ireland regional committee chairperson
- Patient representative
- Primary Care Manager, local health board
- Person to address psychosocial issues
- Practice nurse representative
- Public health nurse
- Community diabetes nurse specialist and dietician
- Community pharmacist.

##### 4.7.2 Remit of the LSDSG

The remit of the LSDSG is to monitor and advise on the services which should be commissioned and provided in order to improve the health of local people with diabetes. This remit is constant but initially the group will need to:

- identify local needs
- adapt national diabetes care guidelines to suit local situation
- prepare participating practices structurally by assisting them to construct practice based registers and recall systems
- provide primary care diabetes education depending on local need and using the support of national bodies such as the Irish Endocrine Society, Irish College of General Practitioners and the Professional Service Section of the Diabetes Federation of Ireland.

- prepare local specialist services to enable structured communication with primary care and provide additional administrative support to the service and its ongoing audit and evaluation
- develop audit using nationally agreed models.

Protocols and guidelines must be set in place which address such issues as who sees a specific type of problem and what examinations and tests are done. The criteria for referral to secondary care and discharge back to primary care must be clear to all. The LDSDG should ensure that primary and secondary care teams address the issues of people who are or may be socially disadvantaged. They may also need to address cultural issues that arise in the community and be aware of the needs of ethnic groups migrating locally.

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# chapter five

## Diabetes Team Members

All members of the diabetes team provide care to the patient on a continuum ranging from the general practice to the tertiary referral centre. Each member of the team is accountable for his or her own practice. There is also a responsibility to ensure practice is evidence based and that research is used, undertaken and disseminated. In order to achieve equity of access to quality care for all persons with diabetes, it is essential that every health board provide an adequately staffed and resourced diabetes team as well as developing community based diabetes services. It is essential that these be well integrated with agreed roles and responsibilities.

### 5.1 The Person with Diabetes

Persons with diabetes have a central role in the diabetes team. Empowerment is essential for self-management and allows the person with diabetes to play an important role in the development of services. Empowerment can only be achieved with confidence building, knowledge of what to expect from each service and understanding of the personal healthcare record.

#### 5.1.1 Current situation

The majority of patients are at the receiving end of a service of which they have little understanding. A minority are very knowledgeable about their own self-management but are unsure of what is optimal diabetes care. The patient and each member of the diabetes team should have shared agendas that are explicit to all. The Midland<sup>1</sup>, the North Western<sup>2</sup> and the Western Health Board<sup>3</sup> have carried out studies to determine patient perceptions of the diabetes service. Some common issues raised include

- The doctor's agenda only at appointments
- Long waits at clinics
- Interruptions during consultations
- Perception that time allocated is not dedicated to them
- Environment is not conducive to aiding communication
- Little opportunity for participation in their own care.

With the exception of the Western Health Board study, the subject selection processes available hampered these studies. The lack of a register of persons with diabetes means that selection is opportunistic and questions the representativeness of findings.

There is an absence of published studies on patients' perceptions of primary care services. However, recent studies on shared diabetes care indicate that patients would like to have available the full services of the diabetes team through primary care without financial penalties. Patients value seeing the same person on return visits and appreciate the reduced time spent waiting and travelling.

#### 5.1.2 Recommendations

Essentially, diabetes should be managed to reduce its consequences to a minimum.

People with diabetes need to:

- Input into the planning of diabetes services

- Access basic diabetes team care at the patient's choice of location, as appropriate
- Engage in consultations with healthcare professionals without interruption that is driven by each patient's agenda
- Be empowered to facilitate leadership of the diabetes team
- Access support from healthcare professionals, support groups, other persons with diabetes, and professional help if desired
- Access information about diabetes and what to expect from the health and social services
- Receive support and advocacy from the Diabetes Federation of Ireland and healthcare professionals
- Access individualised care.

Patients cannot determine if the service they receive is a quality service unless they know what that is. Therefore, all patients regardless of where they receive diabetes care should have written guidelines on what care they should receive, from whom they should receive it and procedures to follow if unhappy with services.

### 5.2 Medical Staff

The consultant diabetologist/endocrinologist is responsible for the management of people with diabetes which should focus on the prevention and management of complications. The consultant provides leadership, support, co-ordination and professional development of all members of the diabetes team. Whereas the primary concern is the daily operational issues within the hospital, consultants should also take responsibility for the global planning of diabetes care within the health board area in which they work. This involves strategic planning to ensure equity of service access and high standards of care for all persons with diabetes. Research should be ongoing to identify best practice and set more stringent targets to reduce mortality and morbidity.

The paediatric endocrinologists have the same responsibilities as the consultant endocrinologist but also have responsibility for the psychosocial needs of the family and to arrange the efficient transfer of patients to adult diabetes services. The consultant must ensure that the child or adolescent with diabetes and their family have practical, flexible, age-appropriate care that meets the needs of the entire family and ensures the well-being of the person with diabetes so that they can partake in all activities whilst minimising the risk of complications.

Other medical staff are required to support the consultants. Training for the care of patients with diabetes is necessary for all such staff. Doctors below the level of registrar should not have unsupervised responsibility for diabetes care. Additional consultants should be appointed. This will allow consultants to spend more time in leadership roles, facilitate research and increase the number of doctors entering the field of endocrinology. The general practitioner has an important role in providing diabetes care to the patient in his or her own psycho-social environment and in integration with other health concerns.

## 5.2.1 Current Situation

In practice, particular qualifications for each individual consultant appointment are set out and approval sought from Comhairle na nOspideal.

There is currently a deficit of consultant posts in diabetes and endocrinology (see Table 2).

**TABLE 2**

### **CONSULTANT ENDOCRINOLOGISTS/ DIABETOLOGIST/ PHYSICIANS GENERAL SUMMARY STATISTICS BY HEALTH BOARD AREA 2001.**

<b>Health Board Area</b>	<b>Consultants Posts in Diabetes and Endocrinology</b>	<b>% of population</b>
Eastern Region Health Authority		
East Coast Area Health Board	3	8.97
Northern Area Health Board	6	12.55
South Western Area Health Board	4	14.21
Board		35.73
Mid -Western Health Board	1	8.75
Midland Health Board	0	5.67
North Eastern Health Board	1	8.45
North Western Health Board	0	5.82
South Eastern Health Board	2	10.8
Southern Health Board	3	15.08
Western Health Board	1	9.72
Total	21	100

The disparity of appointments between the Eastern Region and the rest of the country is clearly shown in this table. This does not of course give an indication of the overall hospital care of patients with diabetes mellitus as many hospitals outside the Eastern Region that do not have a specialist endocrinologist/diabetologist/physician do have diabetes clinics.

It is worth noting that there are two health boards without consultant endocrinology posts and that the only paediatric/endocrinology posts are in the ERHA and Southern Health Board.

General practitioners provide diabetes care as part of their private practice or to individuals with medical cards. There are many benefits to be reaped by general practitioners playing a more structured role in the management of diabetes involving the shared care model.

## 5.2.2 Recommended Staffing Levels

The Royal College of Physicians, London<sup>4</sup> suggests that there should be at least 28.75 sessions per week dedicated full time to diabetes care from consultant diabetologists per 250,000 persons. This recommendation equates to 2 consultant endocrinologist/ diabetologist/ physicians posts per 100,000 population. Therefore, there is a current deficit of 53 such appointments. This situation should be urgently addressed with particular attention to paediatric services and to the health board areas with no current appointments.

## 5.3 Nursing

Diabetes nursing is the provision of primary, secondary and tertiary care to people with diabetes and where nursing interventions contribute to a healthy lifestyle and prevention of complications associated with diabetes<sup>5</sup>.

### **5.3.1 Diabetes Nurse Specialist (Hospital)**

The diabetes nurse/midwife specialist has specialist formal post-registration education at higher diploma level that is underpinned by extensive experience and clinical expertise. The nurse specialist works exclusively in the field of diabetes as an educator, communicator, manager, researcher and innovator<sup>6</sup> and as a counsellor<sup>7</sup>.

In terms of direct patient care, the focus of a nurse's work regardless of expertise is mainly educational. The diabetes nurse specialist's responsibilities include:

- Initial care, education and advice
- Continuing education, support and advice including telephone triage
- Review of patient's knowledge of diabetes and skills in self-management
- Reinforcing understanding and increasing lifestyle flexibility
- Referral and input into other specialist consultations as appropriate
- Providing an educational resource for other healthcare professionals

Indirect care relates to activities that influence others in the provision of direct care and in many cases involves the organisation and co-ordination of services for both inpatients and outpatients.

Traditionally, diabetes nurse specialists (DNS) worked in hospitals and extended their knowledge and expertise to the community via public health nurses. The role of the diabetes nurse specialist is changing through greater participation of primary care teams in diabetes care and the appointment of community diabetes nurse specialists. The community DNS will play a pivotal role in the integration of primary and secondary care.

### **5.3.2 Community Diabetes Nurse Specialist**

The following are some recommendations for the role of the diabetes specialist nurse in the community:

- To co-ordinate the delivery of diabetes care in the community and liaise with the hospital based team
- To be familiar with the policies and practices of all of the diabetes units in their specific area
- To be a resource person for the public health nurses, the practice nurses and the general practitioners
- To have responsibility for the continuing education of the practice nurses and the public health nurses in the community in relation to diabetes care.

The present community care area system that is in use for the public health nurses could be employed to allocate diabetes nurses in the community. It is envisaged that more than one diabetes nurse would be ultimately required in each area.

### **5.3.3 Recommended Staffing Levels**

There is a recognised need for 4 diabetes nurse specialists, either hospital or community, based per 100,000 persons. Currently, there are 62 (full time equivalents) hospital based diabetes nurse specialists with 2 part time community diabetes nurses. There is an urgent need to increase this number. It is important that diabetes nurse specialists remain up to date with developments. Arrangements for study leave and research opportunities are variable, depending on the employing agency, and it is important that these be standardised nationally.

### **5.3.4 Paediatric Diabetes Nurse Specialist**

The paediatric diabetes nurse specialist is a diabetes nurse specialist and a qualified children's nurse. The nurse specialist has an understanding of the physical, psychological and physiological needs of children and their families and tailor care to meet these needs. As the diagnosis of diabetes does not impact on the individual alone but also involves their immediate social environment, the paediatric diabetes nurse specialist must address family life, friends and school issues. Failure to deal with such issues can result in poor metabolic control and the increased risk of developing complications.

### **5.3.5 Practice Nurse**

All nurses working in primary care are to some extent involved in diabetes care. Some hold diabetes certificates. All practice nurses running a primary diabetes clinic should have a recognised level of expertise in diabetes care. There is a need to develop appropriate accredited education courses with clinical input from

the local diabetes centre. The community DNS could form a central link with practice nurses by providing education, support, advice and play a co-ordination role in the seamless provision of diabetes care.

### **5.3.6 Public Health Nurse**

The public health nurse as a home visitor has a unique opportunity of assessing and interpreting the impact of the diagnosis of diabetes on the individual patient and their family and the lifestyle and dietary changes it will bring. They have a wealth of knowledge of individual families and community support structures, which is invaluable in the holistic care of persons with diabetes. In many cases the nurse will have an established personal relationship of trust and accountability with the individual patient prior to their diagnosis of diabetes.

Public health nurses are currently providing direct care to persons with diabetes in their homes and perform diabetes health promotion activities. Their role as part of the diabetes team is acknowledged and should be strengthened by adequate support.

## **5.4 Dietetics and Nutrition**

Nutrition modification is crucial in the treatment of diabetes and in the prevention of complications. All patients with diabetes should receive dietary advice from a qualified dietician in order to optimise control of their blood glucose<sup>8</sup>. Diet and lifestyle modification is first line treatment for diabetes. Therefore all patients should have immediate access to a qualified dietician after diagnosis and thereafter as needed and annually at a minimum. For children and adolescents with diabetes, more intensive intervention is warranted. Initial dietetic advice given at diagnosis should be followed up with more detailed education in the first few weeks<sup>9</sup>.

### 5.4.1 Current situation

Clinical nutrition and dietetics is a profession that is developing in terms of both scientific research and service development. Despite new posts developing there is still a shortage of dietitians to service the area of diabetes.

- The current number of nutritionists / dietitians working in the speciality of diabetes is approx 4 whole-time equivalents.
- There is the equivalent of a further 9.5 whole-time equivalent dietetic posts working part-time in the area, but these are not dedicated diabetes posts.

### 5.4.2 Recommendations

A minimum of 2 full-time equivalent dietitians / clinical nutritionist dedicated to diabetes are required per 100,000 population. This is in keeping with U.K. figures<sup>10,11</sup> and allows time for dietitians to carry out both their clinical therapeutic role and nutrition facilitation role.

The clinical therapeutic role would include:

- One to one patient education
- Group patient education

The nutrition facilitation role would include:

- Development of resources
- Education of staff
- Development of protocols and standards
- Audits
- Research programmes

It has been recommended that obese patients with Type 2 diabetes should see a dietitian on a monthly basis during the immediate post-diagnosis period (i.e. first 6 months), and then with reduced frequency over the next 6 to 12 months<sup>8</sup>. More recently the Finnish Diabetes Prevention Study has shown the benefit of intensive individualised dietetic review every three months in delaying or preventing the onset of Type 2 diabetes<sup>12</sup>.

Based on the current Irish population of 3.8 million, a minimum of 76 full-time equivalent dietetic posts dedicated to diabetes care are required.

### 5.4.3 Paediatric Dietetics

Nutritional requirements change with the different stages of growth and development. This is one of the key factors which differentiates between children and adults with Type 1 diabetes, and establishes the need for a dedicated paediatric dietetic service as distinct from the adult dietetic service.

There are 3 distinct groups in terms of nutrition education: infants and toddlers, school age children and adolescents. Education should be individualised and appropriate for the age and maturity of the child to help engage the child in active learning leading to an independent individual capable in their own nutrition management. Education should consider social and economic factors (e.g. literacy skills, ability to access and purchase foods, ability to comprehend medical and scientific facts). Education should be ongoing and evolving through the different stages of childhood. Initially education will be aimed at parents/carers and as soon as practically possible this will be extended to the child. Education should be available to other care givers: e.g. extended family, schoolteachers, childminders.

It is recommended that there should be a minimum of 1 dietitian per 100 children /adolescents with diabetes.

### 5.5 Footcare

Diabetes mellitus has many complications, but the most common cause of hospitalisation among affected individuals is foot ulceration, which accounts for 20% of all diabetes-related admissions. Diabetic foot ulcers represent a serious medical and economic problem. Foot ulcers have a severe impact on the mobility of patients with the result that the quality of life is greatly impaired. In addition these ulcers are sometimes difficult to heal and are associated with a high risk of amputation.

There is an abundance of research and literature associated with the diabetic foot including good evidence that amputations can be reduced. A foot clinic is cost effective in terms of amputations averted. The conclusions of research on the cost of setting up a diabetic foot clinic stated "If the service outlined were to prevent only one amputation per year the money saved would cover the cost of the clinic". This requires an investment in time, effort and resources and the will to implement the standards of best practice. There is ample research to support the introduction of specialised foot clinics, as 84% of all lower limb amputations inpatients with diabetes are preceded by a foot ulcer.

The essential difference between the person with diabetes and other patients attending the podiatry clinic is that frequently the person with diabetes is asymptomatic and is unaware of foot problems that may be present, and thus must be actively encouraged by carers and other health professionals to look after their feet.

### 5.5.1 The Podiatrist's Role

The role of the podiatrist is

- To assess all diabetic feet and identify those persons with diabetes at risk of foot ulceration (screening)
- To diagnose and manage those minor, perhaps asymptomatic foot problems which can become serious if neglected
- To refer, review, educate and treat these patients according to risk status (recurrence rates for diabetic foot ulcers are 35 > 40% over three years and 70% over 5 years)
- To debride calluses and ulcers, to relieve plantar pressure and facilitate wound healing.

Early intervention in order to prevent potential disaster in the at risk diabetic foot is a great responsibility but also a great opportunity.

### 5.5.2 Current Situation

Public service podiatry in Ireland is severely under resourced. In the community the service is delivered only to medical cardholders. This means that persons with diabetes who do not have a medical card are not routinely seen. If the person with diabetes is attending a hospital clinic they may be seen by the podiatrist irrespective of holding a medical card. This anomaly in terms of access to services requires to be addressed.

Recommendation That persons with diabetes would be made a priority group for podiatry services in the community irrespective of card holding status.

#### Primary Care /Community

There are 16 full time podiatry posts in Community Care throughout the country. However 5 of these are in the North Western Health Board and 6 of these posts in Southern Health Board leaving huge gaps in service throughout the rest of the country. The remainder of provision is by *ad-hoc* sessional arrangements and in the ERHA via approximately 50 private podiatry practices on a capitation fee basis.

#### Secondary Care

Again there is a wide variation in provision of podiatry service. This varies from no diabetic podiatry clinics at many county/general hospitals to two 3 hour sessions per week or month in others. Optimal care cannot be delivered to persons with diabetes via this limited and inequitable provision.

#### Tertiary Referral Centres

There is 1 full-time Senior Podiatrist in Cork University Hospital and an approved but not yet filled post in St. James's Hospital, Dublin. All other podiatry provision in tertiary referral hospitals is by *ad-hoc* sessional arrangement varying from 1 to 6 sessions per week in each hospital. There may be 2 or more persons providing sessions at the same hospital when clearly there is a requirement for a full-time specialist podiatrist in diabetes care.

### 5.5.3 Education

There is as yet no statutory regulation for health professionals including podiatrists. This has resulted in different levels of training, qualifications and standards. The Department of Health and Children recognised minimum standard qualification for podiatrists is the BSc. in Podiatry or the 3-year Diploma from a recognised College in the UK. The Society of Chiropodists and Podiatrists of Ireland (whose members have Department Of Health and Children recognised training) recommend that all podiatrists would avail of the opportunity to undertake post-graduate training in diabetes care and that those working in posts at secondary or tertiary level would have attained a further qualification in diabetes care.

### 5.5.4 Future Needs

The recommended staffing levels for podiatry are 2 whole time equivalents per 100,000 persons with increased staffing levels recommended in ageing populations. Populations of over 70 years should have one podiatrist per 2,000 persons.

Recent reports from both the Mid Western Health Board and the Midland Health Board on podiatry services recommended at least one new post in each community care area with immediate effect to include a podiatry service to the diabetic clinics at the general hospitals as a matter of urgency. It was also recommended in both reports that current staffing levels be enhanced over three years. At least 15 posts should be created in the Boards immediately and reviewed again at the end of 3 year period.

It is envisaged that there would be a Clinical Specialist Podiatrist in each of the 10 tertiary referral centres, or where this is not possible, they could link with primary care as the remit for such posts includes research, audit and interprofessional education.

### 5.5.5 Specialised Foot Clinics

There is need to establish a named footcare team available to both primary and secondary care patients. The podiatrist should have access to consultation with a vascular surgeon, diabetes nurse specialist or tissue viability nurse, endocrinologist/ diabetologist/ physician, dietician, local access to shoe fitter and/or orthotist and availability of the services of an orthopaedic consultant, a microbiologist and a radiology facility.

Such clinics are proposed for each county hospital and tertiary referral centre. Thus 15 clinics are required in secondary care and a further 10 in tertiary referral centres. It is envisaged that this podiatry clinic would integrate with primary care groups in the region and liaise with other care groups e.g. ante-natal clinics, long stay institutions, nursing homes.



### 5.5.6 Costings

As neuropathy and peripheral vascular disease are the two main risk factors for diabetic foot disease, simple, quick, inexpensive and reliable testing for these need to be used to screen large numbers at risk. The capital cost of equipping a foot clinic is in the region of €30,350 with annual costs for custom made shoes, orthotics and specialised boots of approximately €25,000.

### 5.6 Social Work Support

Social workers are trained to intervene not only at an individual level but with family, community services etc. in order to help their clients.

Research evidence supports the close links between positive psychological adjustment and the good management of diabetes<sup>13</sup>. As diabetes is a life long condition it can involve a continual process of adjustment and finding ways of coping. Thus the development of psychosocial support is essential and needs to be incorporated into routine care from the onset rather than when problems arise.

#### 5.6.1 The Social Worker's Role

People vary widely in their psychological response to events. However, it is clear that many of the problems and crises of diabetes management have emotional and psychosocial components. Social workers play an important role in enabling people with diabetes and their family members:

- to express and explore their worries, concerns and expectations
- to develop skills so that they can cope better with challenges faced by people with diabetes
- to foster and promote self-esteem and confidence in dealing with the demands of their life long condition
- to develop parenting skills which are crucial in helping parents manage issues of compliance in young children
- to maintain support to parents who are experiencing difficulties with older children and teenagers.

Social workers assist patients and their families with social and financial issues and are well placed to advocate on behalf of their clients or to enable the client to access support from relevant community based services. These tasks may involve a range of different social work interventions:

- Support work/counselling with individuals (including psychosocial assessments)
- Support work with couples, or other family members

- This work may be in relation to issues involving diabetes or it may address other areas that impact on individuals, such as bereavement, strained personal relationships, addictions, poor self-esteem, poor economic and living conditions
- Group work with adolescents/adults/children/siblings etc.
- Joint work with the diabetes nurse specialist/psychologist etc.
- Conflict resolution and management
- Stress management.

#### 5.6.2 Paediatric Social Work Support

The social worker is an essential member of the diabetes team caring for children and adolescents. Having diabetes can add to the psychological strain of dealing with many life experiences. The incidence of co-morbidity of psychological problems with the diagnosis of a chronic life condition is high. The feedback from a social worker to the diabetes team is crucial to enable the team to assess and plan the level of intervention that may be required for each patient.

#### 5.6.3 Current Situation

The current provision of psychosocial support is dependent on location of treatment and general staffing levels. There is no formal availability of a social worker to primary care patients. Within the acute hospital setting the social work service is limited, due to the fact that all social workers employed in the area of diabetes care are part time and without protected time for diabetes.

#### 5.6.4 Recommended Staffing Levels

The management of a person's psychological care should be an integral part of diabetes care. Existing part-time social work services should be improved and upgraded to a dedicated 1.5 posts per diabetes team.

The Irish Association of Social Workers recommend that one full time senior social worker is allocated to each diabetes team to assess level of need and to develop and provide a social work service. Recognising that children and adolescents need proportionately more support and time than adults, more social work staff should be deployed in areas providing this service (estimated to be 1 social worker per 100 children or young persons with diabetes).

Consideration should be given to the development of counselling/support services to primary care patients. To further the development of diabetes social work services, there is need to establish a special interest group in relation to the psychosocial support of persons with diabetes. This group should have access to funding for development of training and research.

### 5.7 Psychology Services

All persons with diabetes should have access to a clinical or health psychologist. Ideally, such a person should be an integral part of the diabetes team. Psychological support is particularly necessary for individuals and families who are:

- In a transition period e.g. newly diagnosed or transferring diabetes management from the adult to the child
- Experiencing psychological barriers to effective care e.g. difficulties adapting to the diagnosis of diabetes, ineffective coping strategies
- Experiencing family discord that is having a significant impact on their diabetes management
- Experiencing other competing life stressors e.g. other illness, bereavement
- Suboptimal management in the absence of other causes.

The psychologist indirectly supports the other members of the diabetes team and acts as a resource person to all of the team.

### 5.7.1 Paediatric Psychological Support

All children and adolescents with diabetes and their families have their own specific needs related to anxiety, self-esteem, parenting style, family influences, developmental stage and adherence. Poor metabolic control is commonly associated with developmental psychological difficulties.

Appropriate and timely intervention may be the most effective way to improve control. In particular, the adherence difficulties associated with the developmental stage of adolescence needs to be addressed from a psychological point of view. A clinical or health psychologist specialising in childrens' health best identifies and addresses these needs.

### 5.7.2 Current situation

The quote 'psychological support is widely recommended but rarely available' is most relevant to the situation in Ireland where although, there are several psychologists working in the area of diabetes, it forms only part of their workload and is often at a crisis management level<sup>14</sup>. As can be seen from Table 3, there are no psychologists specifically allocated to work solely with people with diabetes on a full-time basis, therefore valuable preventive and intervention work is not possible. Where there is psychological care for adults, it is in the form of a referral to a clinical psychologist working within the hospital.

**TABLE 3**  
**PROFILE OF PSYCHOLOGISTS WORKING WITH PEOPLE WITH DIABETES IN ERHA HOSPITALS**

Employment Type	Adult	Children's
Full-time	-	-
Part-time	1	1
Sessional	4	2
None	5	-

### 5.7.3 Recommended Staffing levels

As can be seen from Table 3, there is at present a dearth of psychological care for people with diabetes. Psychological needs of people with diabetes cannot be easily measured or quantified. No two people will have the same perception or experience of having diabetes. These differences may be attributable to age, location, coping mechanisms, support, illness perceptions and social variables. What is needed is a nationwide co-ordinated service, where there is equitable psychological care available to all people with diabetes regardless of geographical location.

It is proposed therefore that for every diabetes centre there should be:

- one clinical psychologist - or -
- one health psychologist (with access to clinical or counselling psychology services where psychological difficulties warrant ongoing therapeutic input).

An appropriate psychology service includes:

- Routine meeting with psychologist at diagnosis
- Monitoring psychological well-being through the measurement of psychological outcomes and processes
- Implementation and evaluation of psychological interventions to:
  - optimise blood glucose monitoring
  - increase adherence to medication/regime
  - encourage and maintain lifestyle changes such as weight loss and exercise
- Stress management programmes
- Counselling, where appropriate.

### 5.7.4 Training Costs

Due to a lack of training places in Ireland, there are currently unfilled posts for clinical psychologists throughout the country. Therefore, a key aspect of providing adequate psychological care will be the provision of funding to increase training places.

Approximate training costs for one clinical psychologist = €55,868 - €87,612 (inclusive of Psychological Society of Ireland fees) plus expenses. Currently, the training for health psychologists is self-funded. However, it is anticipated that in future health board funded training of health psychologists will be available, with similar training costs to clinical psychologists.

## 5.8 The Pharmacist

The pharmacist is well placed to educate the person with diabetes about their drug therapy. In the Republic of Ireland there is approximately one community pharmacy for every 4,000 people. This means that every pharmacy provides a service to almost 100 persons with diabetes, of whom over 30 are undiagnosed. The pharmacist has contact with a large number of patients on a daily basis, many of whom may rarely or never see other healthcare professionals. Pharmacists play several roles in diabetes care but in an unstructured and undocumented manner. Currently they act as a readily accessible member of the healthcare team for persons with diabetes and offer advice in terms of:

- Reducing the incidence of diabetes through general lifestyle advice and support for specific health behaviours
- Early detection of diabetes by alerting patients at risk in relation to suspicious symptoms that present in the pharmacy
- Avoiding or reducing the complications of the condition by reinforcing education on treatment and monitoring provided by specialist centres and identifying and resolving drug therapy problems relating to both prescribed and over-the-counter medicines.

### 5.8.1 Current Standards and Protocols

There are no specific standards or protocols currently in use in Ireland. The WHO EuroPharm Forum has developed the Pharmadiaß programme for implementation in European countries as part of the St. Vincent Declaration Action Programme. The requirement for pharmacists to detect and resolve drug therapy problems in all patients is formalised in Clause 9 of their contract with the General Medical Services.

### 5.8.2 Recommendations

Because of their 5 year training in medicines, their accessibility and frequency of patient contacts, the role of the pharmacist in the care and management of diabetes should be recognised and formalised. This should include:

- Co-operating in any shared care programme or Diabetes Federation of Ireland activities
- Providing consistent and equitable lifestyle advice to all patients
- Referring patients to a doctor when diabetes is suspected, on the basis of a patient's symptoms, risk factors or as part of an organised multidisciplinary screening programme
- Providing medicines information at a level suitable to the health literacy of patients
- Encouraging and assisting blood glucose monitoring as required
- Documenting and updating all patients medicines – prescribed, over the counter and herbal

- Screening for medication related problems such as compliance, therapeutic duplication, contraindications, drug interactions, effectiveness and side-effects
- Resolving medication related problems in conjunction with the patient and prescribers when necessary
- Assisting persons with diabetes with their self-care.

Thus, the role of the pharmacist should be included as part of any national protocol for the management of diabetes in Ireland. At the moment these services are carried out on an opportunistic basis with no specific recognition or remuneration. Put on a more formal footing, the role of the pharmacist in the prevention, early detection and ongoing care of diabetes will be enhanced significantly. Specialist training on diabetes is already available from the Irish Centre for Continuing Pharmaceutical Education (ICPE) and to date 200 pharmacists have participated in a two-day training course. A formalisation of the pharmacist's future role in diabetes, in terms of consistency of service, equity and documentation would not infringe, but support the work of other healthcare professionals.

The challenge is to ensure consistency and reproducibility of service countrywide. This will be achieved by formalisation of an agreement by the Department of Health and Children with the profession to provide specific services to all diabetic patients from each pharmacy. This will necessitate that appropriate documentation and altered remuneration arrangements are established.

## 5.9 Administration Staff

Clinical care needs to be supported by managers and administrators, if healthcare professionals are to be freed from clerical work. An efficient service can only operate with adequate clerical support. The role of administration staff should be expanded to include:

- Maintenance of the diabetes register
- Recall of patients
- Recall of non-attenders and efforts made to enlist their co-operation
- Streamlining of appointments
- Arranging tests, appointments etc.
- Organisation of diabetes clinic
- Assist with audit and evaluation.

The role of administration staff will vary according to size and location of the diabetes clinic and should be agreed locally.

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## Ophthalmology Services

Cataract and retinopathy are the main causes of blindness from diabetes mellitus. The problem of waiting lists for cataract surgery is a major issue but will not be addressed in this document which is aimed at the management of retinopathy.

### 6.1 Diabetic Retinopathy

Diabetic retinopathy is the leading cause of blindness in people of working age in industrialised countries. Twenty years after diagnosis almost all of those with Type 1 diabetes and 60% with Type 2 diabetes will have some degree of retinopathy. British screening studies suggest that 5% to 10% have sight-threatening retinopathy and up to 40% of people with newly diagnosed Type 2 diabetes have some retinopathy.

In diabetic retinopathy small blood vessels in the retina (back of the eye) become blocked, swollen or leaky causing oedema (swelling). New fragile vessels grow haphazardly in the retina. This process can continue for years without causing sight symptoms or impairment. During this period retinopathy can be detected by eye examination. If it is left untreated, bleeding and scarring will lead to progressive loss of vision. The condition is treated by laser photocoagulation that can prevent blindness if it is given before significant visual loss has occurred. If diabetic retinopathy has been detected and treated before it becomes sight threatening, follow-up with regular examination of the eyes is necessary.

Therefore, retinopathy is an important public health problem and fulfils all the World Health Organisation's criteria for a screening programme. There are diagnostic procedures and adequate screening tests by which it can be identified and there is an

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effective treatment.

It can also be highly cost-effective both in terms of long term health gain and money saved by prevention of visual impairment. Studies suggest that the cost of screening and subsequent treatment can be lower than the cost of dealing with the blindness that could be expected without screening.

### 6.2 National Diabetic Retinopathy Screening Programme

Retinopathy screening should be provided for all people with diabetes mellitus in Ireland. The number of persons with diabetes in Ireland is not known, but if one assumes 3 to 4% of the population, 150,000 patients is an easy figure with which to work for planning a service. USA and UK studies have shown that retinal photography is a practical and effective option in caring for this large number of patients. Retinal photography allows the screening process to be separated from assessment and provides a lasting record of the patient's retina. The problems of early non-mydriatic cameras have been largely solved with digitisation. It can be carried out in a range of settings from clinics to mobile converted vans and ophthalmologists or suitably trained readers can assess the photographs.

### 6.3 Proposal for Screening Retinopathy in Ireland

If one were to assume that there are 150,000 persons with diabetes in Ireland then a programme to screen each one of them at least annually would be as follows:-

#### 6.3.1 Facilities

##### Stationary centres

Each major eye centre, hospital diabetes centre and some community centres should have a screening clinic staffed by a hospital ophthalmic physician or other doctor dedicated and trained in screening for retinopathy, two staff nurses and a photographer (or a person able to use a non-mydriatic camera) i.e. Cork University Hospital, Cork South Infirmity, Tralee Hospital, Waterford Regional Hospital, St. Vincent's University Hospital, St. James's Hospital, Tallaght Hospital, the Royal Victoria Eye & Ear Hospital, James Connolly Memorial Hospital, Beaumont Hospital, Mater Misericordiae Hospital, Our Lady of Lourdes Hospital in Drogheda, Longford/Westmeath General Hospital, Limerick Regional Hospital, Galway University Hospital, Sligo General Hospital, Letterkenny Hospital and other centres or community clinics to bring the total number to 20.

##### Equipment for each centre:

Digitised non-mydriatic camera, slit lamp, biomicroscopy lenses, Snellen chart, applanation tonometry, and direct and indirect ophthalmoscopy.

##### Mobile units

Eight mobile vans with a nurse and driver, equipped with a non-mydriatic camera would be required.

### **6.3.2 Procedure**

Approximately 3260 patients need to be screened each week, assuming a 46 week working year, if each patient is to be reviewed annually.

#### Stationary centres

The twenty stationary eye centres should run one or two dedicated eye screening clinic running for one or two complete days per week. For each patient, the visual acuity would be measured and two photographs (45 degrees) taken of each eye. Each centre should manage to screen an average of seventy patients a day and therefore 1400 patients could be screened per week through these centres. If 15 centres ran two full day clinics per week and 5 ran one full day clinic per week, then 2450 patients could be screened per week through these centres.

#### Mobile Units

The remaining patients would be screened in the community by the mobile units. Mobile units have been shown to achieve good penetration of the population at risk and screen those patients who have the greatest risk of severe retinopathy. Each mobile unit would be capable of screening 100 patients per week; i.e. 20 per day and, therefore, eight mobile units would be required. This would mean one mobile unit per health board. The procedure would involve measuring visual acuity and taking two photographs (45 degrees) with the non-mydratiac camera. The camera and reading test type chart would be removed from the van and set up in a general practitioner's clinic or community clinic for each screening session.

### **6.3.3 Management of patients with retinopathy**

The dedicated screening doctor attached to each stationary centre would be responsible for identifying patients with sight threatening retinopathy (5 to 10% of all patients). Patients with retinopathy requiring treatment would be referred to a retinal surgeon equipped with laser treatment and /or to perform vitreoretinal surgery. Currently, there are 9 consultant retinal specialists in Ireland, all of whom perform laser treatments for diabetic retinopathy and 5 of the 9 perform vitreoretinal surgery for diabetic retinopathy. The number of retinal surgeons should be increased to 15 to manage the increased number of treatments as a result of implementing this screening programme.

### **6.3.4 Administration**

Informing patients of the services, maintaining names and addresses of patients and reminders for defaulters is essential for a successful screening programme. Appointment of management and clerical staff will be required. It is the experience of other screening programmes that this is the most critical part of a successful programme.

### **6.4 National Retinopathy Grading Centre and management of images**

The management of images would be centralised to a National Retinopathy Grading Centre. The images would be sent over the internet and the retinopathy classified by trained graders. It is necessary to centralise the storage of images because of the need to standardise grading and of the expense of large servers in each centre. The national centre will fulfil the need for quality assurance of retinal photography and retinopathy graders. The National Retinopathy Grading Centre would send back the diagnosis (i.e. grade of retinopathy), which would be stored with visual acuity's in a database in a server in each stationary centre.

### **6.5 Software**

Software for the database of images and diagnoses specifically for diabetic retinopathy have been developed and is in use. The company Ocuco in Blanchardstown have developed this software which ophthalmologists have found very satisfactory. The company is willing to set up a national computerised register with the encrypted data being sent by the internet. The Irish Diabetic Retinopathy Study Group (IDRSG) and Ocuco are currently investigating telecommunications for images and data in diabetic retinopathy as part of The European Union funded multicentre study called TOSCA.

### **6.6 Management of patients with retinopathy**

The dedicated screening doctor in each stationary centre would examine patients with sight-threatening retinopathy (5 to 10% of all patients) and the degree of retinopathy required treatment, the patient would be referred to a centre with a retinal specialist equipped with laser treatment or to perform vitreoretinal surgery.

## 6.7 Costings

### **National Diabetic Retinopathy Screening Programme Costs**

#### **National Retinopathy Grading Centre**

		<b>Number</b>	<b>Unit Cost</b>	<b>Full Costs</b>	<b>Total Costs</b>
Capital Costs	Computer Equipment	1	€ 317,435	€ 317,435	
	Grader PCs	5	€ 3,809	€ 19,047	
	Grading Software	1	€ 253,948	€ 253,948	
	Other Equipment	1	€ 63,489	€ 63,489	
<b>Total Capital Costs of Grading Centre</b>					<b>€ 653,919</b>
Ongoing Costs	Personnel	Number	Unit Costs	Full Costs	Total Costs
	Total Graders	8.33	€ 25,395	€ 43,171	€ 359,759
	Quality Control	1.67	€ 54,599	€ 92,818	€ 154,696
	Total Management	1.67	€ 50,790	€ 86,342	€ 143,903
	Total Administration	8.33	€ 25,395	€ 43,171	€ 359,759
	Total Personnel Costs				€ 1,018,117
<b>Other Annual Costs</b>					
	Internet Bandwidth		€ 63,489		
	Maintenance		€ 98,087		
	Rent		€ 25,395		
	Total Other		€ 186,969		€ 186,969
<b>Total Annual Cost of Grading Centre</b>					<b>€ 1,205,087</b>

#### **Stationary Centres**

Capital Costs	Camera	1	€ 25,395	€ 25,395
	Server	1	€ 6,349	€ 6,349
	Patients	1	€ 1,524	€ 1,524
	Software	1	€ 10,158	€ 10,158
<b>Total Capital Cost of Stationary Centre</b>				<b>€ 43,171</b>
Ongoing Costs	Maintenance	0.15	€ 43,171	€ 6,514
	Photographers	0.2	€ 50,790	€ 10,158
	Nurses	0.2	€ 25,395	€ 5,079
	Community Ophthalmology Physician	0.4	€ 54,599	€ 21,839
<b>Total Annual Cost of Stationary Centre</b>				<b>€ 43,590</b>



## Mobile Units in Community Care Centres

Capital Outlay	Camera	1	€ 25,395	€ 25,395
	Computers	1	€ 3,809	€ 3,809
	Van	1	€ 19,046	€ 19,046
	Software	1	€ 10,158	€ 10,158
	<b>Total Capital Cost of Mobile Units</b>			<b>€ 58,408</b>
Recurring Costs	Maintenance	0.15	€ 58,408	€ 8,761
	Photographers	1	€ 25,395	€ 25,395
	Community Ophthalmology Physician /Nurse sessions	250	€ 102	€ 25,395
	<b>Total Annual Cost of Mobile Units</b>			<b>€ 59,551</b>

Costings are based on a target population of 150,000 with one hundred per cent uptake and whole-time equivalents grader reviewing 15 patients per hour. Given the requirement for 20 stationary centres and eight mobile units the total one-off capital costs are estimated to be €1,330,684 (€863,420 for the stationary centres and €467,264 for the mobile units). Thereafter, it is estimated that total annual costs of €1,348,208 will be incurred (€871,800 for the stationary centres and €476,408 for the mobile units).

### 6.8 Benefits of Investment

At the present time, diabetes remains the leading cause of blindness in people of working age. Detection of at risk persons with diabetes in the community remains one of the biggest logistical problems in achieving the aim of reducing visual loss in the population of persons with diabetes. A variety of screening methods with opticians, physicians, ophthalmologists, general practitioners, and photographic methods using non-mydratic cameras have all shown to be effective to some degree. Non-mydratic fundal photography is useful for detecting retinopathy in patients with diabetes and has been shown to be effective in identifying previously unrecognised retinopathy when used in the community. Recently the introduction of mobile screening units in the UK, of which there are now eleven, have been shown to greatly improve detection and resulted in a decline in the incidence of sight threatening retinopathy. Coupled with this is the knowledge that rural based populations are less likely to present to a clinic, and that the incidence of sight threatening retinopathy is higher in the rural population. Present screening methods seem to be less effective in reaching rural patients and they would benefit from the introduction of more mobile units. Furthermore, combining the screening modalities of retinal photography and ophthalmoscopy (retinal cameras with video/digital imaging techniques) have been recommended to increase the sensitivity of screening of diabetic retinopathy, as it has been shown that each modality can miss sight threatening diabetic retinopathy detected by the other. The acquisition of such photographs can be undertaken by trained non medical personnel. The images can be readily stored and retrieved from a computer database. The images also lend themselves to the possibility of image enhancement and analysis. There is the possibility of developing

computer software capable of recognising lesions. Images could also be electronically transferred to the ophthalmologist to help eliminate inappropriate referral and aid in prioritising decisions. Such a mobile screening unit does not exist in the Republic of Ireland. It is proposed to determine the approximate cost to the State of blindness due to diabetic retinopathy and to offset this cost against the provision of establishing such a mobile screening system in the Republic of Ireland, as set out below.

#### 6.8.1 Cost Benefit Analysis

A number of studies have assessed the costs and benefits of screening programmes for diabetic retinopathy. Taylor<sup>1</sup> documented the performance of 12 diabetes eye screening units in different UK health districts. Full data available on 42,803 screening episodes showed 2,400 referrals (5.6%) and 516 episodes of laser therapy (1.2%). The average cost of screening was STG £13.11 with a cost per patient identified for laser screening of STG £1,110.

A US study<sup>2</sup> assessed the cost of preventing vision loss in patients with diabetes mellitus through ophthalmologic screening and treatment. The cost per quality adjusted life year (QALY) for patients with diabetes mellitus were US\$3,190. However, this is an average cost weighted by disease prevalence – the cost per QALY was US\$1,996 for patients with Type 1 diabetes, US\$2,933 for Type 2 diabetes patients on an insulin regime and US\$3,530 for Type 2 diabetes patients not on an insulin regimen.

A US study by Javitt et al.<sup>3</sup> showed preventive care in Type 2 diabetes patients to be cost saving, supporting previous work which demonstrated significant cost savings associated with the detection of eye disease in Type 1 diabetes patients. The study showed screening

and treatment for eye disease in Type 2 diabetes patients to generate annual savings of US\$247.9 million to the federal budget and 53,986 person years of sight, at current suboptimal (60%) service coverage. The study forecast that the net savings would exceed US\$472.1 million and 94,305 person-years of sight if all Type 2 diabetes patients received recommended care.

A further study<sup>4</sup> assessed the welfare costs of visual impairment in Australia and eight European countries. The study showed that government benefits to those with sight impairment (or their carers) can be substantial but only comprise some of the costs associated with blindness and/or sight impairment. Other costs include treatment (e.g. laser surgery for diabetic retinopathy), social care and residential care, carer burden, personal costs of home adaptations and living aids as well as foregone productivity for both those with sight impairment and their carers.

In order to conduct a cost benefit analysis of the implementation and operation of a mobile screening programme in Ireland it is necessary to estimate the costs and benefits of the programme. The costs associated with implementation and operation of a mobile screening programme are outlined above in the description table. The most tangible benefit of the screening programme is a reduction in the incidence of sight threatening retinopathy through appropriate treatment and hence avoidance of the costs associated with blindness and/or visual impairment. Thus the monetary value of the benefits arises from costs saved

as a result of prevention and/or delay of episodes of blindness / visual impairment.

In order to assess the costs associated with blindness / visual impairment, an analysis of the registered blind population on the diabetic register of the National Council for the Blind of Ireland was undertaken, and estimates were made of the costs for provision of State benefits and allowances, currently available to these patients via government agencies.

Currently there are 100 people registered as blind from diabetic retinopathy with the National Council for the Blind. Given current estimates of the population of diabetic patients in Ireland (150,000), and the assumption that 5 % of those have sight threatening retinopathy, this figure of 100 people registered with diabetes-related blindness no doubt grossly underrepresents the current scale of the problem in Ireland and reflects widespread under registration with the National Council for the Blind, and therefore under utilisation of the benefits and allowances available to this population. A study published in the British Journal of Ophthalmology in 1998 estimating the causes of blindness in the Republic of Ireland, based on the register of the National Council for the Blind, listed 147 individuals as blind from diabetic eye disease. The entry criteria have not changed since this time. The discrepancy may be due to high mortality due to coexistent disease

The benefits and allowances currently available to those registered with the National Council for the Blind are outlined in the table below (Table 4). The difficulty in accurately estimating these figures due to means testing has been responsible for the paucity of data of previous reports on estimated costs and several figures have been averaged to enable analysis. The estimates provided are annual costs per 100 persons.

**TABLE 4 - SUMMARY OF BENEFITS AND ALLOWANCES PER PERSON PER ANNUM (n= 100)**

Allowance	Per Week per person	Per Annum per 100 persons
Blind persons pension	€ 109	€ 566,800
Blind welfare allowance	€ 34	€ 176,800
Carers allowance	€ 112	€ 582,400
Disability allowance (€ allowed)	€ 70	€ 364,000
Tax free allowance		€ 92,000
Guide dog allowance		€ 42,000
Free travel – bus/rail pass		€ 38,000
Companion travel 25% reduction		€ 12,700
Electricity allowance 1800 units per year		€ 95,000
Television allowance		€ 9,000
Incapacity benefit	€ 65	€ 365,700
Low vision aids		€ 43,000
Telephone allowance		€ 16,500
	<b>Total</b>	<b>€ 2,403,900</b>

The total annual cost of €2,403,900 per 100 persons translates to an average cost of €24,039 per person per year. Given the total annual costs of operating the screening programme of €1,348,208 means that in order for the programme to break even the ongoing pool of patients who are prevented from becoming blind (and eligible for state benefits and allowances) needs to be 74. The total annual cost of State benefits and allowances for 74 patients is €1,778,886 (74 people x €24,039 per year) which would result in a small cost saving. The assumption is such that each year patients who are prevented from becoming blind will be added to the pool and those patients dying (for whatever reason) will be deducted from the pool. Initially, the number of patients added each year will need to be greater than the number of patients leaving each year so that the pool can build up. Ultimately, these numbers need to at least be the same so that the savings from preventing episodes of blindness can continue to cover the annual operational costs of the screening programme.

These figures do not take into account the once off capital costs of €1,330,684 attributable to implementation of the screening programme. Assuming that a person who is prevented from becoming blind has a remaining life expectancy of 10 years then the total cost saving per person will be €240,390 (€24,039 per year x 10 years) which means that an additional 8 patients need to be prevented from becoming blind in order to recoup the setup costs of the screening programme.

Given that the screening programme employed is expected to result in 150,000 screening episodes each year and given that in the UK 42, 803 screening episodes in 12 centres resulted in 516 episodes of laser therapy<sup>1</sup> then it could be assumed that approximately 1,800 episodes of laser therapy would be conducted in Ireland each year. The costs of this alone are substantial but more importantly, this number of episodes of laser therapy is likely to result in episodes of blindness prevented well in excess of that required in order for the screening programme to break even. And even when assuming that only some blind patients are eligible for benefits and allowances as a result of their financial status it is likely that significant cost savings would accrue. In order to confirm this a full economic evaluation of the proposed service would need to be conducted. Nevertheless, such a confirmation would certainly be in line with the cost savings reported from similar programmes in other countries.

It should be noted that in the outline analysis above, the estimates of cost savings as a result of preventing episodes of blindness are limited to the benefits and allowances paid to eligible claimants. Consequently, the analysis underestimates the monetary benefits attributable to episodes of blindness prevented. The analysis above excludes the costs of inpatient hospital stays, medical and surgical treatment, caregiver burden, the loss of productivity in those registered and in those who despite having disabling visual loss due to retinopathy, do not qualify for registration under the current acceptability guidelines. Inclusion of these costs will no doubt result in substantial cost savings attributable to the implementation and operation of a community screening programme.

The estimates provided above no doubt show that providing a National Screening Programme will improve eye care for persons with diabetes, reduce needless visual loss, and furthermore provide a financial return on the investment of public funds.

TOTAL CAPITAL COST	= €1,984,603
ONGOING COST PER ANNUM	= €2,553,295

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# chapter seven

## Paediatric and Adolescent Services

The EU definition of paediatrics is to the age of 18 years. The St. Vincent Declaration states that the care of children/adolescents with diabetes should be provided with individuals and teams specialised in the management of diabetes and of children. To achieve this, it is required that each health board area should have a paediatric diabetes team. The Patient's Charter states that children with a major chronic illness should be under the care of a paediatrician and a children's nurse. This is not the norm for children with diabetes outside the Dublin or Cork area.

### 7.1 Prevalence

The number of children with diabetes in Ireland is not known. However, the prevalence of diabetes in children is the region of 1 to 2 per 1,000. Based on 1996 census figures, 859,424 persons less than 14 years of age, one could assume a figure of 1,720 children with diabetes in

Ireland. It is worth noting that adolescents with diabetes (14 – 18 years) should be cared for in the paediatric sector until/unless they are psychologically mature adults. This will increase the demand for paediatric diabetes services.

The incidence of Type 1 diabetes is rising by 3 to 5% per annum with a proportionally greater rise in those less than 5 years of age. By definition these children will need diabetes services for the rest of their lives and this fact is important in considering the planning of future services.

### 7.2 Current Situation

The current paediatric and adolescent diabetes services in Ireland are wholly inadequate with only one centre in the country having a full diabetes care team as recommended above. This unit situated in Our Lady's Hospital for Sick Children, Crumlin serves the entire Republic of Ireland (see Table 5).

**Table 5 - NUMBER OF CHILDREN WITH DIABETES ATTENDING OUR LADY'S HOSPITAL FOR SICK CHILDREN**

Area	Number of Children Attending
Dublin	149
Leinster excluding Dublin	133
Munster	39
Connaught	18
Ulster	18
Total	357

Other acute centres that provide diabetes care for infants, children and adolescents are outlined in Table 6.

**Table 6 - CHILDREN WITH DIABETES ATTENDEES BY HOSPITAL**

Health Board	Hospital	Current number of patients attending	Paediatrician with an interest in Diabetes
Midland	Portlaoise General Hospital	45	
	Longford / Westmeath General Hospital	45	
Eastern Regional Authority	Beaumont Hospital	93	
	Mater Hospital	97	
	St. Columcille's Hospital, Loughlinstown	1	
	St. James's Hospital, Dublin	30	
	St. Vincent's Hospital, Dublin	6	
	Tallaght Hospital	164	Yes
	Temple St. Hospital, Dublin	131	
North Eastern	Our Lady of Lourdes Hospital, Drogheda	100	Yes
	Cavan General Hospital	40	
North Western	Letterkenny General Hospital	87	Yes
	Sligo General Hospital	35	
South Eastern	St Joseph's Hospital, Clonmel	24	
	St Lukes Hospital, Kilkenny	15	
	Waterford Regional Hospital	75	
	Wexford General Hospital	27	
Southern	Bons Secours Hospital, Cork	8	
	Cork University Hospital	120	Yes
	South Infirmery Hospital	16	
	Tralee General Hospital	40	
Western	Mayo General Hospital	60	
	Galway University Hospital	105	
Midwestern	Limerick Regional Hospital	85	

### 7.3 Needs of Children with Diabetes

The physical, psychological and physiological needs of children differ widely from those of adults, hence the need for the diabetes team to have an understanding of child development and the importance of the family in a child's life. It is essential that the diabetes team has the ability and temperament to work alongside parents, sharing care with them as equal partners. Children are unique developing individuals who have a right to appropriate diabetes education, support and management of their medical condition to reduce the short-term and long-term complications of diabetes and promote normal growth and development.

Children diagnosed with diabetes usually need hospital admission for the medical management of their acute condition and the commencement of their diabetes education. This is a vulnerable time for patient and family, and messages given at this time are not forgotten. Admission to hospital should allow some breathing space to learn about diabetes in a controlled environment with assistance from competent professionals. Empathy, understanding, child and family centred education and open communication can reduce distress and anxiety.

Outpatient clinics should ideally be situated away from the main hospital building with access to other specialities as required, and with a bright and welcoming waiting area. Appointment times should facilitate a limitation of delays, be flexible within reason and have some means of recall if appointments are not kept.

#### 7.3.1 Psychosocial Factors

Psychosocial factors are the most important influences affecting the care and management of diabetes in children. Poor metabolic control is commonly associated with psychological and social issues. Having diabetes can add to the psychological strain of dealing with many life cycle experiences, especially during the ages of childhood and adolescence. The incidence of co-morbidity of psychological problems with the diagnosis of a chronic life condition is alarmingly high.

Children with diabetes need age-appropriate advice on how to cope with feeling different, jealousy and peer group pressures along with education on how to manage diabetes in daily life. Overt psychological problems require expert attention from a paediatric social worker/child psychologist. It is recognised that children and adolescents need proportionately more support and time allocation in order that problems can be tackled with speed when behavioural changes are more achievable and long lasting.

## 7.4 Management of Diabetes in Children

Diabetes management in young children requires frequent contact with healthcare professionals. The aims of diabetes care in children and adolescents:

- All children/adolescents with diabetes should have their diagnosis recognised promptly to minimise the considerable morbidity and mortality associated with diabetic ketoacidosis (DKA).
- Every child/adolescent with diabetes should have a childhood without discrimination or disadvantage. They should suffer the minimum of short-term complications and have the expectation of adult life without the added burdens of long-term medical or psychological sequelae.
- As psychosocial disadvantage has direct correlation with poor metabolic control, every effort should be made to redress this.

The establishment of agreed standards of care for children and adolescents with diabetes is the cornerstone of improving this care. While not yet completely evidenced based<sup>1</sup>, these standards have been agreed by international consensus. This impressive document can act as a template for local care initiatives, providing clear guidelines in all the important areas of paediatric and adolescent diabetes care, from the protocol for the management of DKA to the importance of dieticians and psychologists in the team approach.

*"From the first day of diagnosis the child or adolescent with diabetes and the family should be cared for by members of a team of specialists. All members of the team should have training, expertise and understanding of both diabetes and paediatrics, particularly child and adolescent development."*

*International Society for Paediatric and Adolescent Diabetes - 2000*

Comprehensive practical education is the key to proper diabetes care and management. The diabetes care team is the best method of achieving this and it should be child / adolescent centred.

Improved public and primary care awareness of the possibility of diabetes in those less than 5 years would be a first step. Specialists in diabetes have a duty to inform their colleagues of the symptoms of diabetes in this age group

and the tendency to rapid deterioration into DKA particularly during intercurrent illness. Currently research in paediatric diabetes in Ireland is limited by the huge service demand on the few people specialising in the field. More people with the common interest and some grouping of patients are required to facilitate this research.

## 7.5 Transition to Adult Services

As children move towards adulthood, a collaborative service is necessary, where the paediatric specialist and the endocrinologist caring for adults work together with appropriate teams to ensure that the change from childhood care to adult care is as smooth as possible. By definition, these children will have diabetes for life and therefore are at greatest risk of the long-term complications of diabetes. It is for this reason that their care should be at regional level. Neglect, failure to attend appointments and poor glycaemic control are not uncommon in adolescence. Tact, understanding and patience are essential if these young people are not to be lost to adequate medical supervision during this stressful period. The recommended interval between follow-up visits for young people with diabetes is one to three months but even more intense follow-up may be required for short periods.

## 7.6 Recommended Staffing

Provision of this care locally is part of local paediatric planning and needs to be in some way integrated with the adult services. The Royal College of Paediatrics and Child Health recommend that children should be cared for by specialist paediatricians and that these children should be seen in a designated diabetic clinic<sup>2</sup>.

### Recommended staffing levels for a diabetes care team are:

- 1 Paediatrician with a special interest in endocrinology or a paediatric endocrinologist
- 1 Paediatric diabetes nurse specialist- who should be permitted to visit schools/homes
- 1 Dietician
- 0.5 Child psychologist.
- 0.5 - 1 Medical social worker
- Administration staff

The team should be able to provide:

- Specialised medical care
- Comprehensive ambulatory care for diabetes and associated conditions
- Proper screening for complications
- Expert advice on sickness, exercise, travel, etc.
- A 24-hour emergency telephone support for parents/adolescents.

Sessional work by an endocrinologist in the paediatric clinic would support the paediatric service and facilitate the transition of adolescents into the adult diabetes services.

## 7.7 Diabetes Centres

The paediatric diabetes care team should have its own unit/centre ideally in the outpatient area with ready access to patient records, with offices for all staff and facilities to run clinics, team meetings and patient / parent / staff workshops. It should be designed to welcome its children / adolescents and have an open door policy. Staff must have a non-judgmental open realistic approach that encourages honesty and continued attendance despite difficulties. There should be ready access to a laboratory that can process small blood samples with a rapid turnaround time for glycosylated haemoglobin (HbA1c), glucose, thyroid function tests, microalbuminuria etc. It should have external quality control and use a universal standard for HbA1c.

The centres with larger numbers, more expertise, etc. should co-ordinate care with smaller centres using shared protocols and procedures. As the initial introduction to diabetes is so important for children / adolescents and their families, strong consideration should be given to some or all of the initial education being done at the larger centre. Expert diabetes ophthalmoscopy must be available for annual screening after 5 years of diabetes (before puberty) or after 2 years in the pubertal children / adolescent with diabetes.

## 7.8 Costings

### Development of centres outside the ERHA- i.e. 7 Paediatric and Adolescent Diabetes Centres

<b>Capital Cost</b>	<b>Cost</b>
Buildings – 7 centres based on a proposed schedule of accommodation of 114 metres sq.	€2,800,000
Equipment – to routine testing and research	€ 755,265
Total	€3,555,265

### **Ongoing Costs**

Maintenance	€ 355,523
<u>Staff not currently in post</u>	
7 additional consultant paediatrician / endocrinologist or paediatrician with training in diabetes with support staff to include 2 specialist registrars and 2 senior house officers per post and includes salaries (inclusive of PRSI) on-call rate, overtime etc	€ 2,489,557
7 additional paediatric diabetes nurse specialists	€ 321,860
7 additional dieticians	€ 336,070
4 additional child psychologists	€ 301,532
4 additional social workers (paediatric)	€ 220,468
Clerical support	€ 100,000
Total	€ 4,125,010

### Development of services within the ERHA

### **Ongoing Costs**

4 Additional consultant paediatrician / endocrinologist staff to include 2 specialist registrars and 2 senior house officers per post. And includes salaries (inclusive of PRSI) on-call rate, overtime etc.

€ 1,396,576

#### Additional Staff required within the ERHA

3 Diabetes co-ordinators	€ 148,353
6 Paediatric diabetes nurse specialists	€ 275,880
5.25 Dieticians	€ 252,052
5 Child psychologists	€ 376,915
6.5 Social workers (paediatric)	€ 358,260
Total	€ 2,808,036

TOTAL CAPITAL COST = € 3,555,625

ONGOING COST PER ANNUM = € 6,933,046

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## Maternity Services

One of the targets of the St. Vincent Declaration is to reduce the incidence of perinatal morbidity and mortality by achieving pregnancy outcome in diabetic women that approximates to that of non-diabetic women. The Irish St. Vincent Group found that infant mortality and malformation rates in Ireland resulting from diabetic pregnancy were similar to the rate for the general population. However, the service to mothers with diabetes is under-resourced. The number of pregnancies where the mother has pre-existing diabetes and number of mothers who get gestational diabetes are increasing, putting extra pressure on these services.

There is no register to confirm the number of births to mothers with pre-existing diabetes or to mothers with gestational diabetes. Similarly, there is no record of the number of miscarriages that may be a result of poor diabetes control preconception or during the first trimester of pregnancy. A large screening study at the National Maternity Hospital found an incidence rate of gestational diabetes to be 2.8% of all births giving a national estimate of 1,500 gestational diabetes mellitus per annum<sup>1</sup>.

During the earliest stages of fetal development there is an increased risk of major congenital malformations in women with pre-pregnancy diabetes. Tight glycaemic control at the time of conception reduces the risk rate to near that of the non-diabetic woman and is an important part of pre-pregnancy counselling. It is advocated that every effort should be made to achieve optimum glycaemic control prior to discontinuation of contraceptive means.

Gestational diabetes if undetected or untreated, may result in accelerated fetal growth after about the 28<sup>th</sup> week. The fetal size can move from about the 50<sup>th</sup> centile to as high as the 90<sup>th</sup> or even higher as macrosomia develops. Delivery of a large baby can cause mechanical problems such as prolonged labour or shoulder dystocia with increased risk of caesarean section. Other potential problems include sudden intra-uterine death, respiratory distress and prolonged neonatal intensive care stay. These problems are preventable with an organised system to detect gestational diabetes and to treat the condition as rigorously as established diabetes.

Diabetes imparts risks to the mother who can potentially suffer from increased incidence of the acute complications of diabetes. Pregnancy can also result in a worsening of nephropathy or retinopathy and pre-eclampsia is more common in persons with diabetes. There is the extra financial and human burden to the mother of extra visits to the hospital and compliance with a strict regime.

# chapter eight

## 8.1 Current Situation

As in many other areas of diabetes care, antenatal diabetes care differs in the capital compared to the rest of the country. In Dublin, there are three diabetes/maternity clinics. Given the number of births annually and the prevalence of Type 1 diabetes, figures from the Dublin maternity hospitals suggest that a large percentage of the mothers with pre-existing diabetes travel to one of these hospitals to have their antenatal care and delivery of their baby.

Outside of the capital, there are virtually no combined diabetes/maternity clinics. The expectant mother attends her obstetrician and her endocrinologist on separate visits. This is not optimal care. Furthermore, there is no screening protocol of any type for gestational diabetes in many maternity centres around the country.

There are diabetes midwife specialists in each of the three Dublin maternity hospitals but their time for diabetes care is not protected time. Outside of Dublin, there is one midwife currently undertaking diabetes training.

Throughout the country, there are only 1.7 whole time equivalents (W.T.E.) dieticians /clinical nutritionists working in all 3 maternity hospitals of which only 0.4 W.T.E. is protected time for diabetes as opposed to the recommended minimum of 0.35 fulltime equivalents (F.T.E.) dietetic posts per maternity clinic.

## 8.2 Recommended Antenatal Diabetes Care

A co-ordinated team is required for optimal management of the diabetic pregnancy and ideally all team members should see the patient together in the one clinic. The team should comprise of a

- Endocrinologist
- Obstetrician
- Diabetes midwife specialist
- Dietician
- Paediatrician
- Access to ophthalmologist, nephrologist, counsellor and social worker.

There are strong arguments for centralisation of the treatment of diabetic pregnancies. A centre should have at least 15 to 20 births annually to insulin dependent mothers<sup>2</sup>. Also, there needs to be close collaboration with the neonatologist both during delivery and afterwards.



### **8.2.1 Preconception Care**

The purpose of preconception care is to insure the best possible glycaemic control at the time of conception, assess microvascular complications, review diabetes knowledge of mother and to establish a rapport between the team and the patient to prepare her for the care of her diabetes during pregnancy.

An optimal outcome may be obtained from pregnancy if excellent glycaemic control is achieved before and during pregnancy. Good nutrition is a critical part of preconception care. Attending pre-pregnancy counselling clinics increases the likelihood of positive outcomes for mothers and their babies.

### **8.2.2 Antenatal Care**

Antenatal care should be combined obstetric / endocrinology care. The first visit should be as soon as pregnancy is suspected and visits increase in frequency as the pregnancy develops. Some centres would see the mother fortnightly until the 36<sup>th</sup> week and then weekly.

Intensive home blood glucose monitoring is necessary with the results monitored by the diabetes team and insulin dosage adjusted accordingly. Hospital blood tests are necessary much more frequently and facilities need to be available to perform these. Admission to hospital is necessary if control is not adequate or complications develop.

Gestational diabetes is asymptomatic and is usually picked up on screening<sup>3</sup>. Once diagnosed, the person attends the combined obstetric / endocrinology clinic. Close monitoring is necessary to ensure achievement of glycaemic targets. Depending on criteria used, up to 40% of gestational diabetes pregnancies will require use of insulin therapy. However, the decision to commence insulin therapy varies from centre to centre. It is based on many factors including effectiveness of screening, mode and intensity of surveillance and individual obstetrical goal ascertainment. The most important component of care of these pregnancies is their identification and early intervention since untreated or undertreated gestational diabetes is associated with adverse outcomes.

Dietary advice should form an integral part of diabetes management in pregnancy. Optimised and individualised dietary advice is a very important factor in the management of postprandial hyperglycaemia. It has been demonstrated that prenatal nutrition education programmes can positively influence pregnancy outcome, notably by reducing prematurity and perinatal mortality rates. All pregnant women should have access to nutrition / dietetic services, as this is the period in their adult lives when their nutrient needs are highest.

Significant maternal hypoglycaemia occurs in between 20 to 40% of insulin dependent mothers with diabetes. It may be severe enough to warrant advice about discontinuing driving for the remainder of the pregnancy. This has implications for many patients, as they must travel a distance to attend their hospital appointments.

There is no research on the recommended level of staffing for diabetes / maternity services. Requirements would need to be assigned based on prevalence of diabetes in the target community and allowances made for ethnic mixes.

### **8.2.3 Delivery**

The goal of diabetic pregnancy is a normal delivery at term. This requires good diabetes control from an early stage for the duration of the pregnancy. In addition, perinatal euglycaemia in the mother will prevent hypoglycaemia in the neonate and reduce the risk of prolonged labour for the mother.

### **8.2.4 Postnatal Care**

Insulin requirements drop dramatically following delivery. Even those patients with gestational diabetes not requiring insulin therapy need glucose monitoring 24 to 48 hours post delivery. Patients are usually discharged with follow-up postnatally in the maternity clinic and diabetes follow-up at a diabetes clinic. All mothers diagnosed with gestational diabetes need accurate diagnosis, regular screening for Type 2 diabetes and dietary advice. The diagnosis of gestational diabetes provides an unique opportunity for intervention to prevent the future development of diabetes in that woman.

### **8.2.5 Additional Difficulties**

With the increasing number of immigrants and asylum seekers entering the country, there has been a dramatic increase in the demands on diabetes pregnancy services. This is a direct result of the pressing need of this population to have babies in Ireland for social and legal reasons and also, because most of these patients come with high background rates of diabetes. This has led to a dramatic increase in both gestational and pre-gestational diabetes straining further an under resourced service.

### **8.2.6 Future Requirements**

There is a need to establish combined obstetric / endocrinology clinics throughout the country and for expansion of the current clinics in the Dublin area. These clinics should be situated in the maternity hospitals where there would be a minimum delivery of 15 to 20 pregnancies of insulin dependent diabetes per year. It is suggested that the facilities in Dublin be expanded with additional endocrinology sessions in each of the hospitals. There should be a designated diabetes midwife in attendance full time and 0.5 dieticians directed to diabetes care per hospital. Outside of Dublin, there is a need to develop a combined obstetrical / endocrinology clinic in appropriate geographical locations with allocated staff.

Recommended staffing levels:

Endocrinologist – at minimum 2 to provide adequate on call rota

Obstetrician with an interest in diabetes

Diabetes midwife specialist

Dietician

Access to social worker and counsellor

Access to ophthalmologist and nephrologist

Cork, Limerick and Galway are the counties with the highest number of births outside of the capital and these should be considered as possible locations.

### 8.3 Costings

Combined obstetric/endocrinology clinic may not be desired by all patients or healthcare professionals but should be available when desired. There is an urgent need to develop services where inadequate services exist.

#### Development of centres within the ERHA

Capital expenditure would not be justified without discussion with relevant persons re current trends. In the interim, it may be more prudent to rent facilities.

#### **Ongoing Costs**

Diabetes midwives (in post) to have protected time for diabetes care i.e 1.5 posts required	€	68,970
Appointment of 1.1 dieticians to supplement current appointments of 0.39 posts	€	52,811
Total	€	121,781

#### Development of Services outside the ERHA

#### **Capital Costs**

Buildings - 3 centres		
Based on a protocol schedule of accommodation of 114 metres sq.	€	1,142,764
Equipment - to include radiology and laboratory facilities	€	380,921
Total	€	1,523,685

#### **Ongoing Costs**

Maintenance		€	152,369
Additional staff required			
Diabetes midwife specialist	by 1.5	€	68,970
Dietician	by 1.5	€	72,014
Total		€	293,393

TOTAL CAPITAL COST	= €	1,523,685
ONGOING COST PER ANNUM	= €	415,133

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## Transplantation Services

There is currently one transplant centre in the country. Beaumont Hospital is the tertiary referral centre for all persons requiring transplantation in Ireland. Due to the small numbers of persons requiring transplantation, it is envisaged that development of this service at its present location would be adequate to service the entire country.

Due to recent improvements in anti-rejection therapy, advancement of techniques and acceptance of this method of treatment, referrals to the national centre have increased. This trend will escalate with the increased prevalence of Type 1 diabetes and earlier surgical intervention for nephropathy. However, inadequate resources should not limit development of the service. There is an acknowledged limitation due to donor availability and campaigns to promote organ donation are recommended.

### Recommendations

- Promotion campaigns for organ donation
- Upgrading of Beaumont Hospital to a national transplantation and research unit with necessary resources.

### 9.1 Current Situation

At present pancreatic transplantation is the only form of treatment that can normalise glucose homeostasis. Because of this fact pancreatic transplantation is currently enjoying an increase in interest in its application not only in persons with diabetes and with renal failure where it is currently an accepted treatment option in conjunction with a kidney transplant but also in the pre-ureamic patient in an attempt to prevent the development of chronic diabetic complications<sup>1</sup>.

The indications for pancreas transplantation have been recently defined in a position statement published by the American Diabetes Association<sup>2</sup>. These include persons with diabetes who have end stage renal failure. In the absence of renal failure, pancreas transplantation should be considered in the following situations:

- 1) a history of frequent acute and severe metabolic complications requiring medical attention
- 2) clinical and emotional problems with exogenous insulin therapy that are so severe as to be incapacitating
- 3) consistent failure of insulin-based management to prevent acute complications.

### 9.2 Results

Thirty-four transplants have been carried out through a pilot programme (1992-1999) at Beaumont hospital. Thirty-one persons had combined pancreas/kidney transplant and three persons had pancreas transplant alone. With a mean follow-up of 44 months the patient,

# chapter nine

pancreas and kidney survival are 97%, 92 % and 97% at 1 year, 97%, 92% and 85% at 3 years. The current level of safety and success with pancreas transplantation has led to a relentless if reluctant acceptance of this procedure as an integral part of diabetic management.

There are at least 15,000 persons with Type 1 diabetes in the country. As the criteria for pancreas transplantation expand, if 0.5% (a conservative estimate) require transplantation this would involve 75 pancreas transplants per year.

### 9.3 Benefits

The results of the Diabetes Clinical Control Trial (DCCT) are generally accepted and intense insulin treatment is acknowledged as superior to standard therapy. The question is which technique produces better glucose control - pancreas transplantation or intense insulin treatment? The answer unequivocally is pancreas transplantation as metabolic control is better with pancreas transplantation and it does not have the penalty of severe episodes of hypoglycaemia seen in the DCCT study<sup>3</sup>.

The future of pancreas transplantation will depend on its utility in preventing the multisystem ravages of this disease. It is however unrealistic to expect significant reversal of complications that took 20 years to develop when pancreas transplantation is applied very late in the natural history of the disease i.e. when patient is already dialysis dependent.

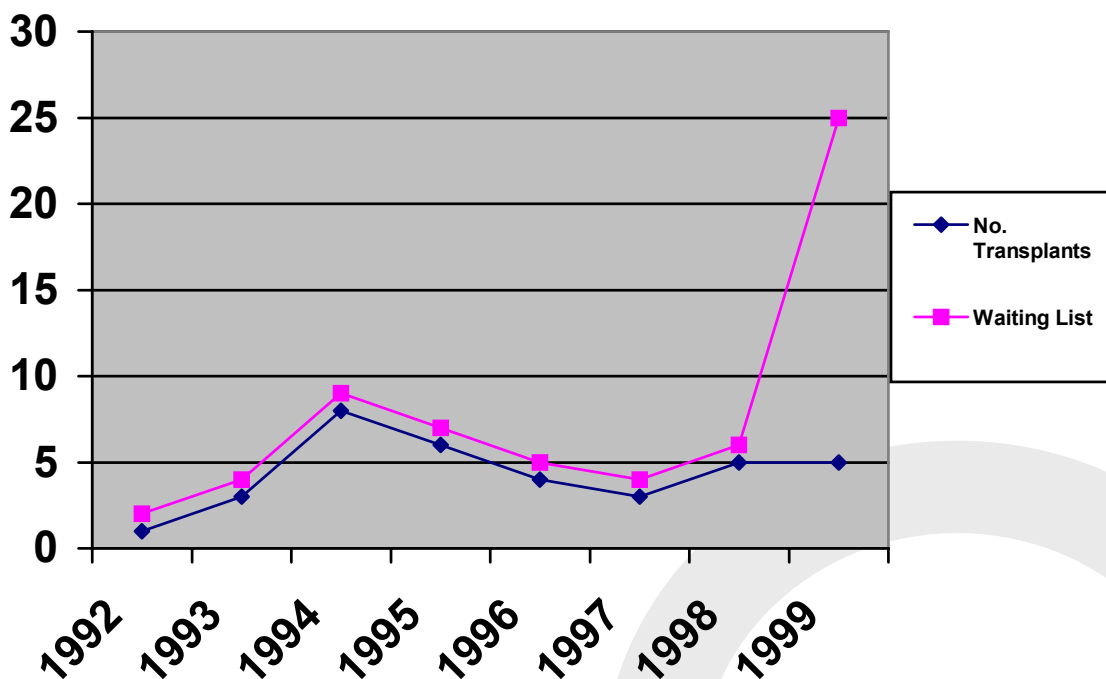
Combined pancreas/kidney transplant has been shown to prevent the recurrence of diabetic nephropathy<sup>4,5</sup>. Combined transplant improves cardiac performance when compared to single transplant<sup>6</sup> and reduces the atherogenic lipid profile<sup>7</sup>. Zehrer & Gross<sup>8</sup> found in a one year follow up of combined versus single transplant, that the quality of life for recipients of combined transplant was much better. Similarly, Baldi et al<sup>9</sup> found that pancreas transplantation had very positive effects on the quality of life of patients with diabetes whilst reporting on four cases of pregnancy after transplantation.

## 9.4 Future Demand on Services

The recommendations of the American Diabetes Association will eventually be followed in this country. As a result the referral of patients will increase. Also, as the indications for the procedure are liberalised the demand is going to proliferate in persons with diabetes

who are not in renal failure (yet) but have troublesome diabetes resulting in emotional and clinical problems. As can be seen from Figure 1, up to 1998, there is a recent significant uptrend in referrals for transplantation services.

**Figure 1 - REFERRAL TO TRANSPLANTATION SERVICES 1992-1998**



The unit at Beaumont Hospital is unable to cope with this surge in demand, with perhaps 30 patients awaiting pancreas transplantation at present. This is consistent with the trends in the United States where the number of transplants required (and performed) is increasing annually. Over the next 5 years it is estimated that 20 to 25 pancreas transplants at a minimum would need to be performed annually.

## 9.5 Dietetic Service Provision

Little literature and research exists concerning dietary requirements and recommendations after a pancreas transplant, so to date experience has been extrapolated from the kidney transplant population.

This patient population are a heterogenous group e.g. age, location, previous dietary restrictions and therefore require individual consultation.

All patients benefit from nutritional intervention for the following reasons:

- poor appetite post-operatively and/or slow post-operative recovery leading to increased risk of malnutrition
- advice about sensible discontinuation of the diabetic diet (i.e. continued avoidance of concentrated simple sugars)
- ongoing monitoring of nutritionally related issues, e.g. diabetic complications, weight, blood pressure etc.

- known nutrition related complications of immunosuppression and steroid medication. These include: obesity. Many trials estimate a weight gain of 8 to 14 kg in the first year post kidney transplant<sup>10,11,12</sup>
- hypercholesterolaemia - approximately 30% of kidney transplant patients develop hypercholesterolaemia in the first year post-transplantation<sup>13</sup>
- high risk of osteoporosis following long-term steroid treatment requiring adequate calcium intake.

All of these medication induced side effects require long-term dietetic monitoring and management.

### 9.5.1 Recommendations

Pancreas transplant recipients require dietary advice post-transplant and long-term dietetic monitoring to prevent complications. The frequency and location of this involvement should be arranged on the basis of the individual patient's requirements. It is preferable that dietary advice takes place where medical management is taking place for logistical reasons.

### 9.6 Nursing Services

Patients undergoing transplantation need ongoing support and counselling during the assessment, decision making and post-operative stages. The diabetes nurse specialist often provides this, as a professional relationship has already been established. The diabetes nurse makes a substantial contribution to patients awaiting transplants as motivation and compliance with therapy have a major impact on the successful outcome of the procedure.

### 9.7 Requirements

The current situation is that Beaumont Transplant Unit cannot possibly achieve anything like the required amount of work without the recognition of being a national service and being staffed and funded appropriately on that basis. In order to upgrade to a National Transplant Unit the following are necessary:

- Appointment of a pancreas transplant recipient co-ordinator with responsibility for the "total logistical" care for the transplant recipient
- A designated outpatient facility with access to phlebotomy and radiology services as required.
- A dedicated operating theatre with supportive staff
- Designated diabetes nursing and dietetic staff
- Research into the specific nursing and dietetic requirements of pre-pancreas and post-pancreas and combined transplantation patients.

The recent appointment of a surgeon with commitment to "on call" rotation for organ procurement and transplantation is a commitment to the advancement of this service. What is needed now is the upgrading of existing facilities and manpower levels to cope with current demand.

### 9.8 Costings

Immediate appointment of a co-ordinator at a cost of €44,441 per annum is justified and would be cost effective in terms of streamlining available resources, and thereby improve productivity and quality of care to the patient.

The Transplantation Unit at Beaumont Hospital has shown the ability, desire and enthusiasm to deliver a pancreas transplant programme of the best international standards over the last 8 years. The demand currently exceeds the possible transplants.

Limitation should not be as a result of inadequate facilities or resources. The expertise is there. However, expenditure in the region of €1.25 million is needed as capital costs. This expense is justified, as significant savings would be automatic from medical costs saved for the ongoing treatment for patients on the waiting lists, which get longer by the month.

### 9.9 The Future

Last year a group from Canada described for the first time a series of successful transplantations using isolated islet cells<sup>14</sup>. Their technique included new immunosuppressant drugs and avoidance of steroids. Their technique also involved a second or even third transplant as soon as there was failure of the initial transplant. This technique is being reproduced in research centres around the world with huge funding from the Juvenile Diabetes Foundation and the National Institutes of Health in the USA.

Although this is an exciting development in the field of transplantation for diabetes, the technique is not likely to be the answer in the long term since two, or even three pancreata would be necessary for one person's successful treatment and organ donations are scarce. To get over this problem two lines of research are at present producing very exciting results. The first is the use of stem cells (immature cells) which have recently been shown for the first time to be available in the ducts of the pancreas and can be grown into mature cells by multiple passage allowing a bank of islet cells to be produced<sup>15,16</sup>.

Another exciting development has been the transformation of hepatocytes. A manipulation of these cells both knocking out genes and inserting genes necessary for insulin secretion in animal studies has been successful in reversing diabetes<sup>17</sup>. Another development is the research into alginate envelopes<sup>18,19</sup>. These envelopes will protect the islets from the circulating immunoglobulins thus protecting from immunodestruction but the pores are small enough to allow glucose and insulin which are small molecules to enter and exit into the circulation. Alginate envelopes have been used to house islet cells from other animals and xenograft transplantation has been successful in animal models<sup>20</sup>. The hope is that pig islets may be utilised in this way to treat human diabetes.

## 9.10 Research in Ireland

In Ireland there is considerable research both north and south of the border into islet cell physiology. In the University of Ulster, Professor Flatt has developed a fusion cell line which has been shown in various publications from his unit to not only secrete insulin but also to secrete insulin according to the glucose concentrations outside the cell. In Dublin City University, Professor Clines has some experience in islet cell growth and is investigating alginate membranes. In University College Dublin, Dr Newsome has done considerable work on apoptosis of the islet cell. Professor Gerald Tomkin of the Royal College of Surgeons, Dublin, has been involved for several years with the Beta Cell Transplant Program funded in part by the EU with the Beta Cell Separation Centre in the Free University of Brussels under the direction of Mr. Danny Pipeleers<sup>21</sup>. Human trials are under way and initial publications suggest interesting developments, which may yield results through the development of a system which may not require immunosuppression therapy other than at the initial time of implant. In Ireland there is considerable expertise available to rapidly develop a national centre of islet cell physiology that could start up clinical trials in a short space of time given the right funding.

## 9.11 Costings for Research

It would be seen prudent that in Ireland we would support research into islet cell physiology and that the facility for whole pancreas transplantation in Beaumont Hospital be enlarged and there would be a co-ordinated effort in order to be ready to start an islet cell transplantation programme should the research over the next couple of years prove to be as exciting and as successful as the Canadian's recent islet transplant programme.

## 9.12 Costings for National Transplantation and Research Unit

Upgrading of current unit to National Transplantation and Research Unit

### Capital Costs

	Cost
Buildings – based on a proposed schedule of accommodation of 335 metres sq.	€ 1,269,738
Equipment – to include testing and research equipment	€ 634,869
Total	€ 1,904,607

### Ongoing Costs

Maintenance	€ 63,487
Support Staff not currently in post – All positions to include a research component	
Transplant recipient co-ordinator	€ 44,441
Diabetes nurse specialist	€ 45,980
Dietician	€ 48,010
Psychologist	€ 75,383
Clerical support	€ 21,586
Appointment of researcher and support research team	€ 507,895
Total	€ 806,782

TOTAL CAPITAL COST = €1,904,607

ONGOING COST PER ANNUM = € 806,782

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## Diabetes Federation of Ireland

The rights of all persons with diabetes must be respected, and information sharing and open dialogue must be encouraged. The Diabetes Federation of Ireland recognises the need for people affected by diabetes to be listened to. This implies identifying and solving their

problems, intensifying contact with them and anticipating new trends in diabetes care. The

Diabetes Federation of Ireland is a non-government-aided organisation dedicated to improving the well-being of every person affected by diabetes. It provides an authoritative source of information on living with diabetes to people with diabetes, those who care for them and healthcare professionals. Activities include dissemination of non-judgemental advice and information through meetings, a quarterly magazine and on request. The organisation provides support through telephone communication and meetings. It raises awareness of diabetes by running campaigns and actively lobbies on behalf of persons with diabetes in areas where they are being discriminated against. All the above activities are possible only through close collaboration of all people concerned with diabetes, whether their interest is tied to their work or to living with the condition.

### 10.1 The Future

For an organisation to be described as national, it should serve the entire country. This can only be achieved with offices throughout the country. Seeing a local address on publicity material encourages people to get in touch and gives them more confidence that their problems will be understood and resolved whilst hearing a local voice also helps. The positioning of offices throughout the country heightens local awareness of diabetes and its potential consequences. This can only be achieved with adequate financial resources, part of which should be provided by the funder of diabetes healthcare. This is of great importance to-day as health boards are taking more responsibility for the services within their area.

The beneficial development of the Diabetes Federation of Ireland as a provider of support to persons with diabetes is based on the fact that enthusiastic volunteers do the major part of diabetes work at regional and local level. Only the Diabetes Federation of Ireland office in Dublin and part-time office in Sligo has paid staff, and even then, voluntary human resources and commercial sponsorship are essential for creating, providing and developing programmes, publications and numerous other activities. The increase in diabetes prevalence underscores the importance of strengthening the Diabetes Federation of Ireland and its work within the national context. This involves empowerment of local support groups and working with them to meet the challenges of diabetes on the individual and local society.

Each health board area has unique needs based on the age profile and in recent years, cultural issues. These issues can best be identified and challenged by local groups working through an established regional office. Having one national diabetes association with input from each region will ensure a single voice for diabetes in the country. Resources – both economic and human – will not be divided and dispersed, and work will not be duplicated.

# chapter ten

The opening of regional offices increases public awareness of diabetes with its benefits:

- New cases of diabetes will be diagnosed earlier. Earlier detection will result in a better and longer life for the individual concerned
- Consumers of diabetes healthcare will create a demand for better services that will meet the local needs
- Understanding of the needs of the person with diabetes will reduce discrimination in employment and social situations
- Fund-raising will be more successful as people contribute for local needs through a national body
- More people will be informed of the services of the Diabetes Federation of Ireland and will join.

It is only through such awareness that people with diabetes will understand that they do not have “a touch of diabetes” or a “borderline or mild case of diabetes” but a serious condition. If they understand the nature of that condition and receive good care, then morbidity and mortality can be drastically reduced.

### 10.2 Future Plans

The Diabetes Federation of Ireland identified a number of initiatives that would help it meet its aims. In summary, the initiatives are:

- A regionalisation programme to meet the needs of people with diabetes and raise awareness of diabetes in local communities. It is envisaged that the Federation will have a resource and information centre in each health board within five years
- Improve detection and prevention of diabetes through a combination of public and professional awareness events, targeted screening programmes based amongst at-risk populations and further focus on people with diabetes who are not managing their condition properly due to lack of information and support, therefore being vulnerable to developing complication in later life

- Financially support further research into finding a cure or diabetes
  - Improve awareness of diabetes and its symptoms in order to reduce the long delay between onset and diagnosis of diabetes.
- Through effective continuous public awareness, the delay in diagnosis can be significantly reduced and this would have important implications in averting the development of complications.

### 10.3 Benefits of Investment

The services provided by a local resource and information office would certainly impact on the cost of care for people with diabetes in the relevant health board area.

The management of diabetes, particularly in those areas with limited provision for diabetes care, will be improved through the range of educational schemes, professional services section activities, public meetings and access to local support services.

### 10.4 Implementation Plan

It would be unrealistic to expect full implementation over four years. However, within this timeframe, a suggested implementation time scale would be:

- |   |   |
|---|---|
| <p><u>Year 1</u> Upgrade Central Office in Dublin to cater for full complement of staff:<br/>Open 1 resource &amp; information centre in Cork, upgrade North Western Centre in Sligo.</p> | <p><u>Year 2</u> Expand Dublin office with staffing to full complement.<br/>Open 1 further resource &amp; information centre</p> <p><u>Year 3</u> Open 2 further resource &amp; information centres</p> <p><u>Year 4</u> Open 1 further resource &amp; information centre</p> |
|---|---|

Regular monitoring and evaluation of services would take place. The Federation would be keen to set up regular meetings with the Department of Health and Children representatives to provide feedback and also to provide relevant input to service development in the area of diabetes. An annual report outlining the activities of the Federation would be produced.

<b>Financial Summary:</b>	<b>YEAR 1</b>	<b>YEAR 2</b>	<b>YEAR 3</b>	<b>YEAR 4</b>	<b>TOTAL</b>
<b>(1) CENTRAL OFFICE</b>					
CAPITAL EXPENDITURE	€ 44,441				€ 44,441
RUNNING COSTS ( STAFF ETC.)	€ 846,915	€ 931,988	€ 1,024,678	€ 1,127,527	€ 3,931,108
<b>(2) REGIONAL OFFICES</b>					
CAPITAL EXPENDITURE	€ 25,395	€ 19,046	€ 38,092	€ 19,046	€ 101,579
RUNNING COSTS ( STAFF ETC.)	€269,185	€ 441,869	€ 805,014	€ 1,060,231	€ 2,576,299
<b>Total Expenditure over 4 years.</b>					<b>€ 6,653,427</b>

including appreciation of 10%

**Table 7 - FINANCIAL SUMMARY OF DIABETES FEDERATION OF IRELAND IMPLEMENTATION PLAN.**

The impact on the costs of care for diabetes can be estimated arising from this investment. Effective public awareness, along with a heightened awareness among primary care professionals, will certainly impact upon the delay in diagnosis experienced by most people with diabetes. It is estimated that the average delay could be reduced by 50% to 3.5 years, and this would have important positive implications for the development of complications in people with diabetes. Half of patients newly diagnosed with Type 2 diabetes present with the symptoms of a complication rather than the symptoms of diabetes. Earlier diagnosis will prevent/delay the onset of these costly complications.

The management of diabetes, particularly in the areas with sparse provision for diabetes care, will be improved through the range of national and local

educational and support schemes, professional services section activities and conferences.

The helpline will assist the Diabetes Federation of Ireland in disseminating sets of standards for good medical care to people with diabetes, allowing them to agitate locally for improvements in local care provision, in co-operation with resource and information centres.

This is a huge bonus, in addition to the inestimable value to 200,000 known and unknown people with diabetes, of improved quality of life, arising from all of the Diabetes Federation of Ireland's activities, from the helpline and regional network, to Family & Youth Section, videos and books, financial services and anti-discrimination campaigns.

# chapter eleven

## Recommendations

The availability of quality care to everyone with diabetes regardless of age or location relies upon action to implement the recommendations outlined in the following sections. It is with this in mind, that the Diabetes Service Development Group urges:

- The Minister for Health and Children to establish a statutory body to take responsibility for implementing this service development plan.
- Commitment by the health authorities to the allocation of more resources to both primary and specialist diabetes care and to research.
- Investment in training of enough personnel to cater for all aspects of diabetes care.
- Protected diabetes budget for each health board administered by a designated official body.

### 11.1 Health Promotion

Improving the availability of health information is a key theme of diabetes care and includes a number of action points which will benefit all persons with or at risk of developing diabetes:

- A. Increased awareness of the symptoms of diabetes among the general public
- B. National mass media campaigns integrated with regional and local programmes to maximise awareness of the seriousness and preventability of diabetes and its complications
- C. Increased awareness of the possibility of diabetes in high risk groups by healthcare professionals
- D. Community awareness programmes aimed at high risk groups
- E. Prompt action and intervention when abnormal blood glucose levels are found
- F. Prompt diagnosis and treatment of diabetes
- G. Research into the prevention of diabetes or reducing the incidence
- H. Extension of the system of shared care
- I. Development of a minimum data set at national level, in order to provide standardised information on all persons with diabetes. It should be suitable to be used by all diabetes services and in all care settings. It should include demographic (e.g. age, sex), administrative (e.g. source) and diagnostic information on all persons with diabetes
- J. Promotion of the Diabetes Federation of Ireland and its membership through core funding by the government, thereby, facilitating empowerment to enhance the lives of all peoples with diabetes
- K. The setting up of regional offices of the national association in each health board region
- L. Health education materials and literature be developed for all persons with diabetes or affected by diabetes
- M. Targeting of schools and work places to ensure non-discrimination of any individual with diabetes.

### 11.2 Specialist Diabetes Services

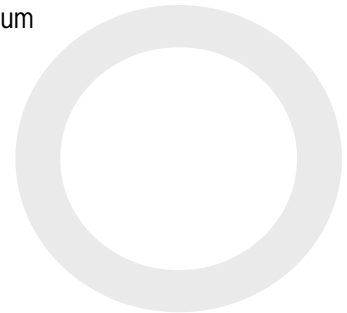
Effective diabetes services require commitment of all stakeholders and availability of resources for the development of services across all boundaries:

- A. Development of paediatric diabetes teams in each Health Board Region and expansion of existing paediatric diabetes centres in Dublin
- B. The development of a National Paediatric Endocrinology Centre within the ERHA to provide a tertiary consultation service to provide combined care with regional centres around the country. Having cognisance of the existing method of care delivery, this national centre would be based in the three locations as currently exist
- C. Development of a national screening programme for retinopathy
- D. Utilisation of primary care resources and further development of this method of diabetes care delivery
- E. Ongoing research into diabetes
- F. Recognition of Beaumont Hospital as a National Transplantation Unit for pancreatic transplantation
- G. Immediate appointment of a transplant recipient co-ordinator at Beaumont Hospital
- H. Expansion of the outpatient facilities for transplantation patients
- I. Support of designated nursing and dietetic staff for all transplantation patients
- J. A dedicated operating theatre with supportive staff for all transplants
- K. Development of a co-ordinated team approach of combined obstetric / endocrinology care
- L. Preconception counselling for all females with diabetes
- M. Delivery of infant in hospital to all insulin treated mothers, with supportive neonatal facilities.
- N. Accurate postnatal diagnosis of all persons with gestational diabetes

### 11.3 Education

Information and education enable people with or at risk of developing diabetes to make informed decisions about their diabetes. Empowerment of patients is dependent on the following action points:

- A. All persons with diabetes and their carers should have access to information and support to facilitate their maximum involvement in the management of their condition
- B. All persons who take responsibility for any individual with diabetes or any requesting individual should have access to information and support to facilitate the optimum wellbeing of any person with diabetes
- C. Healthcare professionals who have a clear understanding of the individual's attitudes, beliefs, learning style, ability and readiness to learn, existing knowledge and goals should deliver education programmes
- D. Formal education should take place in an environment conducive to learning
- E. All persons affected with diabetes should have access to structural, adaptable and individualised, patient centred education, appropriate to their level of understanding and culturally sensitive at a pace that suits their individual needs
- F. There should be regular evaluation of the education process and the materials used
- G. All members of the diabetes team should have access to continued specialised training in diabetes education and education methods.



### 11.4 Manpower

Internationally recognised ratios of personnel as outlined in this report should be adopted. All appointments should include a research commitment and incorporate ongoing education. The LDSDG's should ensure that all members of staff have access to resources and educational opportunities so that they may further their own personal and professional development in the interest of improved patient care. The recommended staffing levels are:

#### A. Medical Staff

Consultant physician/diabetes/endocrinology:

There should be 2 per 100,000 population.

Paediatric endocrinologists:

There should be 1 per 200,000 population.

Paediatricians with training in endocrinology:

There should be 1 per 200,000 population.

General practitioners:

There should be an incentive to encourage participation in diabetes care at a recognised level of expertise.

#### B. Nursing Staff

Diabetes nurse specialist:

There should be 4 diabetes nurse specialists per 100,000 population, some hospital and some community based.

Paediatric diabetes nurse specialist:

There should be 1 paediatric diabetes nurse specialist per paediatric and adolescent diabetes clinic or per 75 children and adolescent with diabetes.

Practice nurses:

All practice nurses running a primary diabetes clinic should have a recognised level of expertise in diabetes care. There should be 1 practice nurse per 2,000 population.

Public health nurses:

They should be formally integrated into the diabetes care team.

#### C. Dietetic and Nutrition

Dietician

There should be a minimum of 2 dieticians specialising in diabetes care per 100,000 population, some hospital and some community based

Paediatric dietician

There should be 1 dietician per 100 children or adolescents with diabetes.

Dieticians working in specialist areas:

There should be a minimum of 0.35 dieticians per diabetes maternity clinic.

#### D Podiatry

Podiatrist:

There should be 2 podiatrists per 100,000 population, some hospital based and some community based.

Adequate funding and resources should be committed to the establishment of a training School of Podiatry in Ireland.

In the interim, all students wishing to pursue a career in podiatry and who secure a place in designated colleges abroad should be funded.

## E. Ophthalmology Services

Each health board region should have a mobile screening unit.

Each major diabetes centre should have an adequately staffed screening clinic.

There is the need to centralise the management of images at a central grading centre.

The number of consultant ophthalmology retinal surgeons should be increased to 15.

## F. Social Work Support

Social worker. There should be 1 social worker per 100,000 population, some hospital and some community based.

Paediatric social worker. There should be 1 social worker allocated to serve the needs of 100 children and adolescents with diabetes

## G. Psychology Support

Psychologist in adult diabetes care; All persons with diabetes should have access to a clinical or health psychologist and it is recommended that one clinical or health psychologist be appointed per 250,000 population.

Psychologist in paediatric and adolescent diabetes care; There should be 1 clinical or health psychologist allocated to serve the needs of 100 children or adolescents with diabetes.

## H. Pharmacy

There should be formal acknowledgement of the work of pharmacists in the prevention, early detection and ongoing care of diabetes. Furthermore, the role of the pharmacist should be expanded in conjunction with the Irish Centre for Continuing Pharmacy Education.

## I. Administrative Staff

Additional administrative staff are required as all levels that diabetes care is provided, to organise care and to ensure that people with diabetes are systematically called and recalled.

Appointment of staff should be closely linked to the extension of current facilities. Each diabetes centre regardless of size should be suitable and be equipped with adequate facilities.

## Implementation Plan:

### Year 1.

	Action
Health Promotion	Establishment of local diabetes groups and national body to oversee the development of diabetes services. Promote health promotion activities that raise awareness of diabetes and utilise prevention strategies to reduce modifiable risk factors for diabetes. Setting of minimal education standard for maintaining status in diabetes care, including ongoing resources for education and research. Commence a regionalisation support programme to meet the needs of people with diabetes. Appointment of additional staff to reduce deficit by 30% in all areas of diabetes care and research.
Primary Care	Alteration of payment to primary care practitioners and development of community services to support the shared care of persons with diabetes by their local general practitioner and specialist hospital team.
Secondary Care	Hospitals who do not have specialist services be twinned with providing hospitals and provision of protected time/beds/facilities to meet the needs of each hospital. Immediate appointment of personnel to approved posts. Commitment to the establishment of a diabetes team in each county hospital, headed by a consultant with adequate support.
Specialist Services	Develop paediatric and adolescent services to the recommended standard in the Western and Mid-Western Health Board Areas. Appointment of a transplant recipient co-ordinator. Development of combined antenatal/diabetes care in areas where none currently exist. Introduction of a screening programme for retinopathy . Establishment of foot clinics in hospitals where none exist.
Audit	Utilisation of available e-technology to compile a national register of persons with diabetes. Audit of implementation plans.

## Year 2.

	Action
Health Promotion	Formation of a network to provide opportunities for mutual support of the multidisciplinary diabetes team. Expansion of the regionalisation support programme to meet the needs of people with diabetes.
Primary Care	Evidence-based screening programs of high risk groups.
Secondary Care	Appointment of diabetes co-ordinators and channelling of all referrals through their office. Appointment of additional staff to reduce deficit by 60% in all areas of diabetes care and research.
Specialist Services	Establishment of at minimum 10 retinopathy centres strategically around the country Mobile retinopathy units to be introduced in each health board if not already present. Develop paediatric and adolescent services to the recommended standard in the North Eastern and South Eastern Health Board areas. Development of combined antenatal/diabetes care in areas where services are deficient. Expansion of foot clinics and the development of specialised foot centres.
Audit	Evaluation and extension of all developments of year 1. Deficiencies identified should be remedied as a priority. Commission further research into the implications of changing trends and the cost effectiveness of current practices.

## Year 3.

	Action
Health Promotion	Various campaigns developed to raise awareness of diabetes. Expansion of the regionalisation support programme to meet the needs of people with diabetes. Appointment of additional staff to reduce deficit by 90% in all areas of diabetes care and research.
Primary Care	Expansion of the shared care schemes.
Secondary Care	Review the adequacy of accommodation for diabetes clinics and the building of appropriate accommodation in deficient areas. Extension of the services of diabetes centres beyond the normal working week hours.
Specialist Services	Establishment of specialist services in county hospitals to meet local desires and needs. Establishment of at a further 10 retinopathy centres around the country Develop paediatric and adolescent services to the recommended standard in the Southern and Midland Health Board Areas. Development of the National Transplantation and Research Unit. Establishment of community foot clinics.
Audit	Audit, evaluation and extension of all developments of year 1 and 2. Deficiencies identified should be remedied as a priority.

## Year 4.

	Action
Health Promotion	Implementation of outstanding recommendations of the Diabetes Service Development Group Report 2001. Establishment of a surveillance system for diabetes. Set targets for the next four years in collaboration with all stakeholders and interested parties. Completion of the regionalisation support programme to meet the needs of people with diabetes.
Primary Care	Inclusion of the majority of general practitioners in shared care schemes.
Secondary Care	Appointment of additional staff to eliminate current deficit and assess the need to appoint additional staff.
Specialist Services	Develop paediatric and adolescence services to the recommended standard in the ERHA and North Western Health Board Areas. Establishment of specialist services in each health board area to meet local desires and needs.
Audit	Audit, evaluation and extension of all developments of year 1, 2 and 3. Deficiencies identified should be remedied as a priority. Review of the advancement towards achievement of the St. Vincent targets. Development of national quality control indicators in a European context.

## Costings

There are many recommendations made in this report, the financial implications of which are difficult to determine. However, the following general estimates are made based on health board areas. These costs reflect annual costs unless otherwise stated or marked as capital expenditure. Salaries are as per Department of Health and Children scales in October 2001 plus P.R.S.I contributions of 12.5 %.

# chapter twelve

## 12.1 Primary Care

These figures are based on an approximate practice prevalence of 2%. There are 2,200 general practitioners (GPs) in Ireland and it is assumed that 25% of general practices will opt to participate, based on uptake rates in the Dublin based shared care schemes.

The following costings are based on 550 GPs participating in the initial 3 years, and based on 0.5 practice nurses per GP and on the assumption that each GP will have an average of 30 patients with diabetes.

An initial capital grant would be required for practices participating in shared care schemes, which will involve the following costs per GP (and 0.5 practice nurse):

Equipment costs	€ 1,905
Training expenses (locum costs based on €153 per session for GPs and € 76 per session for practice nurses)	€ 2,108
Course costs (€952 per participant)	€ 1,746
Total Grant	€ 5,759

Previous workload studies carried out in Waterford, support the Irish College of General Practitioners (ICGP) assessment that routine diabetes care will consume 60 hours of practice time annually, giving a cost of €380 per patient per year. This includes direct patient contact with GPs and practice nurses, administration, audit and continued education. The ICGP proposal to the Department of Health and Children allows for an annual payment on completion of clinical care and quality assurance activities, and for a payment for detection of a new case of diabetes of €152. It is estimated that there would be 10 new cases per practice annually, with a likelihood of higher incidence in the first 2 years.

### 12.1.1 Costing for Primary Care Diabetes Service

Initial capital grant to GPs committing to primary diabetes care	€3,142,600
Detection payment for 10 cases X 550 GPs	€838,027

Annual payment for diabetes care per patient whose diabetes records are audited (Assuming 30 patients for 550 GPs)	€6,285,203
subtotal	€10,265,830

The general practice cost of initiating a primary care diabetes service nationally would be capital expenditure of € 3,142,600 and annual costs thereafter of €7,123,230 depending on uptake of service by patients.

## 12.2 Secondary Care

Costings are based on figures supplied by the individual hospitals. Staff included as part-time are half-time in the case of diabetes nurse specialists. In all other disciplines, part-time refers to undesignated time for diabetes care and therefore is included in the recommended staffing level.

Staffing levels are recommended for hospital based and community based personnel. Decisions on the appropriate ratio should be decided locally.

Manpower costs are outlined in Table 8. All grades are costed at the highest level of that grade. In some disciplines, staff at this level may be unavailable and therefore, a lower grade may be employed. However, any savings in salary should be utilised for education and research.



**Table 8 - SALARY PER ANNUM OF MEMBERS OF DIABETES TEAM**

<b>GRADE DESCRIPTION</b>	<b>Salary per Annum</b>
Consultant physician /diabetes/endocrinology within the ERHA with support staff of 2 registrars and 2 house officers.	€ 349,144
Consultant physician /diabetes/endocrinology outside the ERHA with support staff of 2 registrars and 2 house officers.	€ 355,651
Consultant retinal surgeon with support staff of 1 registrar and 1 house officer	€ 259,232
Diabetes co-ordinator	€ 49,451
Diabetes nurse specialist	€ 45,980
Dietician	€ 48,010
Podiatrist	€ 48,010
Medical social worker	€ 55,117
Clinical or health psychologist	€ 75,383

**12.2.1 Midland Health Board**

The Midland Health Board has a population of 205,542. There are three acute care services through which secondary diabetes care is delivered.

There are no consultant physicians/diabetes/endocrinology working in the Midland Health Board Area. However, diabetes care is provided in each of the acute care settings and there is a very active shared care project in place since 1998. There is a community diabetes care co-ordinator, a diabetes nurse specialists in each of the acute care settings and an approved post for a community diabetes nurse specialist. There is no protected time for dietetic advice to persons with diabetes in hospitals but dieticians carry out this as part of their normal workload. There is a community diabetes dietician. There are part-time podiatry services in the hospitals and one full podiatry post in the community. Social work support and psychology services are by referral only. Ophthalmology services are part-time, both in acute care and community settings. There is a need to increase manpower levels to those outlined in Table 9.

**Table 9 - RECOMMENDED MANPOWER LEVELS IN THE MIDLAND HEALTH BOARD.**

<b>Staff</b>	<b>Number Employed</b>	<b>Recommended Number</b>	<b>Deficit</b>	<b>Cost</b>
Consultant physician/diabetes/endocrinology	1	4	3	€ 1,066,953
Retinal surgeon	2 Part-time	1 Designated Post	1	€ 259,232
Paediatrician with an interest in diabetes	0	1	1	€ 355,651
Diabetes co-ordinator	1	1	-	-
Diabetes nurse specialist	3	8	5	€ 229,900
Paediatrician diabetes nurse specialist	0	1	1	€ 45,980
Dieticians	Equivalent of 1	4	3	€ 144,030
Paediatric dietician	0	1	1	€ 48,010
Podiatrist	Part-time	4	4	€ 192,040
Social worker	Referral	2	2	€ 110,234
Social worker (paediatric)	0	0.5	0.5	€ 27,559
Psychologist	Referral	1	1	€ 75,383
Child psychologist	0	0.5	0.5	€ 37,692

To support these services the capital expenditure as outlined will be required as per Table 10.

**Table 10 - CAPITAL EXPENDITURE REQUIRED IN THE MIDLAND HEALTH BOARD.**

	<b>Capital Costs</b>	<b>Annual Costs to include Maintenance and Materials</b>
Foot clinic	€ 30,350	€ 25,000
Retinopathy centre	€ 43,171	€ 43,590
Mobile retinopathy screening unit	€ 58,408	€ 59,551
Paediatric and adolescent clinic	€ 507,895	€ 50,789
Theatre for retinal surgery	€ 300,000	€ 30,000

Paediatric Service: Although paediatric and adolescent services are unstructured, there is evidence of the commitment of the Midland Health Board to the development of these services with the recent approval of a post for child psychology in diabetes care. Therefore, it is recommended that the Longford/Mullingar Hospital be staffed to recommended levels as per Table 9.

Specific arrangements through twinning with another hospital should be available to provide access to vascular, nephrology, cardiology and ophthalmology surgery.

TOTAL CAPITAL COST	=€ 939,824
ONGOING COST PER ANNUM	=€ 2,801,594

Breakdown of total costs by areas as per Table 11.

**Table 11 - BREAKDOWN OF TOTAL COSTS FOR MIDLAND HEALTH BOARD**

Capital expenditure	€ 939,824
Maintenance	€ 208,930
Medical staff	€ 1,422,604
Retinal surgeon	€ 259,232
Co-ordination	-
Nursing	€ 275,880
Dietitics	€ 192,040
Podiatry	€ 192,040
Social workers	€ 137,793
Psychologists	€ 113,075
Total Expenditure	€ 3,741,418

### 13.2.2 Mid-Western Health Board

The Mid-Western Health Board has a population of 317,196 and has three acute hospitals. There is one consultant physician/diabetes/endocrinology working in the area. There are 3 diabetes nurse specialists and an additional 0.5 unapproved post. There is 0.7 dieticians working in Limerick Regional Hospital providing adult, paediatric and adolescent dietetic advice. There are no designated social support or psychological services available. St. Joseph's Hospital, Nenagh is currently setting up a diabetes service.

**Paediatric Service:** Some paediatric and adolescent services are available at Limerick Regional Hospital. Therefore, it is recommended that it be staffed to recommended levels.

**Maternity Services:** There is no combined obstetric/endocrinology clinic in the Mid-Western Health Board region. Therefore it is recommended that a combined clinic be established.

There is a need to increase manpower levels to those outlined in Table 12.

**Table 12 - RECOMMENDED STAFFING LEVELS IN THE MID-WESTERN HEALTH BOARD.**

Staff	Number Employed	Recommended Number	Deficit	Cost
Consultant physician/diabetes/endocrinology	1	6	5	€ 1,778,255
Paediatrician with an interest in diabetes	0	1	1	€ 355,651
Retinal surgeon		1 Designated Post	1	€ 259,232
Diabetes co-ordinator	0	1	1	€ 49,451
Diabetes nurse specialist	3	12	9	€ 413,820
Paediatrician diabetes nurse specialist	0	1	1	€ 45,980
Diabetes midwife	0	1	1	€ 45,980
Dieticians	No protected time for diabetes	6	6	€ 288,060
Paediatric dietician	0	1	1	€ 48,010
Dietician for maternity services	0	0.5	0.5	€ 24,005
Podiatrist	Part-time	6	6	€ 288,060
Social worker		3	3	€ 165,351
Social worker (paediatric)	0	0.5	0.5	€ 27,558
Psychologist		1	1	€ 75,383
Child psychologist	0	0.5	0.5	€ 37,692

To support these services the capital expenditure as outlined in Table 13 will be required.

**Table 13 - CAPITAL EXPENDITURE REQUIRED IN THE MID-WESTERN HEALTH BOARD**

	Capital Costs	Annual Costs to include Maintenance and Materials
Foot clinic	€ 30,350	€ 25,000
Retinopathy centre	€ 86,342	€ 87,180
Mobile retinopathy screening unit	€ 58,408	€ 59,551
Retinal theatre	€ 300,000	€ 30,000
Paediatric and adolescent clinic	€ 507,895	€ 50,789
Maternity clinic	€ 507,895	€ 50,789

Specific arrangements through twinning with another hospital should be available to provide access to vascular, nephrology, cardiology and ophthalmology surgery.

TOTAL CAPITAL COST = € 1,490,890      ONGOING COST PER ANNUM = € 4,181,791

Breakdown of total expenditure by areas is outlined in Table 14.

**Table 14 - BREAKDOWN OF COSTS IN MID-WESTERN HEALTH BOARD.**

Capital expenditure	€1,490,890
Maintenance	€ 303,309
Medical staff	€ 2,133,906
Retinal surgeon	€ 259,232
Co-ordination	€ 49,451
Nursing	€ 505,780
Dietitics	€ 336,070
Podiatry	€ 288,060
Social workers	€ 192,909
Psychologists	€ 113,074
Total Expenditure	€ 5,672,681

### 12.2.3 Eastern Regional Health Authority

The Eastern Regional Health Authority serves a population of 1,295,939 along with persons from all over the country who travel to the capital for medical care either by necessity or personal desire. By developing regional centres, it is anticipated that a small percentage of patients will opt to receive their care at these centres. However, it is expected that the majority of persons will continue to attend their current diabetes teams. There are 9 centres where adult hospital based diabetes services are delivered.

There are 13 consultant physicians /diabetes/ endocrinology delivering care in the area.

There are 30 diabetes nurse specialists of which 2 by 0.5 posts are community based and there are a further two posts approved.

There are 9 dieticians working in the area but when time is designated to diabetes care this equates to 6.

There is a need to increase manpower levels to those outlined in Table 15.

**Table 15 - RECOMMENDED STAFFING IN THE ERHA FOR ADULT DIABETES SERVICES**

Staff	Number Employed	Recommended Number	Deficit	Cost
Consultant physician/diabetes/endocrinology	13	26	13	€ 4,538,872
Retinal surgeon.	3	3	-	-
Diabetes co-ordinator	1	9	8	€ 395,608
Diabetes nurse specialist	32	52	20	€ 919,600
Diabetes midwife	1.5	3	1.5	€ 68,970
Dieticians	Equivalent of 6,2	26	19.8	€ 950,598
Dietician for maternity services	0.4	1.5	1.1	€ 52,811
Podiatrist	3	26	23	€ 1,104,230
Social worker	2	10	8	€ 440,936
Psychologist	0	9	9	€ 678,447

#### Paediatric Services:

Paediatric and adolescent diabetes services are delivered at three hospitals. Care is fragmented with significant numbers of patients being cared for in adult institutions without paediatric input and in paediatric hospitals without paediatricians with specialised diabetes / endocrinology training. In total there may be more than 700 patients attending the Dublin hospitals. These could be cared for better if there were a large paediatric diabetes care team with 2 consultants in each of the Children's hospitals, each with their agreed catchment areas. However to better provide a Tertiary consultation service to / combined care with the

There is approval for 1 community diabetes post totalling an equivalent of 7 dieticians in the ERHA.

Podiatry services are available at all centres. There are posts allocated specifically to persons with diabetes at 3 centres. Much of podiatry care delivered in the community is through private practices.

Social support is available to all persons with diabetes attending hospitals within the region but the time is not designated to diabetes except in the case of the equivalent of 2 posts.

There are no psychologists specifically allocated to work solely with people with diabetes. However, there are referral facilities available at all centres.

Ophthalmology services are available by referral at all centres. Retinal surgery is available at 2 centres.

regional centres throughout the country a supraregional diabetes care team would be preferable. This team could involve itself in the most difficult cases, in time-consuming insulin pump therapy, islet cell transplantation or whatever is the leading development at the time. This supraregional diabetes care team would have 3 centres (in the children's hospitals) and yet have the efficiencies, collegiality and population base for major research. This would also complement the provision of endocrinology services to the childhood and adolescent population. Suggested staffing is outlined in Table 16.

**Table 16 - RECOMMENDED PAEDIATRIC STAFFING IN THE ERHA**

Staff	Number Employed	Recommended Number	Deficit	Cost
Paediatrician /endocrinologist	1	3	2	€ 698,288
Paediatrician with training in diabetes	1	3	2	€ 698,288
Diabetes co-ordinator	-	3	3	€ 148,353
Paediatrician diabetes nurse specialist	4	10	6	€ 275,880
Paediatric dietician	Equivalent of 1.75	7	5.25	€ 252,052
Child psychologist	Part time	5	5	€ 376,915
Social worker (paediatric)	0.5	7	6.5	€ 358,260

There should be a formal agreement for access to specialist services as required.

#### Maternity Services:

Combined obstetric/endocrinology care is provided by one session weekly in the 3 public maternity hospitals. This service is consultant driven with no non-consultant hospital doctors directly involved. There is also an inpatient diabetes service in each hospital with only two consultant physicians/diabetes/endocrinology providing a 24 hour on-call service. There is a need to provide extra combined care sessions in each hospital. Extra consultant posts are necessary to provide this commitment and to reduce the present 1 in 2 on call rota. Additional diabetes midwives and dieticians are required as outlined in Table 15.

To support these services the capital expenditure as outlined in Table 17 will be required.

**Table 17 - CAPITAL EXPENDITURE REQUIRED IN ERHA**

	Capital Costs	Annual Costs to include Maintenance and Materials
Foot clinic (6 required)	€ 182,100	€ 150,000
Retinopathy centre (8 required)	€ 345,368	€ 348,720
Mobile retinopathy screening unit	€ 58,408	€ 59,551

TOTAL CAPITAL COST = € 585,876

ONGOING COST PER ANNUM = € 12,516,379

Breakdown of total expenditure by areas is outlined in Table18.

**Table 18 - BREAKDOWN OF COSTS IN ERHA.**

Capital expenditure	€ 585,876
Maintenance	€ 558,271
Medical staff	€ 5,935,448
Co-ordination	€ 543,961
Nursing	€ 1,264,450
Dietetics	€ 1,255,461
Podiatry	€ 1,104,230
Social workers	€ 799,196
Psychologists	€ 1,055,362
Total Expenditure	€ 13,102,255

## 12.2.4 North Eastern Health Board

The North Eastern Health Board has a population of 306,165 and has 5 acute hospitals through which diabetes services are delivered. There is one consultant physician/diabetes/endocrinology working in the area. There are 2.5 diabetes nurse specialists and an additional approved post. There is 0.5 dieticians working and an additional approved post. There are no designated social support or psychological services available.

There is a need to increase manpower levels to those outlined in Table 19.

**Table 19 - RECOMMENDED STAFFING LEVELS IN NORTH EASTERN HEALTH BOARD**

Staff	Number Employed	Recommended Number	Deficit	Cost
Consultant physician/diabetes/endocrinology	1	6	5	€ 1,778,255
Retinal surgeon	1	1 Designated Post	1	€ 259,232
Paediatrician with an interest in diabetes	0	1	1	€ 355,651
Diabetes co-ordinator	0	1	1	€ 49,451
Diabetes nurse specialist	2.5	12	9.5	€ 436,810
Paediatrician diabetes nurse specialist	0	1	1	€ 45,980
Dieticians	Equivalent of 1.5	6	4.5	€ 216,045
Paediatric dietician	0	1	1	€ 48,010
Podiatrist	0	6	6	€ 288,060
Social worker	0	3	3	€ 165,351
Social worker (paediatric)	0	0.5	0.5	€ 27,558
Psychologist	Referral only	1	1	€ 75,383
Child psychologist	0	0.5	0.5	€ 37,692

To support these services the capital expenditure as outlined in Table 20 will be required.

**Table 20 - CAPITAL EXPENDITURE REQUIRED IN THE NORTH EASTERN HEALTH BOARD.**

	Capital Costs	Annual Costs to include Maintenance and Materials
Foot clinic ( 2 needed)	€ 60,700	€ 50,000
Retinopathy centre	€ 43,131	€ 43,590
Mobile retinopathy screening unit	€ 58,408	€ 59,551
Retinal theatre	€ 300,000	€ 30,000
Paediatric and adolescent clinic	€ 507,895	€ 50,789

Paediatric Service: Some paediatric and adolescent services are available at Our Lady of Lourdes Hospital, Drogheda. Therefore, it is recommended that it be staffed to recommended levels as outlined in table 19.

Specific arrangements through twinning with another hospital should be available to provide access to vascular, nephrology, cardiology and ophthalmology surgery.

TOTAL CAPITAL COST	= € 970,134
ONGOING COST PER ANNUM	= € 4,017,408

Breakdown of total costs by areas is outlined in Table 21.

**Table 21 - BREAKDOWN OF COSTS IN NORTHEASTERN HEALTH BOARD**

Capital expenditure	€ 970,134
Maintenance	€ 233,930
Medical staff	€ 2,133,906
Retinal surgeon	€ 259,232
Co-ordination	€ 49,451
Nursing	€ 482,790
Dietetics	€ 264,055
Podiatry	€ 288,060
Social workers	€ 192,909
Psychologists	€ 113,075
Total Expenditure	€ 4,987,542

**12.2.5 North Western Health Board**

The population of the North Western Health Board region is 210,872. Over 1 in 5 of the population (22.7%) is over the age of 65. As diabetes increases in prevalence with age, it is recommended that staffing levels should be at the highest level.

Diabetes services are delivered through 2 hospitals. There is no consultant physician/diabetes /endocrinology working in the area. However, there is a paediatrician delivering a diabetes service to children and adolescents.

There is a need to increase manpower levels to those outlined in Table 22.

There are 3 hospital based diabetes nurse specialists and 1 community based. The appointment of a community diabetes nurse specialist is to be applauded except for the fact that this appointment is replacing a hospital post.

There are 0.75 dieticians and the recent approval of a community dietician for diabetes care.

There are no designated social support workers or podiatry service.

**Table 22 - RECOMMENDED STAFFING LEVELS IN THE NORTH WESTERN HEALTH BOARD**

Staff	Number Employed	Recommended Number	Deficit	Cost
Consultant physician/diabetes/endocrinology	0	5	5	€ 1,778,255
Retinal surgeon	0	1 Designated Post	1	€ 259,232
Paediatrician with an interest in diabetes	0	1	1	€ 355,651
Diabetes co-ordinator	0	1	1	€ 49,451
Diabetes nurse specialist	4	8	4	€ 183,920
Paediatrician diabetes nurse specialist	0	1	1	€ 45,980
Dieticians	Equivalent of 1.75	4	2.25	€ 108,023
Paediatric dietician	0.2	1	0.8	€ 38,408
Podiatrist	0	4	4	€ 192,040
Social worker	0	2	2	€ 110,234
Social worker (paediatric)	0	0.5	0.5	€ 27,558
Psychologist	Referral only	1	1	€ 75,383
Child psychologist	0	0.5	0.5	€ 37,692

**Paediatric Service:** Some paediatric and adolescent services are available at Letterkenny General Hospital. Therefore, it is recommended that it be staffed to recommended levels as outlined in Table 22.

To support these services the capital expenditure as outlined in Table 23 will be required.

**Table 23 - EXPENDITURE REQUIRED IN THE NORTH WESTERN HEALTH BOARD.**

	<b>Capital Costs</b>	<b>Annual Costs to include Maintenance and Materials</b>
Foot clinic ( 2 needed)	€ 60,700	€ 50,000
Retinopathy centre	€ 86,342	€ 87,180
Mobile retinopathy screening unit	€ 58,408	€ 59,551
Retinal theatre	€ 300,000	€ 30,000
Paediatric and adolescent clinic	€ 507,895	€ 50,789

Specific arrangements through twinning with another hospital should be available to provide access to vascular, nephrology, cardiology and ophthalmology surgery.

TOTAL CAPITAL COST = €1,013,345 ONGOING COST PER ANNUM = €3,539,347

Breakdown of total Expenditure by areas is outlined in Table 24.

**Table 24 - BREAKDOWN OF COSTS IN NORTH WESTERN HEALTH BOARD**

Capital expenditure	€ 1,013,345
Maintenance	€ 277,520
Medical staff	€ 2,133,906
Retinal surgeon	€ 259,232
Co-ordination	€ 49,451
Nursing	€ 229,898
Dietetics	€ 146,431
Podiatry	€ 192,040
Social workers	€ 137,792
Psychologists	€ 113,074
Total Expenditure	€ 4,552,692

### 12.2.6 South Eastern Health Board

The population of the South Eastern Health Board region is 391,517. There are 4 hospitals delivering hospital based diabetes care. There are 2 consultant physician/diabetes/endocrinology working in the area.

There are 4.5 diabetes nurse specialists, all hospital based and 2 dieticians. There is no podiatry service with patients requested to source their own foot care. Social support and psychological support is only available through referral.

There is a need to increase manpower levels to those outlined in Table 25.

**Table 25 - RECOMMENDED STAFFING LEVELS IN THE SOUTH EASTERN HEALTH BOARD**

<b>Staff</b>	<b>Number Employed</b>	<b>Recommended Number</b>	<b>Deficit</b>	<b>Cost</b>
Consultant physician/diabetes/endocrinology	1 physician 2 posts approved	8	6	€ 2,133,906
Retinal surgeon	2	2	2	-
Paediatrician with training in diabetes	0	1	1	€ 355,651
Diabetes co-ordinator	0	2	2	€ 98,902
Diabetes nurse specialist	4.5	16	11.5	€ 528,770
Paediatrician diabetes nurse specialist	0	1	1	€ 45,980
Dieticians	Equivalent of 2	8	6	€ 288,060
Paediatric dietician	0	1	1	€ 48,010
Podiatrist	Sessional	8	7	€ 336,070
Social worker		4	4	€ 220,468
Social worker (paediatric)	0	0.5	0.5	€ 27,558
Psychologist		1.5	1.5	€ 113,074
Child psychologist	0	0.5	0.5	€ 37,692



Paediatric Service: Some paediatric and adolescent services are available at Waterford General Hospital. Therefore, it is recommended that it be staffed to recommended levels as outlined in table 25.

To support these services the capital expenditure as outlined in Table 26 will be required.

**Table 26 - CAPITAL EXPENDITURE REQUIRED IN THE SOUTH EASTERN HEALTH BOARD**

	<b>Capital Costs</b>	<b>Annual Costs to include Maintenance and Materials</b>
Foot clinic (2 extra needed)	€ 70,700	€ 50,000
Retinopathy centre	€ 43,171	€ 43,590
Mobile retinopathy screening unit	€ 58,408	€ 59,551
Paediatric and adolescent clinic	€ 507,895	€ 50,789

Specific arrangements through twinning with another hospital should be available to provide access to vascular, nephrology, cardiology and ophthalmology surgery.

TOTAL CAPITAL COST = €680,174      ONGOING COST PER ANNUM = €4,438,071

Breakdown of total expenditure by areas is outlined in Table 27.

**Table 27 - BREAKDOWN OF COSTS IN THE SOUTH EASTERN HEALTH BOARD**

Capital expenditure	€ 680,174
Maintenance	€ 203,930
Medical staff	€ 2,489,557
Co-ordination	€ 98,902
Nursing	€ 574,750
Dietetics	€ 336,070
Podiatry	€ 336,070
Social workers	€ 248,026
Psychologists	€ 150,766
<b>Total Expenditure</b>	<b>€ 5,118,245</b>

### 12.2.7 Southern Health Board

The Southern Health Board has a population of 549,640. Hospital based diabetes care is delivered at 7 health board hospitals and 2 voluntary hospital.

It is acknowledged that voluntary hospitals receive their funding directly from the Department of Health and Children. However, the allocation of staff to community or hospitals should be decided locally, therefore, manpower for these hospitals are included in total numbers.

There are 3 consultant physicians/ diabetes/ endocrinology working in the area. Tralee General Hospital is awaiting a decision on a submission to the Department of Health and Children regarding another appointment.

There are 7 diabetes nurse specialists, all hospital based. There are 2.75 dieticians and one podiatrist. Community podiatry is delivered by 5 podiatrists but these are not diabetes-designated posts.

There is the equivalent of 1 social worker and 1 psychologist.

There is a need to increase manpower levels to those outlined in Table 28.

**Table 28 - RECOMMENDED STAFFING LEVELS IN THE SOUTHERN HEALTH BOARD**

Staff	Number Employed	Recommended Number	Deficit	Cost
Consultant physician/diabetes/endocrinology	3	13	10	€ 3,556,510
Retinal surgeon	1	2	1	€ 259,232
Paediatrician endocrinologist	0	1	1	€ 355,651
Diabetes co-ordinator	0	5	5	€ 247,255
Diabetes nurse specialist	7	22	15	€ 689,700
Paediatrician diabetes nurse specialist	0	2	2	€ 91,960
Diabetes midwife	0	1	1	€ 45,980
Dieticians	Equivalent of 2.75	13	10.25	€ 492,102
Paediatric dietician	0.2	1.5	1.3	€ 62,413
Dietician for maternity services	0	0.5	0.5	€ 24,005
Podiatrist	1	13	12	€ 576,120
Social worker	1	6	5	€ 275,585
Social worker (paediatric)	0	1	1	€ 55,117
Psychologist	1	2	1	€ 75,383
Child psychologist	0	1	1	€ 75,383

**Paediatric Service:** Some paediatric and adolescent services are available at Cork University Hospital. Therefore, it is recommended that it be staffed to recommended levels as outlined in Table 28.

**Maternity Services:** There is no combined obstetric/endocrinology clinic in the Southern Health Board region. Therefore it is recommended that a combined clinic be established. The costs are outlined in Table 28.

To support these services the capital expenditure as outlined in Table 29 will be required.

**Table 29 - EXPENDITURE REQUIRED IN THE SOUTHERN HEALTH BOARD.**

	Capital Costs	Annual Costs to include Maintenance and Materials
Foot clinic (4 extra needed)	€ 121,400	€ 100,000
Retinopathy centre (3 needed)	€ 129,513	€ 130,770
Mobile retinopathy screening unit	€ 58,408	€ 59,551
Retinal theatre	€ 300,000	€ 30,000
Paediatric and adolescent clinic	€ 507,895	€ 50,789
Maternity clinic	€ 507,895	€ 50,789

Specific arrangements through twinning with another hospital should be available to provide access to vascular, nephrology, cardiology and ophthalmology surgery.

TOTAL CAPITAL COST = €1,625,111    ONGOING COST PER ANNUM = €7,304,295

Breakdown of total expenditure by areas is outlined in Table 30.

**Table 30 - BREAKDOWN OF COSTS IN THE SOUTHERN HEALTH BOARD**

Capital expenditure	€ 1,625,111
Maintenance	€ 421,899
Medical staff	€ 3,912,161
Retinal surgeon	€ 259,232
Co-ordination	€ 247,255
Nursing	€ 827,640
Dietetics	€ 578,520
Podiatry	€ 576,120
Social workers	€ 330,702
Psychologists	€ 150,766
Total Expenditure	€ 8,929,406

## 12.2.8 Western Health Board

The Western Health Board has a population of 352,353. Hospital based diabetes care is delivered at 3 health board hospitals and 1 voluntary hospital.

Currently, Portiuncula Hospital receives their funding directly from the Department of Health and Children. However, for 2002 it is to be included in the Western Health Board location. Therefore, manpower levels in this report take into account those already employed there.

There is 1 consultant physicians/ diabetes/ endocrinology working in the area. In 2000, the

Western Health Board recommended the appointment of 3 additional physicians/diabetes /endocrinology consultants but as yet, none have been appointed.

There are 2.5 diabetes nurse specialists, all hospital based. There is the equivalent of 1 dietician and 1 podiatrist.

There is referral only to social support and psychological support.

There is a need to increase manpower levels to those outlined in Table 31.

**Table 31 - RECOMMENDED STAFFING LEVELS IN THE WESTERN HEALTH BOARD**

Staff	Number Employed	Recommended Number	Deficit	Cost
Consultant physician/diabetes/endocrinology	1	7	6	€ 2,133,906
Retinal surgeon	1	2	1	€ 259,232
Paediatrician endocrinologist	0	1	1	€ 355,651
Diabetes co-ordinator	0	1	1	€ 49,451
Diabetes nurse specialist	2.5	14	11.5	€ 528,770
Paediatrician diabetes nurse specialist	0	2	2	€ 91,960
Diabetes midwife	0	1	1	€ 45,980
Dieticians	Equivalent of 1	7	6	€ 288,060
Paediatric dietician	Equivalent of 0.1	1.5	1.4	€ 67,214
Dietician for maternity services	0	0.5	0.5	€ 24,004
Podiatrist	1	7	6	€ 288,060
Social worker	0	3.5	3.5	€ 192,909
Social worker (paediatric)	0	1	1	€ 55,117
Psychologist	0	1	1	€ 75,383
Child psychologist	0	1	1	€ 75,383

Paediatric Service: Some paediatric and adolescent services are available at Galway University Hospital. Therefore, it is recommended that it be staffed to recommended levels as outlined in Table 31.

Maternity Services: There is no combined obstetric/endocrinology clinic in the Western Health Board region. Therefore it is recommended that a

combined clinic be established. The costs are outlined in Table 31.

Specific arrangements through twinning with another hospital should be available to provide access to vascular, nephrology, cardiology and ophthalmology surgery.

To support these services the capital expenditure as outlined in Table 32 will be required.

**Table 32 - RECOMMENDED STAFFING LEVELS IN THE WESTERN HEALTH BOARD**

	Capital Costs	Annual Costs to include Maintenance and Materials
Foot clinic (3 extra needed)	€ 91,050	€ 75,000
Retinopathy centre	€ 86,342	€ 87,180
Mobile retinopathy screening unit	€ 58,408	€ 59,551
Retinal theatre	€ 300,000	€ 30,000
Paediatric and adolescent clinic	€ 507,895	€ 50,789
Maternity clinic	€ 507,895	€ 50,789

TOTAL CAPITAL COST = €1,508,419 ONGOING COST PER ANNUM = €4,884,389

Breakdown of total expenditure by areas is outlined in Table 33.

**Table 33 - BREAKDOWN OF COSTS IN THE WESTERN HEALTH BOARD**

Capital expenditure	€ 1,508,419
Maintenance	€ 353,309
Medical staff	€ 2,489,557
Ophthalmology services	€ 259,232
Co-ordination	€ 49,451
Nursing	€ 666,710
Dietetics	€ 379,278
Podiatry	€ 288,060
Social workers	€ 248,026
Psychologists	€ 150,766
Total Expenditure	€ 6,392,808

### 12.3 National Services

#### National Retinopathy Centre and Grading Centre

The management of images from retinopathy screening would be centralised to a National Retinopathy Grading Centre. The capital cost for such a centre is €653,915 for equipment, grading computers and software. Thereafter, annual recurring costs are €1,205,087 which include salaries, quality control and administration costs.

#### Transplantation and Research Centre

Beaumont Hospital supplies a national service and requires the staff outlined in Table 34 to function, as currently there is no designated staff for diabetes related transplantation services.

**Table 34 - RECOMMENDED STAFF FOR TRANSPLANT AND RESEARCH UNIT**

Staff	Recommended Number	Cost
Researcher and medical support	1	€ 507,895
Co-ordinator	1	€ 44,441
Diabetes nurse specialist	1	€ 45,980
Dietician	1	€ 48,010
Psychologist	1	€ 75,383
Clerical support	1	€ 21,586
	Total	€ 743,295

#### National Support for Persons with Diabetes

The capital cost of developing a nationwide network of support for all persons affected by diabetes is €146,020, and annual expenditure of € 2,187,758 thereafter.

## 12.4 Summary

**Table 35 - SUMMARY OF REGIONAL TOTALS**

<b>REGION</b>	<b>Capital Expenditure</b>	<b>Annual Expenditure</b>	<b>Total Expenditure</b>
Midland Health Board	€ 939,824	€ 2,801,594	€ 3,741,418
Mid-Western Health Board	€ 1,490,890	€ 4,181,791	€ 5,672,681
Eastern Region Health Authority	€ 585,876	€ 12,516,379	€ 13,102,255
North Eastern Health Board	€ 970,134	€ 4,017,408	€ 4,987,542
North Western Health Board	€ 970,174	€ 3,495,757	€ 4,465,931
South Eastern Health Board	€ 680,174	€ 4,438,071	€ 5,118,245
Southern Health Board	€ 1,625,111	€ 7,304,295	€ 8,929,406
Western Health Board	€ 1,465,248	€ 4,840,799	€ 6,306,047
Sub Totals	€ 8,813,773	€ 43,683,274	€ 52,497,047
Primary care	€ 3,142,600	€ 7,123,230	€ 10,265,830
National centre – retinopathy	€ 653,919	€ 1,205,087	€ 1,859,006
National Transplantation and Research Unit	€ 1,904,607	€ 806,782	€ 2,711,389
Diabetes Federation of Ireland	€ 146,020	€ 2,187,758	€ 2,333,778
<b>TOTAL</b>	<b>€ 14,660,919</b>	<b>€ 55,006,131</b>	<b>€ 69,667,050</b>

**Table 36 - SUMMARY OF STAFF TOTALS BY DISCIPLINE**

<b>Staff</b>	<b>Current Deficit</b>	<b>Annual Expenditure</b>
Medical staff	53	€ 18,738,884
Researcher	1	€ 507,895
Retinal surgeons	6	€ 1,555,392
Co-ordination	23	€ 1,137,373
Nursing	106	€ 4,827,900
Dietetics	74.15	€ 3,559,942
Podiatry	68	€ 3,264,680
Social workers	42.5	€ 2,342,493
Psychologists	27	€ 2,035,341
	<b>Total</b>	<b>€ 34,705,220</b>

**TABLE 37 - SUMMARY OF COSTS BY SERVICE**

<b>REGION</b>	<b>Capital Expenditure</b>	<b>Annual Expenditure</b>
Primary care	€ 3,142,600	€ 7,123,230
Retinopathy screening	€ 1,984,603	€ 2,553,295
Podiatry services	€ 637,350	€ 3,789,680
Paediatric and adolescent services	€ 3,555,625	€ 6,933,046
Maternity services	€ 1,523,685	€ 415,133
Transplantation and Research Unit	€ 1,904,607	€ 806,782
Diabetes Federation of Ireland	€ 146,020	€ 2,187,758

# chapter thirteen

## The Impact

The socio-economic and public health impact of diabetes on both individuals and society is ever increasing, mediated by its effects on the work force, time taken undergoing treatment, and premature morbidity and mortality. Diabetes, a chronic devastating illness that is progressive and degenerative, results in a considerable health and economic burden to the individual, to the health-care system and society.

Until recently spending on health care has never been subjected to the rigorous principles of economics. With population ageing, technological/medical advances and changing patient expectations causing increasing pressure on health care expenditure, economic issues have become more significant. Regardless of the budgetary situation, the fact that resources are limited and that there are competing needs implies there is a need to ensure that health care resources are being spent wisely. Decision-makers need to assess the relative value for money of health programmes both within a particular speciality and between specialities. Various health economic methods are available to assist in this process.

For example, cost estimates represent a descriptive method. The estimates provide information that describes the resources used in the management of diabetes and the potential resources lost on account of diabetes. Such studies often referred to as burden or cost of illness studies are useful for securing resources for the management of diabetes. If the incidence of diabetes has been shown to be increasing, these studies may help in securing additional resources. Burden of illness studies also provide baseline data for evaluating policy, strategies and technological changes. They also give an indication of the savings that might be achieved if diabetes or its complications could be prevented.

However one of the principal limitations of cost of illness studies is that the information obtained from them is not helpful in determining priorities. The information provided from such studies does not indicate whether existing resources are being used efficiently. An understanding of whether appropriate care is being provided can only be gathered through economic evaluation. Economic evaluations consider the costs and benefits of alternative programmes to determine whether the limited resources are being used efficiently or might be used more efficiently by changing clinical practise. To date, few aspects of diabetes care have been the subject of economic appraisal, with the exception of retinopathy services.

## 13.1 The Cost of Diabetes

The cost of diabetes can be calculated using either direct costs or both direct and indirect costs. The direct costs are of two types: medical and non-medical costs. The direct medical costs are the healthcare resources that a population uses for treatment of a disease or a related illness<sup>1</sup>. For example, the costs of healthcare consultations, drugs, days in hospital, tests and procedures. The non-medical costs are the value of non-medical goods and services that are used in the process of providing care to people with a disease, for example the cost of travelling to and from the hospital clinic. Indirect costs include the resources that are lost as a result of the morbidity, disability and premature mortality resulting from diabetes. Finally, there are intangible costs such as the stress and anxiety that are concerned with the loss of quality of life which might be associated with the diagnosis of a chronic disease such as diabetes. Given that it is difficult to assign a monetary value to these costs, these costs are typically not included in cost of illness studies. Similarly measuring indirect costs can be difficult hence many burden of illness studies have concentrated on measuring direct costs.

This is true of a recently undertaken study in Ireland that measured the direct costs of Type 2 diabetes in over 700 patients. The study, which provides the first comprehensive set of data on the costs of Type 2 diabetes in Ireland, also examined the main components of costs, the cost of patient management and the costs of complications of Type 2 diabetes\*.

Total direct medical expenditure was €350.5 million for the year. Hospitalisation costs accounted for 48.5%, €170 million of direct medical expenditure and were the highest contributing factor to direct medical costs. Overall, 16.6% of patients were hospitalised with a mean hospital stay of 8 days. Drug costs (€147 million) accounted for 41.9% of total costs and ambulatory costs accounted for the remainder (€34 million). It is interesting to note that visits to specialists other than the patient's usual clinic diabetologist accounted for more than 50% of ambulatory costs.

Total per patient costs were €2945, however the costs of patients with both macrovascular and microvascular complications were 2½ those with no complications (Table 38). Costs of complications contributed 58.9% of overall per patient costs, management of diabetes accounted for 15.7% of overall costs and other management costs 25.3%. The type and frequency of complications are shown in Table 39.

\*The average age of the patients in the study was 64 years, 57% were male and the average time since diagnosis was 6.5 years.

**Table 38**      **ASSESSING THE IMPACT OF COMPLICATIONS ON COSTS**

	Overall Cost per Patient
No Complications	€1985
Macrovascular Only	€3427
Microvascular Only	€2297
Both	€4934

The direct non-medical and indirect costs incurred by the patient were not included in the above analysis, hence the €350.5m is a conservative estimate of the true burden of diabetes. However from the results obtained, it is clear that the management of diabetes imposes a significant burden on the Irish healthcare system. The presence of complications has a substantial impact on the costs for managing people with Type 2 diabetes. Clearly early diagnosis of the disease and the prevention of complications would reduce this burden both on the health care system and the patient (Table 40)<sup>2</sup>.

These conclusions are consistent with others who suggest that reducing the costs of diabetes maybe achieved through primary prevention, prevention of complications and reducing hospitalisations<sup>3</sup>.

**Table 39**      **TYPE AND FREQUENCY OF COMPLICATIONS**

	Number of Patients	%
Foot Ulcer(s)	42	5.97%
Amputation	10	1.42%
Photocoagulation	45	6.40%
Blind in 1 eye	5	0.71%
On Dialysis	3	0.43%
MI	87	12.38%
Angina	156	22.19%
Heart Failure	35	4.98%
CABG	59	8.39%
PTCA	46	6.54%
Stroke	27	3.84%
TIA	38	5.41%
Retinopathy	104	14.79%
Neuropathy	179	25.46%
Manifest Neuropathy	45	6.40%
Microalbuminurea	64	9.10%
PVD	114	16.22%
Carpal Tunnel Syndrome	13	1.85%
Diabetes related joint problems	11	1.56%
Hyperlipidaemia	267	37.98%
Hypertension	479	68.14%
Cataract	92	13.09%
Depression	68	9.67%
Obesity	249	35.42%
Other chronic conditions	422	60.03%


**Table 40 THE COMPLICATIONS OF DIABETES: THE IMPACT ON HEALTH SERVICES AND THE PATIENT**

<b>System affected</b>	<b>Disease</b>	<b>Potential patients economic implications</b>
<b>Eyes</b>	Retinopathy, Glaucoma	Photocoagulation therapy
	Cataracts	Social assistance, loss of productivity
	Blindness	Cataract removal surgery, Drug therapy
<b>Blood Vessels</b>	Coronary artery disease (CAD)	Drug therapy
	Cerebral vascular disease (CVD)	Emergency hospitalisation
	Peripheral vascular disease (PVD)	Hospitalisation
	Hypertension	Surgical intervention (CABG, PTCA)
		Home help/living assistance Death – loss of productivity
<b>Kidneys</b>	Renal insufficiency	Drug therapy
	Kidney failure	Hospitalisation – Dialysis - Renal transplantation
		Death – loss of productivity
<b>Nerves</b>	Neuropathies	Drug therapy
	Autonomic neuropathy	Orthotics
		Hospitalisation – Surgery
		Rehabilitation
		Hospitalisation
<b>Skin, Muscle, Bone</b>	Advanced infections	Drug therapy
	Cellulitis	Orthotics
	Gangrene	Hospitalisation - Surgery
	Amputation	Rehabilitation

### 13.2 The Impact of Diabetes on Quality of Life

Diabetes, requiring many life-style changes has wide implications for patient's wellbeing and social life. For example, diabetes patients generally exhibit a higher prevalence of conditions such as depression and anxiety compared with a general population of similar age. Tiredness, loss of enjoyment and decreased participation in leisure activities also seem to positively correlate with the presence of diabetes, as do feelings of restriction when complying with treatment strategies and self-monitoring requirements<sup>4</sup>. People with diabetes frequently report less participation in family activities and a diminished social life. For example a health and lifestyle survey undertaken in the UK on people with diabetes over the age of 50 showed that only 4.7% considered their health to be excellent compared with 31.4% of people without diabetes. A higher proportion of those with diabetes (30%) also felt that their health had significantly limited their activities compared with those without diabetes (15%)<sup>5</sup>.





The complications of diabetes are also likely to have significant effects on the patient's health related quality of life, both at an early stage due to anxiety over future problems, and later when such complications show. Evidence from the United Kingdom Prospective Diabetes Study (UKPDS) indicates that the long-term complications have a detrimental effect on quality of life<sup>6</sup>. Many of the complications result in diminished social function and loss of independence. The burden of more than one complication must have an even greater impact on quality of life.

More recent evidence gathered in the CODE-2 study shows that health related quality of life (HRQoL), measured with the EQ-5D instrument, is an important issue in Type 2 diabetes\*. In particular, people with Type 2 diabetes were shown to have a lower HRQoL score compared with a general population of similar age (0.69 versus 0.78). Furthermore, HRQoL worsened with disease progression, treatment progression and the development of complication. For example, diabetes patients without complications had a HRQoL score of 0.76, however those with either microvascular or macrovascular complications had a score of 0.69 and those with both types of complications had a score of 0.59<sup>4</sup>.

\*The EQ-5D considers five dimensions of health status: mobility, self-care, usual activities, pain & discomfort, and anxiety & depression. A score of one represents perfect health, zero represents death and scores less than zero represent health states that are perceived by the patient to be worse than death.

### 13.3 The Cost Effectiveness of Diabetes Care

As mentioned previously, burden of illness studies do not provide information on whether resources currently directed to the management of diabetes are being used effectively or efficiently. Instead, economic evaluations, comparing the costs and benefits of alternative programmes, are used to help us to understand whether limited resources are allocated appropriately.

In two reports undertaken by the International Diabetes Federation, cost effective strategies are examined. Strategies reviewed include primary and secondary prevention, primary, secondary and shared care services, patient education and training services for health care professionals.

Whilst the cost effectiveness of screening for Type 1 diabetes has yet to be established, there is some evidence showing the effectiveness of screening for Type 2 diabetes. However there is greater evidence supporting the use of limited health care resources on screening programmes for (and laser treatment of) diabetic retinopathy. Similarly the screening for and the treatment of diabetic nephropathy are cost effective strategies. Good foot-care and the effective medical or surgical management of ulcers can prevent amputations. Given the high cost of amputation, low cost interventions of foot care are also cost effective.

In terms of the location of services, there is no doubt that the management of diabetes in primary care has the potential to reduce the financial burden. However in order for these savings to be realised, adequate training must be provided to primary care professionals. In addition, regular screening services must be offered in the community, as any undiagnosed and untreated complications would clearly offset any savings. The provision of diabetes care in an outpatient setting has been extensively researched; the benefits have been shown to outweigh the costs. Shared care and multi-disciplinary team based care have also proven to be effective options both in terms of improved outcomes and reduced costs. Given that the major proportion of healthcare expenditures for diabetes are

attributable to hospital care and are associated with the treatment of complications, strategies aimed at reducing hospital admissions, preventing diabetes and its complications offer the greatest 'value-for-money'.

### 13.4 Summary

**An effective disease management strategy must consider the complications of diabetes and their negative effects on quality of life. Optimal management requires consideration of all aspects of the disease, such as obesity, hypertension, lipid disorders and macrovascular disease, in addition to the measures required to achieve adequate glycaemic control.**

**Public and professional awareness of the risk factors and early symptoms of diabetes are an important step towards effective control and prevention of the disease. Improved education for all individuals involved in diabetes care, including the patients, is an important factor in achieving long term significant improvements in the detection and treatment of diabetes.**

**The burden of diabetes and its complications on the health care system are high, however the early detection and prevention of diabetes related complications will provide benefit to the patients as well as reduce the healthcare expenditures for government.**

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## Diabetes Mellitus in Europe - A problem for all ages in all countries

### A model for Prevention and Self Care

ST. VINCENT (ITALY), 10-12 OCTOBER 1989

Diabetes Care and Research in Europe

#### **The Saint Vincent Declaration**

*Representatives of Government Health Departments and patients organisations from all European countries met with diabetes experts under the aegis of the Regional Offices of the World Health Organisation and the International Diabetes Federation in St. Vincent, Italy on October 10-12, 1989. They unanimously agreed upon the following recommendations and urged that they should be presented in all countries throughout Europe for implementation.*

Diabetes mellitus is a major and growing European health problem, a problem at all ages and in all countries. It causes prolonged ill-health and early death. It threatens at least ten million European citizens.

It is within the power of the national Governments and Health Departments to create conditions in which a major reduction in this heavy burden of disease and death can be achieved. Countries should give formal recognition to the diabetes problem and deploy resources for its solution. Plans for the prevention, identification and treatment of diabetes and particularly its complications – blindness, renal failure, gangrene and amputation, aggravated coronary heart disease and stroke – should be formulated at local, national and European regional levels. Investment now will earn great dividends in reduction of human misery and in massive savings of human and material resources.

General goals and five-year targets listed below can be achieved by the organised activities of the medical services in active partnership with diabetic citizens, their families, friends and workmates and their organisations; in the management of their own diabetes and the education for it; in the planning, provision and quality audit of health care; in national, regional and international organisations for disseminating information about health maintenance; in promoting and applying research.

#### **General goals for people – children and adults – with diabetes**

- Sustained improvement in health experience and a life approaching normal expectation in quality and quantity.
- Prevention and cure of diabetes and of its complications by intensifying research effort.

#### **Five-year targets**

Elaborate, initiate and evaluate comprehensive programmes for detection and control of diabetes and its complications with self-care and community support as major components.

Raise awareness in the population, and among healthcare professionals of the present opportunities and the future needs for prevention of complications of diabetes and of diabetes itself.

Organise training and teaching in diabetes management and care for people of all ages with diabetes, for their families, friends, and working associates and for the healthcare team.

Ensure that care for children with diabetes is provided by individuals and teams specialising both in the management of diabetes and of children, and that families with a diabetic child get the necessary social, economic and emotional support.

Reinforce existing centres of excellence in diabetes care, education and research. Create new centres where the need and potential exist.

Promote independence, equity, and self-sufficiency for all people with diabetes – children, adolescents, those in the working years of life and the elderly.

Remove hindrances to the fullest possible integration of the diabetic citizen into society.

Implement effective measures for the prevention of costly complications

- Reduce new blindness cases due to diabetes by one third or more.
- Reduce numbers entering end-stage diabetic renal failure by at least one third.
- Reduce by one half the rate of limb amputations for diabetic gangrene.
- Cut morbidity and mortality rate from coronary heart disease in the diabetic by vigorous programmes of risk factor reduction.
- Achieve pregnancy outcome in the diabetic woman that approximates that of the non-diabetic woman.

Establish monitoring and control systems using state of the art information technology for quality assurance of diabetes health care provision and for laboratory and technical procedures in diabetes diagnosis, treatment and self-management.

Promote European and international collaboration in programmes of diabetes research and development through national, regional and WHO agencies and in active partnership with diabetes patients organisations.

Take urgent action in the spirit of the WHO programme, "Health for All" to establish joint machinery between WHO and IDF, European Region, to initiate, accelerate and facilitate the implementation of these recommendations.

*At the conclusion of the St. Vincent meeting, all those attending formally pledged themselves to strong and decisive action in seeking implementation of the recommendations on their return home.*



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