



# **DIABETES:**

**PREVENTION**

**&**

**MODEL FOR PATIENT CARE**



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## **Recommendations**

The National Diabetes Working Group has made a number of policy guidance recommendations. These relate to the model of care for people with diabetes as well as recommendations for how services prevent and manage diabetes in the population.

### **Model of Care**

A model of high quality care is provided and sets out what children and adults with diabetes shall expect to receive throughout their lifetime. This includes:

- **Having a voice in the planning and delivery of services**
- **Treatment which is effective, in accordance with national and local guidelines**
- **Care which is delivered by appropriately trained and accredited healthcare providers and which is subject to audit**
- **Patients in high-risk or vulnerable groups should have access to treatment which is appropriate to their needs and access to services should be equitable**
- **An agreed management plan for each patient; whether care is provided in primary care or by a specialist unit**
- **Access to local services; and timely access to primary care and regional specialist services**
- **Integrated generalist care, which can provide care for more than one chronic condition in a holistic manner**
- **Patients should have a comprehensive review of their diabetes at least once a year, and other regular reviews as agreed in their management plan**
- **Patient management will include the modification of cardiovascular risk factors as appropriate**
- **Screening for diabetic retinopathy (every 1-2 years)**
- **Podiatry service - a full foot assessment at least once a year; ideally by a podiatrist, and specialist foot care as determined by risk assessment**
- **A consultation with a dietician following diagnosis and further reviews as appropriate**
- **Access to smoking cessation services and exercise referral as required**
- **Access to psychological support when required**
- **Each patient should be included in a diabetes register, unless they choose to opt out**
- **Education: patients with diabetes should have a clear understanding of their condition and know where to find information regarding their condition and its treatment.**

### **Information**

- **A diabetes register should be developed, starting at local/regional level**
- **Existing hospital and GP practice registers should be used in the development of the register – data should be reviewed and checked, and then linked with the regional database**

- The register should conform with emerging governance frameworks and standards as determined by HIQA.

### Prevention

- There is ongoing research into the effectiveness of screening for diabetes and preventable strategies should take account of emerging evidence in this area
- A combination of population and high-risk approaches should be incorporated into a diabetes prevention programme
- Patient education should be integrated into diabetes prevention programmes
- Because risk factors for diabetes are similar to those for cardiovascular disease, preventative strategies should be integrated so as to reduce the risk factors common to both conditions. Particular attention should be given to strategies aimed at preventing Type 2 diabetes in the general population and in high risk groups
- Podiatry services should be developed as a priority issue to prevent foot care complications in diabetic patients
- The report of the National Task Force on Obesity should be implemented
- Strategies should also be developed to identify people who do not know they have diabetes
- Services should focus on reducing health inequalities due to diabetes. Groups such as children and young people, ethnic minorities, pregnant women and other vulnerable groups require particular attention
- There is substantial evidence of the effectiveness of screening for diabetic retinopathy and on this basis; a structured retinopathy screening programme has been identified as a priority for Irish diabetic patients.

### Diabetes Services

- The development of diabetes services should be prioritised at national level and this should be reflected in the Department of Health and Children's Statement of Strategy and the HSE national service plan. The high level functions that require support at national level include:
  - Diabetes services reflected in the national service plan with performance monitoring systems to support this
  - The development of evidence-based clinical guidelines
  - Supporting structures to support quality in diabetes care. This will be developed in partnership with HIQA
  - Prevention and screening including health promotion, public education and targeted screening of high risk groups
  - The development of ICT to support diabetes care
  - Support of regional networks for continuing professional development
  - The development and support of local diabetes services development groups
  - The availability of high quality laboratory testing for the diagnosis and monitoring of diabetes

- **Local diabetes networks should be developed in accordance with the national service plan and community-based services for patients with diabetes should be enhanced.**
- **Strategic, research and educational support should be identified at national and regional levels.**

## **Acknowledgements**

As Chairman, I wish to acknowledge the commitment and hard work of the members of the group who gave unstintingly of their time and energy in fulfilling the mandate given to us by the Minister.

I would like to thank the Diabetes Federation of Ireland for their work in producing “*Diabetes: Securing the Future*” and for their continued advocacy on behalf of persons with diabetes in our community.

Finally, I would like to offer a word of special thanks to Dr Melissa Canny, Specialist Registrar in Public Health Medicine, who carried out her duties as medical secretary to the group in an exemplary, professional manner and to Dr John Devlin, Deputy CMO, for stewarding the process to completion.

A handwritten signature in blue ink that reads "James Kiely". The signature is written in a cursive style with a horizontal line underneath it.

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**Dr Jim Kiely**  
Chief Medical Officer

# Chapter 1

## Introduction

The emergence of diabetes mellitus as a major public health problem in western society has been well documented over the last number of years. Notwithstanding a deficit in the information available, the situation in Ireland described in this report confirms the existence of a burgeoning problem here, driven by well recognised factors such as lifestyle and demographic factors.

In 2004, the Minister for Health and Children established a Working Group to examine this issue and make recommendations for further action. The work of the group has been informed by a wide range of available evidence nationally and internationally including a major document produced by the Diabetes Federation of Ireland “*Diabetes: Securing the Future*”

It was recognised that the development of a sound, effective diabetes strategy would have to capture all the elements of modern approaches to chronic disease management such as:

- Effective prevention
- Early diagnosis
- Multidisciplinary, integrated care
- Management protocols based on sound evidence
- Achievable and meaningful performance indicators based on accurate information
- Effective information management at individual and population level
- Participation by patients, their families and support groups.

The document that has been produced here is one element of a process. Due to circumstances beyond the control of the group, not all the appointed members felt able to attend the meetings of the group subsequent to the first one. Despite this, much useful and effective work has been done in identifying and progressing a number of very important aspects of this issue. Further work now needs to be done to finalise a diabetes strategy which will have the support and commitment of all those with an interest in diabetes at policy, management, clinical and broader community levels including those who suffer from the disease and their families. It is now proposed to bring this work forward with the Health Service Executive so that the best possible services can be provided to the growing number of persons with diabetes in our community.

## **Chapter 2**

### **Terms of Reference**

The Working Group was to examine:

- The epidemiology of diabetes in Ireland
- Health promotion and preventative initiatives including screening
- Current service provision including the need to achieve better integration of care using current resources and facilities and the expansion of shared care programmes
- Recommendations for diabetes service provision.

### **Group Membership**

The following were appointed members of the group:

Dr Jim Kiely, Chair, Chief Medical Officer, Department of Health and Children

Dr Anna Clarke, Diabetes Federation of Ireland

Ms Siobhan Meehan, Diabetic Liaison Nurse, HSE, Midland Area

Dr Velma Harkin, General Practitioner, Banagher, County Offaly

Dr Tessa Greally, Public Health Specialist, HSE, Mid-Western Area

Ms Deirdre Hall, Diabetic Nurse Specialist, HSE, East Coast Area

Dr Chris Thompson, Beaumont Hospital, Dublin

Prof John Nolan, St James's Hospital, Dublin

Dr Donal O'Halloran, CUH, Cork

Mr Kieran O'Leary, Diabetes Federation of Ireland

Dr Michael Boland, ICGP, Dublin 2

Mr Dan Ryan, HEO, Physical Disability Services, DOHC

Mr Denis O'Sullivan, PO, Acute Hospitals Division, DOHC

Mr Paul McKiernan, AP, Acute Hospitals Division, DOHC

Mr Chris Fitzgerald, PO, Health Promotion Unit, DOHC

Mr Brian Mullen, PO, Community Health Division, DOHC

Ms Tracy O'Beirne, Nursing Advisor, Nursing Policy Division, DOHC

Dr Melissa Canny, Specialist Registrar in Public Health Medicine, DOHC

Mr Tadgh Delaney, AP, General Medical Services, DOHC

Mr Peter Henshaw, HEO, Health Promotion Unit, DOHC

Dr John Devlin, DCMO, DOHC.

### **Meetings Process**

The committee met on 6 occasions. It received submissions from a number of sources and reviewed the Irish and international experience with diabetes in the course of its deliberations.

## Chapter 3

### Establishing the Need

#### Definition

The classification and diagnostic criteria used for the diagnosis of diabetes and disorders of glucose homeostasis has been the subject of much debate. The World Health Organisation defines diabetes mellitus as a metabolic disorder of multiple aetiology characterized by chronic hyperglycaemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both<sup>1</sup>.

In 1999, the WHO recommended changes in the diagnostic criteria for diabetes mellitus<sup>1</sup>. The current WHO diagnostic values for the diagnosis of diabetes are:

- Fasting plasma glucose concentration of  $7.0 \text{ mmol l}^{-1}$  ( $126 \text{ mg dl}^{-1}$ ) and above,
- Fasting glucose concentration of  $6.1 \text{ mmol l}^{-1}$  ( $110 \text{ mg dl}^{-1}$ ) and above for whole blood.

#### Incidence

The incidence of diabetes is increasing in all age groups. Type 1 diabetes is increasing in children, particularly in under fives. Type 2 diabetes is increasing across all groups, including children and young people, and particularly among black and minority ethnic groups<sup>2</sup>.

Incidence rates of type I diabetes show large variation worldwide. Estimates of prevalence in the UK suggest that 0.3 per cent of the population have type 1 diabetes. In Ireland, the incidence rate of type 1 diabetes in children has reported as 16.8/100,000 per year. This is above the European average<sup>3</sup>.

Type 2 diabetes is the most common type of diabetes, accounting for approximately 90% of all cases worldwide. In England, about 85% of people with diabetes have type 2 diabetes<sup>4</sup>.

#### Prevalence

There is a lack of epidemiological data regarding the prevalence of diabetes in Ireland.

International research has estimated that the prevalence of diabetes is between 2-7% of the population, increasing with age to between 10-14% of the population aged over 40 years of age<sup>5-8</sup>.

The World Health Organisation has recently estimated that the prevalence of diabetes for all age-groups worldwide was 2.8% in 2000, and is projected to reach 4.4% in 2030<sup>9</sup>.

The prevalence of diabetes is increasing rapidly. It is estimated that by 2010 the world's diabetic population will probably have doubled from an estimated 110 million in 1994 to 221 million<sup>10</sup>.

Though the increase is mainly due to type 2 diabetes, increases in type 1 have also been observed in many studies. It has been predicted that the numbers of children in Europe with type 1 diabetes will increase from the 1992 level of 10.4 per 100,000 to 24.7 per 100,000 by 2025<sup>11</sup>.

The prevalence of type 2 diabetes increases with age and the increased longevity of many societies has undoubtedly contributed to the rise in the overall prevalence of type 2 diabetes. In the UK, one in 20 people over 65 years of age has diabetes rising to one in five in people over the age of 85 years. It has been estimated that for every diagnosed case of type 2 diabetes there is one case undiagnosed<sup>12</sup>.

### **Ireland**

According to the 2002 Census, the population of Ireland was over 3.9 million<sup>9</sup>.

The WHO has estimated that in 2000 there were 86,000 people with diabetes in Ireland and this is expected to almost double to 157,000 by 2030<sup>13</sup>.

- The figures show that there were over 394,000 people aged over 65 years in Ireland in 2002. If the prevalence of diabetes in this age group is similar to the UK (1 in 20) we estimate that there are over 19,700 people in Ireland with diabetes in this age group<sup>2</sup>.
- The census figures showed a population of almost 42,000 people aged over 85 years. If 1 in 5 have diabetes in this age group, we estimate that there are over 8,300 people over the age of 85 with diabetes in Ireland<sup>2</sup>.

The ageing population and changing ethnic profile in Ireland may also be expected to contribute to the increasing prevalence of diabetes.

A study was conducted in the Southern Health Board in 1997 to estimate the prevalence of cardiovascular disease risk factors, including Type 2 Diabetes Mellitus in the general population of males and females between the ages of 50-69 years.

In the Cork and Kerry Diabetes and Heart Disease Study, 1473 individuals were invited to attend for a 'study of health and lifestyle', of whom 1018 (70%) participated. Subjects were sampled from 17 General Practices in Cork and Kerry between March and August 1998. The research revealed that almost 4% of the population sample had Type 2 Diabetes Mellitus, of whom 30% were undiagnosed. Almost half of the population sampled were overweight and a further one quarter met current international criteria for obesity, one of the highest recorded prevalence rates for obesity in a European population sample. There were also high levels of inactivity, hypertension and hyperlipidaemia amongst study participants.

The Quarterly National Household Survey, which is conducted by the Central Statistics Office, included questions on health in the survey which was used in the third quarter of 2001. Respondents were asked if they had, or at one point had suffered from one of more specified health conditions. Diabetes was one of the conditions included on the questionnaire. The overall prevalence of diabetes was 1.5% for the entire population, with 4.5% of those aged 65 years or older reporting that they had diabetes.

The Institute of Public Health (Population Health Observatory) estimate the overall number of people with diabetes to be approximately 130,000<sup>14</sup>.

### **Mortality Data**

In 1993, the EURODIAB Subarea C Study was published, which examined the certification and coding of causes of death of six clinical case histories of diabetic patients. This study was designed to investigate the large differences in diabetes mortality rates in Europe. In each of the participating countries (France, Germany, The Netherlands, Northern Ireland-UK, Republic of Ireland, Romania, Scotland-UK, Switzerland) a random sample of certifying physicians was asked to certify the causes of death of six case histories which described the deaths of diabetic patients; the responses from an average of 220 physicians per country were analysed. These registered causes were then coded nationally and the underlying cause was compared with that following a central recoding. Overall 28% of the physicians surveyed recorded diabetes on the death certificate as the underlying cause of death – France was 25% below this overall average and Germany 21% above.

The national coding of diabetes as the underlying cause of death differed from the central recoding with a comparative under coding of almost 40% in Romania, 30% in Northern Ireland and 25% in Switzerland; in contrast, there was an over coding of diabetes by 80% in The Netherlands and 60% in the Republic of Ireland. After adjusting for central recoding, in part an adjustment for certification habits, the national coding from this simulation study was able to explain 35% of the variation in the diabetes mortality rates. With such differences in the coding of diabetes, the currently published mortality rates for diabetes are not directly comparable between European countries<sup>15</sup>.

## Data from Ireland

### Public Health Information System (PHIS)

The following data has been extracted from the Public Health Information System. Table 3.1 shows age standardised mortality rates from Diabetes in each of the health boards, and the overall rate for Ireland.

**Table 3.1: 5 Year Age Standardised Mortality from Diabetes by Health Board 2002**

AREA	ALLCASES	CASEOV64	SDRALL	SDRUN65	SDROV64	SMRALL	SMROV64
ERHA	532	456	8.55	1.56	65.1	82.47	83.52
SEHB	270	243	11.98	1.74	94.8	115.72	120.7
SHB	373	309	11.91	3	83.97	112.45	107.45
MWHB	208	176	11.68	2.56	85.49	110.09	107.58
WHB	231	205	9.68	1.91	72.57	94	94.3
MIDHB	144	123	12.27	2.69	89.78	116.53	114.42
NWHB	150	135	11.04	1.81	85.68	102.48	104.32
NEHB	183	158	10.96	2.12	82.45	103.8	103.78
<b>IRELAND</b>	<b>2091</b>	<b>1805</b>	<b>10.46</b>	<b>2.05</b>	<b>78.44</b>	<b>100</b>	<b>100</b>

ALL CASES	total number of deaths
CASEOV64	total number of deaths aged over 64
SDRALL	direct standardised mortality rate per 100,000 population for all ages
SDRUN65	direct standardised mortality rate per 100,000 population for ages under 65
SDROV64	direct standardised mortality rate per 100,000 population for ages over 65
SMRALL	standardised mortality ratio for all ages
SMROV64	standardised mortality ratio for ages over 64

Table 3.2 shows the breakdown of hospital discharges in 2002 with a primary diagnosis of diabetes.

**Table 3.2: Hospital Discharge Data Diabetes 2002 PHIS**

AREA	ALLCASES	CASEUN65	SDRALL	SDRUN65	SMRALL
EHB	1658	1097	128.88	93.9	75.17
SEHB	715	464	169.21	127.86	98.6
SHB	1246	672	214.83	138.74	124.74
MWHB	543	337	162.18	117.49	94.03
WHB	572	325	141.24	99.37	85.08
MIDHB	402	262	181.96	139.17	105.9
NWHB	504	285	210.7	151.43	127.32
NEHB	875	540	271.72	190.94	156.25
<b>Ireland</b>	<b>6515</b>	<b>3982</b>	<b>171.32</b>	<b>121.23</b>	<b>100</b>

ALLCASES	Total number of hospital discharges
CASEUN65	Total number of hospital discharges aged under 65
SDRALL	Direct standardised hospital discharge rate per 100,000 population for all ages
SDRUN65	Direct standardised hospital discharge rate per 100,000 population for ages under 65
SMRALL	Standardised hospital discharge ratio for all ages

## HIPE

Data from the Hospital Inpatient Enquiry Systems shows a large increase in diabetic admissions in recent years and that there were almost 39,000 admissions to Irish hospitals amongst people with diabetes in 2003.

**Table 3.3: Total admissions with a diagnosis of diabetes 2000-2003**

<b>Number of Discharges with a Diagnosis of Diabetes 2000-2003</b>				
Year	2000	2001	2002	2003
National Total	29285	32712	35878	38622

*Note: Data refer to all discharges with any diagnosis of Diabetes (ICD-9-CM 250)*  
*Source: Hospital Inpatient Enquiry (HIPE) 2000-2003*

**Table 3.4: Total admissions with diabetes as a principal diagnosis 2000-2003**

<b>Number of Discharges with a Diagnosis of Diabetes 2000-2003</b>				
Year	2000	2001	2002	2003
Principal diagnosis	6014	6392	6553	6429

Of the 39,000 admissions with diabetes in 2003, 6,429 (17%) had diabetes as a principal diagnosis.

**Table 3.5: Discharges for Type 1 and Type 2 diabetes by Health Board 2003**

Number of Discharges with a Diagnosis of Diabetes 2003									
Health Board	Sex	Type 1 Diabetes				Type 2 Diabetes			
		0-19 Years	20-39 Years	40-59 Years	60+ Years	0-19 Years	20-39 Years	40-59 Years	60+ Years
ERHA	Males	194	235	451	475	31	146	1227	3904
	Females	209	416	364	389	10	163	788	2926
MHB	Males	19	44	58	78	4	17	196	723
	Females	43	24	59	87	3	15	126	597
MWHB	Males	35	66	115	186	1	41	381	1307
	Females	45	141	98	143	4	23	280	1153
NEHB	Males	76	37	109	143	5	18	251	908
	Females	117	74	47	118	7	40	190	824
NWHB	Males	59	45	57	126	10	16	263	842
	Females	53	62	49	100	7	16	120	760
SEHB	Males	97	80	130	247	0	44	526	1823
	Females	72	102	102	202	2	26	326	1382
SHB	Males	68	119	158	243	3	70	567	2395
	Females	59	106	115	192	1	31	430	1434
WHB	Males	51	79	138	136	12	24	294	1362
	Females	53	124	92	125	16	42	222	1111
National Total	Males	599	705	1216	1634	66	376	3705	13264
	Females	651	1049	926	1356	50	356	2482	10187

*Note: Data refer to all discharges with any diagnosis of Diabetes (ICD-9-CM 250)*

*Note: Health Board refers to the area of treatment.*

*Source: Hospital Inpatient Enquiry (HIPE) 2000-2003*

Table 3.5 shows the breakdown of hospital discharges for type 1 and type 2 diabetes by health board. In 2003, 79% of discharges were for type 2 diabetes and 21% were for type 1 diabetes.

**Table 3.6: Discharges with a Principal Diagnosis of Diabetes: Breakdown, 2000-2003**

Number of Discharges with a Principal Diagnosis of Diabetes 2000-2003								
	2000		2001		2002		2003	
	Type 1	Type 2						
Diabetes without mention of complication	1174	1443	1261	1593	1209	1603	1163	1696
Diabetes with Ketoacidosis	510	101	587	108	565	55	591	82
Diabetes with Hyperosmolarity	13	38	10	34	23	50	16	65
Diabetes with Other Coma	151	49	113	31	127	39	106	44
Diabetes with Renal Manifestations	49	57	67	61	42	51	50	96
Diabetes with Ophthalmic Manifestations	379	1065	349	1094	302	1363	270	1059
Diabetes with Neurological Manifestations	50	55	59	73	54	75	51	70
Diabetes with Peripheral Circulatory Disorders	64	158	68	150	47	117	57	173
Diabetes with Other Specified Manifestations	391	266	424	308	461	369	464	375
Diabetes with Unspecified Complication	1	0	1	1	1	0	0	1
Total	2782	3232	2939	3453	2831	3722	2768	3661

*Note: Data refer to discharges with a principal diagnosis of Diabetes (ICD-9-CM 250)*

*Source: Hospital Inpatient Enquiry (HIPE) 2000-2003*

Table 3.6 shows the complications which affected discharges which had diabetes as a principal diagnosis between 200 and 2003. The most frequent complication affecting patients with type 1 diabetes was Ketoacidosis or other coma. Ophthalmic manifestations were the most frequently recorded complication amongst patients with type 2 diabetes.

**Table 3.7: Inpatients and Daycases with a Principal Diagnosis of Diabetes 2000-2003**

<b>Number of Inpatient and Daycase Discharges with a Principal Diagnosis of Diabetes 2000-2003</b>								
Health Board	2000		2001		2002		2003	
	Inpatients	Daycases	Inpatients	Daycases	Inpatients	Daycases	Inpatients	Daycases
ERHA	1349	694	1401	713	1220	964	1186	759
MHB	291	6	272	8	287	17	286	6
MWHB	296	147	340	228	327	182	366	214
NEHB	529	32	502	56	535	43	566	78
NWHB	366	25	364	52	412	90	436	76
SEHB	440	16	630	24	573	47	641	105
SHB	668	521	696	481	768	524	607	438
WHB	507	127	552	73	555	9	585	80
Total	4446	1568	4757	1635	4677	1876	4673	1756

Table 3.7 shows the numbers of patients treated as inpatients and day cases in each board from 2000 to 2003. Overall, there has been a gradual increase in the number of patients treated as day cases.

## Chapter 4

### Patient-Centred Care

The National Diabetes Working Group proposes a model of diabetes care which reflects the principles set out in the health strategy; *Quality and Fairness: A Health System for You* (2001):

- Equity and fairness
- A people-centred service
- Quality of care
- Clear accountability.

Under this new model of care, children and adults with Diabetes should expect to receive high quality care throughout their lifetime provided by accessible services which deliver the following:

- **Enabling people with diabetes to have a voice in the planning and delivery of services**
- **Treatment which is effective, in accordance with national and local guidelines**
- **Care which is delivered by appropriately trained and accredited healthcare providers and which is subject to audit**
- **Patients in high-risk or vulnerable groups should have access to treatment which is appropriate to their needs and access to services should be equitable**
  - **An agreed management plan for each patient; whether care is provided in primary care or by a specialist unit**
  - **Access to local services; and timely access to primary care and regional specialist services**
  - **Integrated generalist care, which can provide care for more than one chronic condition in a holistic manner**
  - **Patients should have a comprehensive review of their diabetes at least once a year, and other regular reviews as agreed in their management plan**
  - **Patient management will include the modification of cardiovascular risk factors as appropriate**
  - **Screening for diabetic retinopathy (every 1-2 years)**
  - **Access to a podiatry service - a full foot assessment at least once a year; ideally by a podiatrist, and specialist foot care as determined by risk assessment**
  - **A consultation with a dietician following diagnosis and further reviews as appropriate**
  - **Access to smoking cessation services and exercise referral as required**
  - **Access to psychological support when required**
  - **Inclusion on a diabetes register, unless they choose to opt out**
  - **Education: patients with diabetes should have a clear understanding of their condition and know where to find information regarding their condition and its treatment.**

## **Chapter 5**

### **Information for Better Diabetes Care**

The diabetes data outlined in Chapter 3 has provided a valuable source of information on the needs of people with diabetes. This should be viewed as a starting point and it is important that information systems continue to be developed to support the planning, management and monitoring of diabetes services within the Health Service Executive. Key areas for future development include information on the needs of people with diabetes, the delivery of integrated care and information on clinical outcomes. The diabetes information infrastructure requirements will be a matter for the HSE in consultation with key stakeholders including HIQA. A key concern is the need for a diabetes register and this section of the report sets out general policy advice in this area.

#### **The Case for a Diabetes Register in Ireland**

Research has shown that computerised central recall, with prompting for patients and their family doctors, can achieve standards of care as good or better than hospital outpatient care, at least in the short term.

The delivery of high-quality care for patients with diabetes relies upon the establishment of effective registers. Without an effective register, it will not be possible to identify those with poor diabetes control or those with newly diagnosed diabetes. A special focus on people with newly diagnosed diabetes is needed to ensure they manage this major transition in their life effectively and reduce their long-term risk of complications.

The development of diabetes registers should be a collaborative effort involving primary care and specialist services. A comprehensive and up-to-date register will provide the cornerstone of care and the basis for call and recall, clinical care, prevention, continuous quality improvement, monitoring and clinical audit. All registers must meet the requirements for confidentiality and security.

Registers will also enable health care providers to gauge the extent of undiagnosed diabetes in their population, and will provide the infrastructure for peer review, internal and external monitoring, benchmarking, resource management and research.

#### **What is a Register?**

A disease register is a special form of clinical database. In compiling a population-based register, an attempt is made to identify and collect data on all cases of a disease or other health condition within a defined population.

Disease registers are best suited to situations where disease or risk factor status do not tend to change much over time. The disease in question also needs to be reliably diagnosed by different clinicians and there should generally be a continuing and specific health need associated with the disease.

The data collected by registries vary widely, but often include personal identifiers, socio-demographic information, disease status (possibly including stage, severity and co-morbidity), details of treatments and other interventions, and eventual outcomes.

A registry should establish systems to:

- Maintain a reliable notification or identification of cases within the studied population
- Ensure comparability of inclusion criteria onto the register
- Minimize under-coverage
- Ensure that duplication of cases within the register does not occur
- Keep the register updated.

### **Diabetes Register**

- A Diabetes Register would allow identification and registration of all patients with diabetes, whether GMS or private patients
- The Register is more than a surveillance tool and would be used to establish need, support service delivery and promote quality in diabetes care
- The register would provide important data required for needs assessment. This information would inform health service providers and planners at national and local levels and would be used in service planning
- A register would assist in local, regional and national diabetes monitoring
- Information about new cases of diabetes mellitus could be collected and collated, and the incidence of diabetes could be accurately monitored
- All patients included in the register should have access to high-quality care, which is subject to audit
- A register would include a nationally agreed minimum dataset which could be used for epidemiological research and audit
- The register would be linked to Primary Care and Specialist Units and would allow recall and review of patients
- Relevant laboratory and other clinical results could be collected and recorded in the register.

### **Issues for Further Consideration**

- There are a number of clinical software packages in use in general practice in Ireland. It is not clear whether these systems 'talk to' each other or to laboratory systems, and so on. However, databases have been established in the ERHA and other areas
- Some practices not computerised; although computerisation is not an absolute necessity, it is desirable
- Although there is no unique identifier for patients in the Irish health system, the PPS number as outlined in the National Health Information Strategy is seen as an appropriate way of achieving this
- Data protection issues will require consideration
- Registers should link with other registers – such as cardiovascular disease, and with laboratory systems
- To enable electronic communication between Primary care and Specialist Units, a fast, secure, robust and comprehensive network infrastructure of suitable bandwidth should be in place.

## **Establishment of Register**

- **A diabetes register should be developed, starting at local/regional level**
- When local registers have been established and validated they will feed into regional and national databases
- **Existing hospital and GP practice registers should be used in the development of the register – data should be reviewed and checked, and then linked with the regional database**
- A system of voluntary registration could be established, such as through community nutrition and/or community pharmacies
- The Register should link with other databases as appropriate, such as GMS, Cardiovascular, and so on
- Patients should be informed that their details are on the practice database and will link with specialist unit; patients may choose to opt-out
- Databases should be updated quarterly
- Each practice should be responsible for its own database and an individual (Project Manager) should have overall responsibility for the regional database.
- **The register should conform with emerging governance frameworks and standards as determined by the Health Information and Quality Authority (HIQA).**

## **Recommendations**

1. **A diabetes register should be developed, starting at local/regional level**
2. **Existing hospital and GP practice registers should be used in the development of the register – data should be reviewed and checked, and then linked with the regional database**
3. **The register should conform with emerging governance frameworks and standards as determined by HIQA.**

## Chapter 6

### Prevention of Diabetes

The prevention of diabetes and its complications is key to reducing the burden of this condition. A comprehensive strategy for diabetes prevention includes:

- Primary prevention: prevention of disease development in the general population, through reduction of risk factors
- Secondary prevention: detecting disease at an early stage – such as targeted screening of high-risk groups
- Tertiary prevention: treating established disease effectively to minimise the occurrence of complications, and detecting complications of diabetes at an early stage (such as retinopathy screening).

### The Need for a Programme of Prevention

- The prevalence of diabetes is increasing. This increase reflects the ageing population and the increasing prevalence of obesity
- One in eight Irish people are obese and every second person is overweight. Forty-seven per cent of people report being overweight or obese (13% obese and 34%<sup>16</sup>)
- Obesity is a major risk factor for Type 2 diabetes and is modifiable
- Only half (51%) of Irish adults report taking some form of regular physical exercise
- Obesity in children has been identified as an emerging public health problem. Data from recent surveys indicate that one in five Irish boys and girls are overweight and one in twenty are obese
- **There is ongoing research into the effectiveness of screening for diabetes and preventable strategies should take account of emerging evidence in this area**
- **Peripheral vascular disease and amputations are important complications and much of this is preventable**
- **Inter-sectoral action is required to promote physical activity and a balanced diet at all ages, but particularly amongst children and adolescents**
- **A combination of population and high-risk approaches should be incorporated into a diabetes prevention programme**
- **Patient education should be integrated into diabetes prevention programmes.**

### Actions

- **Because risk factors for diabetes are similar to those for cardiovascular disease, preventative strategies should be integrated so as to reduce the risk factors common to both conditions. Particular attention should be given to strategies aimed at preventing Type 2 diabetes in the general population and in high risk groups**
- **Podiatry services should be developed as a priority issue to prevent foot care complications in diabetic patients**
- **The report of the National Task Force on Obesity should be implemented**

- **Strategies should also be developed to identify people who do not know they have diabetes**
- **The strategies should include the following:**
  - **Public awareness campaign**
  - **Health promotion programmes aimed at reducing risk factors for diabetes in the general population and high-risk groups**
  - **The development of information systems to monitor the prevalence of risk factors for diabetes in the population**
- **Services should focus on reducing health inequalities due to diabetes. Groups such as children and young people, ethnic minorities, pregnant women and other vulnerable groups require particular attention.**

### **Screening for Diabetic Retinopathy**

Diabetic retinopathy is the leading cause of blindness in people under the age of 60 in industrialised countries. It is also a major cause of blindness in older people. Many people will be asymptomatic until the disease is very advanced. After 20 years from onset of diabetes, more than 60% of people with type 2 diabetes will have diabetic retinopathy. In people with type 2 diabetes, maculopathy is the major cause of visual loss.

The risk of visual impairment and blindness is substantially reduced by a care programme that combines methods for early detection with effective treatment of diabetic retinopathy. The key issue in screening for diabetic retinopathy is to identify those people with sight-threatening retinopathy who may require preventive treatment. Screening and treatment for diabetic retinopathy will not eliminate all cases of sight loss, but can play an important part in minimising the numbers of patients with sight loss due to retinopathy.

### **Screening Methodology**

There are 2 main approaches to screening for diabetic retinopathy:

- Ophthalmoscopy and biomicroscopy (slit lamps)
- Retinal photography with subsequent grading.

According to a Health Technology Assessment Report on the Organisation of Services for Diabetic Retinopathy Screening in Scotland, direct ophthalmoscopy does not achieve sufficient sensitivity to act as a screening test for sight-threatening disease and therefore should not be the basis of a national programme.

Indirect ophthalmoscopy (biomicroscopy) using a slit lamp has been shown to be a sensitive and specific method for screening when used by appropriately trained individuals. It carries the disadvantage that there is no permanent record of the image for quality assurance or monitoring progressive changes. However, biomicroscopy is important for screening failures from other modalities.

Retinal photography, with one or two fields (photographs) has been shown to achieve high sensitivity and specificity for sight-threatening disease. Advantages of digital photography are ease of image acquisition and storage, and quality assurance. The image may be transmitted electronically, facilitating external quality assurance.

Consequently, digital retinal photography is considered the screening modality of choice, and is the screening method recommended by NICE in the UK<sup>18</sup>.

The HTBS considered the evidence on imaging failure rates with and without mydriasis. In the most recent study of digital cameras, the failure rate was 20%. This is judged to be acceptable in the context of the three stage failsafe procedure being recommended.

### **Scottish Three Stage Model**

The HTBS proposed that the national systematic screening programme for diabetic retinopathy in Scotland uses the following three-stage process:

1. Macular single-field digital retinal photography, without mydriasis, for each eye.
2. If there is a technical failure, macular single-field digital retinal photography, with mydriasis, for each eye.
3. If there is a technical failure with mydriatic digital photography, biomicroscopy with a slit lamp.

Visual acuity, with refractive correction if required, should be recorded for each eye.

Studies canvassing patient opinion have suggested that mydriasis may reduce attendance for retinopathy screening because of its temporary effects on vision. If mydriasis is used, tropicamide is the recommended agent.

### **Modes of Delivering Screening**

There are three main ways in which diabetic retinopathy screening can be offered to patients:

1. In a fixed medical facility (such as hospital outpatient unit)
2. From a mobile unit:
  - a. with the camera and associated equipment taken into a medical facility (such as GP's surgery)
  - b. taken to a local site, with patients entering the van to have the examination.
3. By a community optometrist.

The mobile facilities are custom-made and the specifications of the equipment in the van and the van itself will depend on whether option a or b is chosen.

### **Organisational Issues**

The main organisational features of a national screening programme should include:

- Strong quality assurance mechanisms
- Systematic call/recall of all eligible patients
- Trained professionals
- Recorded outcomes and robust quality assurance
- Integration with the overall process of care for those with diabetes
- Evaluation and research as an integral part of the programme.

Diabetic retinopathy screening is just one component of diabetes care and to be effective, the national screening programme must be integrated with routine diabetes care. Tight glycaemic control and careful blood pressure control both reduce the development and progression of diabetic retinopathy in type 1 and type 2 diabetes. Clinicians responsible for ongoing diabetic care must be fully informed of results, not only of sight threatening retinopathy requiring referral to the ophthalmologist but also of any retinopathy.

Quality standards should be developed for the screening programme.

The HBTS recommends that all patients diagnosed with either type 1 or type 2 diabetes mellitus and aged over 12 years, or post puberty should have annual examinations of the retina. Guidance from both the National Screening Committee (UK) and NICE recommends annual screening<sup>18</sup>.

Any suitably trained, accredited and competent professional (diabetologist, ophthalmologist, optometrist or retinal screener) can grade the digital images, supported by second opinions, if necessary, from ophthalmologists and/or diabetologists. The same staff may be used for both grading and screening given suitable training for both roles.

### **Conclusions**

After 20 years from the onset of diabetes, over 90% of people with type 1 and more than 60% of people with Type 2 will have diabetic retinopathy. There is substantial evidence of the effectiveness of screening for diabetic retinopathy and on this basis; a structured retinopathy screening programme has been identified as a priority for Irish diabetic patients. The group noted that a preliminary population-based retinopathy screening service has commenced in one region of the Health Service Executive. This programme uses digital imaging as the preferred method of screening and the results of this evaluation should inform the subsequent rollout of retinopathy screening across all regions.

### **Recommendations**

- 1. There is ongoing research into the effectiveness of screening for diabetes and preventable strategies should take account of emerging evidence in this area**
- 2. A combination of population and high-risk approaches should be incorporated into a diabetes prevention programme**
- 3. Patient education should be integrated into diabetes prevention programmes**
- 4. Because risk factors for diabetes are similar to those for cardiovascular disease, preventative strategies should be integrated so as to reduce the risk factors common to both conditions. Particular attention should be given to strategies aimed at preventing Type 2 diabetes in the general population and in high risk groups**
- 5. Podiatry services should be developed as a priority issue to prevent foot care complications in diabetic patients**
- 6. The report of the National Task Force on Obesity should be implemented**
- 7. Strategies should also be developed to identify people who do not know they have diabetes**

- 8. Services should focus on reducing health inequalities due to diabetes. Groups such as children and young people, ethnic minorities, pregnant women and other vulnerable groups require particular attention**
- 9. There is substantial evidence of the effectiveness of screening for diabetic retinopathy and on this basis; a structured retinopathy screening programme has been identified as a priority for Irish diabetic patients. The group noted that a preliminary population-based retinopathy screening service has commenced in one region of the Health Service Executive. This programme uses digital imaging as the preferred method of screening and the results of this evaluation should inform the subsequent rollout of retinopathy screening across all regions.**

## Chapter 7

### A Model for Diabetes Care

#### Context

##### Role and Nature of the Service

The overall aim in the development of diabetes services is to improve the capacity of the health system to deliver, manage and monitor services for the prevention of diabetes and the care of people with and at risk of diabetes. This includes:

1. Preventing or delaying the development of type 2 diabetes
2. Improving health-related quality of life and reducing complications and premature mortality in people with type 1 and type 2 diabetes
3. Advancing knowledge and understanding about the prevention, cure and care of type 1 and type 2 diabetes
4. Achieving maternal and child outcomes for gestational diabetes and for women with pre-existing diabetes equivalent to those of non-diabetic pregnancies
5. Caring for specific patient groups, for example children, ethnic minorities, and vulnerable groups.

The purpose is to offer high quality, equitable, effective and efficient services to the population, in the prevention and treatment of diabetes. The service will include health promotion and be implemented through primary care, hospital care and health promotion and will build on existing models of good practice.

Patients with diabetes require high quality services, which are coordinated, comprehensive and integrated, and care should be appropriate to the patients' needs. This should involve a seamless pathway of care from initial contact in primary care to specialist services and rehabilitation if required.

The most effective way of realising this is through 'shared care', which describes diabetes care which is shared between primary care and specialist services. 'Shared care' is developed jointly in advance by all participating groups, including specialist hospital services and community services. Already there are practical working models which are achieving good results. In terms of ongoing development, the Primary Care Strategy – *Primary Care-A New Direction* – describes the key role of Primary Care in health education, early intervention and disease prevention. The introduction of an inter-disciplinary team-based approach to primary care provision involving primary care teams and a wider network of other primary care professionals will provide the basis for organising primary care within the shared care framework.

Specialist hospital diabetic services are also essential to the framework. This is of particular importance for individuals with diabetes complications. These services require further elaboration, with regard to their configuration at regional level and include the establishment of diabetic teams in the hospital setting. Paediatric and adolescent services and combined antenatal/diabetes specialist care at regional level are also considered necessary.

## **Outline of the Service Model**

In line with the strategic framework for the service, the care should be delivered as near to the patient as possible. For example, the majority of type 2 diabetes care can be delivered in the community. The service is based on the shared care criteria that has been outlined earlier. Key features of the model include a holistic approach to care by the primary care team that is linked to specialist services when appropriate. This will involve patient registration, recall and regular review; individual goal setting through active patient participation; development of clinical guidelines; continuing education of patients and professionals and quality assurance through audit.

The National Diabetes Working Group proposes a model of diabetes care which is patient-centred and includes the following elements: (See Appendix A)

- Diabetes Networks – Local diabetes service development groups to plan diabetes services for the region
- Shared Care – this refers to care which is delivered at the most appropriate level and is shared between primary and secondary care. Roles and responsibilities are clearly understood and underpinned by clinical protocols
- Multi-disciplinary primary care teams
- Prevention and screening – including health promotion, public education and targeted screening of high-risk groups
- Hospital based specialist centres, with:
  - Referral guidelines for primary care
  - Integrated care pathways, (Appendix B)
  - Links with primary care and rehabilitation services.

## **Implementing the Model**

### **National Level**

The development of diabetes services should be prioritised at national level and this should be reflected in the HSE national service plan. The high level functions that require support at national level include:

- Diabetes services reflected in the national service plan with performance monitoring systems to support this
- The development of evidence-based clinical guidelines
- Supporting structures to support quality in diabetes care. This will be developed in partnership with HIQA
- Prevention and screening including health promotion, public education and targeted screening of high risk groups
- The development of ICT to support diabetes care
- Support of regional networks for continuing professional development
- The development and support of local diabetes services development groups.

The requirement of Health and Children should include diabetes in its statement of strategy and provide appropriate support to the HSE in this regard. It is recognised that the steps outlined in this report will require investment and that implementation should be on a phased basis. The Department's Health and Children will address this with the HSE in the context of its corporate and service plan. The HSE has

responsibility for diabetes service delivery and through needs assessment and the service planning process, should establish the appropriate structures to support the model for diabetes care that is proposed. In particular, strategic support for the development of the service should be through the local diabetes service development group at regional level within the HSE. The number and location of these service development groups is a matter for the HSE.

Educational support for health professionals involved in diabetes care at all levels, national, regional and local, is also required. This development of capacity should be supported by the HSE in partnership with the academic bodies.

Quality assurance and research support are also essential for high quality, effective and efficient diabetes services.

The diabetes service requires a system of quality assurance including audit. National evidence-based clinical guidelines including referral protocols will require development. This will involve the HSE in partnership with HIQA and the academic bodies.

Research networks, linked to academic bodies both nationally and internationally, will also require development.

At national level, ICT support should be developed for primary care and hospitals.

### **Regional and Local Level**

Local diabetes networks should be developed in accordance with the national service plan and community-based services for patients with diabetes should be enhanced. The number and structure of these local diabetes service development groups should be determined by the HSE. Regional health needs assessments should inform the development of local diabetes service plans. Specialist units should be developed at local and regional levels, the location and nature of these units will be a matter for the HSE. The establishment of networks as outlined above should lead to better clinical outcomes, equity of access to diabetes services, and a better patient experience.

The role of the local diabetes service development groups includes:

- Planning
  - Planning and delivery of services in accordance with needs assessment
  - Local implementation of the national strategy/service plan
  - Integration of primary and secondary care services
  - Liaison with patient representatives at local level
  - Management of local registers/databases and information technology
  - Co-ordination of retinopathy screening at local level.
- Clinical
  - Implementation of national standards with regard to care pathways and quality initiatives
  - Implementation of clinical protocols for shared care
  - Audit
  - Multidisciplinary continuing professional development.

The local diabetes service development group is responsible for establishing diabetes networks which are comprised of primary care teams and community services, linking with regional specialist units. It is important that there are clear lines of responsibility and a co-ordinator or manager should be designated for each network. There should be patient representation and involvement on the local diabetes service development group.

### **The Service for the Patient**

The model is based on the development of clinical networks, involving primary care and specialist services. It is important that the service provided is delivered across the traditional service boundaries. The primary care team provides initial patient care. The majority of care for patients with type 2 diabetes, in particular, can take place in primary care. Central to the care process is patient identification/registration, either at diagnosis or through establishing a patient register. The development of practice-based, regional and national diabetes registers should be prioritised. Enrolment should be voluntary and patients are invited to participate and with informed consent.

The patients' primary care team includes the GP, nurse, chiropodist, and dietician. The patient may be referred to a health care professional from the wider primary care network, for example a psychologist, ophthalmologist, smoking cessation facilitator, public health nurse or diabetes nurse specialist in the community.

The process of care for the patient includes a baseline assessment, which is carried out in a holistic manner. An illustration of the assessment is included at Appendix D.

A system of regular review will ensure that patients are recalled for review at regular intervals to achieve initial and longer term targets. For example, patients could attend the practice 10-14 days prior to the clinical appointment to have the relevant blood samples taken, the results of which are then available on the day of appointment.

Chiropody and dietetic appointments are arranged to coincide with regular reviews in order to maximise the service for the patient.

The diagnosis and management of diabetes requires high quality accessible laboratory support. Governance and risk issues related to diagnosis and monitoring, including standardisation of laboratory methodologies, should be considered in the service model outlined above.

Diabetic service provision is recognised as a key element in the treatment of diabetes and preventing its complications. Much of this care is provided in specialist centres including paediatric centres and maternity hospitals. The specialist diabetes dietician should be part of the multidisciplinary diabetes team. Diabetic posts should also be dedicated to shared care. The planning and delivery of this service as part of the model of care for diabetes should be addressed in the HSE Service Plan.

While the model for specialist services has not been fully developed, there are a number of key issues involved:

- Equity of access to basic specialist services

- Specialist units to be physician led and include nurse specialists, dieticians, social workers, psychologists and podiatrists as part of the multidisciplinary team
- Provision of paediatric services
- Provision of maternity services
- Access to renal specialists and transplant services.

The location and further development of these services should be addressed by the HSE. Specialist services should be planned on a demographic basis taking into account the health needs of the population.

### **Support Systems**

A range of systems will support the delivery of care to the patient. These include clinical, strategic, research and educational supports.

- A lead person for diabetes care should be identified at practice level. This person will have a clinical background
- Clinical support provided by a consultant endocrinologist, based at a regional hospital
- Direct access to renal, cardiac and ophthalmology specialties, based at a regional hospital. The regional hospital will form part of a clinical network that includes service level agreements with tertiary/supra-regional centres
- Dedicated practice nurse time to deliver the service
- Clinical nurse specialist in diabetes who visit practices on a regular basis to support the role of practice nurse.

Strategic, research and educational support should be identified at national and regional levels as outlined earlier.

### **Recommendations**

1. **The development of diabetes services should be prioritised at national level and this should be reflected in the Department of Health and Children's Statement of Strategy and the HSE national service plan. The high level functions that require support at national level include:**
  - **Diabetes services reflected in the national service plan with performance monitoring systems to support this**
  - **The development of evidence-based clinical guidelines**
  - **Supporting structures to support quality in diabetes care. This will be developed in partnership with HIQA**
  - **Prevention and screening including health promotion, public education and targeted screening of high risk groups**
  - **The development of ICT to support diabetes care**
  - **Support of regional networks for continuing professional development**
  - **The development and support of local diabetes services development groups**
  - **The availability of high quality laboratory testing for the diagnosis and monitoring of diabetes.**

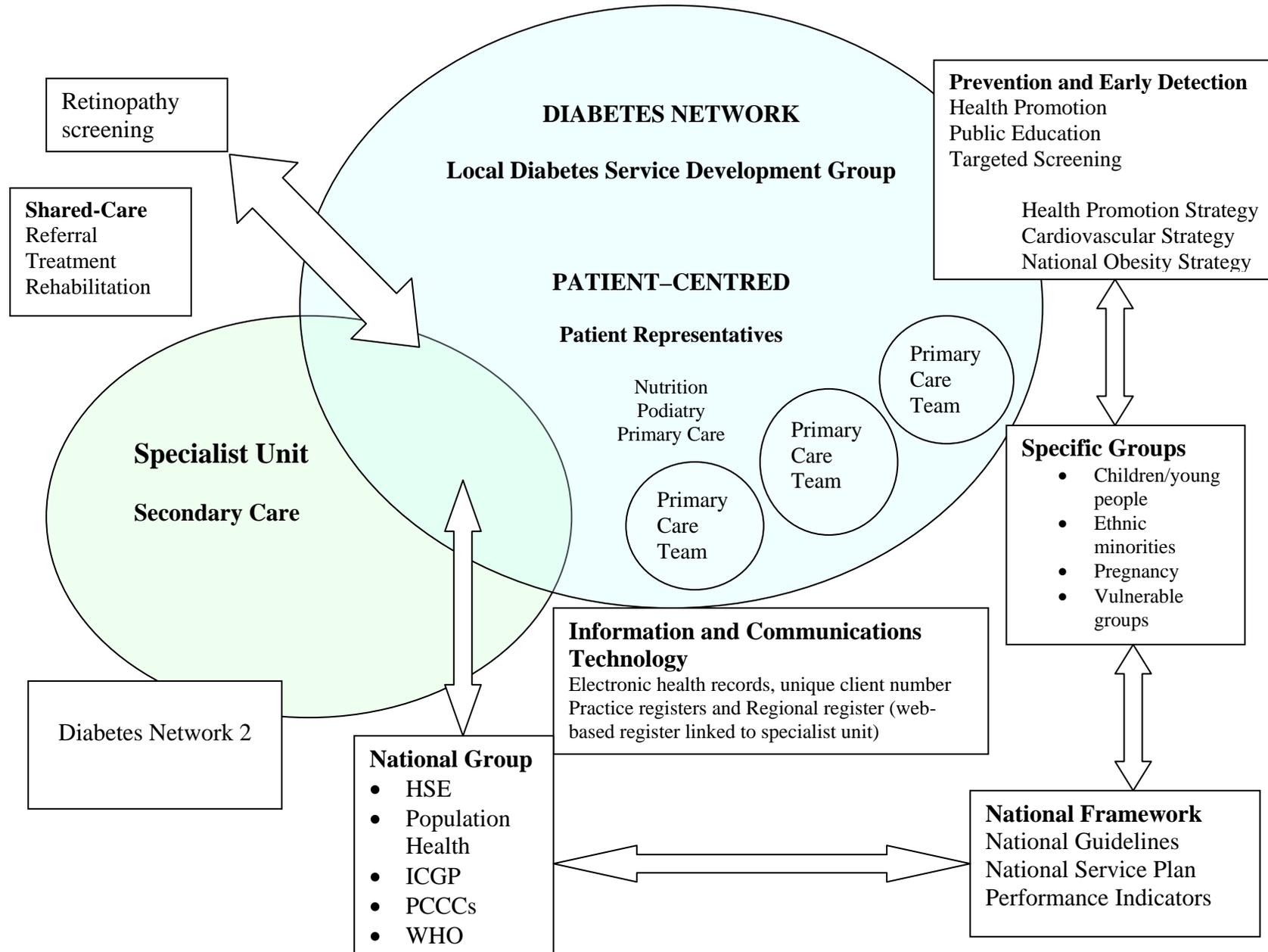
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- 3. Strategic, research and educational support should be identified at national and regional levels.**

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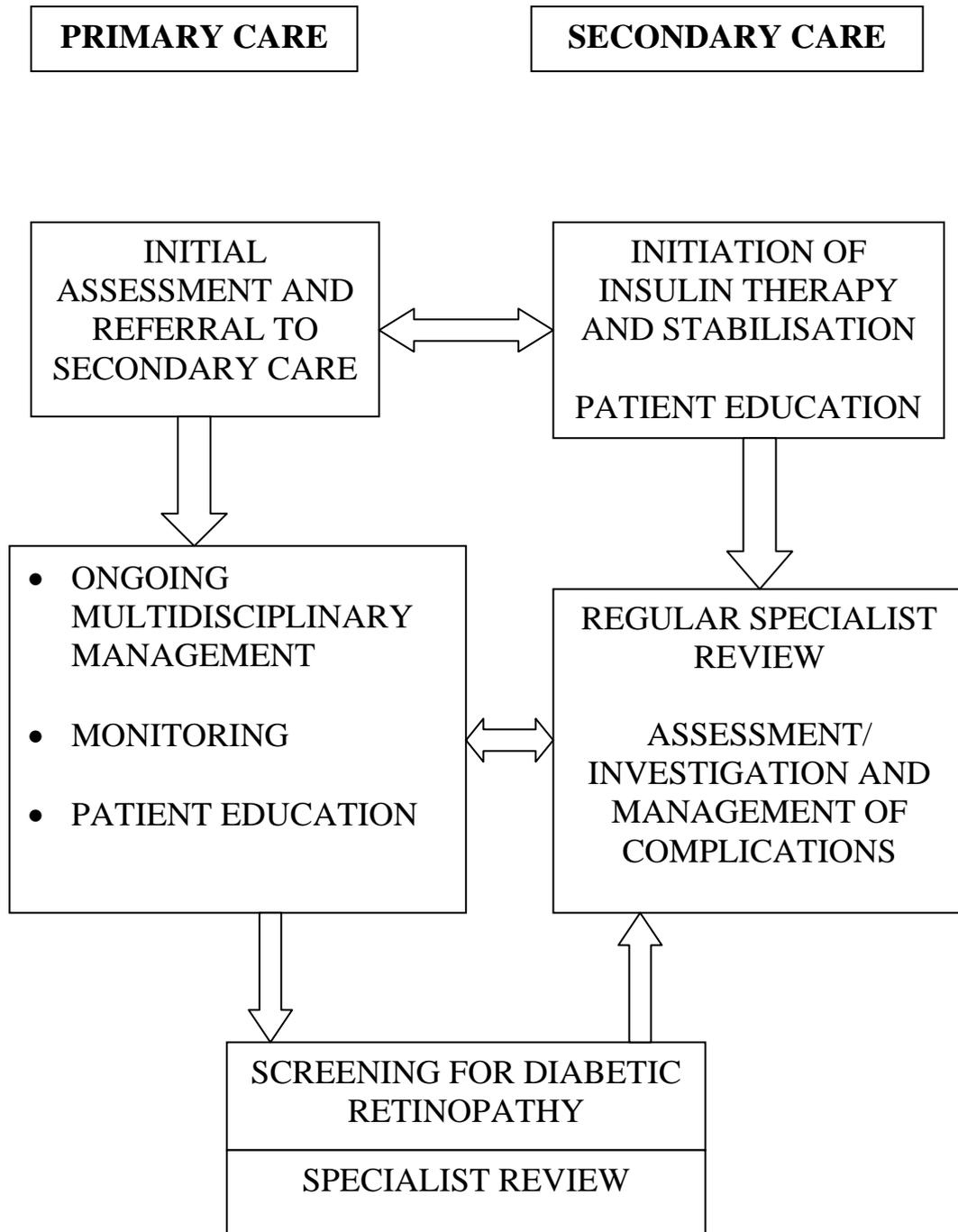
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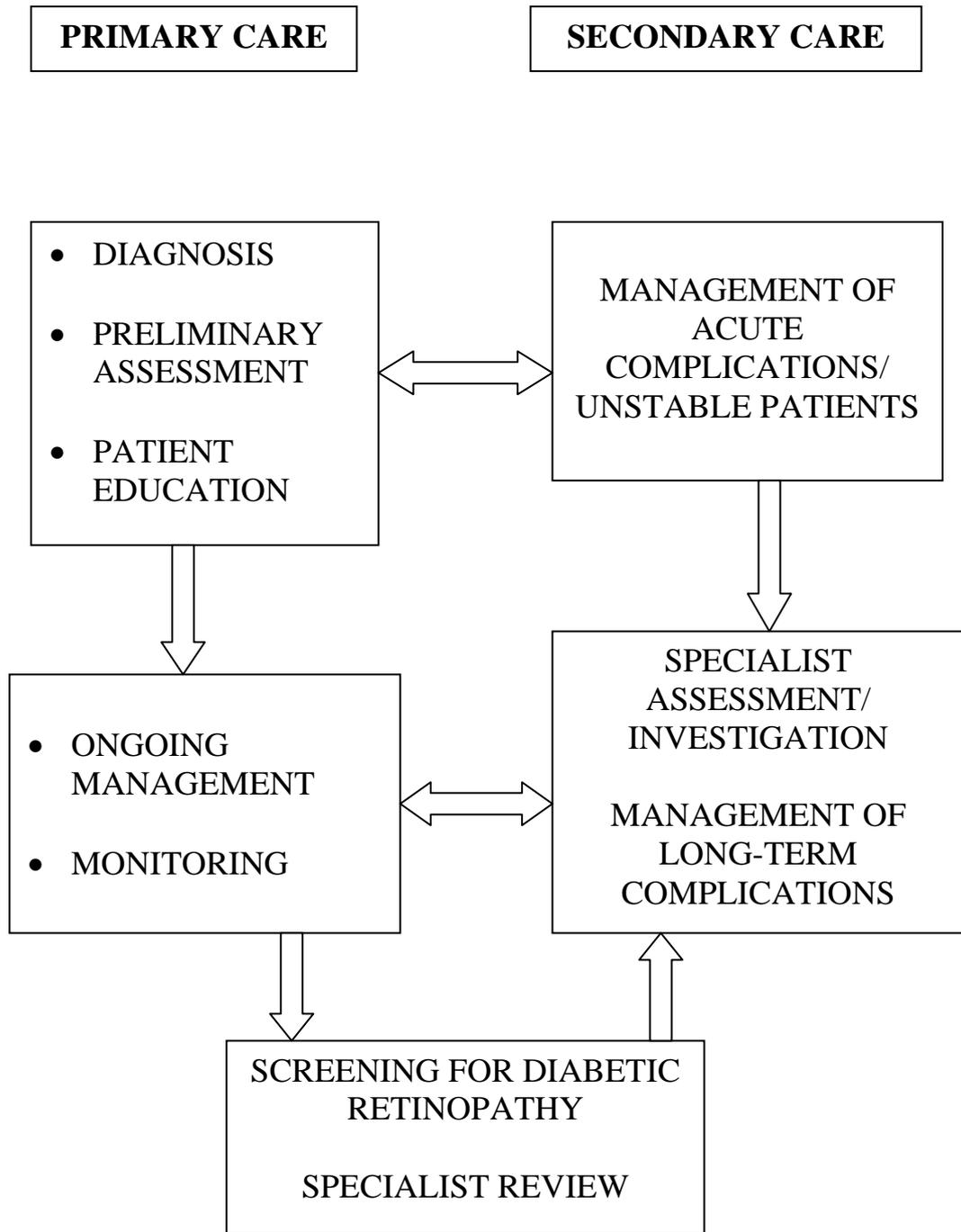
**Model for Diabetes Care in Ireland**



**TYPE 1 DIABETES**



**TYPE II DIABETES**



## Baseline Diabetes Assessment

Classification of diabetes (ADA classification)

Date of diagnosis & family history

Diabetes control

Cardiovascular history and profile (risk factor assessment including pulse and BP)

Renal assessment

Eye screening status-when last seen by the ophthalmologist, retinal status and referral to ophthalmologist annually

General medical history including recommended drug therapy (statins, aspirin, ace etc.)

Lifestyle assessment

Smoking status with referral to smoking cessation service if necessary

Alcohol

Physical activity

BMI with referral to dietician for annual review or more often if required

Foot Risk assessment (based on evidence-based protocol), with referral to chiropodist based on risk category

Social information including family support

Individual target setting

Education & support for the person on the following:

- What is diabetes
- Self-care issues – medication, recognition of complications
- Dietary management
- Lifestyle modification – sick day rules/travel
- General information on entitlements, travel, daily living activities.