Foreword

Type 2 Diabetes mellitus is a chronic progressive disease without a cure. It affects almost 1 in 20 people in Ireland. The prevalence of Type 2 Diabetes is rising rapidly, in large part due to the increasing obesity of the Irish population. The health care costs in looking after people with diabetes is very high and accounts for a substantial proportion of our health expenditure; from 5% to 15% depending on the location. The majority of the costs are required for the hospital management of people with complications of their diabetes such as cardiac and peripheral vascular disease.

To improve the quality of life of patients susceptible to diabetes and at the same time stem the tide of cost increases, we must focus on both preventing diabetes and also the development of complications in those who already have the disease.

Studies have shown that interventions that address obesity and our sedentary lifestyle reduce the prevalence of Type 2 Diabetes. For those with diabetes, good control of their blood sugar prevents the onset and the progression of complications. Unfortunately, many people have developed complications by the time they are diagnosed with Type 2 Diabetes. Many more develop complications because they are unable to keep their blood sugar values close to normal.

The purpose of our panel of Expert Advisory Groups (EAG) is to allow the clinical/health community and patients to drive reform and development in specific service areas; such as diabetes, old age, children etc. They act as important sources of operational policy/strategic advice and propose changes and implementation plans, cognoscente of the wider transformation agenda towards service integration and seamless patient journeys.

Against this backdrop and given the complexity of diabetes and the large number of health agencies and professionals involved in this area, it was appropriate for an EAG to be established to review the issue, make recommendations to and be involved with HSE management in implementing them.

The Diabetes EAG has fulfilled its remit admirably. I would like to express to all who have participated freely in its work and given up their time, my appreciation of their commitment to improving services in this area. This document represents our blueprint for the development of services for patients with diabetes over the coming years and I am pleased to see that already the recommendations are being acted on.

The integrated model of care proposed highlights how we can provide better care and patient experiences when different parts of the service work together in a coordinated way. We are all aware that good diabetes care prevents complications and make sense to patients and staff in our ongoing pursuit of maximising the impact of available resources.

I hope that the regional Diabetes Service Implementation Groups and the EAG itself will be able to assist us in this regard.

Professor Brendan Drumm
CEO HSE
Acknowledgements

Expert Advisory Groups (EAGs) were set up by the CEO Prof Drumm to advise the HSE on the organisation and development of health and personal social services. They comprise health professionals, clinical experts, patients, clients and service user groups. Their objective is to have an active role in health care reform and operational policy development, and to ensure policies are implemented appropriately. EAGs enable service users and the professionals who provide the service, to influence the development of HSE policies. Expert Advisory Groups are at the heart of operational policy, strategy and quality standards.

The Diabetes Expert Advisory Group was established in 2006 and voluntary membership was sought from among the diabetes community. Most people involved knew that the services for people with diabetes in Ireland were behind that available to their counterparts elsewhere in the developed world. They also knew that previous comprehensive reports from experts on how the service could be improved had not been acted on. Yet a significant number answered the call. The EAG that first assembled in December 2006, included people with diabetes, the professional caregivers and the managers that provide the resources for that care. It quickly became obvious that the common characteristic among all these individuals was their interest in what was best for the person with diabetes.

The experience of the members helped us develop; within a short space of time, a priority list of the issues that needed to be addressed. Presentations were made to the committee including those from the Diabetes Federation or Ireland and people performing pioneering work in care delivery. A number of subcommittees were established to look at individual priority areas. Additional people with diabetes and experts in various fields volunteered their time and expertise. The considerable administrative workload required to facilitate the groups was handled by the Assistant National Directors office and staff. The final report was agreed by the members in October 2007. A series of consultation meetings followed with Strategic Planning and Reform Implementation (SPRI) and the HSE National Directors, before the report and gap analysis was presented to Management Team in April 2008. All along the process, we were assisted by many people within HSE and this continues as we move more into implementation.

I would like to thank all the members who put in so much work to the Diabetes EAG. I feel the various reports including this one, reflect the members ability to put patient care ahead of professional sectoral interests. I would hope that the members will continue to be involved in the promotion and implementation of these reports. I feel they represent an overdue opportunity to bring services for all people with Diabetes in Ireland into the 21st Century. Implementation must be progressed urgently as failure to do so will result in more people developing complications of their diabetes, which of course, has a huge human and economic cost.

Colm Costigan
Consultant Paediatric Endocrinologist
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Executive Summary
Executive summary

Diabetes mellitus is one of the major chronic diseases. The prevalence of Type 2 Diabetes continues to increase rapidly, driven by the epidemic increase in obesity. Type 1 Diabetes is also increasing, though much more slowly.

Excellent diabetes care requires the integration of all of the recommendations and approaches identified herein by the Diabetes Expert Advisory Group and attention to all risk factors simultaneously – as shown by the success of the Steno studies (6).

The costs of diabetes care make up a substantial proportion of national health expenditure: from 5% to 15% depending on the location. It has been shown in Ireland that two thirds of this expenditure is currently spent on the complications of diabetes – many of which could have been prevented (7).

Excellent diabetes care and multi-disciplinary preventive care is also costly – but much less so, and the alternative is becoming difficult to defend either on economic grounds or on the simple grounds of human rights.

The onset of Type 2 Diabetes can be prevented by lifestyle intervention and medication. Type 1 Diabetes is not yet preventable. Secondary prevention is the core of clinical diabetes care. Once a patient has been diagnosed with diabetes that is the point from which all clinical care should be focused on the opportunity to prevent diabetes-related complications.

The cost of intensive management of blood glucose in Type 2 Diabetes is offset by potential savings in the treatment of future complications. The following table from the 2002 document Securing the Future highlights the patient costs related to complications.

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Based on a conservative estimated increase in prevalence of 37.49% over the period 2007-2015 the increase in cost to the health service at present day costs is €524m per annum (based on UK estimate that Diabetes or Diabetes related illness consumes of 10% of NHS expenditure).

‘Traditional’ diabetes care has been concentrated around the later stages of disease, when complications have already developed – and when the opportunity for prevention has been missed. This makes no sense from a governmental health budget standpoint, and it is hugely disadvantageous to those living with diabetes.

Diabetes is the leading cause of blindness, renal failure and non-traumatic amputation of lower limbs, and is a major risk factor for all forms of cardiovascular disease.

Foot complications have been shown in many studies to be the most costly of the diabetes outcomes – and to be preventable in more than 80% of cases by reasonably simple interventions in multidisciplinary foot clinics which include trained podiatrists, in addition to general risk factor control.

Many Irish people with Type 2 Diabetes do not have access to specialist evaluation at the time of diagnosis, and have limited or no access to intensified management which has been shown to prevent the complications (1) (2).

Diabetic eye disease can be prevented by general risk factor control. If it develops early detection by retinal screening programmes and treatment with laser photoocoagulation, will prevent loss of sight.

A large proportion of those who develop Type 1 Diabetes do so in childhood. Proper diabetes control from the outset prevents complications, improves quality of life and establishes good self management practices for the future.

Thus there is no longer any argument for not providing every person with diabetes access to intensive diabetes control.

Good primary care has a hugely beneficial effect on the mortality and morbidity from diabetes in adults.

Blood pressure control; regardless of the method, is hugely effective in preventing cardiovascular events (5) and progression of kidney disease in diabetes.

Cholesterol lowering therapy is effective in the prevention of myocardial infarction and stroke (3) (4).

Finally there is a major role for the patient and their family in diabetes care. To optimise this self care there is a need for targeted education, psychological support and social interventions.
## Standards
The EAG has unanimously agreed a core set of standards of care for any person diagnosed with diabetes in Ireland.

All other recommendations from the EAG are based on achieving these minimum standards of care.

## Integrated Model of Care
The EAG has agreed and strongly promotes the national implementation of this model on the premise that integrated care (between primary, secondary and tertiary care) is the ideal model for care of people with diabetes.

## Clinical Guidelines
The EAG has endorsed the recently published clinical guidelines of the ICGP and IES and DoHC. These are a detailed and comprehensive set of clinical guidelines for diabetes care. These guidelines will be reviewed at intervals of 1-3 years, depending on advances in treatment.

The EAG also endorses the paediatric clinical guidelines of the International Society for Paediatric and Adolescent Diabetes 2007-2008.

## Education/Empowerment
Education for people with diabetes has long been an important factor in the management of the condition, but this importance has risen significantly along with our growing understanding of the condition. The EAG has recognised the fundamental role that they play in improving metabolic control and preventing complications of diabetes.

## Transformation programmes

### Programme 5
Developing an ethos of continuous improvement across the organisation supported by robust performance management.

### Programme 1
Developing integrated services across all stages of the care journey by developing integrated care between primary care and hospital services.

### Programme 2
Configure PCCC services to deliver optimal and cost effective results by reconfiguring the existing services that support primary care teams.

### Programme 4
Implementing a model for the prevention and management of chronic illness by developing and implementing control standards and guidelines.

### Programme 4
Implementation of a model for the prevention and management of chronic illness in reducing risk factors and improving patient satisfaction.
## Key recommendations

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<thead>
<tr>
<th>ICT Project</th>
<th>Retinopathy</th>
<th>Podiatry</th>
<th>Paediatric/Adolescent</th>
<th>Research</th>
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<td>An effective Information and communications technology (ICT) system needs to be developed to assist with the integration of care across the primary, secondary and tertiary areas. This would enable risk stratification and decision support for service users and providers. The EAG recommends that a National Project Team be established under the guidance of the EAG to review and make recommendations on the necessary ICT requirements for an effective, integrative and national Diabetes Care Service.</td>
<td>The Diabetes EAG has set out the principles of a National Diabetic Retinopathy Screening Programme. The EAG recognises the fundamental role of retinopathy screening service in diabetes care. It has drawn up a service delivery model and recommends its implementation as a matter of urgency.</td>
<td>Foot-care is critically important in people with diabetes. Foot complications (ulcer, infection, deformity, advanced neuropathy, amputation) are the most costly outcome of diabetes. The EAG feels these initial recommendations will assist the development of this critical area of Diabetes Care.</td>
<td>The EAG has identified the current inadequacy of service provision in this area and proposes a comprehensive regional plan to improve the service.</td>
<td>The Diabetes EAG propose that an Irish based population survey on Diabetes prevalence rates be commissioned to augment the recent publication “Making Diabetes Count”.</td>
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## Transformation programmes

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<td>Development of a unified national ICT infrastructure and support services and the development of clinical and administrative systems.</td>
<td>Implementation of a model for the prevention and management of chronic illness by developing a framework for the prevention and management of diabetes.</td>
<td>Configuration of hospital services to deliver optimal and cost effective results.</td>
<td>To assist in the prevention and management of chronic illness.</td>
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Key transformation and change components

If we are to improve our care processes in line with international evidence and service redesign a sustained programme of investment, re-organisation and/or redirection of resource and focus is needed. The EAG is proposing the adoption of a new integrated, planned, shared and structured model of care in line with the major reform objectives of the HSE’s Transformation Programme, with the following key change components:

- Redesigned model of care which embraces a population health focus and offers a practical national model in linking primary, secondary and tertiary care services within an integrated clinical network (structured, shared and planned).
- Development of national guidelines and standards adopted by key stakeholders for a world class service.
- Clinicians at the heart of management—senior clinical leadership, shared ownership and identification with HSE.
- Utilising the massive resource that is the patient themselves.
- Visible transformational change in approach and design.
- Massive return on investment in avoiding a massive epidemic whose costs will explode and potentially overwhelm the health services if we do not focus on early detection and prevention.

The vision on delivery

There will be a spectrum of services available to the patient; ranging from primary prevention services, self care, and primary care services, including scheduled GP visits to underpin good practice models of care for the patient’s Diabetes. In addition the GP will be able to draw on the services of the rest of the primary care team/network to focus on the particular clinical or social problems. Other services such as screening and community intervention team services could be accessed by the primary care team as appropriate. Community and voluntary services are needed to provide support to patients in their own communities.

Secondary care services will be developed including specialist clinics, shared care systems and appropriate services for complex patients. Patient care plans will be developed on a shared care basis between clinicians as appropriate to the patients needs. Patients with stable disease will be managed in programmes reflecting this model of care with the majority of care taking place in primary care. Patients with more complex disease will require increased levels of specialist care. An important part of this clinical spectrum of care is a contribution of practice support both at primary care level and specialist services at secondary care level. It is underpinned by the adoption and adherence to clear standards, guidelines and protocols and the engagement of a motivated and co-ordinated clinical team who are empowered and accountable for the management of service programmes.

Underpinning this spectrum of clinical care is a complementary programme of patient support. Many patients will become the main manager of their own chronic disease and it is primarily their success in controlling the disease by lifestyle and/or medication which determines the severity of the disease and experience.
Conclusions and key challenges

RESOURCES
The Diabetes EAG are agreed that a significant reorientation, reorganisation and increase in resources is required to bring Irish diabetes care to a standard comparable to good practice in other EU countries. The Diabetes EAG recommends the initial development of 30 Diabetes Nurse Specialists posts. Along with this the Community Dietitians identified for the networks will focus on people with Diabetes in their general workload.

BALANCE OF RESOURCES
The EAG has agreed that resources for diabetes care should follow the patient. Thus the majority of routine Type 2 Diabetes care will take place in primary care with initial and “annual” input from hospital centres. The balance of care will be at secondary and tertiary level. This is for routine review and increased input into those with more complex diabetes, and those at high risk or with complications. The majority of Type 1 Diabetes care including all paediatric/adolescent diabetes care will take place at hospital diabetes centres.

COST SAVINGS
Once established, multi-disciplinary integrated care of the well patient with diabetes has been shown on a per-patient, per-annum basis to cost about 20% of the care of a patient with diabetes complications. The overall Diabetes EAG strategy will lead to real savings, but this is not expected before a 5 year cohort of patients has benefited from the preventive approach.

PERSONNEL
Key personnel shortages are evident in a number of specialist and general services e.g. diabetologists, GP training and specialisation, diabetes nurse specialists, dietitians and podiatrists in particular. There is an urgent need for additional diabetes nurse specialists posts.

ICT
There is an immediate need for the establishment of a National Project Team under the guidance of the Diabetes EAG to review and make recommendations with regard to the future development of Diabetes Services and the ICT needs for a national and integrative service.

CONTRACTUAL
The new GP contract needs to be concluded urgently and in a manner that promotes the participation of these key personnel in the integrated model of care.

CONCLUSION
There is a unique opportunity to develop an integrated service model which adopts a population health focus within the Transformation Programme and to invest in the necessary infrastructure to make it happen. This will contribute to the development of enhanced primary care and specialist services binding local and regional services together in the form of a managed clinical network. The concept of joint working within a managed clinical network has been recognised in the Action Plan for the Health Services in the North East as the key vehicle for enabling the delivery of best acute healthcare and is also a key recommendation of the Acute Hospital Bed Review 2007. A key goal is managing the majority of care needs and processes within the home/community environment, and utilising the skills of the patient/carer.

The model also fundamentally recognises the centrality of clinician involvement in the design, provision and improvement of care and is integrated with other initiatives on the agenda of reform. The service model that ensues could be utilised for other categories of chronic diseases, conditions and for service integration.
two

Introduction
Introduction

The Diabetes Expert Advisory Group held its first meeting in December 2006 and a further nine meetings were since held. The sub groups held approximately 22 meetings, some of which were teleconferences.

Members of the Diabetes Expert Advisory Group are as follows:

Dr. Colm Costigan, Consultant Paediatric Endocrinologist, Dr. Graham Roberts, Consultant Endocrinologist, Dr. Sean Dinneen, Consultant Endocrinologist/Senior Lecturer, Prof. J. Nolan, Consultant Endocrinologist, Dr. Velma Harkins, GP, Dr. Ned Barrett, Consultant Biochemist, Dr. Damian Doyle, GP, Ms Rita Forde, Advanced Nurse Practitioner, Ms. Patricia Crocock, Diabetes Nurse Specialist, Dr. Tony O’Sullivan, GP, Ms. Ann Murphy, Kerry Diabetes Association, Ms. Judy Lee, Pharmacist, Ms. Maeve Carmody, Senior Community Dietitian, Ms. Margaret Humphreys, Clinical Specialist Nutrition & Diabetes, Mr. William Reddy, Programme Manager, HSE Transformation Programme 1, Ms. Louise McMahon, Network Manager, Ms. Antoinette Doocey, Process Design Team, National Transformation Programme, Dr. Orlaith O’Reilly, Director of Public Health HSE South, Mr. Brian Muller/Dr. John Devlin, DOHC, Mr. James Conway, Assistant National Director, (Palliative Care & Chronic Illness), Office of the CEO, Mr. Pat Donnelly, PCCC Rep, Transformation Programme

Subgroups and members are as follows:

Standards of Care
Tony O’Sullivan (Chair), Rita Forde, Sean Dinneen, Antoinette Doocey, Velma Harkins, Margaret Humphreys, Maeve Carmody, Ned Barrett, James Conway

Retinopathy
Orlaith O’Reilly (Chair), Sean Dinneen, Graham Roberts, Louise McMahon, Colm Costigan, Patricia Crocock, James Conway

Paediatrics
Colm Costigan (Chair), Patricia Crocock, Graham Roberts, Margaret Humphreys, Deirdre Bowers, Tom Stack, Denise Gillespie, Terry Bate, James Conway

Education/Patient Empowerment
Rita Forde (Chair), Sean Dinneen, Maeve Carmody, Judy Lee, Willie Reddy, James Conway

Podiatry
Professor John Nolan (Chair), Rick Druggan, Patricia Godwin, Emily Haworth, James Conway

Model of Integrated Care
Damian Doyle (Chair), Graham Roberts (Chair), Willie Reddy, Ned Barrett, James Conway, Patricia Crocock, Rita Forde, Margaret Humphreys
Diabetes – an overview

Diabetes mellitus results from an inadequate effect of insulin either due to its absence (Type 1) or resistance to its action (Type 2). The latter is approximately 10 times more prevalent than the former and essentially associated with the obesity epidemic.

The number of people affected by diabetes is growing at such an alarming rate that it threatens to overwhelm the health service. Today, it is estimated that at least 141,063 adults in the Republic of Ireland (4.7%) have diabetes (diagnosed or undiagnosed) and this is predicted to rise to at least 193,944 or 5.6 % of the population by 2015 – a 37% increase. It is estimated that over 10% of governmental healthcare spending is diabetes related and the costs of caring for the growing number of people with diabetes will increase by up to 25% by 2040. Diabetes represents a very significant risk to the increasingly overweight, ageing and urban population.

- Type 2 Diabetes is largely preventable; this is a preventable epidemic.
- Around one in twenty people in Ireland has diabetes.
  Half of these people will die from a diabetes-related condition.
- Up to a half are as yet undiagnosed.
- Average life expectancy is reduced by 15-20 years in Type 1 Diabetes and by 5 or 7 years (male/female) in Type 2.
- The risk of major medical complications is up to 11 times that for people without diabetes and people with diabetes are five times as likely to need hospital admission.
- If present trends of increasing obesity continue, more people will develop diabetes with its inherent risk of complications. This will raise costs of healthcare which will result in an increase in costs to patients, their families and the whole economy.

Primary prevention of Type 1 Diabetes is not yet possible but all agree that primary prevention of Type 2 is an urgent public health issue. (See below: “A population health approach to care delivery”). Recently, the 25 EU health ministers unanimously supported this by seeking to:

a. Develop and implement diabetes framework plans to address prevention, screening and management of the disease.
b. Develop accessible and affordable public awareness and primary prevention measures to target those at risk and the population as a whole.

Secondary prevention is the core of clinical diabetes care. Once a patient has been diagnosed with diabetes, this is the point from which all clinical care should be focused on the opportunity to prevent diabetes related complications. This has also been endorsed by the EU health ministers who support the multi-sectoral and multi-disciplinary approach with comprehensive diabetes training for healthcare professionals. If complications do develop then they need to be identified at the earliest possible time so that the individual and their medical team can optimise the metabolic control and treat the complications early. An example is retinopathy screening.

Tertiary prevention is really the treatment of those with late complications with their huge morbidity and mortality, not to mention the huge health care costs required. Unfortunately a cohort of such patients will exist; at least until, adequate secondary prevention strategies take effect.

For the management of their diabetes people need long-term support from their healthcare team. The goal of medical treatment for both Type 1 and Type 2 Diabetes is the same: to enable the patient to lead as normal a life as possible, free from adverse effects and complications for as long as possible.
Diabetes is a chronic disease with a major role for self management. As a consequence there is a major role for education and empowerment of the individual and their family to promote this. All impediments to their ability to invest enough focus on this aspect of their lives needs to be removed, if possible. This may involve tailored education, psychological assistance and social interventions.

What is it that costs in diabetes care?

Of all people with diabetes, approximately 75-80 per cent will die of cardiovascular diseases. People with Type 2 Diabetes have a two to four time’s higher risk of coronary heart disease than the rest of the population, and their prognosis is poorer. The risk of cerebrovascular diseases and peripheral vascular disease is also significantly higher in Type 2 Diabetes. Cardiovascular diseases are the main reason for the high cost of diabetes care. According to a major study on diabetes costs by Kangas, hospitalisation forms the greatest expense, accounting for about 56 per cent of the total cost of diabetes care.

Most of the hospital care of diabetes (73%) consists of the treatment of cardiovascular diseases. According to current estimates, the costs will quickly increase in the future owing to the rapid growth in the numbers of people with Type 2 Diabetes. There is also evidence of the significant increasing costs of drug treatment for diabetes related illness in the various community drugs schemes. This is likely to increase further in line with projected increase in prevalence. The future reduction of costs necessitates prompt recognition of the risk factors of cardiovascular diseases and their aggressive treatment.

The cost of intensive management of blood glucose in Type 2 Diabetes is offset by potential savings in the treatment of future complications. The following table from the 2002 document *Securing the Future* highlights the patient costs related to complications.

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*Note:* Based on a conservative estimated increase in prevalence of 37.49% over the period 2007-2015, the increase in cost to the health service at present day costs of €1.4bn (based on UK estimate of 10% would be €524m per annum.

How can Diabetes Care be improved?

In a recent Institute of Medicine report in the USA: A New Health System for the 21st century “Crossing the Quality Chasm” its main conclusions were that current care systems cannot do the job, trying harder will not work but changing care systems will. We require a model of care which supports the delivery of a seamless, responsive and flexible system of long-term patient care, provided by any and all partners in a collaborative, multidisciplinary team working for and with the patient. These system changes will produce productive interactions between an informed, activated patient and a prepared, proactive team that will result in improved outcomes.
Using the Chronic Care Model that reflects a system change concept, a number of main areas need to be addressed:

- Self management support
- Delivery system design
- Decision support
- Clinical information systems.

Where do we direct the level of care?

**Chronic Disease Management: Population Management**

**Level 1**
With the right support many people can learn to be active participants in their own care, living with and managing their conditions. This can help them to prevent complications, slow down deterioration and avoid getting further conditions. The majority of people with chronic conditions fall into this category - so even small improvements can have a huge impact.

**Level 2**
Disease/care management, in which multidisciplinary teams provide high quality evidence-based care to patients, is appropriate for the majority of people at this level. This means proactive management of care, following agreed protocols and pathways for managing specific diseases. It is underpinned by good information systems - patient registries, care planning, shared electronic health records.

**Level 3**
As people develop more than one chronic condition (co-morbidities), their care becomes disproportionately more complex and difficult for them, or the health and social care system, to manage. This calls for case management - with a key worker (often a nurse) actively managing and joining up care for these people.

Deciding the right approach
It is important to have the information and knowledge to be able to carry out a risk-stratification on local populations to identify those who are most at risk.

This shows that most (70-80 per cent) people with long term conditions can care for themselves, and need minimal input from health and social services. They represent the bottom layer of the pyramid. In the middle layer are ‘high risk patients’ – people who need more active disease and care management from professionals. Finally, in the top level, are the patients with highly complex needs. These patients are usually aged over 65, and represent a small proportion of the population, but account for a large number of emergency admissions to hospital. Much of the work that has been carried out in the management of long term conditions has concentrated on ‘case management’ for this third tier of patients. Case management requires a key worker – often a nurse – actively managing and joining up care. Primary and specialist services are available at each level as appropriate to patient need.

Source: Supporting people with long term conditions NHS
www.natpact.nhs.uk/cms/336

Health Promotion

Level 3
High complex patients
Care Management

Level 2
High risk patients
Care Management

Level 1
70-80% of a Chronic Care Management population
A population health approach to care delivery

It is well recognised that health and chronic illness is determined by the interplay of many factors including genetic, lifestyle, social, economic, cultural and environmental. There is a growing recognition that lifestyle behaviours, such as physical activity, diet and smoking are influenced not only by individual choice, but also by a variety of social, economic and cultural factors inherent in the society and environments where people live and work. In addressing the issue of Diabetes and other chronic illnesses we need to develop strategies which prevent and manage these conditions appropriately, whilst recognising that the most significant determinants of health are social and economic factors, not those most strongly linked with healthcare services or personal choices and behaviours. Those on low income are more likely to suffer health inequalities and are most at risk of chronic illness including physical, social and mental health problems and they are also more likely to die at an earlier age from their chronic illness than those on high incomes. The engagement of other Government Departments is essential in the formulation of strategies and inter sectoral co-operation in the implementation of the framework to manage Diabetes and other chronic illnesses.

As the demographic profile in Ireland is changing, with more people in the middle to older age groups and more people living longer, based on international evidence, we are experiencing a significant increase in the incidence of chronic illnesses such as Diabetes. Significant lifestyle factors such as physical inactivity and unhealthy diets have resulted in a twin epidemic of obesity and diabetes which will significantly increase the incidence of those with chronic illness.

The elements of the HSE Chronic Illness Prevention and management model that correlate with a Model of Care for Diabetes and the recommendations within the report are:

- Building healthy public policy
- Reorienting and integrating health services (Ref: Integrated Model of Care)
- Creating environments that support health
- Strengthening community action
- Developing personal skills and self management (Ref: Education and Empowerment)
- Information systems (Ref: ICT).

Building a healthy public policy
The development of policies at a macro level to improve population health involves working towards policy which addresses health inequalities in the first instance.

Reorienting and integrating health services
In order to reorient health services, there is a need to develop and provide high quality, integrated, evidenced based clinical and curative services at the appropriate level and setting. Integrating health promotion, primary preventative, secondary preventative, primary health care and specialist services is essential to maximise the effectiveness of the health care system to manage diabetes and minimise its effect on the population.

Creating environments that support health
Significant integration across sectors will be required to provide a supportive environment for the maintenance of good health in the population, including those who are living with diabetes.

Strengthening community action
This is a critical action in developing and sustaining a robust model of care for Diabetes. It involves working in partnership with community groups to set priorities and to collectively achieve goals that enhance the health of
Developing personal skills and self management
Developing personal skills can be applied to the theory and practice of ‘self-management’, which is a core element of this and other chronic illness models. It refers to the development of personal skills for health and wellness and to the support of self-management in coping with an illness. Patient self management, including self help groups and disease support groups, improve clinical outcomes and reduce health care utilisation cost.

Information systems
In supporting a comprehensive Diabetes model a combination of clinical information systems, information about demographics and health status, information on cultural, social and economic trends is combined with community health needs assessments that are led by community groups. Clinical information systems are essential for integrating care across primary and secondary service providers.

The broader International evidence points us towards a population health approach to prevent diabetes and improve its control. Such an approach will reduce the risk of diabetes developing in individuals without the disease and reduce the risk of complications among those individuals with Diabetes. Structured educational programs can assist and encourage individuals to adopt a healthy lifestyle with effective weight control, increased physical activity, and cessation of smoking. These health promotion messages are not unique to just the condition of diabetes. The central message that needs to be conveyed is that Type 2 Diabetes is by no means a “mild diabetic disease” but a fatal cardiovascular disease if all the risk factors are not properly treated.

The central message to the wider population is an awareness of the risks that their lifestyle and behaviours have on their health and general well being and that there are measures to help them improve. Healthy eating and exercise programmes can assist in the prevention of Type 2 Diabetes.

This needs to be developed and integrated across all elements of health and social care, including independent and voluntary sector providers, to enable the widest possible access for all communities.

Social and community care needs to be interpreted as widely as possible to include education providers and those engaged in promoting healthy communities and environments. This reflects a settings approach which can include transport, schools, sports clubs and dieting programmes.

Care needs to be taken to ensure that different cultural and ethnicity requirements are acknowledged and programmes are sufficiently flexible to meet all needs.

Lifestyle intervention can significantly reduce the likelihood that people at a high risk of diabetes actually get it. Progression rates to diabetes in people without diabetes was reduced:

- 58% in the Diabetes Prevention Program (USA)
- 58% in the Finnish Diabetes Prevention Study (Finland)
- 40% in the Da Qing study (China).
Diabetes Management – Enabling with information and communications technology (ICT)

For a proper ICT intervention in Diabetes management it is necessary to integrate the components of the chronic disease management approach. There are five major types of ICT intervention.

1. Population analysis (risk stratification)
2. Telephone support
3. Self-care (including supporting decision making by individuals with diabetes)
4. Decision support for clinicians
5. Shared information about people receiving care.

## INTEGRATION / TRANSFORMATION

<table>
<thead>
<tr>
<th>Key Recommendations</th>
<th>Transformation Programmes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Standards</strong></td>
<td>Programme 5</td>
</tr>
<tr>
<td>The EAG has unanimously agreed a core set of standards of care for any person diagnosed with diabetes in Ireland.</td>
<td>Developing an ethos of continuous improvement across the organisation supported by robust performance management.</td>
</tr>
<tr>
<td>All other recommendations from the EAG are based on achieving these minimum standards of care.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Integrated Model of Care</th>
<th>Programme 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>The EAG has agreed and strongly promotes the national implementation of this model on the premise that integrated care (between primary, secondary and tertiary care) is the ideal model for care of people with diabetes.</td>
<td>Developing integrated services across all stages of the care journey by developing integrated care between primary care and hospital services.</td>
</tr>
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</table>

<table>
<thead>
<tr>
<th>Clinical Guidelines</th>
<th>Programme 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>The EAG has endorsed the recently published clinical guidelines of the ICGP and IES and the DoHC. These are a detailed and comprehensive set of clinical guidelines for diabetes care. These guidelines will be reviewed at intervals of 1-3 years, depending on advances in treatment.</td>
<td>Configure PCCC services to deliver optimal and cost effective results by reconfiguring the existing services that support primary care teams.</td>
</tr>
<tr>
<td>The EAG also endorses the paediatric clinical guidelines of the International Society for Paediatric and Adolescent Diabetes (2007-2008).</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Programme 4</th>
<th></th>
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<tbody>
<tr>
<td>Implement a model for the prevention and management of chronic illness by developing and implementing control standards and guidelines</td>
<td></td>
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</table>
Education/Empowerment
Education for people with diabetes has long been an important factor in the management of the condition, but this importance has risen significantly along with our growing understanding of the condition. The EAG has recognised the fundamental role that they play in improving metabolic control and preventing complications of diabetes.

ICT Project
An effective Information and communications technology (ICT) system needs to be developed to assist with the integration of care across the primary, secondary and tertiary areas. This would enable risk stratification and decision support for service users and providers. The EAG recommends that a National Project Team be established under the guidance of the EAG to review and make recommendations on the necessary ICT requirements for an effective, integrative and national Diabetes Care Service.

Retinopathy
In 2007 the Diabetes EAG has set out the principles of a National Diabetic Retinopathy Screening Programme. The EAG recognizes the fundamental role of retinopathy screening service in diabetes care. It has drawn up a service delivery model and recommends its implementation as a matter of urgency.

Podiatry
Foot-care is critically important in people with diabetes. Foot complications (ulcer, infection, deformity, advanced neuropathy, amputation) are the most costly outcome of diabetes. The EAG feels these initial recommendations will assist the development of this critical area of Diabetes Care.

Paediatric/Adolescent
The EAG has identified the current inadequacy of service provision in this area and proposes a comprehensive regional plan to improve the service.

Programme 4
Implement a model for the prevention and management of chronic illness in reducing risk factors and improving patient satisfaction.

Programme 10
Development of a unified national ICT infrastructure and support services and the development of clinical and administrative systems.

Programme 4
Implement a model for the prevention and management of chronic illness by developing a framework for the prevention and management of diabetes.

Programme 3
Configure hospital services to deliver optimal and cost effective results.
All of these recommendations from the sub group’s work support the HSE’s transformation programme.

The proposals from the sub groups are also interlinked so that all are required to achieve the system wide change needed to transform Diabetes Services. This is illustrated in that a number of the standards set out in Chapter 3A will be achieved in the delivery of the model of care (Chapter 3B). The model of care will require the national implementation of the clinical guidelines (Chapter C) and roll out of the retinopathy screening (Chapter 3F) and podiatry recommendations (Chapter 3G). Structured education programmes and peer support programmes reflect a population health approach and acknowledge the wider determinants of health.

Integrated care will be expensive but the overall strategy will lead to real savings. This is not expected before a 5 year cohort of patients have benefited from the transformation of the service delivery.

Potential reductions in diabetes complications as a result of the proposed system changes could provide the opportunity to reorient resources.

Immediate requirements are new and additional resources, a reorientation and reconfiguration of existing resources and utilisation of cost savings in the system.

Some of these requirements could include:

- The increase in consultants, podiatrists and diabetes nurse specialists.
- A new GP contract that encourages participation in integrated care.
- Nurse and Allied Health Professionals having joint remits across the service areas.
- Utilisation of the resources identified for developing Primary Care Teams and Networks can benefit the development of Diabetes Services.
- Utilising the potential of service users to more actively manage their care in the home setting and reduce reliance where appropriate on health service professionals.
- Potential savings from drug costs under the LTI scheme and GMS scheme could be utilised for future development of the services.
- Targeted Monies available under the National Development Plan for investment in Information and Communications Technology.
Potential benefits

The development of national standards and clinical guidelines will provide the national leadership and framework to enable local implementation. It is difficult to measure the benefits of a redesigned service that brings an excellence to patients and should be viewed as an investment in the future. For the individual patient and family there is an increase in productivity and reduced outlay on treatment. For society, there is a reduction in absenteeism, early retirement and social care costs with accompanying improved quality of life.

The potential benefits of delivering on these recommendations could impact positively on:

- Number of bed days
- Costs of treating complications
- Drug costs
- Social care costs
- Absenteeism to industry
- Costs to industry of premature death.

The model of care identified in the recommendations could be adapted and adopted for other chronic diseases and conditions e.g. COPD, Ageing.

There are also common areas with the Older Persons EAG and their service agenda that reflects the wider transformation agenda, potential VFM initiatives and increased efficiency of resource usage. This is especially evident in the model of care, guidelines and codes and ICT systems for risk stratification and informed decision making.

These recommendations address the transformation priorities in a number of the programmes.

Other benefits include the highlighting of senior clinical leadership, ownership and meaningful involvement supports a clinical governance agenda, standards driven with local implementation, objective and quantitative indicators for benchmarking and quality improvement, integrated multi-disciplinary structure, provides a direction to GMS contract negotiations and is population and patient focused.

These recommendations also reflect the outputs in the HSE’s service plan for 2007 as it outlines an agreed integrated care model, put forth guidelines for clinical implementation, and prepare an initial plan for structured patient education programmes and an implementation framework for retinopathy screening.

Next phases

The Diabetes EAG needs to continue on with its work and guide the implementation of the recommendations to ensure service improvement.
three

Sub Group Reports and Recommendations
Standards

Standards of Diabetes Care
Diabetes care is multi-faceted and improving the quality of diabetes care at a national level is a major challenge. As part of its approach to this task the Diabetes EAG has agreed 2 sets of standards of care, one for adults and one for children/adolescents living with diabetes in Ireland. The standards reflect high level aspirations of what diabetes healthcare professionals should deliver and more importantly what individuals living with diabetes should expect to receive. The standards are intended to be read in conjunction with other outputs of the EAG including the joint ICGP/IES/DoHC clinical practice guidelines, the proposed integrated model of care and the priority areas for service development identified by the EAG including self-management education, retinopathy screening and foot care. While some of these outputs are dependent on other factors for delivery (e.g., resources or contractual changes) the standards can be “signed off on” at no cost.

The St Vincent Declaration, published in the early 1990’s and endorsed by the World Health Organisation, included a set of high level targets for diabetes care across Europe. It served to focus the minds of policymakers on the growing challenge of diabetes and diabetes care. In many countries and regions of Europe the St Vincent Declaration helped mobilise efforts to collect good quality data on the burden of diabetes and use these data to inform service development. Although many of the targets laid down in the St Vincent Declaration have not been met it has undoubtedly been a force for good and continues to provide inspiration to healthcare professionals involved in diabetes care.

In Ireland in 2008 we have no national (or regional) data on the prevalence or incidence of diabetes. We have very limited data on the personal or societal burden of diabetes. We have no national plan for diabetes and have major obstacles to implementation of good quality diabetes care including a failure to recognise and reimburse general practitioners for preventive services. Despite these deficiencies we have an obligation to move things forward. The HSE has identified diabetes as a priority and the Diabetes EAG is the only EAG to date to advise on a chronic illness. The intention of the paediatric/adolescent and adult standards of care is to point to where we should be with diabetes care in Ireland. The standards are intended to be understandable and motivational to individuals living with diabetes and diabetes caregivers alike. Future work by the standards sub-group of the EAG will attempt to incorporate measurable outputs into the standards to facilitate audit of care delivery. Knowing where we want to be is the first step on the journey to improve diabetes care. How to get there will be the focus of future output from the EAG. How quickly we get there will depend to a large extent on the commitment of the HSE to the concept of the EAG improving care.

Standard 1
People at risk of diabetes in Ireland should...
...be able to access diabetes prevention services including population risk factor reduction, targeted screening and high-risk diabetes prevention strategies.

Standard 2
People with diabetes living in Ireland should...
...receive care that is person-centred and encourages self-management. They should be enabled to participate in clinical decision making, care planning and service planning to the extent that they are confident and comfortable with doing this.
Standard 3
People with diabetes living in Ireland should…
…be able to access diabetes care expertise and self-management education that is appropriate to their needs and in a location that is convenient and acceptable to them.

Standard 4
People with diabetes living in Ireland should…
…be able to achieve optimal control of their weight, blood glucose, blood pressure and lipid levels through appropriate access to lifestyle advice (diet and exercise), drug therapy and modern devices.

Standard 5
People with diabetes living in Ireland should…
…be aware of their risk of diabetes complications (in the eyes, kidneys, feet and blood vessels) and receive high quality screening for these complications on a regular basis.

Standard 6
People with diabetes living in Ireland should…
…be able to access high quality services to treat (and delay progression of) the complications of diabetes if these have already developed.

Standard 7
People with diabetes living in Ireland should…
…when pregnant or anticipating pregnancy, have access to specialist care from a joint diabetes and obstetric team skilled in the management of diabetes in pregnancy.

Standard 8
People with diabetes living in Ireland should…
…expect minimal disruption to the continuity of their care at times of transition of care; e.g., when moving from one area to another and especially during the transition from paediatric/adolescent to adult services.

Standard 9
People with diabetes living in Ireland should…
…be able to access psychological assessment and care, information, peer support and diabetes advocacy at all stages of the condition.

Standard 10
People with diabetes living in Ireland should…
…be aware that high quality diabetes care is all about teamwork and that good communication between members of the diabetes team is essential to enable people to live well with their condition.
Integrating Model of Care

A Model of Care for Type 2 Diabetes

It has been clearly demonstrated that the concept of waiting to refer diabetes patients for specialist care until complications have occurred is financially flawed and fails to provide adequate care to the person with diabetes. Specialist referral and input should occur at diagnosis. The most financially and clinically important Chapter of care during the life of a person with diabetes is the adequate prevention of complications through achieving increasingly strict levels of glucose control, control of blood pressure, control of cholesterol and other factors in diabetes. It is well understood that a Care System that requires co-ordinating the actions of trained general practitioners and secondary care specialists can provide adequate diabetes care to a substantial number of diabetic patients.

It is now essential to develop a formal structure to enable such a Model of Care which includes quality assurance and financial remuneration of episodes of clinical care. The essence of such a Care Model is agreement across the primary-secondary care interface on joint structures and processes of care, including clinical pathways and the development of responsive and accessible patient information systems. The principal rule is to improve the cooperation between primary health care and specialised medical care, while having an appropriate division of labour and straightforward consultation opportunities in both directions. Experience of such Models of Care has given clear feedback from general practice and specialists as to the development of a suitable system. This feedback has included:

- The need for prompt access to early specialist input, ongoing review and early diagnosis of complications.
- The need for adequate funding/financial remuneration for both primary care units and specialist care centres.
- The need for adequate information technology systems capable of communication between general practices and specialist care centres.
- The need for availability of access to both primary care and specialist centres including initial “fast track” referral and review in the secondary care services.
- The need to initially train health care professionals involved in diabetes care and ensure quality of training.
- The need for quality assurance of practitioners during ongoing participation in the scheme.
- The need to increase training resources in order to produce adequate staff numbers to work within such a system.

If we are to succeed in transforming our services along the lines proposed there needs to be clarity and consensus on:

- The framework through which integrated care will be delivered in terms of:
  - Structure
  - Commissioning
  - Governance.
without clarity and commitment on a care model/structure, individual managers, clinicians and indeed the system will struggle to deliver on meaningful, sustainable integrated service development. Core components of a new structure include:

- The development of clinical networks for diabetes across the continuum of services.
- A national clinical specialist leadership forum.
- A mechanism for feedback through multi disciplinary, cross sectoral Local Diabetes Service Implementation (Development) Groups.
- a connection to the delivery process through Local Implementation Teams and resources.

The suggested roles are expanded further in Appendix 1.

Specialist input for Type 2 Diabetes is essential from diagnosis. Once diagnosed, most patients with Type 2 Diabetes can be placed within an integrated primary-secondary care structure and will then receive episodes of care within primary care and episodes of care in secondary care. Such a system can result in up to 75% of care episodes occurring in general practice and simultaneously achieve over 75% of changes in care being made by the secondary care specialist. However, there is a group of patients for whom the majority of care will occur in secondary care. This group will include Type 1 Diabetes patients, Type 2 Diabetes requiring considerable specialist input, pregnant females with diabetes, females with diabetes planning pregnancy, children and adolescents with diabetes. There is a need to provide tailored care targeted at the individual patient's needs (see population health model – Appendix 2). There is then a need to resource such care appropriately.

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 interdisciplinary 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 a managed and integrated clinical network*. Specialist hospital diabetes services (Regional Endocrinology/Diabetes Centres) are also essential to the framework. This is of particular importance for individuals with diabetes complications. They 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 typical composition of a Regional Endocrinology/Diabetes Centre has been previously outlined in report prepared by the Diabetes Service Development Group in 2002 and is discussed in Appendix 3.

*A managed clinical network has been defined as “linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and organisational boundaries, to ensure equitable provision of high quality, clinically effective services”.

First Report from Diabetes Expert Advisory Group
Implementation system

There is a clear requirement to ensure that the work of the Expert Advisory Group can and does influence and inform service planning, service delivery and monitoring at national and local levels. In this regard a robust governance and implementation structure is required with pro-active, visible and accountable clinical leadership.

The implementation system outlined schematically is a new organisational design utilising the concept of managed clinical networks, structured clinical governance and supported by Local Implementation Team structures.
A number of key requirements for progress have been identified which will need active management and consideration. These have been set out in Appendix 4.
The Vision: What will we get?

There will be a spectrum of services available to the patient; ranging from primary prevention services, self care, and primary care services, including scheduled GP visits to underpin good practice models of care for the patient’s specific illnesses. In addition the GP will be able to draw on the services of the rest of the primary care team and the primary care network to focus on the particular clinical or social problems. Other services such as screening and community intervention team services could be accessed by the primary care team as appropriate. Community and voluntary services are needed to provide support to patients in their own communities.

Secondary care services will be enlarged and developed including specialist clinics integrated care systems and appropriate services for complex patients. Patient care plans will be developed on an integrated care basis between clinicians as appropriate to the patients needs. Patients with stable disease will be managed in programmes reflecting this model of care, largely in the primary care setting. Patients with more complex disease will require increased levels of specialist care. An important part of this clinical spectrum of care is a contribution of practice support both at primary care level and specialist services at secondary care level. A number of patient pathways are shown in Appendix 5.

Approval from the participating specialist and general practitioner both will be required prior to the patient’s entry into the system of shared care and will be required annually or as agreed locally from the participating specialist and general practitioner both for a patient’s continuance in the system with an agreed care plan. While it can not be insisted that a particular specialist or GP will participate in the shared care system, it is necessary that for those who do, the time involved in clinically directing services is recognised by the HSE. Both primary care and secondary care need to be funded to provide these services. A number of patient pathways are shown in Appendix 5.

Underpinning this spectrum of clinical care is a complementary programme of patient support. Many patients will become the main manager of their own chronic disease and it is primarily their success in controlling the disease by lifestyle and/or medication which determines the severity of the disease and experience. Patient support programmes support patient self care. The programmes are built around the patient and tailored to his/her particular level of complexity and risk.

Within the EAG a number of sub groups have been established on different component parts relating to Diabetes Care. The work of these sub groups in Retinopathy Screening, Podiatry, Education and Patient Empowerment and Standards development are complementary and congruent with this model of care. It is envisaged that the development and completion of these pieces of work will assist in the proposed next phase of implementation.
Appendix 1

**Roles within Care Model**

<table>
<thead>
<tr>
<th><strong>Person with diabetes</strong></th>
<th>Central. Self-care management. Peer support, Expert patient.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Patient Support Services including Diabetes Federation of Ireland</strong></td>
<td>Support for children, parents, adolescents, adults of all ages. Support at diagnosis and regularly throughout life with diabetes including advice on driving, legal issues, Political and public awareness. Social issues e.g. discrimination.</td>
</tr>
<tr>
<td><strong>Primary Care Team (GP assisted by practice nurse and practice administrator)</strong></td>
<td>Providing bulk of routine medical care. Providing routine review of diabetes parameters. Gatekeeper role. CVD risk assessment. Glucose testing in practice. Some diabetes education. Patient training e.g. in home glucose testing. Day-to-day support. Compilation of a practice diabetes register. Recall and organisation of practice clinic appointments. The number and ratio of healthcare professionals required for the primary care team will depend on needs assessment and the geographic location of the team.</td>
</tr>
<tr>
<td><strong>Primary Care Network: a range of health and social care professionals</strong></td>
<td>Each primary care team will have access to primary care network members who will provide services for their clients with diabetes. Primary care network members include Community Dietitians, Community Podiatrists, Community Pharmacists, Community Welfare Officers and Psychologists amongst others. We envisage Diabetes Nurse Specialists being a resource to the GP / practice nurse / the practice’s diabetes patients and a link to the hospital system. Members of this primary care network will work with more than one primary care team.</td>
</tr>
<tr>
<td><strong>Role of Local Diabetes Service Implementation Group. One per HSE region.</strong></td>
<td>Each area should establish a group to help advise on the services which should be commissioned and provided in their area in order to improve the health of local people with diabetes. Initially the group will help to:</td>
</tr>
<tr>
<td></td>
<td>• Identify local needs.</td>
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<tr>
<td></td>
<td>• Adapt national diabetes care guidelines to suit local situation.</td>
</tr>
<tr>
<td></td>
<td>• Prepare participating practices structurally by assisting them to construct practice based registers and recall systems.</td>
</tr>
<tr>
<td></td>
<td>• Discuss education of health care professionals depending on local need.</td>
</tr>
<tr>
<td></td>
<td>• Discuss structured communication and additional administrative support to the service and its ongoing audit and evaluation.</td>
</tr>
<tr>
<td></td>
<td>• Discuss audit and guidelines for referral. They may also need to address cultural issues that arise in the community and be aware of the needs of ethnic groups migrating locally.</td>
</tr>
</tbody>
</table>
The composition of the group and method of working is likely to vary to meet local needs but suggested makeup is as follows:

- A local specialist endocrinologist involved in diabetes care provision (chair).
- Three general practitioners, including one without a practice nurse, and one who is a General Practice Unit doctor.
- The Diabetes Federation of Ireland regional committee chairperson.
- The Primary Care Manager, local health board.
- A person to address psychosocial issues.
- A practice nurse representative.
- A public health nurse.
- A community/hospital diabetes nurse specialist.
- A community/hospital diabetes dietitian.
- A community pharmacist.

Secondary Care Team (Consultant endocrinologists assisted by Diabetes Nurse Specialists, Diabetes Dietitians, Podiatry specialising in diabetes and a Diabetes Co-ordinator).

Specialist team, hospital-based.

- ‘Annual’ or more frequent review of all diabetes patients including screening for early micro-vascular and macro-vascular complications.
- Patient care planning/Integrated Care schedule planning.
- Poly-pharmacy review.
- Initiation of new therapies and complex therapies.
- Patient education. Quality assurance.
- Multi-disciplinary management e.g. obesity.
- Routine care for complex adult cases at discretion of endocrinologist.
- Diabetes care during in-patient admission for co-existing conditions.

Regional Diabetes Centre (Comprising an expanded Secondary Care Centre)

Roles may include: Establishment of scheme locally, advising on targets and mechanisms, referral and discharge criteria, developing clinical protocols, clinical formulary, initial and ongoing professional education, audit, planning enlargement of scheme. Training and coordination of staff.

- Co-ordination of diabetes education, clinical audit, research, professional education, clinical training and quality assurance.
- Patient group education.
- Co-ordination of laboratory services liaison.
- Routine care for complex adult cases at discretion of endocrinologist.
- ‘Annual’ or more frequent review of all diabetes patients including screening for early micro-vascular and macro-vascular complications.
- Patient care planning Integrated Care schedule planning.
- Poly-pharmacy review.
- Initiation of new therapies and complex therapies.
- Patient education. Quality assurance.
- Multi-disciplinary management e.g. obesity.
- Routine care for complex adult cases.
- Coordination of management of at-risk feet, eyes, kidneys– orthotics, ulcer management, retinal services, renal liaison diabetic foot liaison, obstetric liaison (diabetic pregnancy/gestational diabetes) and liaison with paediatric/adolescent services for proper transition to young adult services for Type 1 Diabetes.
Diabetes care during in-patient admission for co-existing conditions.
The regional paediatric/adolescent diabetes centre will most likely be alongside the adult unit in the Regional Hospital (see paediatric/adolescent report).

**Dietitian: Primary Care, Secondary Care & Regional Diabetes Centre**
- Use nutritional therapy to enable people with diabetes to optimise clinical outcomes e.g. blood glucose, HbA1c, blood lipid and blood pressure levels and empower them to achieve best quality of life.
  Behavioural change and patient empowerment are core to care delivery.
- To minimise cardiovascular risk through ongoing education and support around body weight, hypertension and other lifestyle factors e.g. physical activity and smoking.
- Healthcare professional education and delivery of structured education programmes.

**Diabetes Specialist Podiatrist**
This should be a protected resource for diabetes, not for general podiatry.
Appendix 2

Levels of Care for People with Chronic Disease

**Chronic Disease Management: Population Management**

Deciding the right approach
It is important to have the information and knowledge to be able to carry out a risk-stratification on local populations to identify those who are most at risk.

**Level 3**
As people develop more than one chronic condition (co-morbidities), their care becomes disproportionately more complex and difficult for them, or the health and social care system, to manage. This calls for case management - with a key worker (often a nurse) actively managing and joining up care for these people.

**Level 2**
Disease/care management, in which multidisciplinary teams provide high quality evidence-based care to patients, is appropriate for the majority of people at this level. This means proactive management of care, following agreed protocols and pathways for managing specific diseases. It is underpinned by good information systems - patient registries, care planning, shared electronic health records.

**Level 1**
With the right support many people can learn to be active participants in their own care, living with and managing their conditions. This can help them to prevent complications, slow down deterioration and avoid getting further conditions. The majority of people with chronic conditions fall into this category - so even small improvements can have a huge impact.

This shows that most (70-80 per cent) people with long term conditions can provide the majority of care for themselves, and may need minimal input from health and social services. They represent the bottom layer of the pyramid.

In the middle layer are ‘high risk patients’ – people who need more active disease and care management from professionals.

Finally, in the top level, are the patients with highly complex needs. These patients are usually aged over 65, and represent a tiny proportion of the population, but account for a large number of emergency admissions to hospital. Much of the work that has been carried out in the management of long term conditions has concentrated on ‘case management’ for this third tier of patients. Case management requires a key worker actively managing and joining up care. Primary and specialist services are available at each level as appropriate to patient need.
## Appendix 3

**MANPOWER TO BE PUT IN PLACE IN REGIONAL HOSITALS AND REGIONAL DIABETES CENTRES**

<table>
<thead>
<tr>
<th>Manpower</th>
<th>Minimum number required per Regional Hospital/Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultant endocrinologist</td>
<td>5 (if population of regional catchment area is less than 360,000)</td>
</tr>
<tr>
<td></td>
<td>6 (if population of regional catchment area greater than 360,000)</td>
</tr>
<tr>
<td>Diabetes co-ordinator</td>
<td>1</td>
</tr>
<tr>
<td>Diabetes nurse specialist</td>
<td>10</td>
</tr>
<tr>
<td>Diabetes dietitian</td>
<td>5</td>
</tr>
<tr>
<td>Social worker</td>
<td>1.5</td>
</tr>
<tr>
<td>Specialist diabetes podiatrist</td>
<td>2</td>
</tr>
<tr>
<td>Ophthalmologist</td>
<td>1</td>
</tr>
<tr>
<td>Psychologist</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td><strong>Paediatrician with a special interest in the management of children with diabetes supported by paediatric trained specialist nursing, dietetic and psychology services.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Obstetrician with a special interest in the management of the pregnant woman with diabetes supported by a diabetes midwife specialist.</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Access to cardiovascular, nephrology and neurology services.</strong></td>
</tr>
<tr>
<td>Manpower</td>
<td>Minimum number required per Hospital</td>
</tr>
<tr>
<td>--------------------------------</td>
<td>----------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Consultant endocrinologist</td>
<td>Minimum 1 to 3 (depending on population of the catchment area)</td>
</tr>
<tr>
<td>Diabetes co-ordinator</td>
<td>1.0</td>
</tr>
<tr>
<td>Diabetes nurse specialist</td>
<td>3 or 4 (depending on population of the catchment area)</td>
</tr>
<tr>
<td>Diabetes dietitian</td>
<td>1 (depending on population of the catchment area)</td>
</tr>
<tr>
<td>Social worker</td>
<td>0.5</td>
</tr>
<tr>
<td>Specialist diabetes podiatrist</td>
<td>0.5</td>
</tr>
<tr>
<td>Ophthalmologist</td>
<td>0.5</td>
</tr>
<tr>
<td>Psychologist</td>
<td>0.5</td>
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</tbody>
</table>

Access to cardiovascular services
Appendix 4

Prioritised Action Plan

<table>
<thead>
<tr>
<th>Action</th>
<th>Proposed by</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PHASE 1</strong></td>
<td></td>
</tr>
<tr>
<td>Appointment of LDSDG in each HSE region</td>
<td>2008</td>
</tr>
<tr>
<td>Appointment national clinical leadership team</td>
<td>2008</td>
</tr>
<tr>
<td>Staffing gap analysis completed by each LDSDG</td>
<td>2009</td>
</tr>
<tr>
<td>Proposals for prioritised service development over 3-year time frame e.g:</td>
<td></td>
</tr>
<tr>
<td>• Staffing of all regional diabetes clinics to base level of diabetes centres</td>
<td>2009</td>
</tr>
<tr>
<td>• Capital investment needs</td>
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<td>• Trainer status for regional diabetes specialists</td>
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<td>• Upscale quantity of training resources</td>
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<td>• Manpower planning</td>
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<td>• Protocol development-roles, communication etc</td>
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<td>• Evaluation process</td>
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<tr>
<td>Agreed GP contract for chronic care management</td>
<td>2009</td>
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<tr>
<td>ICT needs identification, costing and tender</td>
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<td>Resource plan for further development of existing facilities capable of integrated care within primary care. Interim remuneration scheme for established trained GPs</td>
<td>2009</td>
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<tr>
<td>Preparation of plans for further resourcing of further diabetes centres (County hospitals)</td>
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<tr>
<td>Initial enlargement of retinopathy screening programme</td>
<td>2008</td>
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<td>Development of common standards and guidelines for case management across care continuum</td>
<td>2009</td>
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<tr>
<td>Action</td>
<td>Proposed by</td>
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<tr>
<td>National professional training structures, research and QA programme</td>
<td>2009</td>
</tr>
<tr>
<td>ICT systems procurement</td>
<td>2009</td>
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<tr>
<td>Staffing all specialist diabetes clinics to level of diabetes centres</td>
<td>2009</td>
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<tr>
<td>Education of primary care teams in networks previously participating in diabetes care schemes</td>
<td>2009</td>
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<tr>
<td>National organisation for retinopathy screening</td>
<td>2009</td>
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<tr>
<td>Patient self management support programme-structured education (Expert patient)</td>
<td>2009</td>
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<tr>
<td>Commence education of primary care teams in networks not previously participating in diabetes care schemes</td>
<td>2009</td>
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<tr>
<td>Evaluation of initial programmes</td>
<td>2009</td>
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</tbody>
</table>
Appendix 5

Patient pathway 1

Example patient journey:
Adult with stable Type 2 Diabetes

- John is a 64 year old teacher. He has had Type 2 Diabetes for 10 years and has always felt well.
- John is seen by his GP and then called to the diabetes centre for an appointment with the diabetes consultant. He notices that he receives a great deal of attention and education. He is then told that “all is well we will check you next year”.
- John meets his GP every 3 month and is pleased to hear that the blood pressure, cholesterol and glucose control all remain excellent. He is called to the hospital diabetes centre for a one year review then again meets his GP at 3 months, 6 months and 9 months.
Patient pathway 2

Example patient journey:
Female with stable Type 2 Diabetes becomes pregnant

- Mary is a 40 year old bank clerk. She has had Type 2 Diabetes for 3 years and has always felt well. Her care is undertaken by the GP and hospital in collaboration they call ‘Shared Care’.
- A month after her usual diabetes check she finds out that she is pregnant. She had not planned to become pregnant, but is pleased to hear the news.
- Mary attends her GP who arranges that her annual hospital check-up is brought forward to next Wednesday.
- Mary attends the diabetes centre every week or two until she delivers her third son, Paul.
- After the delivery, the diabetes consultant tells Mary that all is well and she is returning to her GP for the next year.

Specialist Appointment

Allocated to a year of shared care system

3 Month General Practice Review

Pregnant / planning pregnancy

Specialist Care for duration of Pregnancy

Successful completion of pregnancy

Returned to Shared Care system

Annual Specialist Review

Allocated to a year of shared care system
Example patient journey:
Adult with stable Type 2 Diabetes developing complications/failing to achieve control

- Joe is 55 year old bus mechanic. He has had Type 2 Diabetes for 5 years and has always felt well. He has often thought that the doctors and nurses fuss about nothing. Last year his GP asked him to come on regular visits at the surgery and occasionally at the hospital.
- At one of Joe's visits he is surprised to hear that his kidneys are not doing well. The doctor arranges that the next hospital appointment is brought forward to next Tuesday.
- At the hospital Joe learns that his kidneys are not working well but that “if glucose and blood pressure are brought to perfect values” he may avoid kidney dialysis. The information he recives makes Joe change his diet and exercise. He even stops smoking.
- Joe receives regular visits at the hospital and a few months later Joe is pleased to hear that his kidneys are “nearly back to normal”. The consultant explains that for the next year appointments will be mainly with his GP.
Clinical Guidelines

“A Practical Guide to Integrated Type 2 Diabetes Care”

The Irish College of General Practitioners and Irish Endocrine Society working alongside the EAG have, in June 2008, published a set of Clinical Guidelines for Type 2 Diabetes for national implementation. This was produced in consultation with the Diabetes Federation of Ireland, the Diabetes Nurse Specialists of Ireland and the Diabetes Interest Group of the Irish Nutrition and Dietetics Institute.

This is the first such guide agreed at national level between primary, secondary and tertiary care and sets out a model for the integrated care of Type 2 Diabetes. The guidelines provide clarity in regard to diagnosis, targets for clinical care and the interventions that are appropriate at each stage of the disease.

The explosion in the prevalence of diabetes mellitus, predominantly Type 2, has lead to the recognition that the adequate care of such individuals requires structured involvement of the primary care sector together with the diabetes units and diabetes centres. This has demonstrated the need for a more pro-active model of care which also requires flexibility to deal with the different demands of people at different stages of their disease.

This has lead to the concept of “integrated care” which espouses the joint involvement of all levels of care, primary, secondary and tertiary levels of care, to optimise outcomes in people with diabetes mellitus. In practical terms this means that both primary and secondary care centres assume joint responsibility for the patients and that funding of resources for both going forwards will take place according to their relative needs.

The majority of patient visits will take place in general practice with “annual review” taking place in the diabetes centre at a frequency to be agreed at a local level but certainly every 1-2 years. This quality of care cannot be implemented without the appropriate allocation of resources to practices involved in its delivery.

The fundamental aims and objectives of these guidelines are to:

• Enable people with diabetes to achieve a quality of life and life expectancy similar to that of the general population by reducing the complications of diabetes.
• Deliver integrated, quality care uniformly to all affected people and their families.

Topics covered in the guidelines are:

• Classification and diagnosis of Type 2 Diabetes.
• Diabetes care including patient education, treatment, pre-conceptual and emergency care.
• Prevention, early detection and management of complications.

The Diabetes EAG see that these guidelines are not just a fundamental pillar of our integrated model of care, but that they themselves will significantly improve the care of patients with Type 2 Diabetes.
Education/Empowerment

Introduction

People with acute illness are generally inexperienced and passive recipients of their medical care. Chronic disease has become the principal medical problem accounting for about 80% of GP consultations, 60% of hospital bed days and two-thirds of emergency admissions. With chronic or long term illnesses, the patient must become a co-partner in the process. They have a vested interest in so doing. Evidence now exists that the systematic management of long term conditions with patient/user involvement can decrease emergency attendances and in-patient admissions leading to less demand for services the capacity of which attracts the majority of media and public attention. Public and patient involvement in healthcare delivery must be a key element of the framework for reform of our health services if we are to genuinely improve the service in line with stated goals and avail of the resource that is the patient themselves.

Education and Empowerment

Diabetes self-management education is the ongoing process of facilitating the knowledge, skill and ability necessary for diabetes self-care (Funnell et al 2008). The aim of diabetes education is to assist people living with diabetes and their families to understand the condition and its treatment, to live healthily, to maintain or improve their quality of life and to co-operate with healthcare providers (ADA 2005). In order to facilitate this, the healthcare providers must take into account how the person will adapt to their illness, what their beliefs are about the illness while incorporating their subjective and objective needs. Health education involves more than just providing information. The goal is to help and empower those with disease to live well. Real empowerment is the result of a patient education process that should enable people to acquire the knowledge, know-how and attitudes in order to improve their ability to manage and treat their condition (Anderson et al 1995).

Goals of diabetes self management education is to support the persons' efforts to:

- Understand the nature of their illness and its treatments.
- Identify emerging health problems in the early and reversible stages.
- Adhere to self-care practices.
- Make needed changes in their health habits.
- Assists the person in coping with the mental and physical demands of their illness given their unique economic cultural and social circumstances.
- Know when and where to seek assistance with their diabetes management.

How should this be delivered?

Diabetes education is provided in a variety of settings and numerous education programmes are being utilised currently in Ireland (Appendix 2). These education programmes are driven by dedicated healthcare professional who are often struggling to proved education to very large numbers of people living with diabetes. There is an absence of national direction and the geographical location of the person with diabetes is a major influence on access to the various programmes.

There are many terms used to describe various programmes and recent years have seen the proliferation of structured education programmes. While in Ireland there is no definitive definition of what a structured education programme is, in the UK there is a nationally agreed criterion to describe it. The NICE HTA (2003) and
the National Service Framework for Diabetes (DH, 2001) the Patient Education Working Group of the UK Department of Health and Diabetes UK (2005) established that the key components of effective structured patient education for diabetes should:

- Have a philosophy;
- Have a structured written curriculum;
- Have appropriately trained educators;
- Be quality assured;
- Be audited.

The planning and implementation of patient education is an aspect that deserves much consideration. The EAG is proposing a national framework that is integrated within an overarching care and governance model linking self management education and support with the delivery system design, decision support and enabling clinical information systems and infrastructure.

The intention is to promote system changes that will produce productive interactions between an informed, activated patient and a prepared, proactive practice team that will result in improved outcomes. There will be a spectrum of services available to the patient; ranging from primary prevention services, self care, primary care services, including scheduled GP and specialist visits to underpin good practice models of care for the patient’s specific illnesses. Underpinning this spectrum of clinical care is a complementary programme of patient support. Many patients will become the main manager of their own chronic disease and it is primarily their success in controlling the disease by lifestyle and/or medication which determines the severity of the disease and experience. The programmes are built around the patient and tailored to his/her particular level of complexity and risk.

To advance this process the group is recommending the following:

**National leadership and direction**
- There should be defined national leadership and strategic direction for programmes of patient education and empowerment. It is our intention to identify criteria, which all programmes will need to meet. Key contributors in this regard could be the National Consumer Affairs and Health promotion Directorate in association with the national diabetes nursing and dietetic organisations.

**Governance**
- There should be clear governance mechanisms providing clarity on:
  - Standards development and monitoring-accreditation;
  - Accountability and feedback;
  - Integration within a care system framework;
  - Resources and Implementation mechanisms.

**Training and education**
- There should be a continuum of service responses to the need for training and education from informal informed feedback to structured accredited education programmes.
- Programmes should build upon the knowledge and expertise of specialist resources and empower front line service delivery e.g. link Specialist Diabetes Nurses to primary Care Teams and Networks.
- Innovative potential of ICT should be explored as part of a number of service delivery models.
- The role of patient education and empowerment should be a key focus on undergraduate and postgraduate clinical education programmes.
Partnership:
There should be a partnership approach all key stakeholders including academia and the voluntary, private and public sector healthcare providers.

Conclusion
The desired cultural change in health care is likely to lead to a fundamental shift in the way that clinicians and patients think about their roles and responsibilities in relation to managing diabetes mellitus. Empowered patients may be expected to be more aware of good health behaviours for their particular condition, endeavouring to improve or maintain their health, as an expert patient, facilitated in this role by the health care worker, or indeed by other patient mentors. We can imagine these patients seeing themselves as being in overall charge of their health care, supported by a developing knowledge base and self-management skills. They may see themselves as the ‘pilot’ of their care, with the health care worker acting as a ‘navigator’, providing useful information, guidance and expertise.

For this to happen the environment must be supportive and enabling in equipping all partners with the tools and resources to bring practical and enduring solutions to life.

Not alone the Diabetes Nurse specialists but all the medical and paramedical carers with whom the patient interacts have a role in education. Therefore they themselves will need development of these skills with subsequent monitoring and accreditation.

The EAG are planning to hold a major workshop in the near future on patient empowerment/education involving all the stakeholders. It is anticipated that a number of education programmes which meet key criteria will be endorsed for widespread implementation throughout the country.
Appendix 1

Resource requirements

Year 1
Irish study on patient preparedness for self-care/patient empowerment €150,000
Consultancy support to develop a national framework and model/s €60,000.
Major conference/workshop €40,000

Year 2
National recommendations for programme setup and pilot.
Lead team and resources (based on output of year 1).
Training and education programme for facilitators.
ICT investment and programme materials

Year 3
Evaluation and rollout in line with agreed model/framework
Staffing and non-pay
Appendix 2

Irish experience of existing structured education programmes
Structured diabetes education is a collaborative process through which people with diabetes gain the knowledge and skills needed to modify behaviour and successfully self-manage diabetes mellitus (Funnell & Anderson, 2002). The intervention aims to achieve optimal health status, better quality of life and reduce the need for costly healthcare (Norris et al, 2002). Patient education has been shown to be an essential component of the quality diabetes care (Mensing et al, 2005) and that it is effective in the promotion of health practices that could prevent or delay potential diabetes complications (Strine et al, 2005).

There are currently several educational programmes available, some of which have been subject to research evaluation, DAFNE, DESMOND and X-PERT. These are all available to people with diabetes in some parts of Ireland.

DAFNE (Dose Adjusted For Normal Eating) is currently receiving much acclaim as an educational programme for self-management of Type 1 Diabetes. DAFNE is a five day intensive skills based education programme in which people learn how to adjust their insulin dosage to suit their free choice of food, rather than having to work their life around their insulin doses. DAFNE aims to encourage and equip people who have Type 1 Diabetes to manage their insulin regimens actively and independently. Attendance at a single DAFNE programme results in improved quality of life, well being, treatment satisfaction (NICE 2003) and long-term improved glyceamic control. Six centres in the Republic of Ireland, four in Dublin, one in Galway and one in Kilkenny, are taking part in a randomised controlled trial using a modified DAFNE intervention as part of a Health Research Board funded project.

DESMOND is Diabetes Education and Self management for Ongoing and Newly Diagnosed (Type 2 Diabetes). DESMOND provides 6 hours of structured group education according to a formal curriculum (one day or two and a half-day courses). Groups consist of six to ten people with newly diagnosed diabetes and each participant is provided with written materials. Two DESMOND educators (professional with two day DESMOND training) deliver the programme. DESMOND supports people in identifying their own health risks and responding to them by setting their own specific behavioural goals. Initial reports indicate that DESMOND changes key illness beliefs and that these changes predict quality of life and metabolic control at three month follow-up (Skinner et al. 2006). DESMOND is currently only available to patients in the Galway area.

The X-PERT (Patient Education versus Routine Treatment) UK programme is a health professional led, group-based, structured education programme for people with Type 2 Diabetes. This group programme for people with Type 2 Diabetes is facilitated through six weekly two hour sessions. A dietitian-led, randomised controlled trial (RCT) of X-PERT UK has shown it to impact positively on clinical, lifestyle and psychosocial outcome parameters (Deakin, 2004).

X-PERT UK has been adapted, piloted and evaluated by the Community Nutrition and Dietetic Service of the HSE South. The adapted X-PERT Programme was piloted in early 2006 with 47 individuals. Patient response (30%), attendance (87% to four or more of six sessions) and interest in the programme were excellent and X-PERT Ireland was found to result in significant improvements in terms of many of the clinical (body weight, waist circumference, glycated Hb, fasting blood glucose, HDL-cholesterol and diastolic blood pressure), lifestyle (diabetes knowledge, fruit and vegetable consumption) and psychosocial (diabetes empowerment score, perceived understanding of diabetes and its treatment) outcomes evaluated.
As a direct consequence of the positive outcomes of X-PERT Ireland the first X-Pert Ireland Train the Educators programme was developed and delivered in Cork in 2007. Seventeen community dietitians from around the country were trained in August 2007 to deliver the X-Pert Ireland programme. By September 2008, 450 people with diabetes had attended the X-PERT Ireland programme. Furthermore in October 2008, 22 more dietitians were trained as X-pert educators and these combined with those trained in 2005 and 2007 bring the total to 42 dietitians that have been trained as X-PERT Ireland educators. X-PERT Ireland won the overall HSE National Achievement Award in April 2008.

In 2007, the Diabetes Federation of Ireland (supported by the HSE) commenced a community-based programme, Community Orientated Diabetes Education (CODE) in Ireland as an action research project to allow for immediate change of the programme based on on-going evaluation. The initial programme (CODE T2) is delivered to people with Type 2 Diabetes (attending primary care centres). The programme of 4 sessions, each 2.5 hours duration, is delivered over 6 months by one healthcare professional. The programme is complemented by community diabetes raising awareness activities such as media contacts, public meetings and diabetes awareness days in community or/and work settings.

This programme has been evaluated, the results of which have shown that participants had positive outcomes for biomedical markers, positive changes in behaviour and improved psychological perceptions. The programme has demonstrated the effectiveness of community education in raising the awareness of diabetes (DFI 2008).

The ‘Berger Programme’ has been successfully used for the past 25 years in Germany to teach patients with diabetes self-management skills. This education programme developed by eminent endocrinologist Prof. Michael Berger was the first of its kind to recognise the value of teaching patients how to adjust insulin to match their daily food intake. Other programmes such as DAFNE have been developed from the concept of the original Berger programme. The Programme was evaluated in the Bucharest-Dusseldorf Study (Mulhauser et al, 1987) demonstrating an improvement in glycaemic control in those patients who undertook the intensive training arm of the study.

With support of the German group, Roche Diagnostics developed the Accu-Chek branded English templates of the Berger programme: Accu-Chek Education Programme Intensive Insulin Therapy. EASD staff conducted the initial training of Irish healthcare professionals. Subsequent to this and in agreement with Roche Diagnostics the programme has been restructured and piloted as a 3-day Type 1 Diabetes Education Programme at a Dublin centre. The aim of the programme being to teach individuals the required tools for improved self-management with the primary focus on insulin adjustment and carbohydrate counting. The programme is due for audit in January 2009 and will coincide with a roll-out to a number of other diabetes units nationally. There is no direct cost associated with the delivery of this programme to either healthcare professionals or people living with diabetes.

Although not structured education programmes, several other projects have developed to support people with chronic illnesses (initially cardiology and diabetes). First Patient is a joint HSE/AMNCH initiative aimed at developing and supporting a model of patient-centred, needs-led, seamless integrated care that empowers the client to self-manage their condition. Another Irish project is the Peer Support in Diabetes Study, a 5 year HRB funded project in the Dublin region, started in 2005 which examines if peer support improves a broad range of diabetes outcomes. People with diabetes are trained in supporting others and voluntarily give of their time to support eight people in close liaison with a practice nurse. Results will be available in 2009.
Until recently in the Republic of Ireland, diabetes education was delivered informally at both primary care level and in secondary care settings. Internationally, there is support for structured diabetes education but no direction as to the effectiveness of any specific programme (NICE 2006). The ad hoc adoption of English based structured diabetes education programmes is occurring in some secondary care centres but in the absence of a national policy these efforts may not be sustained and there is no link to primary care.

Until recently there was no published evidence into the effectiveness of diabetes education in Ireland. The pilot of the X-PERT Ireland programme and the CODE programme as outlined above, suggests the positive future potential of structured patient education in Ireland. However, in the absence of a national policy and dedicated funding these efforts may not be sustained.
ICT

Chronic Disease Management - Enabling with information and communications technology (ICT)

Introduction
A proper ICT intervention is recommended to integrate the components of the chronic disease management approach. There are five major types of ICT intervention.

- Population analysis (risk stratification)
- Telephone support
- Self-care (including supporting decision making by individuals with diabetes)
- Decision support for clinicians
- Shared information about people receiving care.

We advocate a high level ICT strategy to implement this component of our recommendations.

Overview
The diagram below presents an overview of the ICT-based ‘interventions’ set out in the paper which can together enable an integrated chronic disease management approach.
The Most Important Interventions for Chronic Disease?

The ‘Chronic Care Model’

To provide a suitable ‘frame of reference’ within this paper the ‘Chronic Care Model’ is used and ICT ‘interventions’ examined are related to the key components of that model.

The Chronic Care Model focuses on:
linking informed and active people with long-term conditions with pro-active teams of professionals…

acknowledges that a substantial portion of chronic care takes place outside formal healthcare settings and

suggests that six elements are of central importance in initiatives to improve chronic care: 1) community

resources; 2) the healthcare system; 3) patient self-management; 4) decision support; 5) delivery system redesign;

and 6) clinical information systems (Singh and Ham, 2006). [For reference see Appendix B table setting out sub-

components of each of these major elements].

Tsai et al. (2005), having undertaken a meta-analysis of 112 studies looking at components of the
‘Chronic Care Model’, concluded that:
• Changes to delivery system design significantly improved processes and outcomes;
• Self-management support significantly improved processes and outcomes;
• Decision support improved care processes, but not outcomes;
• There were no significant benefits from clinical information systems; and
• There was insufficient evidence about community resources and organisational elements.

Further, an observational study of 17 US clinics using the Chronic Care Model to improve diabetes care found that delivery system redesign was the only factor linked to improved clinical outcomes, with self-management and clinical information systems having no significant impact on clinical outcomes (Sperl-Hillen, Solberg, and Hrosckoski et al., 2004).

Delivery system design

The chronic care model suggests that in undertaking delivery system design the structure of medical practice

must be changed to ensure clearly defined roles, full use of non-medical staff, and a division of labour within

clinical teams (Lewis and Dixon, 2004). In particular, care must be planned with case management available for

persons with complex problems. (Lewis and Dixon, 2004).

Three commonly discussed service delivery frameworks for supporting people with chronic conditions are the
approaches developed in the US by (Singh and Ham, 2006):

• Kaiser Permanente;
• EverCare (United Healthcare); and
• Pfizer.

The major distinguishing features are that the Kaiser model focuses on integrating services and removing

distinctions between primary and secondary care for all persons with the condition, whereas the EverCare and

Pfizer approaches focus on targeting those at higher risk of hospitalisation (Singh and Ham, 2006).

Notwithstanding these differences in focus, these approaches have many common characteristics, including some
form of ‘case management’ as a key component; people with the condition as ‘partners in care’; and unplanned
hospital use experienced as a ‘system failure’ – the intent being to provide care in the ‘least intensive’ setting
possible (Singh, 2005).
 ICT interventions

A number of very clear ICT based interventions are encompassed in these approaches and in other adoptions of the ‘Chronic Care Model’ (Singh, 2005) and similar approaches (Singh and Ham, 2006).

Considering these possible interventions, in the context of the findings of Tsai et al. (2005) and Sperl-Hillen, Solberg, & Hrosckoski et al. (2004) regarding the direct impact of ‘clinical information systems’ per se, the ICT ‘interventions’ with greater impact on health outcome would seem to be:

• Population evaluation (risk stratification) often using data already collected as part of clinical and administrative contacts relating to persons in the population.
• Proactive contact with people at highest-risk using telephone support, based on standard-based clinical guidelines.
• Provision via various ICT routes of tailored information to people to facilitate self-care and enable shared decision-making with the people with the condition.
• Decision-support for clinicians.
• Shared data and information about people receiving health care across the delivery system to assist case management.

The above having been said, with regard to clinical information systems, the more advanced parts of the ‘Kaiser system’ have “sophisticated and efficient information technology systems that reduce administrative time, particularly clinician’s time spent taking medical histories, dictating letters, and locating patient records” (Feachem et al., 2002, p.140). Such systems are therefore very important certainly in regards to the efficiency of operations. Further, carefully selected and integrated clinical information systems can provide an underpinning to the other ICT interventions (Mittman, 2004).

The five major types of ICT intervention

The five key areas of ICT interventions identified are now explored in more detail.

Population analysis (risk stratification)

‘Managed care’ and ‘health management’ organisations in the USA have for a number of years carried out population-based targeting through ‘risk screening’, with high-risk members being subsequently triaged for interventions, such as geriatric care management (Alessi et al., 2003; Boult et al., 2001; Coleman et al., 1998; Fillit et al., 1998; Vojta et al., 2001). There are various approaches, for example including via ‘trawls’ of GP practice lists, via brief telephone or face-to-face surveys, or via ‘semi-automated’ ‘filtering’ of data already captured for other purposes.

In the examples described by Coleman et al. (1998) and Vojta et al. (2001) a very small number of data items – age, gender, and the number of hospitalisations and GP visits in the past year - were taken together with analysis of coded data on medications and clinical diagnosis (extracted from administrative systems for contract management/payments purposes) to provide the necessary ‘input’ data to enable sufficient accurate risk stratifications of large populations of ‘enrolees’ of HMOs. The analysis of medication and diagnostic data applied the ‘Chronic Disease Score’ methodology (McGregor et al., 2005) which ‘filters’ data based on a clinically validated algorithm, and the Deyo-Charlson co-morbidity index (Vojta et al., 2001), respectively.
The author of this paper recently appraised the potential of applying such methods in Ireland to ‘GMS’ and HIPE data and concluded that the required data appeared to be available here to the required completeness and ‘population coverage’, certainly with regard to ‘risk stratification’ of older people with respect to risk of functional decline.

**Telephone support**

Internationally, there has been growing interest in the use of telephone call centres (Turner et al, 2002). These initiatives originated mostly in the United States and became widespread in the early 1990s as part of a broader strategy by US healthcare organisations to implement ‘demand-management’ strategies focused on improving consumer health knowledge and preventing unnecessary use of expensive health resources such as emergency departments (Turner et al, 2002).

The services typically involve nurses using computerised decision-support systems; patient education and the provision of information; as well as guided access to the most appropriate care (KPMG, 2001).

Kim and Oh (2003) found in a study on the impact of nurse telephone calls on the adherence to diabetes control recommendations that this intervention improved diet and blood glucose testing adherence.

**Self-care (including supporting decision making by ‘patients’)**

Enabling self care is not simply a matter of providing information to patients, it is a range of different things, but those that work the best are (Department of Health, 2004):

- Patient and carer education about self management of their illness, helping them to understand what to do, how to adjust their medication dose, and how and when to use health care;
- Prompts and reminders for when they should be doing something and attending for care;
- Support from a knowledgeable patient (often, but not always an expert in their disease) and broader networks, including attending practices as part of a group of patients with the same condition.

The table below presents a synthesis of the potential routes to enable self-care with the technology and content requirements for these (Abidi, 2001; Bosworth and Gustafson, 1991; US Department of Health and Human Services, 1999).
<table>
<thead>
<tr>
<th>Approach</th>
<th>Component</th>
<th>Technology</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Manage demand for health services</td>
<td>Ask an expert</td>
<td>E-mail, computer-assisted telephone advice systems, interactive voice response systems, and electronic consultations with health professionals.</td>
<td>Automated response/’over-night’ expert answers to questions.</td>
</tr>
<tr>
<td>Enable informed Decision-making</td>
<td>Resource finding</td>
<td>Databases of resources</td>
<td>‘Match-making’ functions and training in how to access &amp; use resources.</td>
</tr>
<tr>
<td></td>
<td>Making choices</td>
<td>Decision aids based on decision analysis models.</td>
<td>Structured ways of thinking through decisions.</td>
</tr>
<tr>
<td></td>
<td>Health promotion</td>
<td>Telephone advice lines, databases of ‘wellness’ information, tools based on theories of behaviour change.</td>
<td>Provision/exploration of ‘wellness’ information, skills training to change life-style.</td>
</tr>
<tr>
<td></td>
<td>Support group</td>
<td>Network (internet)</td>
<td>Network (internet) on-line interaction with peers.</td>
</tr>
<tr>
<td>First Report from Diabetes Expert Advisory Group</td>
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</table>
A systematic review of decision aids (O’Connor et al, 2001) concluded that they can increase people’s knowledge and understanding of their condition, and their active participation in decision-making.

Further Van Dam et al. (2003) concluded that primary care or outpatient clinic diabetes teams should focus on programmes for directly enhancing patient participation, for example by ‘assistant-guided’ patient preparation for patient-provider encounters.

**Decision-Support for Clinicians**

The effective deployment of chronic disease programmes needs to ensure the providers of care have access to the clinical expertise which can be facilitated through evidence based guidelines (Siminerio, Zgibor and Solano, 2004).

Although providers should act in alignment with such expertise as guidelines, they have been reluctant to do so (Siminerio, Zgibor and Solano, 2004).

This reluctance can be overcome by engaging in progressive dialogue with professional groups as part of wider quality improvement and practice development activity towards implementing establishing standards of care (Siminerio, Zgibor and Solano, 2004).

**Shared Information About People Receiving Care**

The principal providers of chronic disease care are primary care teams, and evidence from other countries has demonstrated that by the team registering and following up people with chronic conditions there is an improvements quality of care and a better use of resources (Department of Health, 2004).

These primary care teams need information systems to enable: 1) registration of a ‘population’ of patients; 2) recall of people to ensure they get the care they need through the use of prompts and reminders; and 3) review of these people to ensure the are getting the most effective support to manage their condition (Department of Health, 2004).

Moving beyond this core requirement, the more ‘ideal’ information system has a number of characteristics including, crucially (Mittman, 2004):

- Support of all aspects of the continuum of chronic disease care including self-care;
- Availability to clinicians (and the patient) at ‘the point-of-care’; and
- Provision of both clinical decision support and recording of clinical encounters.

It is of note though that single-disease focused systems may further contribute to fragmentation of care, with many people experiencing co-morbidities, such as diabetes and heart disease together (Mittman, 2004).

Finally, whatever solution is considered, an important consideration will be that it should as much as possible draw on existing data flows/workflows/information systems and be sufficiently adaptable to different conditions and approaches to chronic disease care (Mittman, 2004).
Conclusions
The fundamental ethos throughout the EAG recommendations is integration of care. As the patient journey is often back and forth across the traditional primary/secondary/tertiary care levels and the number of observations; clinical and otherwise, required are finite a specialised diabetes management package may not be that difficult to put in place. However the selection/implementation process needs to start as soon as possible.

A formal project team is established to scope and make recommendations on the ICT needs of a National Diabetes Service in to the future. This team is analysing current systems, scoping relevant systems from a national and international perspective and will make recommendations with regard to an integrative service design and delivery of Diabetes Care in to the future.
Appendix A

Chronic care model – elements & components

The table bellows sets out the sub-components of the six major elements of the Chronic Care Model (Singh and Ham, 2006)

Delivery system (redesign)
- Care management roles
- Team practice
- Care delivery/co-ordination
- Proactive follow-up
- Planned visits
- Visit system changes

Self-management support
- Patient education
- Patient activation/psychosocial support
- Self-management assessment
- Self-management resources and tools
- Collaborative decision making with patients
- Guidelines available to patients

Decision support
- Institutionalisation of guidelines/prompts
- Provider education
- Expert consultation support

Clinical information systems
- Patient registry system
- Use of information for care management
- Feedback of performance data

Community resources
- For patients
- For community

Health care organisation
- Leadership support
- Provider participation
- Coherent system improvement and spread.
Retinopathy

Introduction
The National Retinopathy Screening Committee of the EAG was established in February 07. The terms of reference of the Committee are:

1. To prepare the national strategy for the development, implementation, and monitoring of a National Screening Programme for the detection of Diabetic Retinopathy.
2. To set out the principles of the Diabetic Screening Programme.
3. To set out the monitoring arrangements for the programme.
4. To advise HSE on the governance and quality assurance standards required.
5. To advise on and support implementation of the programme in each of the 4 HSE areas.
6. To monitor and advise on the implementation of a national screening programme.
7. To advise on the requirement to have retinopathy screening supported by suitable IT systems, which are integrated with the rest of diabetic care.
8. To identify the additional work created, for the Ophthalmic Services as a result of retinopathy screening.
9. To work with the EAG to facilitate diabetic retinopathy screening being fully integrated with all aspects of diabetic care.
10. To invite proposals from each HSE area on the development of services in their area for diabetic retinopathy screening, based on the programmes principles set out by the sub committee.
11. To make recommendations to HSE on service developments nationally and within each HSE area.

In 2007 the Committee set out the principles of a National Diabetic Retinopathy Screening Programme. HSE areas which were known to have an active programme in part of their area were contacted, this included HSE West and Dublin North East. Work was done with these areas to develop bids for funding for the development of the programme in 2008. These were submitted as part of the EAG estimates bids. Some funding had been made available to Population Health to commence Transformation Project 4.2.2 for extension of the North Western retinopathy programme. Work was commenced with HSE West. Clinicians and Managers from across the new area of HSE West came together to form an Implementation Committee to roll out retinopathy screening across the whole area in conjunction with the North Western portion of the area. The National Committee worked with the HSE West Implementation Committee to set out the quality standards, governance arrangements, monitoring and information systems required.

Integration/Transformation
The National Committee works closely with Transformation Project 4.2.2 “Implementation of Chronic Illness Strategy for Diabetes”. This project is part of Transformation Programme 4 led by Population Health. Project 4.2.2. There is good integration between the objectives of the Transformation Project and the work of the Committee. Implementation of the screening programme is beginning with the extension of the programme from the old North Western Health Board into the rest of HSE West. There is representation from the HSE West Implementation Group on the National Retinopathy Screening Committee, this greatly facilitates the integration of EAG recommendations with the ongoing implementation. This alignment of the Expert Advisory Group, with Transformation lead and budget holder together with the implementation executive functions at local area, has worked well and allowed significant progress to be made in 2007.
Priority recommendations

The following recommendations were made by the EAG to HSE at the end of 2007.

1. That funding for the development of the National Retinopathy Screening Programme be prioritised in 2008.
2. That funding be made available incrementally over the next 3 years, from 2008 to 2010 to implement the programme in each of the remaining 3 HSE areas, commencing the programme in a new area each year.
3. That the HSE immediately prioritise funding and commence procurement for an eye specific IT System to support the National Retinopathy Screening Programme.
4. That HSE set up a formal governance structure for the National Diabetic Retinopathy Screening Programme. Each HSE area will implement the programme and report to the National Governing Structure.
5. That agreed internationally recognised standards, screening processes and quality assurance methods be adopted and be subject to ongoing monitoring.

Potential benefits

Diabetic retinopathy is a disease of small blood vessels of the retina and is the most common cause of blindness in people aged 60 to 65. Approximately 5 to 10% of people with diabetes have a sight threatening retinopathy which requires ophthalmic following up and treatment. It is estimated that there are 140,000 people with diabetes in Ireland currently, this will rise to 160,000 by 2010, therefore approximately 14,000 to 16,000 people will develop a sight threatening retinopathy. Diabetic retinopathy is very preventable, an annual population based screening programme, using retinal photography has been shown to be highly sensitive and specific for sight threatening disease. Currently there is no national screening programme, while there are some examples of excellent initiatives e.g. the North Western scheme, a national programme operating to comparable international standards is urgently required.

Progress in 2007

Funding of €750,000 was made available to HSE for extension of retinopathy screening in 2007. Through work with the National Retinopathy Screening Committee an Implementation Group comprising Managers and Clinicians across HSE West has been established and an action plan for extending retinopathy screening from the North Western Area into the rest of HSE West was developed. The implementation of this plan has begun and the necessary equipment is being procured. Recruitment processes had commenced to recruit the initial 8 staff into the programme, these have been put temporarily on hold due to the 2007 directive on recruitment. It was anticipated that if this recruitment could proceed, and procurement continue, that HSE West would be in a position to extend screening early in 2008.

An essential element in progressing the roll out of the programme is the procurement of an IT system for the national programme. The old North Eastern Health Board Region and the Western Region had different IT systems. These are not adequate to support international standards. Suitable systems exist and are operational in other jurisdictions, this required an urgent national procurement.

The EAG developed estimates bids for consolidation of the HSE West programme and extension of a national programme into the Dublin North East Area in 2008. This was dependent on receiving the appropriate funding in the 2008 allocation.

2008 update

No additional funding was made available to the programme in 2008. A detailed blueprint for the development of a National Screening Programme, the Framework for Retinopathy Screening, was finalised by the EAG in 2008. Detailed plans were finalised in HSE West for the implementation of the programme in that area.
In early 2008 the procurement process for the mobile vans and digital cameras for the National Diabetic Retinopathy Screening Programme was completed. The Contract Approval requests have been signed and these items can now be purchased as the service develops.

A working group of the EAG Sub Committee developed the proposal and business case for procurement of a National IT System for the Retinopathy Programme. This was approved by HSE and the Department of Finance and the Department of Health.

The recruitment of staff for the implementation in HSE West was approved by the HSE Leadership Team in the second quarter of 2008, using the €750,000 funding which had been made available in 2007. Unfortunately, due to the overall adverse HSE financial position, there has been no recruitment of staff or procurement of equipment proceeding in 2008.
Podiatry

Introduction
Foot-care is critically important in people with diabetes. Foot complications (ulcer, infection, deformity, advanced neuropathy, amputation) are the most costly outcome of diabetes. This has been studied in many countries, including Ireland (1), and the findings are universally the same.

In the Irish study, the inpatient care of one foot ulcer in one patient was approximately €30,000. Foot complications of diabetes are related to the duration of the disease and the degree of glucose control. These complications are almost completely preventable by regular screening of those at risk, by good control of glucose and risk factors, and by intervention (by podiatrists) in those requiring specific treatments.

Screening
All people with diabetes should undergo regular foot examination. Primary care networks would provide screening, and minor foot interventions Hospital clinics would provide screening, but focus mainly on high-risk and complex cases – hence the manpower distribution (see below).

Manpower - current
Ireland has by far the lowest manpower in Podiatry for diabetes – only 2 full time posts in the whole country. This is a tiny fraction of the manpower in N Ireland, UK, and other EU countries where diabetes foot care is up to standard.

Manpower Needs
The 2002 document (Diabetes Care – Securing the Future) included a region-by-region manpower deficit. That document estimated a need for:

- 2 x WTE Podiatrists (for diabetes) per 100,000 of total population

Thus: For the total population of Ireland, a total of 90-100 full time podiatrists would be needed, for diabetes footcare.

Immediate manpower priorities
The immediate priority is to fund one full-time podiatrist in each hospital diabetes centre around the country, ie a total of at least 20 new positions. This will provide a focused foot service for each primary care network to refer to, and for each hospital diabetes clinic.

Equipment
Each podiatrist will need, at a minimum, a basic range of equipment (chair, surgical supplies, dressings, lighting, instruments). This basic equipment is estimated to cost €15,000 per podiatrist.

Special services
Access to Orthotics
Access to custom-made footwear
These are specialised additional services for foot care, and would need to be made available on a regional basis, e.g. 4-5 centres around the country to supply regions.
Paediatrics/Adolescents

As of now the majority of diabetes in this age group have Type 1 DM. However unless urgent remedial action is taken to reverse the obesity epidemic, we will have shortly have a big increase in Type 2 DM as seen in other countries.

In the absence of a national diabetes register, we estimate that there are between 2000 and 2500 children with diabetes 18 years of age or less. The annual incidence here is approximately 17/100,000/year. (1) Worldwide the incidence is rising by about 2%/year. The biggest increase is in pre-school children. In the UK, over the last 20 years there has been a 20 fold increase in this age group and a doubling in the older children. Most people who get Type 1 DM, get it in childhood. The younger the onset of diabetes, the more severe it appears to be. There is a higher incidence of Diabetic Ketoacidosis at presentation with its mortality of 0.15 -0.3% from cerebral oedema. The diagnosis of diabetes is a huge challenge to the psychosocial functioning of the child and the family. Good blood glucose control is more difficult to achieve than in adults. There is a higher life time risk of complications and they are seen early with some studies showing complications in 50% after just 12 years of diabetes. Children are more likely to suffer brain damage from severe hypoglycaemia which is a major consideration in our attempts to keep blood glucose values low.

The internationally accepted method of improving diabetes control is that the child/adolescent be cared for by a multidisciplinary team of specialists in both diabetes and paediatrics.

Ireland has very poor paediatric diabetes care, with over half the patients having no access to a proper multidisciplinary team and many of the rest travelling long distances for care (2).

The EAG made paediatric/adolescent diabetes care a priority. To date we have drawn up Standards of Care, reviewed and endorsed the clinical practice guidelines of the international society for paediatric and adolescent diabetes (ISPAD) 2007-2008 and proposed a reorganisation of care in Ireland to a regional model.

EAG standards of care for paediatric/adolescent diabetes:
Until a cure for diabetes is possible, every child/adolescent should have their metabolic control optimised to prevent long term complications of diabetes while minimizing their risks of short term problems. This balance is to be achieved while allowing the individual have as near normal life as possible.

Standard 1
Every effort to be made to prevent all types of diabetes.

Standard 2
The diagnosis of diabetes to be made correctly and at the earliest possible time.

Standard 3
Diabetes care should be provided in a dedicated ambulatory setting and every effort made to minimise hospitalisation.

Standard 4
That the provision of diabetes service for children/adolescents be equitable and fair throughout the country.
Standard 5
The care provided to the child/adolescent with diabetes be of an internationally accepted standard from a multidisciplinary team of professionals sensitive to his/her needs and those of the family.

Standard 6
The child/adolescent and the family should receive information/education in a manner appropriate to their needs and abilities. They should be progressively empowered to manage the diabetes themselves.

Standard 7
The child/adolescent should be supported by having access to good effective advice at all times.

Standard 8
The child/adolescent with diabetes should have access to the full range of available technologies/opinions, if they are appropriate to his/her needs.

Standard 9
Proper transitional care to the adult diabetes services should be provide for all adolescents / young adults at around 18 years of age.

Provision of care for children/adolescents with diabetes
We propose that care be centralised for each region with the provision of the full range of services in a dedicated paediatric/adolescent diabetes centre. We recommend that at a minimum, the centre should care for 150 children/adolescents less than 18 years of age. This number takes into account the populations of the regions, the distances to travel and the need to have sufficient numbers so that all modalities of intensive therapy can be provided at the regional centre. Ideally, the centre should be in a regional hospital that has an adult diabetes centre to facilitate smooth transition of the 18 year olds.

We recommend that the multidisciplinary team be led by a paediatrician with a special interest and training in diabetes. He/she must have a significant time commitment to paediatric diabetes. There should be as a minimum a paediatric diabetes nurse specialist per 100, a paediatric nutritionist per 150, and a paediatric psychologist and medical social worker per 300 children/adolescents with diabetes attending the centre.

We recommend that the paediatric diabetes centres in the capital begin the process of amalgamating into the national tertiary diabetes centre and be available to assist the regional development with advice, support and most of all training for the new members of the regional multidisciplinary teams.

We recommend that each paediatric diabetes centre have a specialized diabetes management system capable of communicating with families and there equipment remotely and with the national diabetes centre if required. This system will improve the efficiency of the centre, act as a local register and contribute to a national register. It will enable clinical outcomes to be audited, which is so essential for proper monitoring of the care provided.

To speed the process we recommend that funding be linked to regionalisation of care and local implementation groups be established immediately. The centers envisaged are in the major regional hospitals and in the new regional hospital in the north east. We feel that formal approaches should be made to the health service in Northern Ireland exploring cross border delivery of paediatric/adolescent diabetes care in the North West.

We feel these recommendations are sensible, pragmatic and represent an opportunity to dramatically improve the way the children/adolescents with diabetes receive their care.

First Report from Diabetes Expert Advisory Group
four

Costs
Costs of Diabetes

Diabetes is an expensive disease for society here in Ireland. People with Type 2 Diabetes are heavy consumers of health-care services because of inadequate control of their glucose metabolism and insufficient treatment of their cardiovascular risk factors.

Current research suggests that savings can be achieved through correct allocation of care, improvement in the productivity of care organisation and investment in the prevention of Type 2 Diabetes and its complications. International research suggests the health care of people with Diabetes is at least 2.5 times more expensive than the health care of age- and gender- matched control populations and about 5 times as expensive as the average for the entire population.

A recent study from the Economist Intelligence Unit indicates that diabetes exacts three broad categories of economic cost:

**Direct healthcare costs**
These are categorised as costs associated with medication, devices, outpatient and hospital care, and professional interventions both specialist and general.

**Indirect healthcare costs**
These costs include nursing home care and informal care.

**Productivity costs**
This includes the loss of earnings from mortality, morbidity and disability associated with diabetes and its complications.
Research carried out in the UK and Finland show increasing healthcare costs for the care of Diabetes. In the UK the following figures for the years 2004 to 2007:

Table 1

<table>
<thead>
<tr>
<th>USD (BN) UNLESS STATED</th>
<th>2004</th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
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<tbody>
<tr>
<td>Total cost of Diabetes</td>
<td>8.93</td>
<td>9.51</td>
<td>9.94</td>
<td>10.60</td>
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<td>National healthcare expenditure</td>
<td>172.3</td>
<td>184.6</td>
<td>196.8</td>
<td>209.1</td>
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<tr>
<td>(% of GDP at market prices)</td>
<td>0.4%</td>
<td>0.4%</td>
<td>0.4%</td>
<td>0.4%</td>
</tr>
<tr>
<td>Per patient (US$)</td>
<td>4,522</td>
<td>4,631</td>
<td>4,662</td>
<td>4,794</td>
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</table>

<table>
<thead>
<tr>
<th>Healthcare costs</th>
<th>6.3</th>
<th>6.8</th>
<th>7.0</th>
<th>7.3</th>
</tr>
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<tbody>
<tr>
<td>(% total healthcare expenditure)</td>
<td>3.7%</td>
<td>3.7%</td>
<td>3.6%</td>
<td>3.5%</td>
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<tr>
<td>Cost per patient (US$)</td>
<td>3,185</td>
<td>3,302</td>
<td>3,306</td>
<td>3,316</td>
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<tr>
<td>Hospitalisation</td>
<td>2.3</td>
<td>2.5</td>
<td>2.6</td>
<td>2.7</td>
</tr>
<tr>
<td>Ambulatory care</td>
<td>2.5</td>
<td>2.7</td>
<td>2.8</td>
<td>2.9</td>
</tr>
<tr>
<td>Treatment</td>
<td>1.4</td>
<td>1.5</td>
<td>1.6</td>
<td>1.7</td>
</tr>
<tr>
<td>Oral anti-diabetics and insulin</td>
<td>0.3</td>
<td>0.3</td>
<td>0.4</td>
<td>0.4</td>
</tr>
<tr>
<td>Other drugs</td>
<td>1.1</td>
<td>1.2</td>
<td>1.2</td>
<td>1.3</td>
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</table>

<table>
<thead>
<tr>
<th>Productivity loss*</th>
<th>2.6</th>
<th>2.7</th>
<th>2.9</th>
<th>3.3</th>
</tr>
</thead>
<tbody>
<tr>
<td>(% of GDP at market price)</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.1%</td>
<td>0.1%</td>
</tr>
<tr>
<td>Cost per patient (US$)</td>
<td>1,336.9</td>
<td>1,329.0</td>
<td>1,355.6</td>
<td>1,478.6</td>
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<tr>
<td>Mortality</td>
<td>1.2</td>
<td>1.2</td>
<td>1.3</td>
<td>1.4</td>
</tr>
<tr>
<td>Average lifetime earnings loss (US$)</td>
<td>59,171</td>
<td>61,156</td>
<td>64,764</td>
<td>73,243</td>
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<tr>
<td>Morbidity</td>
<td>0.3</td>
<td>0.3</td>
<td>0.3</td>
<td>0.3</td>
</tr>
<tr>
<td>Disability</td>
<td>1.2</td>
<td>1.3</td>
<td>1.3</td>
<td>1.5</td>
</tr>
</tbody>
</table>

* The year of reference for productivity losses is 2004 and figures for 2005 to 2007 have been uprated using growth in average nominal wages.

Finland

In Finland the direct costs of the health care of people with diabetes were 115 of total health care costs which equates with 1 billion USD. The share of hospital care was 6.4% of the total costs. The costs were principally caused by the care of people with Type 2 Diabetes.
Table 2
Costs of health care for people with diabetes and their age and gender matched controls (USD * 1000). Helsinki 1997. The length of hospital stay was limited to 365 days/admission.

<table>
<thead>
<tr>
<th>Type of care</th>
<th>Type 1 diabetes</th>
<th>Type 1 controls</th>
<th>Type 2 diabetes</th>
<th>Type 2 controls</th>
<th>Total for diabetic population</th>
<th>Total for control population</th>
<th>Excess costs caused by diabetes</th>
<th>% of total excess costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospital care with diabetes as a primary diagnosis</td>
<td>501</td>
<td>0</td>
<td>1108</td>
<td>0</td>
<td>1609</td>
<td>0</td>
<td>1609</td>
<td>3.5</td>
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<tr>
<td>Hospital care of macrovascular complications</td>
<td>321</td>
<td>19</td>
<td>11879</td>
<td>3940</td>
<td>12200</td>
<td>3959</td>
<td>8241</td>
<td>17.9</td>
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<tr>
<td>Hospital care of microvascular complications</td>
<td>865</td>
<td>108</td>
<td>2050</td>
<td>553</td>
<td>2915</td>
<td>661</td>
<td>2254</td>
<td>4.9</td>
</tr>
<tr>
<td>Hospital care for illnesses unconnected to diabetes</td>
<td>1300</td>
<td>671</td>
<td>23260</td>
<td>10719</td>
<td>24560</td>
<td>11390</td>
<td>13170</td>
<td>28.7</td>
</tr>
<tr>
<td>Acute hospital care, total</td>
<td>2987</td>
<td>798</td>
<td>38297</td>
<td>15212</td>
<td>41284</td>
<td>16010</td>
<td>25274</td>
<td>55.0</td>
</tr>
<tr>
<td>Long-term inpatient care</td>
<td>49</td>
<td>239</td>
<td>6359</td>
<td>5937</td>
<td>6408</td>
<td>6176</td>
<td>232</td>
<td>0.5</td>
</tr>
<tr>
<td>Acute and long-term hospital care, total</td>
<td>3036</td>
<td>1037</td>
<td>44656</td>
<td>21149</td>
<td>47692</td>
<td>22186</td>
<td>25506</td>
<td>55.6</td>
</tr>
<tr>
<td>Outpatient care</td>
<td>2933</td>
<td>589</td>
<td>15541</td>
<td>6926</td>
<td>18474</td>
<td>7515</td>
<td>10959</td>
<td>23.9</td>
</tr>
<tr>
<td>Medicines for diabetes</td>
<td>1533</td>
<td>0</td>
<td>3222</td>
<td>0</td>
<td>4755</td>
<td>0</td>
<td>4755</td>
<td>10.4</td>
</tr>
<tr>
<td>Medicines for other diseases</td>
<td>1246</td>
<td>334</td>
<td>7032</td>
<td>3786</td>
<td>8278</td>
<td>4120</td>
<td>4158</td>
<td>9.1</td>
</tr>
<tr>
<td>Self-care equipment</td>
<td>747</td>
<td>7</td>
<td>1271</td>
<td>44</td>
<td>2018</td>
<td>51</td>
<td>1967</td>
<td>4.3</td>
</tr>
<tr>
<td>Travel costs and other compensations</td>
<td>390</td>
<td>236</td>
<td>1876</td>
<td>1765</td>
<td>2266</td>
<td>2001</td>
<td>265</td>
<td>0.6</td>
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<tr>
<td>Total expenditure</td>
<td>9885</td>
<td>2378*</td>
<td>73598</td>
<td>35193*</td>
<td>83483</td>
<td>37571*</td>
<td>45912</td>
<td>100.0</td>
</tr>
<tr>
<td>Population (n)</td>
<td>2324</td>
<td>2153</td>
<td>11414</td>
<td>10920</td>
<td>13738</td>
<td>13073</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Expenditure/individual (USD/year)</td>
<td>4253</td>
<td>1105*</td>
<td>6448</td>
<td>3223*</td>
<td>6077</td>
<td>2874*</td>
<td>3203*</td>
<td>-</td>
</tr>
<tr>
<td>Population receiving hospital care (n)</td>
<td>616</td>
<td>226</td>
<td>4558</td>
<td>2549</td>
<td>5174</td>
<td>2775</td>
<td>2399</td>
<td>-</td>
</tr>
</tbody>
</table>

* The expenditure for missing controls added as an average
Ireland

In the recent CODEIRE study in Ireland it highlighted that Diabetes is costing Ireland €580m each year with individual patient costs being €2,468k. This study was undertaken to investigate the direct healthcare costs of managing T2D in Ireland. It showed that two thirds of all current expenditure on Diabetes is for the treatment of high complications of diabetes – complications which are largely preventable by early assessment and preventive management. Hospitalisations were the main driver of costs, accounting for almost half of overall costs, while ambulatory and drug costs accounted for 27% and 25% respectively. Hospitalisation costs were high because 60% of patients had developed complications.

It also pointed out that similar to figures from the UK and Finland that an epidemic in T2D is unfolding because of increasing obesity, more sedentary lifestyles and an ageing population.

Its clear message is that preventing Diabetes and its associated complications could reduce the financial burden of the disease on the state and introduce substantial cost savings in the long term.

Diabetes care is cost effective

Effective and efficacious care for people with diabetes who could be categorised as high risk individuals in a health sense, is generally always cost effective.

The several areas in Diabetes Care where cost effectiveness is particularly evident these include:
- Prevention of cardiovascular diseases among people with Type 2 Diabetes.
- Lowering the blood cholesterol of Irish people with diabetes.
- Intensive glycaemic control.
- Prevention of complications is always cost effective.
- Prevention and early detection of both diabetic retinopathy and diabetic neuropathy with Type 1 Diabetes

With their number and multiple risk factors people with Type 2 Diabetes are the key group with regard to costs. People with Type 1 Diabetes economic burden on society is not as heavy due to the lower prevalence of the disease, it is still vitally important to provide effective treatment for a life threatening disease and a costly one due to its severe consequences.

Return on investment

The areas which will highlight significant return on investment for adoption of this model includes:
- Reduced ED and in-patient admissions due to preventative approaches and treatment in appropriate settings.
- Reduced medication costs from self management and clinical interventions that are timely within disease cycle.
- Clinical governance and leadership model enables integrated and efficacious decision making.
- Meets transformation goals and principles set out for the HSE.
- Recent research from institute of public health identified in stark terms the increasing prevalence rates of T2D and obesity that could create crisis level in terms of direct, indirect and productivity costs for the health services and society in general.
- This approach reflects a whole system approach that could become a visible model of success.

Costs associated with the Reports Recommendations

This report’s primary aim was to identify key recommendations to improve Diabetes Care nationally into the future. The costings related to these recommendations are estimated and would require specific financial validation. It was also envisaged from the report that the economic estimations would be one of the first tasks of the Local Diabetes Service Delivery Groups in each HSE region as recommended in the report.
Standards
These are standards to guide service delivery and direction. In the “drill down” towards achievement of these standards there will be additional costs but they will be incorporated in costings identified for specific delivery recommendations.

Clinical guidelines for Type 2 Diabetes
Again similar to the standards the adherence to the guidelines will result in some resource requirements that should be reflected in service delivery recommendations. There would be publishing costs as well associated with national guidelines.

Integrated care model
The costings for such a model are estimated below but require specific financial assessment. There are also a number of national issues that will impact on any estimation such as Contractual negotiations. These estimates are based on the action plan and its phases and will refer to one managed clinical network area (local DSIG) of approximately 500,000 population. In this population there will be a number of areas with varying staffing complements that will require reorganisation and reorientation. There is also potential in savings that could emanate from differing cost variations within the LTI and GMS provision of the 4 main Diabetes Drugs. The potential of more consultant posts with resulting lowering of NCHD numbers provides opportunities along with the further expansion of the 100+ scheme. Within the concept of integrated care some of these nursing and allied health professional posts could be associated with the development of Primary Care Teams and Primary and Social Care Networks. An example of this would be the development of Clinical Nurse Specialist posts. The development of a diabetes ICT capacity to enable screening and register requirements could be an area for early adoption of a national client index with capital input from the NDP. The developments suggested in self care management through structured education and peer support could be a demonstration model for potential roll out of a generic model. This would harness the input of educational, voluntary and patient support agencies. The roll out of the DSIG’s as managed clinical networks would take place over a two year period 2008-2010.
### Regional diabetes centre and primary and social care network for 500,000 population (as per consolidated payscales at 01.09.08)

<table>
<thead>
<tr>
<th>Consultant Type</th>
<th>Estimated Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultants in endocrinology/diabetologists x 5</td>
<td>€197,296 x 5 = €986,480 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 1</td>
<td>€197,296 x 2 = €394,592 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 2</td>
<td>€197,296 x 2 = €394,592 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 3</td>
<td>€197,296 x 1 = €197,296 + non-pay costs + 10.75% ER PRSI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Diabetes nurse specialists x 15 (brief across service domains)</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>€54,188 x 5 = €270,940 + allowance + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 2</td>
<td>€54,188 x 5 = €270,940 + allowance + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 3</td>
<td>€54,188 x 5 = €270,940 + allowance + non-pay costs + 10.75% ER PRSI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Specialist diabetes podiatrists x 2</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>€64,061 x 2 = €128,122 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 1</td>
<td>€64,061 x 2 = €128,122 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 1</td>
<td>€64,061 x 2 = €128,122 + non-pay costs + 10.75% ER PRSI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Professionally qualified social worker x 1.5 (brief across service domains)</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>€52,662 x 1.5 = €78,993 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 1</td>
<td>€52,662 x 1.5 = €78,993 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 1</td>
<td>€52,662 x 1.5 = €78,993 + non-pay costs + 10.75% ER PRSI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Senior diabetes dietitian x 10 (brief across service domains)</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>€58,192 x 10 = €581,920 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 1</td>
<td>€58,192 x 5 = €290,960 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 2</td>
<td>€58,192 x 3 = €174,576 + non-pay costs + 10.75% ER PRSI</td>
</tr>
<tr>
<td>Year 1</td>
<td>€58,192 x 2 = €116,384 + non-pay costs + 10.75% ER PRSI</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ophthalmologist x 1</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>€94,648 + non-pay costs + 10.75% ER PRSI</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Psychologist x 1</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>€68,231 + non-pay costs + 10.75% ER PRSI</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>GPs contract</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Still under consultation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ICT Needs</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>€170k (project team to be established nationally)</td>
</tr>
<tr>
<td></td>
<td>On-going costs would be determined by project team for the three years</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Retinopathy screening (Per HSE region)</th>
<th>Estimated costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 1</td>
<td>€1m pay and non-pay costs including eight posts</td>
</tr>
<tr>
<td>Year 1</td>
<td>€1m once off National Capital IT costs</td>
</tr>
</tbody>
</table>
Self-care management programmes

Estimated costs

€250k pay and non-pay with one coordinator post

Educational requirements

Estimated costs

€100k

Paediatric/adolescent

For 1 regional centre with 150-200 children/adolescents with diabetes

0.5 Consultant Paediatrician with an interest in Diabetes €197,296 + non-pay costs and 10.75% ER PRSI

2 Paediatric Diabetes Nurse Specialists €108,376 + allowances + non-pay costs and 10.75% ER PRSI

1 Senior Dietitian €58,192 + non-pay costs and 10.75% ER PRSI

0.5 Clinical Psychologist €68,231 + non-pay costs and 10.75% ER PRSI

0.5 Medical Social worker €52,662 + non-pay costs and 10.75% ER PRSI

Diabetes management package linked to central server at national centre €14,770

Podiatry

The recommendations suggest 10 podiatrists for population of 500,000 working across service domains. The integrated care model has identified a number and it is hoped the more generalist care will be undertaken in a community setting as part of the primary and social care networks. It is envisaged that chiropody/podiatry services will cover these needs. However it is estimated that there is a need for specialist equipment which would equate with €15k per podiatrist in specialist setting. There will also be additional non-pay costs related special orthotic services and footwear.

Self-care management

The costing for this component is reflected above for a population of 500,000. It is envisaged that there would be non-pay costs associated with this component. The coordinator post would access existing staff inputs and work closely with external providers. The coordination consists off structured education sessions and peer support sessions that would utilise existing preventative and health promotion interventions.
five

Conclusions
Conclusions of the first report of the Expert Advisory Group on Diabetes

- There is a unique opportunity to develop an integrated service model which adopts a population health focus within the Transformation Programme and to invest in the necessary infrastructure to make it happen. This will contribute to the development of enhanced primary care and specialist services binding local and regional services together in the form of a managed clinical network. A key goal is managing the majority of care needs and processes within the home/community environment, and utilising the skills of the patient/carer. The concept of joint working within a managed clinical network has been recognised in the Action Plan for the Health Services in the North East as the key vehicle for enabling the delivery of best acute healthcare and is also a key recommendation of the Acute Hospital Bed Review 2007.
- The model also fundamentally recognises the centrality of clinician involvement in the design, provision and improvement of care and is integrated with other initiatives on the agenda of reform. The service model that ensues could be utilised for other categories of chronic diseases, conditions and for service integration.
- Excellent diabetes care requires the integration of all of the approaches outlined earlier and attention to all risk factors simultaneously.
- The costs of diabetes care makes up a substantial proportion of national health expenditure, from 5% to 15% depending on the location. It has been shown in Ireland that two thirds of this expenditure is currently on the complications of diabetes – many of which could have been prevented.
- Excellent diabetes care and multi-disciplinary preventive care is costly – but much less so, than continually having to treat the advanced complications. From an economic and social justice perspective it is becoming the only alternative.
References
Integrated Care Model

2. Intensive blood glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with Type 2 Diabetes UKPDS Group Lancet (1998); 352: 837-853
5. Tight blood pressure control and risk of macrovascular and microvascular complications in Type 2 Diabetes UKPDS Group. British Medical Journal (1998); 317: 703-713

Podiatry


Education/Empowerment


ICT
52. Siminerio, L, Zgibor, J, and Solano, F X (2004) “Implementing the Chronic Disease Model for Improvements in Diabetes Practice and Outcomes in Primary Care : the University of Pittsburgh Medical Center Experience”. Clinical Diabetes. 22(2), 54-58.

Paediatric/Adolescents