Department of
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Report of Diabetes Review Steering group

Reflecting on Care for people with Diabetes 2003-2013

Review of the Joint Taskforce Report (2003) by the Steering Group Chaired by CMO (DHSSPSNI) June 2014

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1.0 Introduction and Background

1.1 Background to the Review of Diabetes Care in Northern Ireland

In January 2012 following representations from healthcare professionals and patient groups, the DHSSPS Minister decided that it was timely to assess care for people with diabetes in Northern Ireland. This was also within an increasingly complex policy context in relation to long term conditions and commissioning of health and social care services. This included:

- the inclusion of standards for diabetes in the Cardiovascular Health and Well-being Service framework;
- the publication of Living with Long Term Conditions; a Policy Framework for Adults with Long term Conditions
- the "Transforming Your care" review of Health and Social Care in Northern Ireland
- the significantly altered landscape in the Health and Social Care sector following the Review of Public Administration (RPA).

The Minister considered a number of options in relation to reviewing diabetes care and the development of a diabetes strategy. After careful consideration it was decided that:

"A review of the CREST/Diabetes UK Joint Taskforce Report (2003)would enable a thorough "stock take" of the current position regarding the development of services and standards of care currently in place in relation to the aspirations of the report. It would also provide a basis for identifying current gaps in the service as well as enabling the identification of emergent priorities."

1.2 Terms of Reference

The following Terms of Reference were agreed.

Primary aim:
To review the Diabetes UK / CREST Joint Taskforce Report (2003) in order to assess progress against original report objectives and identify current gaps in service provision.

Tasks:

The review will comprise the following tasks:

1. **Assessment of Joint CREST / Diabetes UK report (2003) in respect of progress against report objectives and hence the identification of gaps in service provision.**

2. Assessment of current standards of care relating to diabetes and if they are deemed appropriate.

3. Identification of emergent issues relating to the management of diabetes over the last decade. These include those influenced by technological advances, organisational and professional developments and demographic change.

4. Assessment of the new policy context (including Transforming Your Care) and proposed implementation mechanisms and how these can best be utilised and harnessed to ensure diabetes services are commissioned effectively.

1.3 Methodology

This report will describe the current epidemiology and key statistics relating to diabetes and describe progress against the key areas described in the Diabetes UK / CREST Joint Taskforce report (2003). The report includes written submissions from members of the Steering Group and the specific expertise of others who are knowledgeable about the area under consideration (see appendix A). Recommendations are included which it is envisaged will facilitate enhancement of service provision for people with diabetes.

1.4 The History of the Joint Taskforce Report (2003)

In 2003 a Joint Taskforce, chaired jointly by CREST[1] and Diabetes UK and comprising of approximately 50 members from across the health and social care sector in Northern Ireland, produced the "Blueprint for Diabetes Care in Northern Ireland in the 21st Century".[2]

It was acknowledged at the time, that diabetes was developing into an increasingly important public health issue for the people of Northern Ireland with significant increases in the numbers of people diagnosed with the condition projected over the next decade associated with an increasing burden on the health and social care sector.

The Terms of Reference for the taskforce in 2003 were to:

1. Review the 1996 CREST Guidelines for diabetes[3].

2. Consider the developments taking place in diabetes services in Scotland, Wales, England and the Republic of Ireland, including the development of a National service Framework in England.

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[1] CREST (Clinical Research Efficiency Support Team, predecessor to GAIN, Guidelines and Audit Implementation Network)
[2] Blueprint for Diabetes Care; Report of the Joint CREST/ Diabetes UK Taskforce. CREST (2003)
[3] Diabetes Care in Northern Ireland (CREST) 1996; the predecessor to the 2003 Report

3. Produce updated clinical and service guidance for Northern Ireland with particular reference to consumer issues, public health strategy, resources and screening for diabetes.

The Joint Taskforce Report (2003) was seen by its authors as an "Integrated Service Framework" analogous to service frameworks for diabetes in other parts of the UK and the Republic of Ireland at the time. It was envisaged that it would set a strategic direction for diabetes care which would take five to ten years to implement.

The taskforce agreed a number of underpinning principles for the provision of diabetes care in both the primary and secondary care sectors. These were:

Underpinning Principles for Diabetes Care as Described in Joint Taskforce Report (2003)

- People with diabetes should be involved in planning services for diabetes and should be involved in decisions about their care.
- All people with diabetes should have access to high quality comprehensive care including education and information.
- An information infrastructure should support the delivery of diabetes care.
- Structured programmes of diabetes care should be delivered in primary and Secondary care that reflects evidence-based practice.
- Care should be delivered by professionals with appropriate training and skills.
- Equivalent standards of care should be achieved in primary and secondary care with appropriate referral to secondary care when complications or problems arise.
- Diabetes services and clinical standards of care should be subject to regular audit and evaluation.
- People with diabetes should be enabled to live as healthy and normal a life as possible through regular (annual) review and appropriate treatment.
- Vulnerable groups should receive targeted support and services. Vulnerable groups include those living in residential settings, ethnic minorities, travellers, people with mental illness, people with learning difficulties, homeless, asylum seekers and children and young people. The role of carers and support carers is particularly important. People with diabetes who are pregnant should be considered as a vulnerable group.
- Partnership between people with diabetes, service providers and policy makers should be central to the development of diabetes care.

The taskforce favoured the then "Scottish approach" to developing a framework for care for diabetes which consisted of "building blocks" grouped around five key areas.

- Prevention and early detection.
- Care, monitoring and treatment.
- Targeting vulnerable groups.
- Planning and managing services.
- Implementation issues.

Within the five key areas a number of priority areas were highlighted for early action which it was felt should be implemented within a shorter timescale of approximately two to five years.

Diabetes Framework for Northern Ireland (2003)

Prevention and Early Detection

Health Promotion	Public Education	Screening High-Risk Groups	Community issues and Interagency Working

Care Monitoring and Treatment

Education for People with Diabetes and Professionals	Eye Screening	Integrated Diabetes Care and Guidelines
	Emotional and Psychological Support	

Targeting Vulnerable Groups

Children and Young People	Ethnic Minority Communities	Pregnancy and Sexual Health	Other Vulnerable Groups*

Planning and Managing Services

Strategy, Leadership and Team Working	Workforce Planning	Information Management and Diabetes Registers
User Forum and Empowerment	Audit, Research and Monitoring	

Implementation

Implementation and Monitoring

NB - shaded areas are those identified for early action

*People with learning disabilities, mental illness and those in nursing/residential care

2.0 Diabetes; Epidemiology and Economic Impact

2.1 Introduction

The Joint Taskforce Report (2003) reported that in Northern Ireland an estimated 40,000 people were known to have diabetes, a figure which was expected to double by the end of the decade. A further 25,000 people were thought to have diabetes but had not been diagnosed. An estimated 5% of NHS expenditure and 10% of hospital in-patient resources were used to care for people with the condition.

2.2 Changes in the Epidemiology of Diabetes; 2003 to Present

There has been a one third increase in diabetes in adults (those aged seventeen or over) in Northern Ireland between 2004/5 and 2010/11 so that at the end of March 2012 there were almost 76,000 adults with the condition.

Almost all of this increase is attributable to Type 2 diabetes. The observed increase in cases is largely due to improved detection and recording of people with diabetes in primary care, rising levels of obesity and the overall ageing of the population. It is not surprising that the impact and the additional workload of the increasing numbers of Type 2 diabetes is already being experienced by GP and hospital services including those specialties which manage complex cases such as obstetrics and complications such as renal impairment and cardiovascular disease.

There are just over 1000 children with Type 1 diabetes in Northern Ireland and sporadic cases of Type 2 diabetes are being detected in adolescents.[4]

[4] QUB Database of Children in Northern Ireland with Diabetes Chris Patterson; School of Medicine, Dentistry and Biomedical science

Table 1 Northern Ireland -Quality and Outcomes Framework (QoF) Raw Prevalence Data[5]

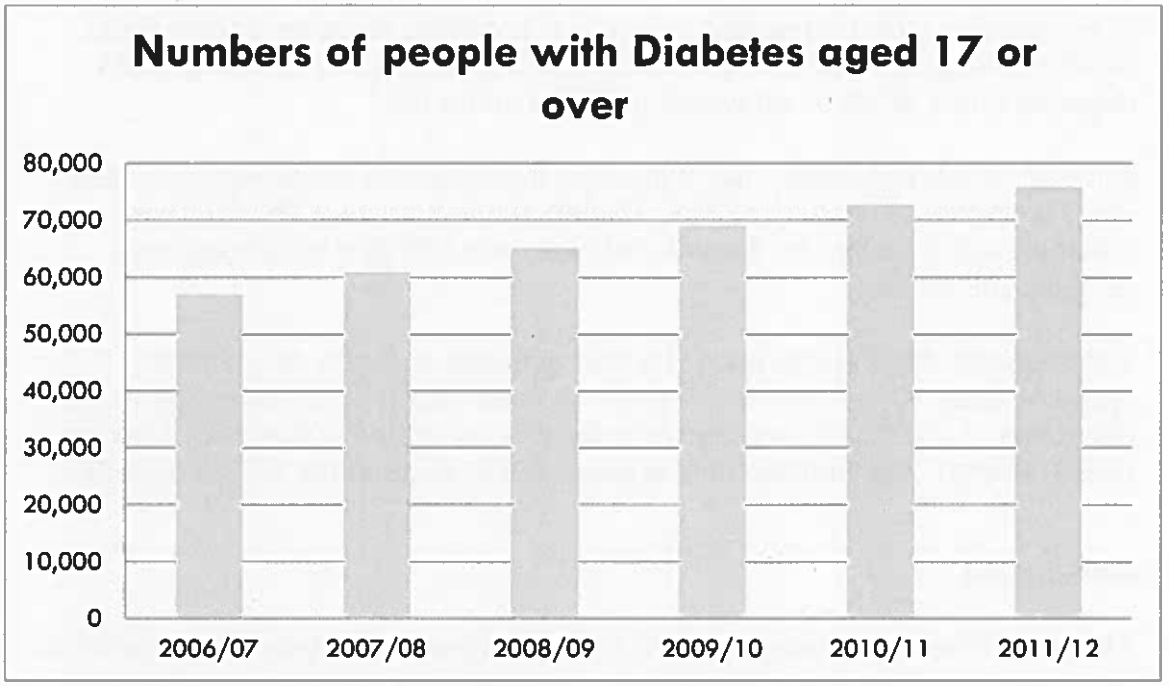
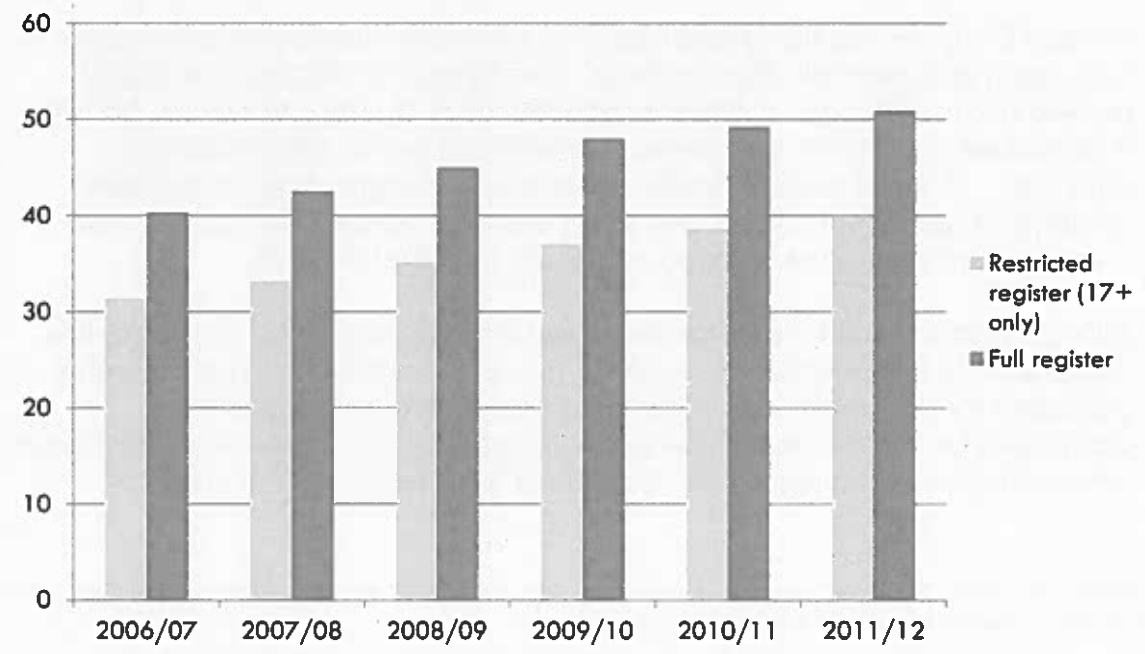


Table 2: Raw prevalence per 1,000 patients (using the full and restricted register, age 17+)



[5] Quality and outcomes Framework Prevalence Data (DHSSPS)

2.3 The Economic Impact of Diabetes

It is challenging to disaggregate the costs of treating diabetes within the health and social care sector from expenditure for other conditions. A London School of Economics report on estimated costs of providing diabetes care in 5 EU countries suggests that approximately £2 billion is spent on treating type1 diabetes and £12 billion on type 2 diabetes in the UK.[6]

Another recent publication has estimated that diabetes costs approximately £23.7bn in the UK in 2010/2011: £9.8bn in direct costs (£1bn for Type 1 diabetes and £8.8bn for Type 2 diabetes) and £13.9bn in indirect costs (£0.9bn and £13bn).[7]

The research cited above suggests that diabetes currently accounts for approximately 10% of the total health resource expenditure according to best estimates, a significant increase from the 5% estimated in the Joint Taskforce (2003) Report. Furthermore this is projected to account for 17% in 2035/36.

2.4 Conclusion

There have been marked increases in the numbers of people with diabetes in Northern Ireland over the last decade in line with the predictions of the Joint Taskforce Report (2003), reflecting global and national trends in the epidemiology of the condition. The most significant increases have been in Type 2 diabetes and this has been driven by rising obesity levels and the ageing population.

Primary Care GP registers have helped to ascertain numbers of those aged seventeen and over with the condition. The figures for children are largely derived from a database collated by academics at Queen's University Belfast. Robust data is essential for assessing needs and hence commissioning effectively. It would also be helpful to be able to disaggregate more exactly numbers of people with type1 and type 2 diabetes as the QOF returns from General Practice are not required to provide this level of detail.

Although robust data for precise direct and indirect costs is not available, it is reasonable to assume that costs will continue to rise leading to considerable pressures for the Health and Social care sector. It may be helpful to commission a specific health economic analysis for the indirect and direct costs of providing care for people with diabetes in Northern Ireland in order to

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[6] Diabetes expenditure, burden of disease and management in 5EU Countries, P. Kanavos, S. Van Den Aardveg and W. Schurer, London School of Economics (2012)

[7] Estimating the current and future costs of Type 1 and Type 2 diabetes in the UK, including direct health costs and indirect societal and productivity costs. Hex N, Bartlett C, Wright D, Taylor M, Varley D. (Diabetic Medicine; July 2012)

adequately plan for future cost pressures and to assist commissioners in the development of services which can cope with increasing demand.

Key Summary Points

- There has been a one third increase in the numbers of people with diabetes over the last five years.
- Numbers of people with diabetes have doubled since the publication of the 2003 Joint taskforce Report.
- More precise figures are needed for those with type 1 and type 2 diabetes respectively in Northern Ireland.
- Health and Social Care expenditure on diabetes is estimated at ten percent of the total HSC budget; projected to rise to 17 percent in two decades.
- It would be helpful to have more robust local data about direct and indirect costs to the HSC from treating diabetes and its complications.

3.0 Public Health Approaches to Preventing Diabetes and its Complications

3.1 Prevention and Early Detection of Diabetes

The original Joint Taskforce Report (2003) acknowledged the importance of prevention and early detection in respect of diabetes and described the links between obesity and the increasing numbers of new diagnoses of Type 2 diabetes. The report cited the need for **health promotion** targeted at promoting healthy food choices, increasing levels of physical activity and smoking cessation. It emphasised the need for **Public Education** campaigns, particularly aimed at raising awareness of the condition and its complications and for **targeted screening of high risk population** subgroups. The report also emphasised the need for a **community based approach** to tackling lifestyle issues with an emphasis on **interagency work** and early intervention.

3.2 Development of the Public Health Function in Northern Ireland Since 2003

There is considerable evidence that Type 2 diabetes can be delayed or prevented by promoting healthy eating, physical activity and preventing obesity as stated in the Joint Taskforce Report (2003) and confirmed more recently.[8]

Data from the Health Survey Northern Ireland 2011/12 indicated that 37% of adults are overweight and a further 23% are obese; this means that 60% of adults in Northern Ireland carry excess weight. [9]

The problem of obesity, globally, at a UK level and within Northern Ireland has considerably worsened since 2003 hence contributing to the increased prevalence of Type diabetes.

3.3 Raising Public Awareness of Diabetes

The Joint Taskforce Report (2003) highlighted the need to raise public awareness about diabetes, its symptoms and associated health risks. Since 2003, Diabetes UK has sought to increase awareness of the condition through campaigns which have highlighted particular issues. Examples include, raising awareness of type 1 diabetes in children (Let's Talk Diabetes), (2011) and diabetic eye disease (2012) as well as diabetes week which takes place annually in June.[10] Foot health was promoted in 2012 and 2013.

In 2011, NICE Public Health Guidance was issued which focussed on interventions aimed at shifting the degree of risk of developing Type 2 diabetes

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[8] A systematic review of lifestyle modification and glucose intolerance in the prevention of type 2 diabetes. Thomas GN, Jiang CQ, Taheri S, Xiao ZH, Tomlinson B, Cheung BM, Lam TH, Barnett AH, Cheng KK.

[9] Health Survey Northern Ireland; Bulletin 1; November 2012

[10] Diabetes week 2013 http://www.diabetes.org.uk/Get_involved/Diabetes-Week/

within the wider population.[11] In addition to recommendations about the lifestyle measures required to prevent Type 2 diabetes, it also recommended interventions to raise awareness of risk factors and signs and symptoms particularly amongst at risk groups.

3.4 Screening High Risk Groups

The UK National Screening Committee position remains that there is no justification for universal (population) screening for diabetes. The position is now clearer regarding guidance on screening populations at higher risk of diabetes. NICE Public Health Guidance on this topic was issued in July 2012. [12]This guidance focuses on identifying people aged 18 years and over at high risk of type 2 diabetes and offering them effective lifestyle-change programmes to prevent or delay the condition.

3.5 Community Issues and Interagency Working

The Joint Taskforce Report (2003) stated that opportunities should be taken to involve communities in raising awareness about diabetes and its risks. There has been progress in terms of interagency and cross-departmental working in obesity prevention. There has also been work to engage local communities at higher risk of diabetes, for example work in the Belfast Local Commissioning Group. Much of this work has been driven by the publication of key strategies relating to public Health and in particular obesity prevention.

- *Fit Futures* – this was published in 2006 and sought to address childhood obesity. The strategy was the first to directly tackle obesity in Northern Ireland, and in particular focused on children and families and relied on a collaborative cross-sectoral approach particularly between health and education.

- *A Fitter Future for All (2012)* – a 10 year cross-sectoral integrated life course framework to prevent and address obesity in Northern Ireland for 2012-2022. This seeks to build on the success of "Fit Futures" and has employed a life course approach to preventing obesity across all age groups mitigating the effects of the "obesogenic environment"[7]

- *Healthy Child, Healthy Future:* A Framework for the Universal Child Health Promotion Programme in Northern Ireland. (May 2010).

- *New Public Health Strategic Framework;* this is the follow up to "Investing for Health". [13] A draft for consultation was published in July 2012. The final

[11] NICE Public Health Guidance 35 Preventing Type 2 diabetes; Population and Community level interventions (2011)
[12] NICE Public Health Guidance 38 Preventing Type 2 diabetes; Risk Identification and Interventions for individuals at High Risk (2012)
[13] Investing for Health; a Public Health Strategy for Northern Ireland DHSSPS (2002)

version of the strategy will seek to bring together actions across Government to improve public health by addressing the determinants of ill health and health inequalities.

Over arching strategies such as "Investing for Health" and the new Public Health Strategic Framework and a range of other public health strategies have a significant bearing on the prevention of Type 2 diabetes and the development of complications of diabetes. These seek to encourage healthier lifestyles, through better nutrition, smoking cessation and responsible alcohol consumption.

3.6 Conclusion

The Review of Public Administration (RPA) as it related to the Health and Social Care sector instigated the formation of the Public Health Agency (PHA) in 2009. An intersectoral multi agency approach lies at the heart of PHA practice in public health as well as a commitment to early years intervention. The Agency is also committed to tackling inequalities in health.

In general many of the public health aspirations of the Joint Taskforce Report (2003) report have been met in terms of public health infrastructure, approaches to tackling health inequalities and refined approaches in respect of health improvement.

Strategic public health frameworks have been published which focus on intersectoral approaches to tackling lifestyle issues which have a significant bearing on the development of diabetes and its complications.

Whilst considerable progress has been made in implementing prevention strategies there is now updated guidance on public education and risk identification which it would be helpful to implement.

It has not been possible to reverse the upward trend in obesity and new diagnoses of Type 2 diabetes and it remains to be seen if the implementation of current public health strategies will have the desired impact. This has to be considered within the context of an increasingly challenging "obesogenic" environment. Moreover, it is important to ensure that "front line" health and social care services enhance their public health role which includes ensuring people with diabetes are suitably informed and have access to public health interventions which can reduce complications and improve outcomes. It would also be helpful if relevant NICE Public Health Guidance could be endorsed and adopted as appropriate to inform public health policy and practice within Northern Ireland.

Key Summary Points

- There have been improvements in Public Health infrastructure, practice and strategic context since 2003.
- Obesity levels in the population of Northern Ireland continue to rise; accelerating the numbers of new cases of Type 2 diabetes.
- Front line health and social care staff need to be more fully engaged in employing public health as well as clinical interventions in preventing and managing diabetes.
- NICE Public Health Guidance should be adopted as appropriate to inform policy and practice in Northern Ireland.

4.0 Education for People with Diabetes and Professionals

4.1 Structured Diabetes Education

The Joint Taskforce Report (2003) stated:

"People with diabetes should receive a service that encourages partnership in decision making, supports them in managing their diabetes and helps them to adopt and maintain a healthy life style".

In addition the report recognised the benefit of structured education in allowing people with diabetes to:

- Adjust their own insulin dosage to facilitate daily living.
- Know how to recognise and act on symptoms.
- Cope with stress.
- Make the most effective use of medicines and treatments.
- Understand the implications and rationale of professional advice.
- Access health and social services.
- Manage work.
- Deal with exacerbations of disease.
- Develop strategies to cope with the psychological consequences of illness.
- Learn to cope with other people's responses to their diabetes.
- Understand the relevance of good control, to the development of diabetic complications.

The report further acknowledged the impact structured diabetes education programmes may have on improving knowledge, blood glucose control, weight, dietary management, physical and psychological well being.

The Joint Taskforce Report (2003) recommended education for both people with diabetes and health and social care professionals (see below) as ***an area for early action.***

4.2 The Rationale for Structured Diabetes Education

In 2005, Diabetes UK and the Department of Health stated *"The aim of patient education is for people with diabetes to improve their knowledge skills and confidence, enabling them to take increasing control of their own condition and integrate effective self-management into their daily lives. High-quality structured education can have a profound effect on biomedical outcomes, and can significantly improve quality of life and satisfaction"*[14]

The primary goal of diabetes care in children and adolescents is the maintenance of optimal glycaemic control (ie a glycosylated haemoglobin[15] of

[14] Report of the Diabetes Structured Education Working Group; Diabetes UK, DH (2005)
[15] Measurement of average blood glucose concentration over a prolonged period of time.

less than 7.5% or 58 mmol/mol) whilst ensuring good physical and psychological well-being, and normal growth and development.[16]

Structured Diabetes Education Programmes for Type 1 and Type 2 diabetes have different objectives.

Type 1 diabetes is an insulin deficiency disorder and people need skills to replace insulin safely and flexibly. This includes matching insulin dose precisely to carbohydrate intake.

Type 2 diabetes is associated with several cardiovascular risk factors that can be improved by lifestyle modification. Structured diabetes education for people with type 2 diabetes therefore emphasises lifestyle changes.

The nature of both Type 1 and Type 2 diabetes is such that it requires constant monitoring and adjustment of diet, medication and exercise if optimal glycaemic control is to be achieved. Thus effective self-care behaviours are an essential requirement for those diagnosed with diabetes and must be underpinned by knowledge of both diabetes itself and the impact each variable (ie diet, insulin, exercise, stress) may have on an individual's glycaemic control.

The complexity of diabetes management is well recognised as is the need to provide a healthcare environment in which both healthcare professionals and patients act in partnership to achieve best possible outcomes. One of the main goals is optimising glycaemic control in an effort to delay the onset of long-term complications such as retinopathy, neuropathy and nephropathy. [17]

Although many diabetes teams do provide diabetes education for their patients it is not always structured, appropriately quality assured or delivered by those who have been formally trained for that purpose. Hence, it is not surprising that a significant number of people with diabetes are not given the opportunity to achieve optimal glycaemic control.

4.3 Development of Policy to Support Structured Diabetes Education; the National Context

A number of policy changes have been implemented in recent years in an effort to address the issues of unstructured and poorly evaluated education.

In 2001 the Department of Health in England (DH) launched the National Service Framework (NSF) for Diabetes: Standards (DH, 2001).

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[16] NICE Clinical Guidelines; Diagnosis and Management of Diabetes in Children, young people and adults (CG 15),:2004

[17] The Effect of Intensive Treatment of Diabetes on the Development and Progression of Long-term Complications in Insulin Dependent Diabetes Mellitus. Diabetes Control and complications Trial Group; N Engl Journal of Medicine (1993)

This document contained twelve standards related to the delivery of diabetes care and services within the UK. Standard 3 of the NSF stated that:

"All children, young people and adults with diabetes will receive a service which encourages partnership and decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle". (DH, 2001, p5).

NICE (2003) conducted a health technology appraisal on the use of patient-education models for diabetes[18] which recommended that structured education should be made available for all individuals with diabetes. Structured Education was described as

"A planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individual's clinical and psychological needs, and adaptable to his or her educational and cultural background".

The DH (2004) highlighted the need to offer timely access and advice to all children and young people ensuring that their social, educational and emotional needs are met during periods of illness. Subsequently NICE (2004) stipulated the need to deliver educational content on the basis of a young person's age, maturity, culture, wishes and existing knowledge.

In their technology appraisal NICE (2003) stated that at that time there was insufficient evidence available to recommend one specific type of education, however the following guiding principles should be employed.

- Programmes should reflect established principles of adult learning,
- Group education is favoured unless contraindicated,
- Programmes should be delivered by trained healthcare professionals and be accessible to all,
- A variety of techniques should be employed to ensure active learning and
- Each education team should have a minimum of a diabetes specialist nurse and a dietitian.

These principles have been further developed by the DH and Diabetes UK requiring all structured education programmes to have a patient centred philosophy, a structured curriculum, trained educators, and to be quality assured and audited.

These criteria have been more recently reiterated in NICE clinical guidelines on type 2 diabetes.[19]

[18] Guidance on the use of patient education models for diabetes NICE (2003)
[19] National Clinical Guidelines; Type 2 Diabetes NICE (2008)

- "that every person and/or carer should be offered structured diabetes education at and around the time of diagnosis with annual reinforcement and review"
- That people and their carers should be informed "that structured education is an integral part of diabetes care"
- "that these programmes should be integrated with the rest of the care pathway"
- "that patient education programmes provide the necessary resources to support educators and that educators are properly trained and given time to maintain their skills"

4.4 Structured Diabetes Education, the Northern Ireland Context

Following publication of the Joint Taskforce Report (2003) the Department endeavoured to enhance access to diabetes structured education and introduced the following target in "Priorities for Action" which set out the high level priorities for commissioners of health and social care services.

"By 31 December 2006, Boards and Trusts should develop proposals to introduce a Structured Educational Programme, including psychological support, for people with diabetes to help them to manage their own condition more effectively".

This encouraged commissioners to evaluate provision of diabetes structured education within their localities; and highlighted disparities in provision.

An audit of diabetes structured education was undertaken within Northern Ireland in 2007. (Brown et al) The aim of the audit was to assess group structured diabetes education against standards informed by both Diabetes UK position statement on structured diabetes education and NICE (2003) guidance.

The audit identified a total of 26 diabetes education programmes delivered by thirteen teams across four Trusts between 1 May 2007 and 31 August 2007. Of these 13 were based on nationally recognised programmes[20] (DAFNE, BERTIE and X-PERT) with the remaining programmes being developed locally. The audit highlighted under-provision of structured diabetes education with the majority of people in Northern Ireland with diabetes having little access to structured diabetes education programmes.

Although programmes which were delivered achieved the majority of the standards set, only one programme was able to demonstrate achievement of all

[20] Recognised programmes for diabetes structured education include DAFNE (Dose Adjustment for Normal Eating), DESMOND (Diabetes Education and Self Management for Newly Diagnosed), BERTIE (Bournemouth, Type 1 Intensive Education), CHOICE (Carbohydrate, Insulin Collaborative Education), and X-PERT.

standards, this being the DAFNE programme. The main area of difficulty encountered by diabetes teams was in quality assurance of programmes.

The audit made a number of recommendations which included the integration of diabetes structured education into the routine clinical care of patients; proper training of staff who deliver education and access to systematised quality assured programmes. It also highlighted that there would have to be an increase in the provision of structured patient education, delivered in a range of care settings in order to deal with incident and prevalent cases of diabetes in Northern Ireland.

4.5 Current availability of Diabetes Education in Northern Ireland (2012):

There remains disparity in the delivery of diabetes education across Northern Ireland with each Health and Social Care Trust engaged in their own strategy for the delivery of education. Primary care provides little or no structured education. Following contact with each Trust the following information has been obtained in respect of the current provision of diabetes education within the Trusts.

Table 3: Provision of Diabetes Structured Education by Health and Social Care Trust

Provision of Diabetes Structural Education By Health and Social Care Trust					
	X-PERT (Type 2 established)	DAFNE (Type 1)	BERTIE (Type 1)	CHOICE* (Paediatric)	DESMOND (Type2; newly diagnosed and established)
BELFAST		√	√	√	√
WESTERN			√	√	√
SOUTH EASTERN		√	√	√	√
SOUTHERN	√		√***	√	
NORTHERN**					

*CHOICE specifically aimed at children and adolescents (resourced by CAWT European funding until December 2013 across all 5 HSC Trusts)
**Northern Health and Social care Trust commenced SPE in June 2013 (DAFNE)
***Condensed version of BERTIE

Belfast Health and Social Care Trust:
The Belfast Trust currently delivers 4 structured diabetes education programmes. These programmes are not delivered at every site and there is disparity between sites. The predominant programme utilised in Type 1 diabetes is the DAFNE programme which is delivered eight times per year. There is currently a waiting list of approximately 200 people for this programme. Although the DAFNE programme is Trust funded currently there is no funding for the DESMOND programme which is a community based programme aimed at people with Type 2 diabetes.

Western Health and Social Care Trust:
In contrast to the Belfast Trust there is no specific funding for Type 1 structured diabetes education programmes in the Western Trust. Staff try to facilitate this education within existing resources. The Trust runs the BERTIE programme (referred to as CHOICE locally) in 3 sites in the Trust, approximately 12 programmes are organised each year.

The CAWT CHOICE course for children and young people is funded by the Cooperation and Working Together (CAWT) programme of European money.

The DESMOND programme is funded by the Trust for Type 2 education and is organised in various locations throughout the Trust. Thirty six sessions per year are provided. The programme is offered as a 1 day course is Tyrone and Fermanagh parts of the Trust and in Derry/ Londonderry, Limavady and Strabane the programmes is delivered in 2 half day sessions

South Eastern Health and Social Care Trust:
Similar to the Belfast Trust the programmes are not delivered at all sites and disparity exists between sites. All programmes are Trust funded with the exception of the CHOICE programme which is specifically tailored to children and young people with Type 1 diabetes and is currently funded by the CAWT programme of European money until December 2013. This programme is funded in this way across all Trusts and will cease to run in all areas after December 2013 unless integrated into routine care and funded locally.

Southern Health and Social Care Trust:
As with other Trusts there is disparity between sites in delivery. Funding has proved an area of concern in respect of sufficient capacity to deliver structured diabetes education programmes.

Northern Health and Social Care Trust:
At the time of writing the Northern Trust did not deliver any structured diabetes education programmes despite some individuals having been trained in the DESMOND programme with the assistance of Diabetes UK NI. Patients were educated on a one-to-one basis. However, it is understood that the Trust began to deliver structured diabetes education in a group setting (DAFNE) in June 2013.

4.6 Programme for Government Commitments

The Programme for Government 2011-15 includes a commitment that people with long term conditions who wish to be enrolled on a dedicated chronic condition management programme, will have the opportunity to do so.

A number of milestones have been established to support the PfG commitment. The first Milestone (2012-13) is to identify and evaluate the current baseline of patient education and self management support programmes in place in each Trust area. The second Milestone (2013-14) commits the Health and Social Care Board and Public Health Agency to working with key stakeholders to develop and secure a range of quality assured education, information and support programmes to help people manage their long term conditions effectively, alongside full application of the Remote Telemonitoring contract. Milestone 3 (2014-15) states that people with a long term condition will be offered access to appropriate education, information and support programmes relevant to their needs, including innovative application of connected health.

The Department has developed a Delivery Plan to support this commitment. As part of this, the Department has, in conjunction with the Public Health Agency carried out a baseline audit of patient education/self management programmes, including diabetes programmes, across Northern Ireland and is establishing a system for ongoing monitoring of the availability of patient education programmes to inform future commissioning arrangements.

Conclusion

Current provision of structured diabetes education is variable and insufficient to meet the numbers of people with diabetes. There should be a strategic approach to ensure the development of consistent and needs based delivery of structured diabetes education within Northern Ireland. The disparity of delivery across Northern Ireland means that people with diabetes do not have the opportunity for equity of access and are dependent on their location in accessing structured diabetes education. The differing nature of programmes across the region makes peer review and quality assurance increasingly complex.

There has been significant progress in the education of children and young people with Type 1 diabetes following the introduction of the CHOICE programme. This programme is delivered consistently across all five Trusts and data is collected and managed centrally which will facilitate auditing processes. The next step in the development of CHOICE should be the instigation of a quality assurance process which meets with the recommendations of both NICE and Diabetes UK. The CHOICE programme is only funded by European money until December 2013. Action, therefore is needed to ensure funding continues at a local level and the programme remains part of routine care if children and young people are to continue to be educated in the management of their condition.

Key Summary Points

- Provision of diabetes structured education has increased over the last decade.
- Provision still remains variable, inequitable and insufficient to meet the demands of incident and prevalent cases of diabetes.
- The CHOICE programme for children and young people represents comprehensive provision for this group of patients
- Overall, provision would have to be markedly increased in order to meet the needs of the growing numbers of people with diabetes.

4.7 Education for Professionals

The Joint Taskforce Report (2003) recognised the need for those working within the area of diabetes care to be trained and competent in order that they may function successfully within a multidisciplinary team. Education for professionals was identified *as an area for early action* along with structured education for patients. (see section 4.4)

At the time of publication of the Joint Taskforce Report (2003) a number of education programmes were highlighted as being available in Northern Ireland, in particular the multidisciplinary course (MDT) offered by the University of Ulster. The report further highlighted the need to have a range of courses for staff involved in diabetes care ranging from short courses, for example diplomas to degrees and postgraduate courses. Particular emphasis was placed on the need for all involved in the diagnosis and management of diabetes to ensure they remain up to date and current in their care practices. In addition the report recommended:

- Continuing Professional Development (CPD) for all specialities and professional groups involved in diabetes care which should include regular updates on diabetes care.
- Consideration should be given to establishing a diabetes education committee in Northern Ireland which would be responsible for reviewing the education curriculum, teaching methods, accrediting teaching programmes for professional staff and education materials for people with diabetes.

Since publication of the report the only MDT course in Northern Ireland which was provided at University of Ulster has been withdrawn. Locally diabetes education for professionals is provided primarily in a discipline specific format as outlined below:

Nurses
Nurses have access to a range of courses relating to diabetes care which include short courses to develop specific competencies through to specialist degree courses, masters and diploma level courses. These are provided at a local Trust level, through the University of Ulster or at centres on the UK mainland such as Warwick and Birmingham.

Dietitians
The training opportunities for dieticians are more limited than nurses with short competency based courses available locally to enhance the skills of the more general or specialist dietician respectively. Dieticians may be able to avail themselves of specialist modules linked to Masters courses in Warwick and Nottingham if identified as a professional learning need.

To date there is no programme of education leading to Postgraduate or MSc qualifications which specifically meet the needs of dietitians working within the area of diabetes care.

Podiatry
The educational opportunities provided for podiatrists working within the area of diabetes care is similar to that of dieticians in that there currently exists no programme of education that leads to a postgraduate or MSc award tailored to their needs. The Society of Chiropodists and Podiatrists (SCP) require all qualified podiatrists to undertake and update at least every 3 years. This update is normally provided as a one day event in Northern Ireland and applies to those staff working within Health and Social Care only. In addition the SCP offers a one week programme on diabetes in January and July of each year in London. Locally podiatrists may undertake the Level 7 masters module on the diabetic foot at the University of Ulster. In previous years many podiatrists would have availed of the MDT course available at University of Ulster.

Doctors
The training needs of junior hospital doctors, especially in Foundation Years, in relation to safety of insulin administration and basic prescribing have received significant attention. [21] The continuing education of hospital based diabetes specialists is a requirement for appraisal, and opportunities are available at local and national level to update and extend training

Many General Practitioners have acquired diabetes skills through completing postgraduate diploma courses. The increasingly important role of the GP in managing diabetes will require appropriate development of competence in this field. There is an opportunity to do this by joint Primary/Secondary Care multidisciplinary meetings which will both deliver education and enhance building the teams necessary to deliver integrated care.

[21] The Adult Patient's Passport to Safer Use of Insulin. HSC (SQSD 3/11)

Conclusion

In respect of education for professionals, there appears to be a large disparity in the current educational opportunities for healthcare professionals working within diabetes care in Northern Ireland. The discontinuation of the MDT programme has resulted in a more discipline specific approach to diabetes education locally despite the need to work as a multidisciplinary team.

A one day conference on diabetes is provided each year locally by Diabetes UK which provides an opportunity for all healthcare professionals to update themselves and network with colleagues. The establishment of a diabetes education committee as suggested within the Joint Taskforce Report (2003) does not appear to have materialised and there is a need to offer some coherent structured to diabetes professional education in order to ensure the needs of all healthcare professionals are realised. The issue of interdisciplinary education requires particular attention and should be given further consideration in order to promote a more multidisciplinary approach to diabetes care and enhance competence and capacity in managing the condition.

Key Summary Points

- A range of training opportunities exist for professionals but they vary markedly between disciplines.
- There is a lack of interdisciplinary and multidisciplinary training opportunities which undermines the team based approach to diabetes care.
- Currently there is no strategic regional approach to assessing the training needs and capacity and competency of health and social care professionals who deliver care for people with diabetes.

5.0 Screening for Diabetic Eye Disease

5.1 Eye Screening

The Joint Diabetes Taskforce report (2003) described the impact of diabetes on eye health, in particular diabetic retinopathy which is the leading cause of blindness in working aged people. The UK National Screening Committee (NSC) had recommended annual retinal screening using digital retinal photography for all people aged 12 or over with diabetes and the CMO (Northern Ireland) therefore set up a diabetic retinopathy screening working group to consider how a screening programme could be implemented across Northern Ireland and what resources would be required to deliver such a programme.

The working group re-iterated the recommendations of the NSC in respect of an annual screening programme including the use of retinal digital photography. The service could be delivered in fixed settings or by means of a mobile unit which travelled to specified locations.

The report also highlighted the other characteristics of a systematically delivered screening programme with robust quality assurance mechanisms built in. The establishment of a diabetic retinopathy screening programme was identified as an area ***for early action.***

5.2 Progress Since 2003

The requirement to develop a diabetic retinopathy screening programme in Northern Ireland was detailed in Priorities for Action 2005-2008. The programme would be commissioned regionally and screening offered to all eligible people with diabetes (then approximately 50,000).

The Northern Ireland Diabetic Retinopathy Screening Programme (DRSP), which was established in 2007 aims to reduce visual morbidity caused by diabetic retinopathy by facilitating early diagnosis and treatment of sight-threatening retinopathy through population screening.

5.3 Service Model

The screening programme uses a mixed model, with the screening test delivered primarily in GP practices in the Belfast, Northern, Southern and South Eastern localities using mobile equipment, and in six fixed community sites in the Western locality.

- **Call-recall:** Practices are notified when the patients under their care are due for re-screening, at the agreed interval.

- **Eligibility Criteria:** Practices are responsible for identifying all patients eligible for screening, from each GP Practice clinical data system, following criteria agreed by the DRSP Project Board. An invitation to attend the

screening episode is sent to each individual patient by the GP practice, together with a detailed patient information leaflet, which explains the purpose of screening and what it entails. This forms the basis of informed consent for screening. Practices are required to provide a completed minimum data set on each person invited in advance of the screening episode.

- **The Screening Test**: This consists of digital imaging of the retina of each eye, according to agreed protocols.

- **Images:** Images are captured by trained photographers; Medical Technical Officers in the Belfast, Northern, Southern and South Eastern localities and optometrists in the Western locality. All images are transferred to the grading centre at the Belfast Health and Social Care Trust. Images are graded by trained graders to agreed protocols and within a quality assured pathway.

- **Results:** Screening reports are sent to the GP's practice with advice for further action, e.g. referral to hospital eye services, if indicated. GP's are encouraged to inform all patients of results in writing. These letters will ensure that patients, who have been referred, will know when and how soon they can expect to be seen.

Diabetic Retinopathy Screening Programme 2010/11

*Total diabetic population QOF/ Primary Care	72,693
**Total diabetic population on DRSP database	59,093
Patients on DRSP Database eligible for screening	54,419
Patients on DRSP database ineligible for screening	4,674
Number of appointments scheduled	50,058
Number attending for screening	37,541
% of eligible population screened	69%

*QOF/Primary Care figure is for all general practices across NI
**DRSP database is for general practices called for screening during 2010/11 and does not include all practices.

Diabetic RetinopathyScreening Programme Summary Figures 2011/12

Number of appointments scheduled	46,619
Number attending for screening	34,273 (73%)

5.4 Conclusions

The Northern Ireland Diabetic Retinopathy Screening Programme represents a fulfilment of the overall aspirations of the Joint Taskforce report (2003). However, due to workload and capacity issues there have been temporary increases in the screening interval in some areas. However, action has been taken to address this issue. Moreover, some concern has been expressed with regard to the numbers who attend for screening in relation to the numbers eligible for screening and if there needs to be further work in relation to raising awareness of the programme and highlighting the consequences of untreated diabetic eye disease. The population to be screened is currently ascertained from individual databases in primary care; hence a comprehensive regional database of people with diabetes would greatly facilitate identification of the eligible population and overall monitoring of the programme.

Key Summary Points

- A substantial proportion of diabetes related eye disease and blindness could be avoided by screening and early intervention.
- The Diabetic Retinopathy Screening Programme has largely fulfilled the aspirations of the Joint Task Force Report (2003).
- Approximately a quarter of people with diabetes do not attend their screening appointments.
- Capacity issues have resulted in temporary increases in screening intervals.
- A regional database of the population with diabetes would facilitate identification, monitoring and quality assurance of the programme.

6.0 Integrated Diabetes Care and Guidelines

The Joint Taskforce Report (2003), recognised that diabetes care in Northern Ireland required an approach which promoted partnership between people with diabetes and the multidisciplinary teams which cared for them as well as closer working and integration between services delivered in primary and community care and the hospital sector. Underpinning these aspirations were

- Leadership within Trusts and within primary care through the Local Health and Social care Groups (LHSCGs) in respect of overseeing diabetes services within their organisations and localities and encouraging integration.
- Agreed guidelines and protocols for management of patients including indications for appropriate specialist referral.
- Systematic annual reviews of patients for the purposes of screening, prevention and treatment of complications.
- Management goals agreed between the person with diabetes and the diabetes team caring for the patient.
- Accessibility of the diabetes team by the person with diabetes; for example telephone and face to face contact for advice.
- Education and information as an integral part of diabetes care.
- People with diabetes who are hospital inpatients able to manage their own care in hospital if they choose to do so.
- All service providers in receipt of regular education and updates on developments in diabetes care.

This was highlighted as an area *identified for early action.*

6.1 Progress since the publication of the Joint Taskforce Report (2003)

Over the last decade there have been a number of important developments which have enabled many of the aspirations of the Joint Taskforce Report (2003) to be realised. Overall there has been a greater degree of collaboration across the different sectors of care with emphasis on a team based approach focussed on enabling people with diabetes to take greater responsibility for their own care in conjunction with advice from the diabetes care team. Moreover, since the publication of the Joint Taskforce Report (2003) there have also been a number of significant policy developments which have enhanced the management of diabetes for individuals and across different sectors of care.

The Quality and Outcomes Framework for General Practice

The Joint taskforce report (2003) was published before the introduction of the Quality and Outcomes Framework (QOF), of the General Medical Services Contract in 2004, which rewarded GP Practices for the provision of quality care and sought to standardise improvements in the delivery of clinical care

There are four domains within QOF; clinical, organisational, patient experience and additional services. These define the specific process or outcomes that Practices should achieve for their patients, therefore providing for more focused

activities and more recording of activities. One of disease categories within QOF's clinical domain is diabetes mellitus. Much of the management and monitoring of diabetic patients, particularly patients with Type 2 diabetes, is now undertaken by the GP and members of the primary care team.

The diabetes mellitus QOF service has 15 indictors, one of which covers records, with the other 14 covering ongoing management. The indictors for diabetes are based on widely recognised approaches to the care of diabetes and are generally those which would be expected to be done or checked in an annual review. The management indictors include, checking Body Mass Index and ensuring that patients have had retinal screening, blood pressure checks and foot checks.

In 2011-12 all 353 GP practices in Northern Ireland obtained the maximum QOF points for diabetes care. This equated to a total of £4.million. In addition a QOF indicator for obesity equated to £367,000 for the same period.

The Cardiovascular Health and Well-being Service Framework

The Cardiovascular Health and Well-being Service Framework (2009)[22], includes standards regarding diagnosis, care and ongoing support of people with diabetes. The standards were found not to be measurable therefore data on progress is not available. Other standards are linked to diabetes, such as healthy eating, smoking cessation, high blood pressure, foot care, heart disease, stroke and renal disease.

An RQIA independent review of the Cardiovascular Service Framework in November 2012 found that success in relation to diabetes had been limited. The report recorded that there was a widely held view that diabetes was considered too complex to be part of a generic Cardiovascular Service Framework. RQIA recommended that 'The standards relating to diabetes should be reviewed as part of the fundamental review of the Cardiovascular Service Framework'. This review is currently ongoing.

Transforming Your Care (TYC)

The TYC Report [23]identifies long term conditions as a key area for health and social care in NI. Proposals for improving services for people with long term conditions include:

- Partnership working with patients to enable greater self care and prevention;
- personalised care pathways for home-based management of long term conditions
- stronger role for community pharmacy in medication management;
- the use of telehealth in supporting people to self manage their condition.

[22] Service Framework for Cardiovascular Health and Wellbeing; DHSSPS (2009)
[23] Transforming Your Care; a Review of Health and Social care in Northern Ireland (2011)

The TYC consultation process "Transforming Your Care: Vision to Action" which was launched in October 2012, included proposals relating to long term conditions, the personalisation of care and the movement of more services into the community. A key vehicle to support this is the establishment of 17 Integrated Care Partnerships, which are proposed as multi-sectoral collaborative networks of health and social care providers to respond innovatively to the assessed care needs of local communities. Initially the focus of Integrated Care Partnerships is on the frail elderly and aspects of long term conditions, namely diabetes, stroke care and respiratory conditions. This includes palliative and end of life care in respect of these agreed areas.

Long Term Conditions Policy Framework

The Department's Policy Framework "Living with Long Term Conditions" was published in April 2012. The Policy Framework reinforces the strategic shift from hospital-based treatment and care to more care provided in the community for adults with long term conditions. Self management and patient education and information are key themes within the Policy Framework.

It provides a framework within which commissioners and providers can improve services, share and extend good practice and develop systems and practices that deliver best outcomes for patients, clients and carers.

It is also intended to be a useful source of reference for people who live with long term conditions, setting out the services they and their carers should expect and in addition outlining the contribution that self management can make in ensuring the best outcomes for personal health and well-being and quality of life.

The Policy Framework is neither disease nor condition specific and is applicable across all care sectors. The Framework is designed around 6 key development areas. These are:

i. Working in partnership;
ii. Supporting self management;
iii. Information to service users and carers;
iv Managing Medicines;
v. Carers; and
vi. Improving care and services.

A number of themes run through the Policy Framework including effective needs assessment, better partnership working, improved communication, improved education and training, empowerment of individuals, and support for carers. A key focus is on providing care and support for people with long term conditions in the community, through partnership working and self management.

A Regional Implementation Steering Group has been established consisting of stakeholders from statutory, independent, voluntary and community sectors,

including the Long Term Conditions Alliance NI. The Regional Implementation Steering Group has been tasked with developing an Action Plan for by the Department.

6.2 Conclusion

The policies described above underpin and support the commissioning and delivery of high quality services for people with diabetes. The Quality and Outcomes Framework (QOF), for diabetes has resulted in considerable additional investment for diabetes management, amounting to over £4 million annually. There is a greater knowledge of numbers of patients diagnosed with diabetes and of the processes involved in their systematic management. However, further evaluation is required to ascertain if the investment through QOF has resulted in quantifiable improvements in long term outcomes for patients.

Transforming Your Care (TYC) also represents a pivotal opportunity to achieve the long coveted goal of integrated patient centred services, particularly through the vehicle of Integrated Care Partnerships. These are currently being established; with many localities choosing diabetes as the condition for which care pathways are being developed in the initial phase of the implementation of the project.

The Long Term Conditions Policy Framework is also still in the early stages of implementation hence it will be some time before the effects of this particular strategic approach to managing chronic diseases can be assessed in relation to improvements for the care of people with diabetes.

Key Summary Points

- The health and social care policy context has altered considerably since the publication of the Joint taskforce Report (2003).
- The Quality and Outcomes Framework, (QOF) has resulted in greater investment and systematised care within the Primary Care setting.
- There are positive opportunities to enhance care for people with diabetes through Transforming Your Care and the Long term Conditions Policy Framework.

7.0 Emotional and Psychological Support

7.1 Introduction

This was identified as *an area for early action* in the 2003 Joint Taskforce Report. The document highlighted that amongst people with diabetes:

- Rates of depression are three times higher than the general population.
- Increased level of eating disorders, for example anorexia nervosa and bulimia nervosa particularly in females.
- Significant levels of binge eating disorder.

The report predicted that from a clinical perspective, psychological factors had to be addressed as psychological distress was a predictor of non adherence to medical and lifestyle advice which in turn determined the likelihood of developing microvascular and macrovascular complications. The report described the significant behavioural change required of someone with diabetes in order to manage their condition effectively. This included dietary control, regular exercise, compliance with medical treatment and attendance at clinics. It was stated that up to three quarters of people with diabetes did not make the necessary behavioural changes to optimise control.

In 2003 only 0.7 whole time equivalent (wte) psychologists were available to provide dedicated clinical psychology provision to diabetes teams in Northern Ireland and this represented only 10% of the provision recommended by Diabetes UK and the British Psychological society.

The report stated the case for increasing provision of clinical psychologist support for diabetes teams. Nevertheless it also accepted that psychological support could also come from appropriately trained members of the diabetes team and from others with the condition who were acting in the capacity of "peer counsellors" or "expert patients"

7.2 Progress Since 2003

Over the last decade there has been increased investment in psychological services dedicated to people with diabetes. There are now approximately 3.5 wte clinical psychologists across Northern Ireland; an almost five fold increase on the situation at the time of the original CREST report. [24] However, this still represents a considerable shortfall against the benchmark set out in the original report and even more so if one takes into account the increase in prevalence of the condition.

7.3 Conclusion

Levels of dedicated Consultant Clinical psychologist support have increased considerably since 2003 but still fall short of the levels which were aspired too. Also a survey of the trusts in relation to this progress report reveal

[24] Survey conducted by Steering Group of psychological services dedicated to diabetes in NI HSC Trusts.

considerable disparities between different trusts with much of the provision being concentrated in the Western and Belfast trust and with minimal access in Southern and South Eastern Trust. It will have to be acknowledged that dedicated Consultant clinical psychologist resources are not the only way of providing emotional and psychological support and other ways such as those alluded to in the original report will require consideration.

Key Summary Points

- Psychological well being has an important bearing on good diabetic control and long term outcomes.
- There has been some investment in dedicated psychological support for people with diabetes since the publication of the Joint taskforce Report (2003).
- There is inequity of access to specialist psychological support across the region.
- Alternative models of psychological support need to be explored in addition to specialist psychology services.

8.0 Targeting Vulnerable Groups

8.1 Children and Young People

Services for children were discussed in some detail in the Joint Taskforce Report (2003) and were highlighted as an *area for early action* under the section "Targeting Vulnerable Groups". It was recognised that childhood and adolescence represented a particularly complex and challenging time when it came to managing diabetes. The report emphasised the need for optimal metabolic control in order to minimise the risk of developing complications later. Therefore a range of issues had to be dealt with by the diabetes team and other associated professionals and support services. Areas highlighted included:

- Timely access to psychology services.
- Managing the transition from paediatric to adult services.
- Maintaining good metabolic control in order to minimise microvascular complications whilst avoiding hypoglycaemic attacks.
- The importance of education about the condition for the people with diabetes, parents and carers.

The report then went on to describe ideal staffing levels for a service with a clinic population of approximately 1000 children. Major increases were proposed for diabetes specialist nurses with further more modest increases in physicians, dieticians, podiatry and psychology.

8.2 The Diagnosis of Diabetes in Children and Young People

Type 1 diabetes cannot be prevented and usually occurs in children and young adults where there may or may not be a family history of diabetes. Following diagnosis, treatment is lifelong with frequent blood testing, insulin injections or use of an insulin pump. Good diabetes control reduces the risk of short term complications such acute hypoglycaemia or diabetic keto-acidosis, as well as reducing long-term morbidity and premature mortality.

Type 2 diabetes is an uncommon condition in childhood but sporadic cases are being seen in paediatric clinics as a result of rising levels of childhood obesity.

8.3 Epidemiology of Diabetes in Young People

A paediatric diabetes register is maintained in the Department of Epidemiology and Public Health in Queens University Belfast. Every year in Northern Ireland approximately 100 children develop Type 1 diabetes. This represents a 25% increase on the numbers of new cases observed in the late 1980s, with the biggest increase in numbers being seen in the under five age group. In January 2011 there were 1092 children/adolescents under the age

of 18 years in Northern Ireland who were diagnosed before their 15th birthday. Of these, 60 were aged less than 5, 357 were aged between 6 and 11 and 675 were aged 12 and over. Children diagnosed between the ages of 15 and 17 are not included in this register and can attend either adult or paediatric services.

8.4 Current Organisation of Services

Paediatric diabetes services are provided by multidisciplinary teams consisting of a paediatrician, diabetes specialist nurse, dietician, psychologist, social worker and play therapists. Older children have access to podiatry, retinal screening and ophthalmology if required. Paediatric diabetes is managed by secondary care who review children every three months as well as an annual review for complications of diabetes. Children and their families are encouraged to contact the diabetes team between clinic visits if problems arise. Supporting young people and their families is considered to be central to the provision of high quality care for this group. Ambulatory, outpatient care is preferred where possible to hospital inpatiient admission.

Primary care has a supportive role in the general health care of the child as well as immunisations and developmental checks. Primary care also looks after carers (parents and siblings) health and well being.

Education staff need to be supported in understanding diabetes and the differing medical and psychosocial needs of the child by age so that the child can be empowered to participate fully in academic and other school activities.

8.5 Objectives for an Ideal service for Children and Adolescents

Early Diagnosis and Management

This is a crucial period in management of diabetes for children and young people. The important aspects of this are increased awareness of the signs and symptoms of diabetes amongst the general public in order to avoid serious complications such as diabetic keto-acidosis.

At the time of diagnosis, children and young people with type 1 diabetes should be offered home-based or inpatient management according to clinical need, family circumstances and wishes, and residential proximity to inpatient services.

Education

Children and young people with type 1 diabetes and their families should be offered timely and ongoing opportunities to access information about the development, management and effects of type 1 diabetes. The information provided should be accurate and consistent and it should support informed decision-making.

Monitoring Glycaemic Control

Children and young people with type 1 diabetes and their families should be informed that the target for long-term glycaemic control is an HbA_{1c} level of less than 59 mmol/l without frequent disabling hypoglycaemia and that their care package should be designed to attempt to achieve this.

Diabetic Ketoacidosis

Children and young people with diabetic ketoacidosis should be treated according to the guidelines published by the British Society for Paediatric Endocrinology and Diabetes.[25]

Screening for complications and associated conditions

Children and young people with type 1 diabetes should be offered screening for:

- Coeliac disease at diagnosis and at least every 3 years thereafter until transfer to adult services;
- Thyroid disease at diagnosis and annually thereafter until transfer to adult services;
- Retinopathy annually from the age of 12 years;
- Microalbuminuria annually from the age of 12 years;
- Blood pressure annually from the age of 12 years.

Psychosocial Support

Children and young people with type 1 diabetes and their families should be offered timely and ongoing access to mental health professionals because they may experience psychological disturbances (such as anxiety, depression, behavioural and conduct disorders and family conflict) that can impact on the management of diabetes and well-being.

Transition to Adult Services

During childhood and adolescence there is a gradual shift from care supervised by parents and other adults to self care management. During adolescence plans are made to transfer care to adult services. Timing of transition for young people depends on the emotional maturity, physical development, stability of health and other life circumstances. Transition is an important and sometimes difficult time for young people and their families. It is often a time of major life change and for many a period of emotional vulnerability.

All Trusts need to have transition clinics in place that allow for the gradual transfer (over a period of 1 year or more) of care to adult services that take account of the individual circumstances of the young person and the need for additional support during early adulthood. Preparation for transition should

[25] British Society for Paediatric Endocrinology and Diabetes Guidelines for management of DKA (2009), Revised August 2012.

include greater emphasis on self-management for the teenager, making appointments, ordering medication and ensuring adequate supplies of insulin, syringes and pump consumables etc.

Contraception, pregnancy planning and risk of sexually transmitted illnesses, use of alcohol, drugs, smoking and driving should be discussed with the teenager by both adult and paediatric services during transition highlighting how they affect their diabetes. A summary of care provided and ongoing issues should be provided to adult services by paediatric services.

8.6 Developments in Paediatric Services in Northern Ireland Since 2003

These include:

- Investment in paediatric diabetes teams in all 5 trusts;
- greater use of Multiple Daily Injections (MDI), carbohydrate counting and self adjustment of insulin;
- all five Trusts use a common information system to record care provided;
- since 2009, a planned expansion in access to insulin pumps between 2009 and 2014 so that by the end of 2014 approximately 35% of children and young people will be using pumps;
- introduction of the "CHOICE" Structured Education program via Cooperation and Working Together (CAWT) which is being offered to all children and young people with diabetes in Northern Ireland;
- improved glucometers so that blood glucose, insulin dose and carbohydrate counting are recorded electronically allowing better insight into diabetes control between clinic visits;
- a managed clinical network for paediatric diabetes which oversees service developments.

8.7 Conclusions

There have been improvements in services for children and young people with diabetes over the last decade as highlighted above. However, there are still a number of areas which continue to be of concern. These include focussed help from schools in conjunction with the diabetes team, particularly at the time of diagnosis so that young children and their parents can be supported within the school setting. Psychosocial support is of particular importance to younger people in whom the diagnosis is likely to trigger anxiety and other psychological morbidity.

The transition to adult services also seems to be a particularly critical time and it is important to ensure that this is handled smoothly with the range of resources in place to support the young person as they endeavour to adjust to their new care team.

Key Summary Points

- There are over 1000 children and young people with diabetes in Northern Ireland.
- Young people with diabetes in Northern Ireland are in receipt of high quality, systematic team based care.
- Access to psychological support, support in schools and transition services are particular areas which require focus.

8.8 Diabetes in Pregnancy

The original Joint Taskforce Report (2003) identified pregnant women as a "vulnerable group" and referenced and endorsed the recommendations of the 2001 CREST report "Management of Diabetes in Pregnancy" [26]but the topic was not dealt with in any particular detail in itself at that time.

Risks associated with Diabetes in Pregnancy

Despite considerable advances in the management of diabetes in pregnancy over the last few decades, it remains a high risk condition which requires a careful and coordinated approach to management. According to a Confidential Enquiry into Maternal and Child Health (CEMACH) report on the subject, pregnancy planning is still poor, many aspects of diabetes care are deficient and congenital malformation and perinatal mortality rates remain 3-5 times higher than the background population.[27]

Over the last decade there have been significant changes in the demography of diabetes in pregnancy. Up to 50% of women of childbearing age are now overweight or obese and this has undoubtedly contributed to the rising prevalence of gestational diabetes and type 2 diabetes in this demographic group. Recent diagnostic criteria for diabetes have been published and these suggest that 15% of women in NI have gestational diabetes mellitus (GDM).[28] A meta-analyses has shown that adverse pregnancy outcomes in type 2 are similar to those of type 1 diabetes.

8.9 Development of Services for Pregnant women with Diabetes since 2003

Current Provision of Regional Antenatal Metabolic Clinics and the Role of the Diabetic Specialist Midwife

[26] Management of diabetes in pregnancy CREST (2001)
[27] Pregnancy in women with type 1 and type 2 diabetes in 2002-2003; England, Wales and Northern Ireland CEMACH (2005)
[28] International association of Diabetes and Pregnancy Study groups recommendations on the diagnosis and classification of hyperglycaemia in pregnancy. Metzger BE, Gabbe SG et al. Diabetes Care 2010

The recommendation of the CREST 2001 "Management of Diabetes in Pregnancy" was that there should be a greater coherence of care in dedicated centres, offering a joint diabetes antenatal clinic and with access to level 1 neonatal intensive care. In the intervening years, this recommendation has generally been adopted, and care is now largely provided in the context of 5 joint metabolic antenatal clinics across Northern Ireland. These are;

- Royal Jubilee Maternity Hospital,
- Ulster Hospital,
- Craigavon Area Hospital,
- Antrim Area Hospital
- Altnagelvin Hospital

The NICE Guidelines for the management of diabetes in pregnancy[29] recommend that the specialist team should include a physician, obstetrician, dietician, diabetic specialist nurse and diabetic specialist midwife. The role of the midwife is central to education and management antenatally, perinatally and postnatally. In spite of increasing numbers of women with gestational diabetes there are no diabetic specialist midwives currently employed in Northern Ireland.

8.10 OTHER SPECIFIC AREAS NEEDING SUPPORT

Availability of Pre-pregnancy Counselling Clinics

There is clear evidence that pre pregnancy counselling results in improved pregnancy outcome and reduces the risk of congenital malformations. A regional audit of women with pre-gestational diabetes in 2009/2010 demonstrated only 55% had planned their pregnancy and 36% had not had pre-pregnancy counselling.

In Northern Ireland pre pregnancy counselling has been done opportunistically in contrast to the rest of the UK. In 2011 provision was made available through a North/South CAWT project grant to establish pre-pregnancy counselling clinics in each Trust in Northern Ireland. Audit data from these clinics will be available shortly. The project is to finish in December 2013 but funding has been secured to enable the clinics to continue beyond this.

A DVD and online resource has also been developed by Queens University Belfast which provides pre-pregnancy information for women with diabetes and this has been utilised by the CAWT pre-pregnancy clinics. However, it is hoped that it can be utilised further by healthcare professionals who can direct women with diabetes to the web based resource.[30]

[29] Diabetes in pregnancy; management of diabetes and its complications from preconception to the postnatal period. NICE (2008)
[30] http://www.qub.ac.uk/elearning/public/WomenWithDiabetesThingsYouNeedToKnow/

Implementation of Guidelines for Screening and Diagnosis of Diabetes in Pregnancy

As stated above new diagnostic criteria have been developed which indicate that 15% of pregnant women in Northern Ireland may have gestational diabetes. Hence, more rigorous antenatal screening is required in order to detect and manage these women in an appropriate and timely way. However, this is resource intensive, therefore currently a much more selective screening policy has had to be adopted. Random blood sugars are measured at booking and at 28 weeks and approximately 5% of women undergo a glucose tolerance test. The divergence from recommended guidance requires attention.

Retinal screening

The NICE Guidelines for Diabetes in Pregnancy (2008) make a number of recommendations regarding the optimal management of diabetes in pregnancy. NICE have recommended that women with pre existing diabetes should have eye screening at booking and at least on one further occasion during pregnancy. At present this done in a disparate manner across Northern Ireland and easy access to retinal screening during pregnancy is not available.

Support for Educational Initiatives

The role of the DAFNE (dose adjusted for normal eating) is now clearly established in the management of type 1 diabetes and increasing number of women who have been DAFNE trained are being seen during pregnancy. These women need additional medical, nursing and dietetic advice which has implications for specialist resource required.

Increased Dietetic Input

Dietetic education is fundamental to the management of type 2 and gestational diabetes mellitus. The literature would suggest that some 70-80% of women with GDM can be managed with diet alone. All of these need regular dietetic input at baseline and periodically through the rest of pregnancy. The need for dietetic advice is further exemplified by the increased prevalence of women who are overweight during pregnancy. A recent Belfast Health and Social Care Trust review highlighted that only 60% of women had seen a dietician during pregnancy and identified major staff issues if these deficiencies were to be rectified.

Increased Education & Awareness of Women of Childbearing Age in Primary Care

The increasing prevalence of type 2 diabetes is now being translated into the pregnancy context. Unlike type 1 diabetes, whose management largely resides within secondary care, many women with type 2 diabetes will be managed exclusively in the community prior to pregnancy. Appropriate education of these women will increasingly rest within primary care and this will necessitate

appropriate awareness and education of staff. The poor pregnancy outcomes of women with type 2 diabetes mandate that this be addressed urgently.

8.11 Conclusions

There have been welcome advances in development of services for pregnant women with diabetes over the last ten years particularly in relation to the joint antenatal metabolic clinics which operate in each Trust area. However, as highlighted, concerns remain around availability of pre-pregnancy counselling in a consistent sustainable way. Staffing issues also particularly centre on Diabetic Specialist Midwives of which there are currently none in Northern Ireland and an enhancement of resources for dietetics and diabetes specialist education. New diagnostic criteria for gestational diabetes also require further resources for screening for this condition in pregnancy.

Key Summary Points

- Pregnant women with diabetes are at an increased risk of poor pregnancy outcomes.
- An increase in the levels of obesity amongst women of child-bearing age has resulted in a higher incidence of gestational diabetes.
- Joint antenatal and metabolic clinics in each Trust area have enhanced antenatal services for women with diabetes.
- Enhancement of screening for gestational diabetes is required in order to fulfil the requirements of new diagnostic criteria and recommendations for gestational diabetes.
- Staffing gaps in antenatal care identified include dietetics and diabetes specialist midwives.

8.12 Other Vulnerable Groups

The Joint Taskforce Report (2003) highlighted the need to ensure that services were accessible and equitably provided for vulnerable groups such as those with learning disabilities, mental illness, minority ethnic groups and the frail elderly for example those in nursing homes. It has been difficult to ascertain extensive information relating to the development of services for these groups. However, some research has been done locally in respect of the challenges faced by people with intellectual disabilities who have diabetes. This group are more likely to develop diabetes in the first place compared with the non disabled population and a substantial proportion have poor glycaemic control.[31]

[31] Management and quality indicators of diabetes mellitus in people with intellectual disabilities. L Taggart and V Coates 2013.

9.0 Planning and Managing Services and Implementation

The Joint Taskforce Report (2003) emphasised the need for effective planning and management of services for people with diabetes. There were a number of strands which were drawn out as being particularly important in order to deliver high quality care for users of services.

The main issues highlighted included:

Strategic priority which would be afforded to diabetes through the Programme for Government and the DHSSPS Priorities for Action (PFA)[32].

Empowerment of users of the service and carers through Local Diabetes Advisory Groups (LDSAGS).

Leadership which included clinical leadership at a local Trust level and within primary care (LHSCG) structures.

Information management and diabetes registers in order to support clinical management, audit, commissioning and screening programmes.

Workforce Planning which included an assessment of numbers of staff currently employed in delivering services for people with diabetes in primary, community and acute care settings.

Audit, research and development and the importance of strengthening the overall level of activity in these areas in a sustained way.

Implementation of the Joint Taskforce Report so that its strategic objectives would be achieved within the perceived time frame of the document.

9.1 Progress Since 2003

In respect of strategic priority, diabetes has featured in "Priorities for Action" which set strategic direction for the commissioning of Health and Social Care Services in Northern Ireland over the last decade. This has included, encouraging the development of the diabetes retinopathy screening programme, establishing projects to manage chronic conditions within primary care and requesting the Health and Social Care Boards to develop plans for diabetes specialist education within their localities. Recent strategic policies which have also featured diabetes include, the Cardiovascular Service Framework, Transforming Your Care and the Long Term Conditions Policy Framework which are referenced in section 6 on integrated diabetes care and guidelines.

[32] The Planning Framework for Health and Personal Care services in Northern Ireland

User Forum and Empowerment

As part of the development of the 2003 Joint Taskforce Report a "User Forum" was established and a user survey was carried out which questioned over 2,000 local members of Diabetes UK. The results of this survey, which was analysed both quantitatively and qualitatively helped to inform a number of the report recommendations. The Joint Taskforce Report (2003), argued in favour of robust user involvement. For example "People with diabetes should be involved in planning services for diabetes and should be involved in decisions about their care" is set out as a key principle for diabetes services as described in the section on the "taskforce approach". The report goes on to argue within the section on user forum and empowerment that "effective user participation is essential in developing and managing services to ensure a patient centred care approach is adopted"

Following the publication of the 1996 CREST Diabetes Report a network of Local Diabetes Service Advisory Groups (LDSAGs) was established. These groups were based within the old Health Board boundaries and structures and included representation from the full diabetes medical team and local service users.

The LDSAGs did function effectively for a number of years but as pressure grew on the health service and the planning and delivery of services became more complex or unclear, the effectiveness of the groups reduced greatly.

Following the Review of Public Administration (RPA) reorganisation of the Health and Social Care Trusts, the LDSAGs were disbanded with an assumption that they would be replaced by Diabetes Managed Clinical Networks (MCN) in each of the new Health and Social Care Trusts. However this was not widely implemented and the Western Trust was the only Trust to make any progress with developing a diabetes MCN in 2007.

The current perception is that user involvement in the design and delivery of services has if anything regressed since the publication of the 2003 Joint Taskforce Report.

Information Management and Diabetes Registers

The Joint Taskforce Report (2003) clearly identified the requirement for a comprehensive regionalised computerised clinical information system which would facilitate:

- Clinical Management of people with diabetes;
- Delivery of patient centred care;
- Improved communication between primary and secondary care;
- Targeted interventions for people with diabetes at high risk of developing complications;
- Development of a Regional diabetes register;

- Development of call-recall systems for screening programmes such as eye screening;
- Regular audit and collection of epidemiological data;
- Effective planning of services.

Since 2003, there has been roll out of the HICOM [33]Diamond.net diabetes database across secondary care in Northern Ireland. This constitutes a comprehensive database of those whose diabetes is managed by hospital consultants. Within primary care, there continue to be individual practice based clinical databases enabling GPs to comply with the requirements of the Quality and Outcomes framework. Clinical information relating to children and young adults is captured on the TWINKLE.net clinical information systems across the five trusts. Moreover, Queen's University Belfast is the custodian of the "Northern Ireland Children's Diabetes Register" which provides epidemiological data including trends in new diagnoses and is the basis for associated research and audit.

Workforce Planning

The 2003 Joint Taskforce Report, focussed on workforce planning as an *area for early action*. A modelling exercise was undertaken which sought to describe the extant staffing levels across a range of disciplines and compare these with an "ideal" level of staffing based on a population prevalence of diabetes of three percent which was pertinent at the time. The modelling exercise along with the "workforce census" demonstrated large disparities between the resources available and what was perceived to be the requirement at the time. Over the last decade there has been significant investment in staff which comprises multidisciplinary diabetes care teams. Appendix B shows the current staffing of diabetes teams as ascertained from each of the Health and Social Care Trusts for adult and paediatric diabetes. The review team has also ascertained information independently relating to clinical psychology, medical consultants and dietetics which is also appended. It should be noted that there may be discrepancies between staffing levels as ascertained from different sources.

Also, in the Joint Taskforce Report (2003), reference was made to the potential contribution of primary care to managing diabetes in the community. The Report was published before the finalisation of the new GP contract and hence could not have predicted the resources which subsequently went into primary care for the management of diabetes through QOF, which currently stands at approximately £4 million per annum.

[33] HICOM is a software company which specialises in web-based software solutions for a number of sectors including healthcare.

Audit, Research and Development

Within Northern Ireland a number of regional audits for diabetes services provision have been undertaken, including an audit of diabetes education published in 2007 and a regional audit of hospital care undertaken in conjunction with Co-Operation and Working Together (CAWT) in 2010. Confidential enquiries into maternal and child health and pregnancy outcomes with diabetes have also been conducted.

In 2009 the Diabetes Consultant Group in Northern Ireland was allowed to use the National Diabetes Audit template to complete a Northern Ireland submission. The results were analysed by the clinician in charge of the exercise, who provided the results for Northern Ireland. The intention is to do a similar exercise at intervals. In addition, as described above each HSC Trust has computer systems for adults and children with diabetes to allow them to conduct audits of their patients.

The Department does not hold figures centrally on the numbers of people with diabetes (types 1 & 2 in adults and children), however there are a number of sources of information which the Department draws upon to indicate the current prevalence of the condition as well as the numbers which are likely to occur in the future. These include the Quality and Outcomes Framework (QOF), a system to remunerate GPs for providing good quality care to patients. Disease prevalence data is used within the QOF to calculate points and payments within a range of clinical domain areas, including diabetes.

In addition, HSC Trusts hold figures on the numbers of diabetes patients under their care. The Centre for Public Health at Queen's University, Belfast keeps a register of children with diabetes and the Institute of Public Health, Ireland produces reports of diabetes prevalence estimates.

Implementation

The 2003 Joint Taskforce Report only made passing reference to implementation of its findings in as much that it stated that it was essential that an implementation strategy be pursued. However, beyond this, little detail was provided.

Conclusions

In general, diabetes has been given a certain degree of strategic priority in Northern Ireland over the last decade and progress has been made across many of the "building blocks" described above.

Notwithstanding the progress which has been made over the last decade which includes more systematised data collection in primary care and implementation of large scale IT systems and databases in trusts, there still remains the issue of sharing of information between the different information systems hence enabling the aspirations outlined above to be realised.

If it were possible to finally "close the loop" in respect of clinical information systems then it would enhance the ability to set measurable quality standards, measure performance and audit quality of care and outcomes in a consistent way across the region. This would highlight inequity in care and enable comparisons to be made between providers as well as comparing performance with the rest of the UK. This is also a limiting factor in respect of patient's themselves being able to access data and hence work in collaboration with their diabetes care teams in respect of managing their condition.

It is also unclear as to what the actual status of the Joint Taskforce Report (2003) was after publication as its implementation was not formally driven forward, although a Regional Group of interested parties did meet on a number of occasions under the auspices of the primary care directorate in order to track progress in a number of key areas.

Nevertheless, the report did *influence* commissioners and hence the development of diabetes services in Northern Ireland; however; it could be argued that a greater degree of strategic focus would have led to a more coordinated and equitable evolution of services over the last decade.

Key Summary Points

- The Joint Taskforce Report (2003) has influenced service developments in diabetes care over the last decade.
- Opportunities for user involvement in planning and designing services for people with diabetes remains limited.
- Clinical information systems for diabetes operate across many sectors but the ability to share information particularly between primary and secondary care is still an issue.
- Effective workforce planning for diabetes teams across the region remains a challenge.

10.0 Reflecting on Care for People with Diabetes 2003-2013

10.1 Introduction

This Review of the Joint Taskforce Report (2003) has enabled a broad assessment to be conducted of the current state of services for people with diabetes relative to the aspirations of the original report.

The Joint Taskforce Report (2003) was ambitious in its aims for improving services with sound fundamental principles underpinning its approach. It drew on the best evidence available at the time in terms of good practice and clinical effectiveness. It aspired to synthesise the various components of care for people with diabetes as described by the "building blocks" into a coherent "Health Service Framework" analogous to pre-existing frameworks published in the devolved administrations at that time. In terms of the actual development of the report, there was a genuine and earnest attempt at building consensus amongst the health and social care community in respect of a coherent "vision" for diabetes care.

Moreover, Diabetes UK employed a large user survey in order to gauge the needs of people with diabetes who were managing their condition and navigating the health and social care services in order to receive care. Many of those who were involved in developing the Joint Taskforce Report (2003) are still active in providing care for people with diabetes and developing services and hence it is important to assess candidly and fairly how services have evolved and whether general aspirations have been fulfilled in respect of diabetes care in Northern Ireland.

It is also not unreasonable to assess whether anything can be learned from implementation of the Joint Taskforce Report (2003).

10.2 Areas Where Progress has been made since the Publication of the Joint Taskforce Report

The Steering Group assessed progress against the individual building blocks in the original Joint Taskforce Report (2003) by means of utilising the expertise of the Steering group members as well as submissions by individual local experts. It is important to acknowledge that in many spheres diabetes care has improved and progressed for the benefit of people with diabetes across Northern Ireland.

Prevention of diabetes is an obvious case in point, where public health measures and interventions have become more sophisticated and "nuanced" over the last decade. There is more emphasis on community based initiatives and a greater range of public health strategies targeted at encouraging healthier lifestyles hence preventing type 2 diabetes and the onset of complications.

Since the publication of the Joint Taskforce Report (2003) Northern Ireland has also seen the development of a comprehensive screening programme for

diabetic eye disease. This also represents a significant fulfilment of a key aspiration of the original report.

Staffing levels have increased substantially across most of the disciplines which comprise multidisciplinary diabetes teams with particular increases seen in dietetics, and diabetes specialist nursing. The collated workforce statistics which are appended, demonstrate this, nevertheless further analysis is required in terms of making meaningful comparisons between Health and Social care Trusts and how the data relates to need given the substantial increase in prevalence of diabetes. Moreover the multidisciplinary nature of delivery of care also requires that a more sophisticated approach be taken to workforce planning beyond analysis of staffing levels by single disciplines.

A decade ago, it was widely acknowledged that provision of diabetes care in primary care was an obvious area of concern. However, this has undergone substantial transformation following the introduction of the new GP contract in 2004 (which occurred after the publication of the Joint Taskforce Report) and the inclusion of diabetes as one of the clinical domains within the Quality and Outcomes Framework (QOF). This has led to a more systematic approach to ensuring that people with diabetes are subject to important regular checks within the practice setting and seen by health professionals such as podiatrists at regular intervals. Moreover, primary care has significantly progressed in respect of initiating evidence based therapy amongst patients; for example lipid lowering drugs and ACE inhibitors[34].

Care for patients in hospitals has been further enhanced over the last decade with a greater commitment to the development of multidisciplinary diabetes teams with an emphasis on enabling patients to be more proactive in managing their own condition with appropriate support from professionals. Hospitals have also seen the introduction of new technologies such as insulin pumps and telemonitoring enabling patients to work in concert with their diabetes team in managing their condition. The capacity of diabetes teams has also been augmented for example with improved access to diabetes specialist nurses and dietetics. There has been a steady if somewhat incremental improvement in access to diabetes structured education with greater provision for adults and comprehensive access for newly diagnosed children with type 1 diabetes.

Vulnerable groups such as children and pregnant women have seen the development of services more tailored to their needs over the last decade. For children, care by the specialist diabetes team has meant a more proactive approach where partnership between the diabetes team, the child with diabetes and the parents as well as partner agencies such as the school has enabled diabetes care to be more receptive to individual needs.

Joint metabolic and antenatal clinics across all five Health and Social Care Trusts have optimised care for pregnant women with diabetes.

[34] Angiotensin converting enzyme inhibitors; drugs used to treat high blood pressure and slow down progression of diabetic kidney disease.

Information systems and registers have also been developed over the last ten years. Primary Care Teams record basic information about their patients with diabetes and hospital based systems such as DIAMOND.net and TWINKLE.net enabling clinicians at a Trust level to access important clinical information about those attending their clinics and audit their caseload.

10.3 Highlighted Areas for Improvement

In spite of steady improvements in the provision of services for people with diabetes across the range of the "building blocks" highlighted in the draft report there is a recurring theme which is unavoidable; that notwithstanding investment which has occurred; there is nevertheless, inequitable provision of services across certain areas of diabetes care. Inequities relating to diabetes structured patient education, access to clinical psychology, differing numbers of staffing across Trusts within the same discipline are all apparent following this evaluation of the Joint Taskforce Report (2003). While some of this could be explained by differences in the way services are configured and delivered in different localities, as well as differing levels of need there is undoubtedly a wide variation in patient experience depending on where patients live and which services are accessed. In certain instances under-provision as well as inequity is apparent.

Other issues highlighted by the Steering Group include the need for a renewed focus on people with Type 1 diabetes as much of the emphasis has been on Type 2 which has generated most of the new cases of diabetes. However, whether it is children, adolescents or adults, this is a particularly resource intensive group of patients who require expert input from a range of disciplines and for whom intense management is required in order to delay or prevent the onset of complications. It should also be noted that there is a considerable cohort of "ageing" adults with Type 1 diabetes who may feel that the system does not focus on their particular requirements.

Vulnerable groups also continue to be an area of concern with further emphasis required on the needs not only of children and pregnant women but other groups such as those with learning disabilities, the frail elderly in nursing homes and black and ethnic minority groups.

The other issue which has stood out is that clinical information systems which have undoubtedly assisted care teams in patient management and audit; nevertheless are lacking as a holistic entity on a region wide basis. This is a particular issue between GP systems and hospital databases. In summary, across Northern Ireland, it is not possible to get an overview of the quality of diabetes care and of patient outcomes which enable commissioners to make comparisons and to focus commissioning with the necessary information to target resources based on need.

10.4 Lessons from Implementation of the 2003 Joint Taskforce Report

Whilst it can be acknowledged that much has improved and changed over the last decade in respect of diabetes care, it is reasonable to consider briefly what can be learned from the implementation of the Joint Taskforce Report (2003).

As stated above, the Framework was produced jointly by Diabetes UK and CREST and benefited from a wide spectrum of input from across the Health and Social Care sector and other key stakeholders. However, once it was published, there was no formal mechanism established for its governance or implementation. Nevertheless, Primary Care Directorate within the Department did convene a number of meetings which monitored progress in a few key areas, but there was no specific mechanism which enabled it to be embedded into commissioning processes which existed at the time. Progress was monitored, but not necessarily across the spectrum of diabetes related activity.

The more successful elements of the implementation were particularly related to improving access to community based disciplines which of course was an appropriate response given the desire to reconfigure services closer to patients and institute a more systematic approach to basic checks for people with diabetes in primary care and community settings. It could be argued that this provided a foundation for the current "shift left" policy which underpins "Transforming Your Care" and the requirement for patient management to be centred closer to home and using resources based in local communities as opposed to hospitals.

By 2009, approximately six years after publication, it appears that the Regional Steering Group was no longer meeting and that certain aspects of diabetes, particularly the defined quality standards relating to diabetes had been subsumed into the cardiovascular framework which had a separate implementation infrastructure.

Another possible disadvantage was that although many of the proposals related to secondary care, ie, hospital based issues, the Regional Steering Group working within their particular remit at the time would have found it challenging to make some of the necessary linkages with other important commissioning developments such as the contemporaneous expansion of renal medicine and the major service and capital investments which occurred throughout much of the last decade. Nevertheless, there were important improvements made to care across the different sectors as highlighted above.

Some aspects of the report were broadly aspirational, whilst others were quite prescriptive about what was needed. There was an attempt to describe the numbers of professionals estimated to deliver the service for both adults and children with diabetes. Describing normative staffing needs is always challenging and often controversial as choosing a commonly agreed and appropriate benchmark is central to the process. This exercise perhaps would have benefitted from a more formalised approach to workforce planning based

on further refined needs assessment to follow up on the recommendations in the report which were in fairness a genuine attempt to link need with resources. Other aspirations were more fully realised, for example the establishment of a screening programme for diabetic eye disease and the report described in some detail, how that would be configured and how it would be achieved.

One cannot disaggregate with certainty how much change was directly driven by the Joint Taskforce Report (2003) and which would have evolved nevertheless as a result of other initiatives. However, the Joint Taskforce Report (2003) provided an important framework which underpinned service developments and was taken into account by DHSSPS, the Health and Social Care Boards and other agencies with a responsibility for developing services for people with diabetes in Northern Ireland. In summary, the period covered by the Joint Taskforce Report saw considerable developments in services for people with diabetes; but implementation of the framework was not sufficiently robust across the entire range of building blocks to be able to deal with inequity of service provision which still remains an issue.

10.5 Key Challenges for Diabetes in Northern Ireland

Having examined the Joint Taskforce Report (2003) in and its subsequent implementation in some detail it is possible to now describe some of the key challenges facing people with diabetes in Northern Ireland.

Public Health, Epidemiology, Health Economics and Demographics

This is undoubtedly an important area with the dramatic increases in the numbers of people with diabetes and prevalence increasing by over 50 percent over the last ten years. This is strongly linked to the increasing prevalence of obesity so the public health dimension with an emphasis on prevention of Type 2 diabetes has to be a key challenge for the future. Linked to this is secondary prevention and delaying onset of complications through a combination of optimal clinical management and public health interventions. Moreover, the current growth in resources required to manage diabetes and its complications are unsustainable with some estimates suggesting that 17% of health and social care resources could be utilised to treat diabetes and its complications by 2035. Therefore urgent action is required to focus public health interventions to stem the increase in the condition.

Integrating Information Systems

Fundamental to improving care is the need to optimise and build on the clinical information systems which are already in place in Northern Ireland. These include the GP based systems, DIAMOND.net, TWINKLE.net and other related databases such as those for retinal screening, the Electronic Care Record[35], renal medicine and the database held at QUB for children with diabetes. Without integration of clinical information systems which enable data to be shared across the different sectors of care, it will not be possible to adequately

[35] The Electronic Care Record was launched in Northern Ireland in June 2013

assess patient needs and measure the quality of care and patient outcomes. The Steering Group has already benefitted from hearing of the experiences of colleagues in Scotland where integrated clinical information systems have driven change and encouraged an emphasis on quality throughout the system in respect of diabetes care.

Empowering Patients through Diabetes Structured Education

Whilst structured patient education programmes operate in most Trust areas there is no clear strategy at a regional level to ensure that structured education is delivered in a consistent way which is targeted at clearly defined groups or according to agreed criteria for prioritisation which apply across Northern Ireland. There is also the important issue of quality assurance of programmes; where there needs to be reassurance that programmes which are being commissioned and delivered meet pre-defined standards.

Building Capacity and Enhancing Skills in Frontline Staff

The increase in numbers of people with diabetes requires that front line staff have the necessary skills to provide treatment and care for patients and support people to self-manage their diabetes. There are opportunities for health and social care professionals to undertake appropriate training in order to enhance their management of people with diabetes; however this needs to be linked closely to workforce planning and a strategic approach to enhancing competency and capacity on a multidisciplinary basis.

Ensuring Commissioning is aligned to the Complex Nature of Diabetes

There is a genuine commitment in many quarters to ensure diabetes is commissioned effectively. At the HSCB and the PHA, diabetes care falls within the Long Term Conditions stream. Diabetes has a considerable impact on a range of specialties outside of general medicine and endocrinology, for example those disciplines which are affected either by managing complications (for example renal medicine and cardiology) or are required to provide intensive input to people with diabetes (for example, obstetrics). The challenge is to ensure that there is an emphasis on *co-ordination and synergy* across different sectors of care and between the various components of the current commissioning architecture, for example Transforming Your Care.

Clinical Leadership and User Involvement

It is essential that diabetes in Northern Ireland benefits from clear clinical leadership; not only at the level of individual organisations but within the context of providing a coherent voice for diabetes at a regional level. This should be, by necessity, multi professional in its nature as envisaged in the implementation of Integrated Care Partnerships which offer an opportunity to maximise the potential of our integrated health and social care system to support care a treatment for those with diabetes. Within the current evolving policy context, particularly Transforming Your Care and the resultant Integrated Care

Partnerships, there need to be robust mechanisms for service users to be able to engage in an effective and meaningful way so that they can input into service design and ensure services are responsive to their needs and concerns.

The age of multimorbidity[36]

As the population ages and multimorbidity becomes increasingly common, the challenge for healthcare providers will be how to ensure that patients with multiple long term conditions can be managed effectively in an integrated healthcare system. This continues to be the most important driver for policy documents such as Transforming Your Care (TYC) and the Long Term Conditions Policy Framework. The debate continues as to whether commissioners and service providers will in the long run best serve their patients by continuing to manage them within a disease specific model or whether true integration of services and optimal management of patients can only happen if individuals with a range of co-morbidities are best managed with more generic approaches.

Managing new technologies and Innovation

The technological armoury in diabetes management has changed considerably over the last ten years with new classes of drugs, more sophisticated ways of delivering insulin (insulin pumps) and monitoring of blood glucose levels. The challenge is to ensure that innovation is encouraged and that the introduction of new technologies is achieved in a managed way, for example through the NICE process with a Regional approach to introduction and adoption taking into account clinical and cost effectiveness but with " investing to save" as an underpinning ethos.

[36] Two or more co-existing conditions.

11.0 Recommendations Following Review of Joint Taskforce Report (2003)

Given the summarised findings and key challenges described above the following recommendations have been formulated. These are seen as important requirements which would underpin a sustainable future for the provision of care for people with diabetes as well as identifying those areas which require urgent consideration

Actively involve clinicians and people with diabetes in decision making about service development.

There is an enthusiastic desire from health professionals, patient representatives and patients themselves to participate in the planning and design of services, influence the commissioning of care and set priorities for diabetes. However, the available opportunities to do this, in particular at a regional level are limited. This has compromised the ability to ensure a focussed, regional, patient centred approach to the development of diabetes services. Good practice in this has already been established through the Managed Clinical Network in place for paediatric diabetes services.

Recommendation 1

It is recommended that the Health and Social Care sector in Northern Ireland should develop an appropriate mechanism to enable service users, patient representatives and clinicians to engage with commissioners in developing services for people with diabetes. This could be configured as a "forum" or "Managed Clinical Network". This should be adequately resourced in terms of administrative support, as well as ensuring there is appropriate clinical leadership, multidisciplinary participation and appropriate stakeholder engagement.

Integrate Clinical Information Systems

In spite of an assortment of systems across the health and social care sector for capturing data about people with diabetes there is still difficulty in integrating datasets effectively in particular between primary care and the hospital sector. The lesson from Scotland seems to be that this is neither tenable nor necessary and integration is central to effective sharing of clinical data across care sectors, assessing needs and driving up quality of diabetes care.[37] This would enable health and social care organisations to report regularly on the quality of care they provide and to facilitate comparison of performance across the region.

Recommendation 2

It is recommended that the current clinical information systems used across sectors of care for managing people with diabetes should be

[37] Professor McKnight described the SCI Diabetes system which operates in Scotland to the Steering Group.

reviewed with the objective of facilitating appropriate sharing of data. This would enable optimal clinical management, assessment of needs and measurement of quality of diabetes related care across Northern Ireland.

Public Health Measures should be focussed on preventing type 2 diabetes and the complications of diabetes

The rise in type 2 diabetes poses a significant risk to the health and well being of tens of thousands of individuals in Northern Ireland. The increase in the numbers of people with diabetes will also increase the demands placed on the health and social care system. Therefore, a concerted effort is required to ensure that public health strategies and the public health function is closely aligned to tackling the causative factors of chronic disease. Moreover, there should be increased engagement by front line health and social care staff in ensuring that public health approaches are also employed in managing people with diabetes including preventing complications.

Recommendation 3

It is recommended that healthcare staff should be more fully engaged in ensuring that public health interventions complement and augment clinical management of people with diabetes. The new Strategic Framework for Public Health should encourage capacity building and competency in public health skills amongst front line staff as well as the wider public health function in order to fulfil this role.

Widen access to diabetes structured patient education

The review has demonstrated variable access to diabetes structured patient education programmes across Northern Ireland. Access to structured patient education and self management programmes for people with long term conditions is already a commitment under the Programme for Government. An extensive baseline audit has already taken place which has identified the provision and scope of patient education and self management programmes for people with chronic diseases, including diabetes in Northern Ireland.

Recommendation 4

It is recommended that results from the baseline audit of structured patient education and self management programmes are utilised as a basis for assessing provision and identifying unmet need for people with diabetes. The Long Term Conditions Policy Framework Regional Implementation Steering Group should lead on formulating priorities with a view to widening access to high quality, quality assured patient education and self management programmes in an equitable manner across Northern Ireland.

Enhance capacity in clinical management of diabetes through education and training

The review has identified that opprtunities for education and training in enhancing clinical skills needed to manage diabetes are available to health professionals in Northern Ireland. However, much of this is provided on a single discipline basis with little interface between professional groups. The review has identified the need for a regional approach to education for health professionals with greater opportunity for development across specialities and a renewed emphasis on multidisciplinary training.

Recommendation 5

Training needs should be assessed in respect of management of diabetes on a regional basis, for individual professional groups and across diabetes care teams. Access to multidisciplinary education opportunities in managing diabetes requires urgent attention

A Workforce Plan for Diabetes Services

The review has identified that there has been an increase in capacity in the numbers working in diabetes care in Northern Ireland over the last ten years. However, this is within the context of inequities in provision across the region. Moreover development of the workforce should be clearly linked to needs and an assessment of skills across disciplines required for the future configuration of services.

Recommendation 6

It is recommended that a workforce plan should be developed for diabetes services which takes into account the changing epidemiology of the condition, future reconfiguration of services and the assessment of skills required in order to deliver a high quality service for people with diabetes.

Addressing gaps in services for Children and adolescents and a renewed focus on type 1 diabetes

There are currently over 1000 children and adolescents with diabetes in Northern Ireland and numbers are growing steadily by almost one hundred a year. The Steering Group has identified enhancements to services for this group over the last decade but issues still remain in respect of psychological support, transition services and support in educational settings. Given the extended duration of the condition in children and young people and the long term risk of complications; this is a group which requires intensive support.

Recommendation 7

It is recommended that the issues relating to gaps in services for children and adolescents are addressed and that commissioners including the

current MCN for specialist diabetes services for children continue to build on the progress of the last decade. It is recommended that the CHOICE structured patient education programme continue to be funded beyond December 2013.

Ensuring Optimal Care for pregnant women with diabetes

The review has identified gaps in care for pregnant women with diabetes which include access to pre-pregnancy counselling and more comprehensive screening for gestational diabetes. Workforce issues include the absence of any diabetes specialist midwives in Northern Ireland to support the work of the joint antenatal metabolic clinics. Given the risk of poor pregnancy outcomes in women with diabetes this is a matter of some concern.

Recommendation 8

It is recommended that the gaps identified in services for pregnant women with diabetes are given urgent consideration by commissioners. The role of the diabetes specialist midwife requires assessment within the context of the joint antenatal metabolic clinics operating within each Health and Social Care Trust.

Diabetes Services for Vulnerable and disadvantaged groups

The review has highlighted that there is still little information on the patient experience and longer term outcomes of people with diabetes who are from "vulnerable groups" such as black and ethnic minority groups, the frail elderly and those with learning difficulties. Amongst the latter group, local research has demonstrated that this group is more prone to develop diabetes and more likely to be affected by complications.

Recommendation 9

It is recommended that commissioners and service providers acquire further information including appropriate research evidence about the needs of vulnerable groups. This would include an assessment of patient experience and clinical outcomes within vulnerable and underserved groups and ensure services are tailored to their particular requirements.

Managing Innovation effectively for the benefit of patients

There are a range of technological advances which include new drugs, monitoring devices; insulin delivery systems as well as innovations in service delivery and public health approaches which can greatly improve outcomes for patients including delaying complications. Many of these have been implemented in Northern Ireland over the last decade.

Recommendation 10

It is recommended that a managed approach is taken to the introduction of new innovations ensuring that patients across the region have access to new interventions in an equitable way whilst ensuring that Northern Ireland continues to provide a leadership role in the introduction of new technologies and research. NICE Technology appraisals and public health guidance related to diabetes should be implemented as appropriate.

12.0 Conclusion and suggested next steps

The work of the Steering Group has provided a clear appraisal of the issues which are pertinent to providing high quality services for people with diabetes. The learning from this exercise and the expertise of the participants should be consolidated into an overall strategic and coherent view of the key priorities for services for people with diabetes building on the findings thus far.

Recommendation 11

It is recommended that the key findings and recommendations of the review of the Joint taskforce Report (2003) are consolidated appropriately as a strategic way forward or "roadmap" for diabetes so that the gaps in services and emerging priorities identified by the Steering Group can provide the basis for a way forward for service development, enable priorities to be identified for commissioners and the formulation of appropriate standards for the provision of care for people with diabetes.

Next Steps

It recognised that implementing the recommendations of this report, is a complex process given that services for people with diabetes are already commissioned through a variety of structures.

It is important to establish early on, issues of leadership, resources, governance and accountability in respect of how the findings and recommendations of this report are taken forward. It is suggested that the Steering Group who formulated this report produce a strategic way forward and action plan based on the findings and recommendations summarised above. This could then be formally adopted as policy document for diabetes care for a prescribed period.

Appendix A

REVIEW OF DIABETES UK / CREST JOINT TASKFORCE REPORT STEERING GROUP

Dr Michael McBride, Chief Medical Officer, DHSSPSNI

Dr Kate Ritchie, Chair, N.I Consultant Diabetologists and Endocrinologists Group

Professor Patrick Bell, Honorary Professor of Medicine, Belfast Health & Social Care Trust

Iain Foster, Head of Diabetes UK (NI)

Dr David Chaney, Chair, Specialist Nurses

Nicki Perry, Chair, Diabetes Specialist Dietitians Group

Lesley Hamilton, Diabetes Network Manager, Western Health & Social Care Trust

Dr Jackie McCall, Consultant in Public Health, Public Health Agency

Dr Brid Farrell, Consultant in Public Health, Public Health Agency

Michelle Tennyson, Assistant Director, Allied Health Professions & Personal Public Involvement

Marie Carie, Primary Care Nurse Advisor, Public Health Agency *(left to take up new post)*

Rose McHugh, Nurse Consultant, Public Health Agency

Dr Naresh Chada, Senior Medical Officer, DHSSPSNI

Karen Campbell, Safety, Quality & Standards Directorate, DHSSPSNI

Gillian Seeds, Primary Care Directorate, DHSSPSNI

Irene Wilkinson, Secretariat, DHSSPSNI

Advice and Input received from:

Professor John McKnight, NHS Lothian

Professor David McCance, Consultant Physician/Honorary Professor of Endocrinology, Belfast Health & Social Care Trust

Dr Laurence Taggart, Lecturer in Nursing, University of Ulster

Appendix B

Workforce Statistics
Workforce statistics have been collated from the five Health and social care Trusts as supplied to DHSSPS information and analysis directorate. The information has been supplied in slightly different ways by each Health and social Care Trust depending on their current configuration of services. (Figures supplied April 2013)

Belfast Health and Social Care Trust

Adult Diabetes Service

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian*	11	5.55	
Podiatrist*	6	2.5	
Diabetic Specialist Nurse	9	7.7	
Clinical Psychologist	1	1.0	
Consultant	12	3.925	
Associate Specialist/Staff Grade/Specialty Doctor			
Specialty Registrar			
Social Worker			
Other staff groups (please specify)			

Paediatric DiabetesService

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian	3	0.6	
Podiatrist	0	0	
Diabetic Specialist Nurse	3	2.0	
Clinical Psychologist	0	0	
Consultant Paediatrician	1	5 PAs	Interview pending locum in post
Associate Specialist/Staff Grade/Specialty Doctor			
Specialty Registrar			
Social Worker			
Other staff groups (please specify)	1	0.6 CAWT Nurse Project	

* Dietetics and Podiatry: These figures reflect dedicated posts working within Diabetes. However, there will in addition, be activity undertaken across the whole service for patients presenting with Diabetes as an element of their clinical condition and who will receive treatment from staff outside of this WTE.
Clinical Psychology: Children's services have no dedicated time. That is not to say that children with diabetes are not seen by clinical psychologists in RBHSC and elsewhere but there is no dedicated, funded service.
PAs = programmed activities
CAWT = co-operation and working together

Northern Health & Social Care Trust

Adult Diabetes Service

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian	4	2.6(B6)	
Podiatrist	4	2.8	Causeway Hospital 1 wte podiatrist Mon – Fri 9am – 5pm mainly with Diabetes remit. Antrim Hospital 1 session outpatient per week 1 session wards per week. The remainder of this post is community based Whiteabbey Hospital 2 sessions per week, Mid-Ulster Hospital 2 sessions per week All Podiatry staff are trained in Diabetes as an excess of 40% of current case load has diabetes.
Diabetic Specialist Nurse	8	7.37	
Clinical Psychologist	1	1	
Consultant	5	5.0	Integrated as part of Acute General & Endocrine Team
Associate Specialist/Staff Grade/Specialty Doctor	4	3.6	Integrated as part of Acute General & Endocrine Team
Specialty Registrar	1	1.0	Integrated as part of Acute General & Endocrine Team
Social Worker		0.5	
Other staff groups (please specify)			

Paediatric DiabetesService

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian	1	0.5 (B7)	
Podiatrist			Causeway Hospital 2 sessions per month Antrim Hospital zero
Diabetic Specialist Nurse			
Clinical Psychologist			
Consultant Paediatrician			
Associate Specialist/Staff Grade/Specialty Doctor			
Specialty Registrar			
Social Worker			
Other staff groups (please specify)			

South Eastern Health and Social care Trust

Adult Diabetes Service

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian	10	7.5	
Podiatrist	12	9.8	
Diabetic Specialist Nurse	8	7.6	
Clinical Psychologist	3 sessions	0.3	
Consultant	4	3.8	
Associate Specialist/Staff Grade/Specialty Doctor	0	0	
Specialty Registrar	0	0	
Social Worker	0	0	
Other staff groups (please specify)	2 qualified nurses (training to be diabetes specialists)	2	

Paediatric Diabetes Service

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian			4-6 hrs per week
Podiatrist	0	0	
Diabetic Specialist Nurse	2	1.8	67.5hrs
Clinical Psychologist	0	0	
Consultant Paediatrician		0.2	8hrs
Associate Specialist/Staff Grade/Specialty Doctor		0.2	8hrs
Specialty Registrar	0	0	
Social Worker	0	0	
Other staff groups (please specify)	0	0	

Southern Health and Social care Trust

NOTE: The SHSCT offers one Diabetes Service covering both children and adults.

Diabetes Service (Children and Adults)

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian	5 + 2	4.77 + 0.48 Funded from CAWT	
Podiatrist	8	3.84	
Diabetic Specialist Nurse	10 + 2 funded from CAWT	7.6 + 0.75 funded from CAWT	
Clinical Psychologist	0	0	
Consultant	3	3.0	
Associate Specialist/Staff Grade/Specialty Doctor	0	0	
Specialty Registrar	1 + 1 Vacant post filled by Locum	1.0 1.0	
Social Worker	0	0	
Other staff groups (please specify)	0	0	

CAWT = Co-operation And Working Together

Western Health & Social Care Trust
Adult Diabetes Service (Acute and Community information)

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian	9	5	
Podiatrist	6	5	
Diabetic Specialist Nurse	10	9.3	
Clinical Psychologist	3	1.25	
Consultant	3	3.0	
Associate Specialist/Staff Grade/Specialty Doctor	Sessions from other consultants to support clinics (6 sessions)	1.2	
Specialty Registrar	1	1.0	
Social Worker	0	0	
Other staff groups (please specify) • Exercise professional • Foot care assistant	 1 2	 1 2.0	

Paediatric DiabetesService

Staff Group	Headcount	Whole-time Equivalent	OR approximate hours dedicated to diabetes service
Dietitian	2	0.5	
Podiatrist	0	0	
Diabetic Specialist Nurse	4	2.7	
Clinical Psychologist	0	0	
Consultant Paediatrician	2	2.0	
Associate Specialist/Staff Grade/Specialty Doctor	0	0	
Specialty Registrar	0	0	
Social Worker	0	0	
Other staff groups (please specify)			

- **Diabetes Network Manager 1.0 WTE for the Trust (includes Dietetic clinical remit approx. 0.2 WTE for diabetes clinical support and patient education)**
- **Clinical session support from consultant staff, registrars and GP assistant, including support for renal clinic and transition clinics (joint visits with Diabetologist)**

Consultant Clinical Psychology Services as ascertained by the Steering Group

Health and Social Care Trust	Whole Time Equivalent Clinical Psychology
Western	1.5 wte
Belfast	1.0 wte
South Eastern	0.3 wte
Southern	0.2 wte
Northern	0.6 wte

Consultant Physician (Diabetology) as ascertained by the Steering Group
Estimate of time spent in diabetes as a proportion of overall time (1.0) and excluding time spent doing general internal medicine and non diabetic endocrinology.

Health and Social Care Trust	Whole Time Equivalent Consultant Physician
Belfast	3.925
Southern	1.5
South East	2.05
Western	1.3
Northern	2.1
Total	10.875

There are 24 consultant physicians contributing. About 1.55 of this total is provided by chemical pathologists/clinical biochemists.

2012 dietetic workforce figures as ascertained by the Steering Group (WTE)
Adult services

	BHSCT	SEHSCT	NHSCT	WHSCT	SHSCT
Band 7	1.0	0.7	0	1.0	1.13
Band 6	4.45	7.0	2.6	3.9	3.44
Band 5	0.5	0	0	0	0
Total	5.95	7.7	2.6	4.9	4.57

Joint taskforce Report (2003) stated that the estimated dietetic staffing levels required for adult services for a population prevalence of 3% was 37 WTE. There are currently only 25.72 WTE dietitians working in diabetes despite the increased prevalence of diabetes.
Note: All Trusts also have 0.13 Band 7 CAWT posts for pre-pregnancy clinics

Paediatric services

	BHSCT	SEHSCT	NHSCT	WHSCT	SHSCT
Band 7	0.4	0.3	0.5	0	0.11
Band 6	0.2	0	0	0	0.09
CAWT Band 7	0.56	0.3	0.5	0.37	0.35

Joint Taskforce Report (2003) stated that the estimated dietetic staffing levels required for paediatric services for a clinic population of 1000 children was 2 WTE. There are currently 3.68WTE dieticians funded for paediatric diabetes in Northern Ireland.