

# Diabetes UK Northern Ireland - Response to 'A Healthier Future: A 20 Year Strategy for Health & Well Being



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**Submission by:**

## **DIABETES UK NORTHERN IRELAND**

Bridgewood House  
Newforge Lane  
Belfast  
BT9 5NW

Tel: 028-9066-6646

Fax: 028-9066-6333

Email: [n.Ireland@diabetes.org.uk](mailto:n.Ireland@diabetes.org.uk)

### **General Comments:**

Diabetes UK Northern Ireland welcomes the opportunity to respond to the document 'A Healthier Future – A 20 Year Vision for Health & Wellbeing in Northern Ireland'. We welcome a strategy for the way forward for Northern Ireland Health & Social Services in the next two decades.

We also support the prioritisation of the four issues as outlined in the introduction to this consultation document:

- Promoting health & wellbeing
- Protecting and caring for the most vulnerable
- Delivering services effectively and efficiently with the available resources; and
- Closer working between all people and organisations who influence health & wellbeing

### **Looking ahead – a changing world:**

In relation to the issue of diabetes, prevalence of diabetes is increasing, as figures in Northern Ireland estimate around 49,000 people have been diagnosed with diabetes and a further 25,000+ undiagnosed<sup>1</sup>. Diabetes statistics are set to double by 2010.

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<sup>1</sup> 'Diabetes in the UK 2004, A report from Diabetes UK, October 2004.

In line with the report, various factors will have an impact on health service. As identified in the document, there will be an increase in age-related chronic (long-term) conditions such as diabetes. As outlined in our recently published ‘Diabetes in the UK Report’, October 2004, the prevalence of diabetes is increasing due to a variety of factors including:

- An aging UK population
- The risk of developing Type 2 diabetes increases by up to ten times in people with a body mass index (BMI) of more than 30<sup>2</sup>
- The UK has the fastest growing rate of obesity in the developed world<sup>3</sup>
- Prevalence of Type 2 diabetes is at least five times higher amongst those from a Black Minority Ethnic (BME) background in the UK<sup>4</sup>

The impact of diabetes over the next 20 years will be immeasurable for the individual, their family and carers as well as society. In terms of the financial impact, the NHS spends around 5% of its budget or close to £10 million a day treating diabetes and its effects.<sup>5</sup> The NHS spend on diabetes will rise to 10% by 2011.<sup>6</sup>

In terms of personal impact, diabetes can have the following impact:

- In the UK people with diabetes spend 1.1 million days in hospital every year<sup>7</sup>
- 80 per cent of people with diabetes will die from cardiovascular disease<sup>8</sup>
- People with diabetes are two to three times more likely to have a stroke compared to those without the condition<sup>9</sup>
- Life expectancy is reduced on average by 20 years in those with Type 1 diabetes and up to ten years in Type 2 diabetes<sup>10</sup>
- By the time they are diagnosed with Type 2 diabetes, 50 per cent of people have evidence of complications<sup>11</sup>

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<sup>2</sup> Diabetes Contemporary issues Companion Gerdes, L.I. (Editor) 2003 Greenhaven Press Maine

<sup>3</sup> 2004 Br J Cardiol 11 (4) p271

<sup>4</sup> Mather HM, Chaturverdi N, Fuller JH. Mortality and morbidity from diabetes in South Asians and Europeans: 11 year follow-up of the Southall Diabetes Survey, London, UK. *Diabetic Medicine* 15: 53-59

<sup>5</sup> National Service Framework for Diabetes: Standards, 2002

<sup>6</sup> Management of Type 2 diabetes Mellitus in Primary care Levene, L.S. 2003 Butterworth Heinmann New York

<sup>7</sup> Coronary Heart Disease statistics, Diabetes supplement, British Heart Foundation Statistics Database 2001

<sup>8</sup> Barnett and O’Gara, 2003. Diabetes and the Heart. Churchill Livingstone.

<sup>9</sup> *Diabetic Medicine*. 13 (Suppl. 4): S101-121

<sup>10</sup> Kanters et al “Incidence and determinants of mortality and cardiovascular events in diabetes mellitus: a meta analysis” *Vascular Medicine* 1999 vol 4 pp 67—75.

<sup>11</sup> United Kingdom Prospective Diabetes Study

- Diabetes is the leading cause of blindness in people of working age in the UK<sup>12</sup>
- The rate of lower limb amputation in people with diabetes is 15 times higher than in people without diabetes<sup>13</sup>

### **THEME 1 – Investing for Health & Wellbeing:**

Policy Direction 1 – Our overall aim is still to improve the physical and mental health and social wellbeing of the people of Northern Ireland.

Diabetes UK Northern Ireland welcomes this policy approach and would like to highlight the importance of paragraph 3 in which the document identifies the impact of chronic conditions on both the individual and society. As outlined on page 2 of this response, diabetes will have both a personal, social and economic impact on the NHS and society in general.

We would also draw attention to paragraph 4 in which the issue of obesity has been highlighted. The recently published Diabetes UK report ‘Type 2 Diabetes & Obesity: A Heavy Burden’, describes the impact of obesity on both individuals and the NHS as being enormous. Diabetes alone can lead to serious complications such as heart disease, blindness, kidney failure, and stroke and nerve damage leading to amputation.

- Up to 75 per cent of deaths in people with Type 2 diabetes are due to cardiovascular disease, many of these are premature.<sup>14</sup>
- Diabetes is the leading cause of blindness in people of working age.<sup>15</sup>

The report also stated the linkage between weight and diabetes. The more overweight you are, the higher your risk of developing Type 2 diabetes.

- Over a ten year period those with a BMI of over 35 are up to 80 times more likely to develop the condition than someone with a BMI of less than 22.<sup>16</sup>

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<sup>12</sup> Kohner et al (1996) Report of the Visual Handicap Group, *Diabetic Medicine*, 13, (Suppl. 4.) S13-S26

<sup>13</sup> Williams, G. & Pickup, J.C., (2004) *Handbook of diabetes* (3<sup>rd</sup> edition) Blackwell Publishing, Oxford

<sup>14</sup> Ross, S. & Gadsby, R. *Diabetes and related disorders*. 2004 Mosby: London.

<sup>15</sup> Report of the Visual Handicap Group, Kohner et al 1996, *Diabetic Medicine*, 13, Supplement 4, S13-S26

<sup>16</sup> *Handbook of Diabetes*. Gareth Williams, John C. Pickup. Blackwell Publishing, 2004.

- Once your BMI is over 30 you are already up to 10 times more likely to develop Type 2 diabetes.<sup>17</sup>

Diabetes UK Northern Ireland would also like to highlight the significance of paragraphs 7 and 8 in which ‘Health and wellbeing is the responsibility of everyone and not only health and social services....’ The joint Diabetes UK / CREST Report on Diabetes recommends a patient centred approach in order to deliver high quality care to people with diabetes. Diabetes care should be person-centred and should aim to empower individuals to manage their own diabetes.<sup>18</sup>

We strongly advocate the importance of rolling out structured patient education programmes as a method of effectively involving people with diabetes in the management of their care.

Empowering people with diabetes through a structured information programme coupled with structured peer support will make significant progress to meeting this policy objective. In order for individuals, families and communities to work together towards making healthier choices, significant investment must be allocated towards the following:

1. General Public Health initiatives such as:
  - a. Increasing physical activity (in all age groups)
  - b. Clear food labelling
  - c. Ban of smoking in work places
  - d. Increased emphasis on smoking cessation initiatives
2. The introduction of structured patient education programmes for people with diabetes – this will provide people with diabetes with education they need to be able to effectively manage their condition on a day to day basis
3. Increase access to emotional & psychological support services for people with diabetes

Policy Direction 2 – we reaffirm investing for health – the government policy for promoting health & wellbeing and reducing health inequality.

Diabetes UK Northern Ireland welcomes the commitment to pursue outcomes, in particular, relating to:

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<sup>17</sup> Diabetes Contemporary Issues Companion. Louise I Gerdes. 2003. T Greenhaven Press.

<sup>18</sup> Education Study Group of EASD Survival Kit. 1995 A document for health care providers and patients. Working party report. Diabetic Medicine 12 (1022-1043)

- Diabetes
- Coronary heart disease & circulatory disease
- Stroke

We look forward to working closely with key health service providers and decision makers regarding achieving outcomes in all three areas.

Diabetes UK Northern Ireland welcomes the areas identified for joint up action but would stress that a co-ordinated approach both regarding the implementation within the DHSSPS as well as across government departments is needed. In addition, a holistic approach within healthcare teams is also essential in order to execute this joined up approach in the areas highlighted.

Policy Direction 3 – promoting health and wellbeing is the responsibility of everyone across the HPSS, including commissioning organisations and organisations, which deliver services.

Diabetes UK Northern Ireland agrees with the objective of promoting health and wellbeing among vulnerable groups for whom preventative measures could have the greatest effect.

We recently conducted two surveys – one survey concentrated on client groups from both Action Mental Health and Diabetes UK Northern Ireland and the second survey concentrated on men’s health issues from Diabetes UK Northern Ireland’s client group.

In reference to the joint survey between Action Mental Health and Diabetes UK Northern Ireland the following issues were raised which are important to include within this and future strategies:

- Almost 70% of all respondents stated they felt anxious regarding the future of living with their condition(s)<sup>19</sup>
- 70% of respondents from both client groups stated that they had not been asked to bring their own knowledge and experience in making decisions on their individual care<sup>20</sup>
- Furthermore, 40.5% of both client groups felt that they did not know enough about their treatments and its benefits<sup>21</sup>

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<sup>19</sup> <sup>20</sup> <sup>21</sup> ‘Mental Health & Diabetes – Challenges for the Future’ Joint Report by Diabetes UK Northern Ireland & Action Mental Health, October 2004.

- Almost 40% of the total sample survey stated that they did not find it easy to express their individual concerns to health care professionals<sup>22</sup>

The joint report recommended the following to address the problems facing both client groups:

1. A holistic approach to treatment. Patients should be recognised as unique individuals with complex needs requiring a multi-disciplinary approach
2. Patient involvement in their own care – there is a need for user involvement at each stage of the patient’s care pathway
3. Increased and targeted investment in more effective prevention measures
4. Importance of access to structured patient education programmes from the point of diagnosis and on an ongoing basis

In reference to the Men’s Health survey carried out on men with diabetes based in Northern Ireland the following was identified:

- Over 80% of survey respondents stated they had not been given any information on sexual health issues related to diabetes
- Approximately 60% of respondents were dissatisfied or very dissatisfied with the level of support received

## **THEME 2 – Involving people- building caring communities:**

Diabetes UK Northern Ireland welcomes the policy of involving people and communities in helping to take the action they need to prevent illness and harm.

Policy Direction 4 – We will make it a policy aim to fully involve, and support the development of, people and caring communities who will:

- Actively promote health & wellbeing
- Have a central role in managing chronic conditions; and
- Be partners in designing and managing our health & social services

We particularly welcome the policy commitment regarding the three key bullet points above. As outlined the introduction of structured education programmes, coupled with health promotion

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<sup>22</sup> Mental Health & Diabetes – Challenges for the Future’ Joint Report by Diabetes UK Northern Ireland & Action Mental Health, October 2004.

initiatives will help empower communities and people to become involved in their health and wellbeing.

In reference to becoming partners in designing and managing health & social services, we would strongly advocate the roll out of effective user involvement. We believe it is essential to have buy-in from service users both in terms of managing their condition and service planning in order to achieve a positive and productive outcome. Effective user involvement can only be achieved as long as the engagement is both meaningful and constructive. Involving people and communities at service plan level will need additional resources as capacity building is essential in order for user representatives to be effective.

Diabetes UK Northern Ireland would like to highlight the potential role of Local Diabetes Services Advisory Groups (LDSAGs). Local planning mechanisms should offer people with diabetes opportunities to get involved in improving the quality of local diabetes services. LDSAGs have provided an effective model for partnership working, to influence priorities and to plan, deliver and monitor diabetes services. The diabetes NSF Delivery Strategy builds on the success of LDSAGs and recommends the development of similar mechanisms to ensure that decisions and priorities are appropriately influenced by the needs of people living with diabetes, through the development of managed diabetes networks.

Such groups have provided a model for long-term medical conditions as they enable a partnership between people with diabetes, carers and members of the multidisciplinary team across all health and social care sectors. Diabetes UK Northern Ireland suggests that local health service providers should build on existing mechanisms for diabetes service planning, or establish diabetes-planning groups if none are in existence, to be at the centre of service commissioning.<sup>23</sup>

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<sup>23</sup> Guidance for Primary Care Trusts: User Involvement and the Diabetes NSF, January 2003. Diabetes UK

**THEME 3 – Responsive integrated services:**

Policy Direction 5 – we will break down boundaries over the next 20 years to improve the ability of our services to respond to people’s needs.

Diabetes UK Northern Ireland agrees with the objective of breaking down barriers between primary, secondary and community care but would raise the importance of IT improvements. As part of breaking down barriers we would strongly advocate that regional diabetes registers are put in place as this will act as a mechanism for improved communication between the sectors as well as making the patient’s care pathway more smooth.

Policy Direction 6 – we will focus on delivering effective community based services with a special focus on managing chronic conditions and the problems associated with disadvantage.

Diabetes UK Northern Ireland welcomes this commitment to deliver effective community based services. We especially welcome the focus on managing chronic conditions especially with reference to problems associated with the disadvantaged. We would like to highlight a number of areas, which must be included when considering this policy direction, namely:

- The importance of health promotion at community level and closer working with community and voluntary groups in specific areas in delivering or receiving a health message
- The importance of taking forward a joined up approach from government departments such as DENI, DHSSPS, DCAL, OFMDFM and DEL regarding removing the barriers to delivering effective community services. The barriers will include:
  - Employment discrimination – removing barriers to people with diabetes relating to all fields of employment
  - Unhealthy eating – lack of access to healthy food (price of healthy foods, etc)
  - Safe areas to participate in physical activities – activities such as walking, running, etc.
- Any form of managing chronic conditions must address both the emotional/ psychological aspects as well as the physical impact of a condition such as diabetes. For example between 20-30% of people with diabetes will experience significant depression, a rate three times higher than the general population & depression is associated with poor self

care and lifestyle behaviour. Any form of chronic disease management structure must include a comprehensive support mechanism.

Policy Direction 7 – over the next 20 years, we will work towards providing services against clear standards of access. Our vision is that, when people need health & social care, they will have immediate access to services based in their communities and to any form of emergency care. People in the future will not wait more than three months for any form of treatment or care. Access standards will apply equally across all areas of Northern Ireland.

Diabetes UK Northern Ireland agrees with this important policy direction. It is crucial that diabetes services are of high quality irrespective of where anyone lives in Northern Ireland.

We agree with the importance of preventing diabetes. As part of our 2005 campaign, ‘Action Today, Health Tomorrow’, Diabetes UK Northern Ireland stresses the importance of rolling out diabetes structured patient education programmes, as people with diabetes need education to enable them to effectively manage their condition. This is important because only just over half of people with diabetes realise it can lead to heart disease and death and because 95% of diabetes care is self-care.

In reference to accessibility we would also highlight the importance of patient care pathways and the involvement of people with diabetes at every stage of their pathway.

Policy Direction 8 – we will develop multi-skilled teams based mainly in communities but supported by, and including, people working in hospitals.

Diabetes UK Northern supports this policy objective, as a holistic approach is needed in delivering high quality diabetes services to people with diabetes living in Northern Ireland. We would re-iterate the importance of structured patient education programmes and emotional and psychological support in helping to achieve this objective, as self-care and support should be central to delivering effective diabetes care.

Policy Direction 10 – we will place a special emphasis on meeting the needs of important groups by tailoring services to those needs and by placing a greater emphasis on them.

Diabetes UK Northern Ireland supports the special emphasis on meeting the needs of important groups and we welcome the particular emphasis on groups such as carers, people with disabilities; children who need care or extra support; people with mental-health problems; people with a learning disability; and older people

We also welcome the emphasis on needs of men and women. In a recent user survey on sexual health and diabetes (specifically focusing on men's health) Diabetes UK Northern Ireland found that approximately 20% of men with diabetes stated they had received any information regarding sexual health issues associated with diabetes. The survey also identified that 60% of respondents were dissatisfied or very dissatisfied with the level of support received on this area. The survey outlined that this area of diabetes care needed more support and structure.

#### **THEME 4 – Teams that deliver:**

Policy Direction 11 – we must make sure that employers in health & social services become ‘employers of choice’ to recruit and keep staff.

Diabetes UK Northern Ireland welcomes the acknowledgement of the important role of relatives, carers and the community and voluntary sectors in delivering a high quality of care. We would emphasise the importance in people with diabetes, their carers/relatives and Diabetes UK Northern Ireland actively participating in the planning of local diabetes services.

Policy Direction 13 – we will create plans, which provide for changing roles and skills across the health & social services over the coming years.

In reference to this policy direction, we welcome the commitment to appropriately train and education numbers of people in each of the professional groups. The CREST/Diabetes UK report on diabetes highlighted the importance of training and education for both people with diabetes and health care professionals. We would highlight the importance of protected time for health care professional training.

**THEME 5 – Improving quality:**

Policy Direction 14 – we will work to meet clear quality standards in line with a new legal duty of quality, which has already been placed on boards & trusts

The joint Diabetes UK / CREST Report on Diabetes identifies key principles for the delivery of high quality diabetes services. The key principles include:

- 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
- 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.<sup>24</sup>

Diabetes UK Northern Ireland believes that quality can only be achieved if considerable investment both in terms of workforce and resources is allocated. In addition to an increase in investment, time must be protected to enable healthcare professionals to be trained to deliver diabetes services and related services.

We welcome the commitment to work with service users to design new complaints procedures, which is easy to use, fair to everyone, and makes sure that complaints are dealt with locally, effectively and speedily. Diabetes UK Northern Ireland also calls for greater use of the LDSAGs and user involvement within all areas of policy and service planning and the delivery of diabetes services as this will help achieve an effective and efficient delivery of local diabetes services.

Policy Direction 15 – we will set in place flexible plans, appropriate structures and effective, efficient processes to support putting ‘A Healthier Future’ into practice.

Diabetes UK Northern Ireland welcomes the commitment to making it happen but we would stress the importance of having user representation / involvement in monitoring and evaluating the service.

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<sup>24</sup> Report of the Northern Ireland Task Force on Diabetes, A Blueprint for Diabetes Care in Northern Ireland in the 21<sup>st</sup> Century. June 2003. p 13 CREST/Diabetes UK.

Policy Direction 16 – we will continue to develop a positive, active and responsible relationship with private, community and voluntary sector providers here over the coming years.

Diabetes UK Northern Ireland welcomes the policy objective of continuing to develop a positive and active relationship with the community and voluntary sector and we look forward to working more closely with the DHSSPS on all areas related to diabetes.