Health and Social Care Committee

Inquiry into the implementation of the National Service Framework for diabetes in Wales and its future direction

DB 11 Diabetes UK Cymru

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Submission by Diabetes UK Cymru

Diabetes UK

Diabetes UK *is the leading charity that cares for, connects with and campaigns on behalf of every person affected by or at risk of diabetes. There are currently 3.7 million people in the UK with diabetes, including an estimated 850,000 people who have Type 2 diabetes but do not know it.*

The charity helps people manage their diabetes effectively by providing information, advice and support and works with healthcare professionals to improve the quality of care across the UK's health services. It funds pioneering research into care, cure and prevention for all types of diabetes and works to stem the rising tide of Type 2 diabetes - through risk assessment, early diagnosis, and by communicating how healthy lifestyle choices can help many people avoid or delay its onset.

The charity has 300,000 supporters nationwide, 5,000 volunteers and 332 voluntary groups to raise funds and awareness, and to provide support and campaign for change

It has a professional membership of more than 6,000 healthcare professionals and provides a range of professional forums for exchanging ideas and sharing information.

Diabetes UK sits on the National Specialist Advisory Group for Diabetes (formerly the All Wales Diabetes Forum), the body that provides clinical advice to the Minister for Health on diabetes issues and is the lead organisation and funder of the Cross Party Group on Diabetes in the Welsh Assembly

Representatives from the charity attend all Diabetes Planning and Delivery Group meetings across the seven health boards in Wales. With no central co-ordination of diabetes services in the Welsh Government or NHS Wales, we are the only body that has a presence in all of these meetings and we deliver bi-annual co-ordination meetings with senior representatives from all health boards DPDGs to explore sharing of best practice

Diabetes UK would be happy to provide oral evidence if requested by the committee.

What is diabetes

There are two main types of diabetes: Type 1 and Type 2. Type 1 diabetes is most commonly diagnosed in childhood or in young adults but can occur at any age. Without insulin the condition is usually fatal and those with diabetes must therefore self-inject insulin. Insulin must be carefully balanced to prevent the blood glucose being too high which raises the risk of life-threatening and disabling complications and to prevent the blood glucose being too low which may cause life-threatening hypoglycaemia. Those with Type 1 diabetes must learn these balancing skills themselves.

Type 2 diabetes can progress slowly and with no obvious symptoms. Herein lies one of its grave dangers: at the time of diagnosis, around half of people with Type 2 diabetes have unwittingly sustained tissue damage. In cases where blood glucose control is not being achieved through diet, weight control and exercise, treatment with oral medication will commence. Ultimately, people with poor control of their Type 2 diabetes will progress to insulin treatment. 20% of people manage on diet and exercise alone. 80% take medication: 50% take hypoglycaemic agents and 30% take insulin.

Diabetes in Wales

There are 160,000 people with diabetes in Wales. Approximately, 16,000 (10%) have Type 1 diabetes and 144,000 (90%) have Type 2. This equates to 5.0% of the population. 1,373 children and young people have diabetes (97% have Type 1 and 3% Type 2).

An estimated 350,000 people have pre-diabetes (higher than normal blood glucose levels). This group has a fifteen times higher likelihood of developing Type 2 diabetes than the general population.

QOF data has shown a significant and consistent increase in prevalence each year. There have been approximately 7,000 new diabetes cases annually in Wales equating to a 5% annual increase. Increases in Type 2 diabetes are due to an ageing population and rapidly rising numbers of overweight and obese people. The Welsh Health Survey 2009 showed 57% of the welsh population are overweight or obese. In some respects, this upward trend is a global phenomenon. The World Health Organisation predicts a doubling of Type 2 diabetes between 1995 and 2025.

Poorly managed diabetes is associated with serious complications that contribute a substantial financial cost to diabetes care as well as a significant impact on the quality of life for the individual. Cardiovascular disease is the leading cause of death in people with type 2 diabetes. Around 80% will die, many prematurely, as a result of heart attack or stroke.

5% of the population have diabetes but account for 15-20% of hospital inpatients with a greater length of stay in hospital and more complex admissions. People with diabetes have a 2x higher risk of experiencing a stroke. 1 in 3 people with diabetes will develop kidney disease; diabetes is the most common reason for starting dialysis. Diabetes is the leading cause of blindness in people of working age. People with diabetes are 15x more likely to have an amputation

Diabetes costs NHS Wales £500m each year. This equates to 10% of the total NHS Wales budget. At the current rate of increase in prevalence, it will cost £1bn by 2025. The vast majority of the cost is due to diabetes complications, which account for 80% of the total. Diabetes medication costs approximately 7% of the total. Evidence suggests that the costs of medication are rising. There was an 89% increase in prescribing costs in England for Type 2 diabetes between 1997 and 2007. Newer therapies now approved by NICE will increase the cost of diabetes medication significantly.

1. The National Service Framework on Diabetes (2003 – 2013)

1.1 The National Service Framework on Diabetes was established (2003). Developed by the Welsh Government in collaboration with senior clinicians and patient representatives; it is an impressive and thorough strategy with strong operational elements to improve and standardise diabetes services and care throughout Wales. It has remained the core document for diabetes planning and service delivery since its development.

1.1 *The National Service Framework on Diabetes: Consensus Guidelines* (2008) was a timely restatement of the original 2003 document. The Consensus Guidelines acknowledged the changing nature and treatment of diabetes in Wales, re-iterated the 12 standards of the original 2003 document and provided clarification on how Wales could work towards the NSF's full realisation by 2013. The Consensus Guidelines were distributed widely across Wales

1.2 *The National Service Framework for Diabetes: Delivery Strategy (2009*) was produced by the Welsh Government's Lead Co-ordinator for Cardiovascular Disease. It identified the degree to which diabetes services across Wales had achieved the NSF standards and provided recommendations to enable full compliance. The strategy's findings were not acted on, nor was the strategy distributed.

1.3 It has not been possible to ascertain how far the NSF has been delivered in Wales after 2009. Little data exists and where partial information is available, it has not been assessed.

1.4 The new Diabetes Delivery Plan (draft) produced by the Welsh Government will shortly be available for wider consultation. The strategy looks to extend the key elements of the National Service Framework from 2013 to 2016. The Committee's inquiry is timely as it has not been possible to establish what areas of the existing NSF have been delivered and why that is the case.

2. National Service Framework on Diabetes: Responsibility and accountability at a national level

2.1 Until late 2009, the Lead Coordinator for Cardiovascular Disease in the Welsh Government was responsible for diabetes services at a national level. The role was responsible for the assessment of NSF progress, the provision of advice on areas that required attention and coordination of that work across health boards. The role was discontinued at the end of 2009 and no replacement has been made.

2.2 Just prior to the termination of the role of Lead Coordinator for Cardiovascular Disease, an implementation document was produced, *National Service Framework for Diabetes: Delivery Strategy (2009)*. It noted achievements and areas of concern across all health boards in Wales. A new reporting format was attached to the delivery strategy as the Lead Coordinator noted that it was difficult to assess health board information and some reporting areas were incomplete. The delivery strategy was never distributed to health boards and it is not possible to confirm what happened to it. In meetings with senior health board representatives conducted by Diabetes UK Cymru during 2010, the report was unknown, and information on the areas of concern that required rectification had not been communicated to them. At the time, Diabetes UK Cymru concluded that because the Lead Coordinator role had not been replaced, the report was forgotten and no-one had assumed responsibility for taking the work forward. A hard copy of the report has been forwarded to the Chair of the Health & Social Care committee.

2.3 *The All Wales Diabetes Forum*, now the *National Specialist Advisory Group on Diabetes (NSAG)* was established in 2008. It was formed to provide clinical advice to the Minister for Health on diabetes issues. In an advisory capacity, it worked constructively alongside the Lead Coordinator for Cardiovascular Disease. Diabetes UK Cymru is a member of the NSAG. The NSAG meets for two hours every three months. It has communicated its concern to the Welsh Government that the Lead Coordinator for Cardiovascular Disease has not been replaced. It has also communicated that it is not possible for the body to replace the vacant Lead Coordinator role. Requests made to the Welsh Government for support to enable the NSAG to cover the most pressing shortfalls that have emerged since the Lead Coordinator was not replaced, have been declined.

2.4 Since the end of 2010, Diabetes UK Cymru has attempted to clarify where responsibility for diabetes services resides at a national level. When the Lead Coordinator position ceased to exist, health boards were instructed to submit their quarterly reports to the Health and Social Services department and in early 2011, to NHS Wales. Neither body has provided a response to the health boards' reports.

3. National Service Framework on Diabetes: Health Board accountability and compliance

3.1 With the re-organisation of health boards in Wales (a reduction from twenty two to nine) in 2009, *Local Diabetes Service Advisory Groups* were changed into *Diabetes Planning and Delivery Groups* (DPDGs). The groups are tasked with developing a local delivery plan for the National Service Framework on Diabetes.

3.2 Each DPDG is led by a chair, usually but not always a senior clinician. The membership of each DPDG varies between health boards but is usually composed of diabetes clinicians, specialists in related disciplines and front line staff such as diabetes specialist nurses. Patient representatives from the local community also attend. Some DPDGs are attended by 15+ health board professionals while others have meetings with only five attendees. Rarely do meetings occur where all disciplines are represented. Secondary care professionals predominate many meetings making aspects of diabetes services that relate to primary care or public health difficult to consider. If some disciplines are not represented, it is not possible to obtain an update of work in that area or ascertain how well services are meeting NSF requirements.

3.3 DPDGs meetings occur for two hours every quarter. A rigorous assessment of the health board's work in meeting the NSF is not possible in meetings of this duration. It is never attempted. Discussions tend to focus on a small number of contemporary issues or updates on discussions from previous meetings. While Diabetes UK acknowledges that work is also conducted outside of these meetings, it is difficult to ascertain when a thorough assessment of the health board's delivery plan against the NSF occurs.

3.4 DPDGs appear to be quite isolated bodies. Quarterly reports to NHS Wales or the Welsh Government have not received responses. If the quarterly reports that are also sent to the health board's Management Board do receive a response, these responses are not mentioned in DPDG meetings. DPDG attendees have discussed frustrations with not being able to action work agreed in meetings or to change practice to meet NSF obligations because decisions need to be taken higher up in health boards. There is a reluctance to raise issues that have financial repercussions acknowledging the budget cuts that are occurring across all health boards until 2015. Patient representatives report raising the same issues over and over again with little progress made. Many report disillusionment and are starting to disengage.

3.5 The Health & Social Services Department have stated in meetings with Diabetes UK Cymru that delivery of NSF is the responsibility of the health boards. Putting local decision making in clinical hands has obvious advantages but assuming that consultants with full time clinical roles can also develop, manage and deliver complex diabetes strategies without any support systems is in the charity's view erroneous. DPDGs appear to operate in isolation, there is minimal co-ordination between health boards, issues with financial repercussions are parked, and there appears little or no assessment of NSF progress at a health board or national level through this framework

4. **National Service Framework on Diabetes: Reporting**

4.1 Until the end of 2009, quarterly reports from health boards on NSF compliance were submitted to the Lead Co-ordinator for Cardiovascular Disease in the Health & Social Service Department. These reports were collated and feedback provided. After the Lead Coordinator's departure, health boards continued to submit quarterly reports to the Health & Social Services Department but received no feedback.

4.2 In early 2011, health boards received updated instructions from the Medical Director for NHS Wales. Health Boards were to use a new self assessment tool that was utilised by many PCTs in England to better enable them to implement NICE Quality Standards for Diabetes in Adults and the National Service Framework on Diabetes. The utilisation of this new questionnaire produced by a company called Innove was negotiated by the All Wales Diabetes Forum (now the National Specialist Advisory Group on Diabetes). Health Boards were requested to complete this new questionnaire and send information to the Health and Social Service Department.

4.3 In England, PCTs complete the questionnaire and send it to Innove which assesses the raw questionnaire data and produces an annual national report and specific reports for each PCT explaining how they rank against neighbouring PCTs. The PCT reports also provide recommendations on areas that the PCT needs to focus on to improve their diabetes services and to ensure they meet the guidelines and standards of NICE and the NSF on Diabetes.

4.4 Health Boards in Wales started to utilise the new reporting framework in mid 2011. The self assessment tool was completed and raw data sent to the Health and Social Services Department. As well as utilisation of the self assessment tool, Innove offered one year of free assessment of this raw data to enable NHS Wales and health boards to receive analysis of this raw data and to establish a benchmark of their performance. The offer was declined. The NSAG on Diabetes requested assistance from the Health and Social Services Department to enable assessment of the raw data. The request was declined.

4.5 Information submitted through the old reporting framework and through the new self assessment tool submitted on a quarterly basis has received no response from the Health and Social Services Department. Health boards have received no feedback for nearly three years. It seems clear that while data capture systems exist, there are no arrangements in place to assess the data.

4.6 In Spring 2012, Diabetes UK Cymru collated all of the self assessment data and produced an individual report for each health board. A collated report was given to the Minister for Health. Individual reports were given to the Chair of each DPDG at a best practice away day organised by the charity. It was the second meeting of its kind but the first time health board staff tasked with delivering the NSF had come together to discuss best practice and mutual challenges with some information to inform discussions. The reports demonstrated that all health boards were struggling with significant aspects of the NSF, and that a number of areas required a national approach if they were to be dealt with effectively. The reports have been submitted to the Chair of the Health and Social Care Committee for Inquiry consideration.

As is perhaps clear, Diabetes UK Cymru is concerned at the process and systems currently utilised to manage diabetes services in Wales. Our submission has been informed by our attendance of Diabetes Planning and Delivery Group meetings in all health boards since their establishment in 2010, meetings with the Minister for Health and officials from the Health & Social Services Department, and our attendance of the All Wales Diabetes Forum/NSAG on Diabetes and the lead role we play in the Cross Party Group for Diabetes.

Lack of information has not made it possible to provide the Committee with a more detailed assessment of how diabetes services in Wales meet the twelve standards of the National Service Framework for Diabetes established in 2003. We do not believe any contributor to the Committee's considerations can provide this information with confidence. With the launch of a new Delivery Strategy to replace the National Service Framework in 2013, this is an unfortunate position.

While a granular assessment of each of the standards is not possible, Diabetes UK Cymru feels that the Committee's work would benefit from a consideration of the broad themes and recommendations listed below.

Together for Health: A Diabetes Delivery Plan consultation document was received by Diabetes UK Cymru on the 19th September 2012. The draft document represents the Welsh Government's replacement of the National Service Framework and its plans for diabetes services from 2013 – 2016.

It is hoped that recommendations that are made when the Health & Social Care Committee concludes its Inquiry can be included in the final version of the new Delivery Plan. This would naturally avoid a repetition of the mistakes made over the previous decade implementing the NSF on Diabetes.

Diabetes UK Cymru believes the following issues merit consideration by the Committee.

- The Ministerial Forward to 'Together for Heath: A Diabetes Delivery Plan' states, *'I expect by 2013, services will meet the Standards set out in the Diabetes National Service Framework published in 2003 and by 2016, we will deliver the new commitments to the public that are outlined in this Delivery Plan for NHS Wales*'. The presumption is erroneous. Significant elements of the NSF have not been delivered. The reasons why the NSF has not been implemented and how this shortfall should be rectified need to be acknowledged, an understanding of why this has occurred established, and remedial action articulated in the new Diabetes Delivery Plan

- As previously stated, the National Service Framework on Diabetes is a commendable strategy. It appears clear that its primary failing has been its lack of implementation and more specifically, a failure of effective oversight. Systems of assessment and clear processes to rectify areas of concern have not been present since 2009. Large amounts of raw information and data have been produced

by health boards but no assessment of that information occurred. There appears no clear system or processes in place to assess that information in the health boards or at a national level. There appears no clear system or processes to respond to health boards on their reports and where diabetes services are unacceptable. It has not been possible to identify lines of responsibility or accountability at a health board or national level.

- The draft Diabetes Delivery Strategy suggests the formation of an All Wales Implementation Group to oversee the new plan. Diabetes UK Cymru believes the success of the new strategy rests on how this group is composed, how it functions, how frequently it meets, how well it is supported by research and administrative functions in the Welsh Government, and the authority it retains to hold health boards to account. It is estimated that diabetes and its complications costs NHS Wales £500m annually. What type of oversight body does the Committee feel is required to effectively manage this level of expenditure?

- To rectify the shortcomings in implementation of the NSF and provide the leadership required to ensure effective delivery of the new Delivery Strategy, Diabetes UK Cymru feels that a full time Diabetes Lead is required to manage and be accountable for the operational delivery of the new Delivery Plan. This role would provide direct reports to the All Wales Implementation Group (AWIG). The AWIG should be composed of senior clinicians and Health & Social Services representatives to ensure a close working relationship between Government and the NHS. It should meet bi-annually to assess reports from the Diabetes Lead operational role. Clear lines of reporting and accountability should be established between the Diabetes Lead and the Diabetes Planning and Delivery Groups in each health board. The Diabetes Lead should be operational in focus. The role should have access to appropriate levels of administrative and research support in the Welsh Government to enable it to assess information from the health boards to make informed judgements on progress and compliance to the new Delivery Plan's objectives in a timely and appropriate manner. The resource required to provide this level of leadership and accountability would cost less than 0.01% of NHS Wales annual diabetes expenditure

- The ability to ascertain the effectiveness and quality of diabetes services has been hampered by the lack of an effective secondary care information and IT system. The new Diabetes Delivery Strategy commits NHS Wales to the establishment of a new integrated national diabetes patient management system. It is a bold move and the charity commends the Welsh Government. It will enable NHS Wales to gather high quality information on future diabetes care and services and fills an important gap that has become apparent when trying to assess NSF compliance over recent years.

- The Welsh Assembly Government has an agreement in place with NICE meaning that the Institute's Technology Appraisals, Clinical Guidelines and Interventional Procedure Guidance all apply in Wales. NICE appraisals, guidelines and guidance are common threads through many standards in the National Service Framework on Diabetes. A number of existing commitments were included in the National Service Framework in 2003 and have yet to be delivered. Examples such as the provision of Structured Diabetes Education for people with Type 1 diabetes and the provision of insulin pumps have fallen short of expectations and what is legally required. While it is commendable that a recommitment to these services is evident in the new Diabetes Delivery Plan, a financial commitment to their provision is also required or their implementation will continue to fail. £1.5m ring fenced funding for insulin pumps in Scotland and £2.5m in Northern Ireland demonstrate how other countries in the UK have approached the issue.

- Every person with diabetes is supposed to receive a planned programme of nationally recommended checks each year. Derived from both the National Service Framework and NICE guidance, there are nine key care processes. They are: Blood glucose level measurement, Blood pressure measurement, Cholesterol level management, Retinal screening, Foot and leg check, Kidney function testing (urine) and (blood), weight check and smoking status. The checks exist to

identify and effectively respond to problems before they become serious. It is estimated that 80% of diabetes costs are associated with the treatment of complications. In 2010 – 2011, 37.7% of people with Type 2 diabetes did not receive all of their checks and 61.4% of people with Type 1 diabetes did not receive all of their checks.

- The National Service Framework (Standard 2) and the new Diabetes Delivery Plan rightly acknowledge the importance identification and early diagnosis of diabetes. There are an estimated 66,000 people with undiagnosed diabetes in Wales and 350,000 people with higher than normal blood glucose levels. This group has a 15x higher likelihood of developing Type 2 diabetes than the general population. By the time they are diagnosed, 50% of people show signs of complications. The only national public awareness/risk assessment campaigns in Wales over the last two years have been paid for by the third sector. There are no plans for a national campaign in 2013.

- The importance of a complete and thorough reassessment of the management and oversight of the delivery of the National Service Framework and the new Diabetes Delivery Plan can be evidenced with the following unfortunate incident that received national coverage a few months ago. Mr David Joseph (a gentleman with Type 2 diabetes) was admitted to a hospital in Wales in 2008. Following a number of errors, Mr Joseph died a few months later. A key complaint by the family was that nursing staff demonstrated unacceptable levels of awareness and skills in caring for diabetes patients. An investigation by the Public Services Ombudsman for Wales upheld the family's complaint, and made a wide range of recommendations to rectify the failings identified. One key recommendation was that the health board '*carry out an in-depth review of the skills and knowledge of nursing staff regarding diabetes care and take appropriate action thereafter*'. Quarterly reports produced by health boards on the National Service Framework required confirmation of appropriate training of ward staff on diabetes care. As explained above, these reports have been produced by health boards but no person or body in NHS Wales or the Welsh Government have read or assessed the reports. In the last quarterly reports produced and seen by Diabetes UK Cymru, all health boards in Wales reported failing to train their ward staff on diabetes care. It is not possible to say how long this deficiency has been in place or how it can be rectified.

  http://www.ombudsman-wales.org.uk/en/investigations/public-interest-reports-listed-by-subject/case-201100456.aspx

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