GIG CYMRU NHS WALES
Grwpiau Cynghori Arbenigol
Cenedlaethol Diabetes ac Endocrinoleg
Diabetes and Endocrinology
National Specialist Advisory Group

**Chair:** Dr Philip Evans MD FRCP

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Health and Social Care Committee
National Assembly for Wales
Cardiff Bay
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Dear Sir/Madam

Diabetes is a chronic condition affecting approximately 5% of the population (9.1% aged 16 or over). Type 2 Diabetes is linked to social deprivation and its prevalence continues to increase each year (estimated 5.2% increase per annum) due to its association with obesity (Wales has the third highest childhood obesity rate in the world), and the increasing age of the population.

The Diabetes National Service Framework (NSF) was launched in 2003 to improve the standard of care for individuals with Diabetes and implementation was due to be completed by 2013. There are 12 standards – see Appendix 1. Whilst there has been some progress against these standards there is still much to be done. The following issues have impaired progress:-

**Failure to Replace Central Co-ordinator for Welsh Government**

We do not know the current National picture because the last Diabetes NSF National Implementation Progress Review (demonstrating inadequate progress) was undertaken by Mrs Helen Husband (Welsh Government Lead Co-ordinator for Diabetes & Vascular Disease) in August 2009 (summary copy enclosed). Mrs Husband's seconded post with Welsh Government came to an end in 2010, and to date there has been no replacement. As a consequence there has been no single person with the required knowledge whose primary responsibility is to co-ordinate all matters pertaining to Diabetes within Welsh Government. The nature of Diabetes is such that it has relevance for most, if not all Welsh Government Departments, not only in the health sphere where it is the most common cause of blindness (working age population), amputation and end stage renal disease, and is a major cause of cardiac disease and stroke, but also departments of education, planning and transport to name but a few. This role and an appreciation of the clinical condition is crucial to co-ordinate the multi-departmental work relating to Diabetes within Welsh Government. The importance of this role, and the problems caused by its absence have been highlighted by the Diabetes National Specialist Advisory Group (NSAG - previously called All Wales Diabetes Forum) before the post was terminated and several times each year since then. It was also highlighted by the Diabetes Task and Finish Group (2011) Chaired by Professors Keen and Alberti from England.

## Opportunities Lost by Inadequate Information Technology

A lack of current reliable data added to a failure to collate data already submitted from Health Boards has led directly to an inability to understand the current state of implementation of the Diabetes NSF in Wales. The lack of a National integrated patient management system cannot be underestimated.

> In Scotland there has been an integrated Diabetes patient management system for over 10 years. This links primary and secondary care data, facilitates efficient and effective patient management by provision of timely information in acute or community settings, reduces duplication, enables medicines management and the measurement of hard clinical outcomes. It facilitates participation in the UK National Diabetes Audit (NDA), and allows for a local and national view on the progress of the Diabetes NSF.
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> In England NHS Diabetes have employed an external company (INNOVE) to prepare an annual report on the progress of Diabetes Services across the country. It combines data from a self assessment tool undertaken locally by primary and secondary care, QOF, and the NDA to produce an annual local and national report. The NSAG, with Welsh Government and INNOVE agreement, developed and circulated a modified self assessment questionnaire to replace the quarterly Welsh Government Diabetes Report. The NSAG negotiated a free 12 month trial of data compilation by INNOVE to produce a live report on the Diabetes Service in Wales, similar to the material produced in England but this was not progressed by Welsh Government.

## Inadequate and Patchy Structured Diabetes Education Provision

Another key requirement of high quality Diabetes care is patient empowerment, and patient education is a pre-requisite for this. A paper reviewing the provision of Structured Diabetes Education across each Health Board in Wales was submitted by the Diabetes NSAG to Welsh Government in October 2011. The position is poor with only 2.7% of the Type 1 and 1.4% of the Type 2 Diabetic population able to access Structured Diabetes Education over the 12 month period 2010-2011. This issue has been subject to NICE guidance but has yet to be prioritised by Welsh Government or delivered by Health Boards across Wales. Health Boards have recently been asked to comment on this paper by the patient group, Diabetes UK Cymru.

## Retasking and Failure to Replace Existing Service

The constriction of resources at a time when the prevalence of Diabetes continues to increase is also a significant challenge to the successful implementation of the Diabetes NSF. For example the recent in-patient audit revealed that 16-17% of acute beds across Wales are currently occupied by patients with Diabetes (higher in rehabilitation settings). The ability of hospital Diabetic Teams, in particular Diabetes Specialist Nurses (DSNs), to undertake their core duties in the face of an increasing number of in-patients is a particular concern. Vacant DSN posts are being frozen and Specialist Nurses are being asked to undertake general nursing duties on the wards. This is on a background of seeking to increase community diabetes nursing expertise, within current establishment, to promote the 'Setting the Direction' agenda. None of this is conducive to delivering the standards demanded by the Diabetes NSF by 2013.

There is clearly much work to be done to fully implement the Diabetes NSF, although the exact amount remains to be quantified. The Welsh Government has recently requested that the Diabetes NSAG submit a provisional Diabetes Delivery Plan for Wales up to 2016. This has been completed and submitted (copy available if required) but a suggested "must do" is to complete the implementation of the Diabetes NSF. This is currently being considered by Welsh Government. An

integrated Diabetes Patient Management System will be key to the successful implementation of both the NSF and Diabetes Delivery Plan particularly when faced with reducing resources. This has been accepted by Welsh Government and NWIS but will also require implementation. The IT system will enable the provision of an integrated individualised care plan which when combined with participation in Structured Diabetes Education will support patient empowerment. All of this needs to be overseen and facilitated by a Diabetes Co-ordinator possessing specialist clinical knowledge of this field, with appropriate infrastructure support and dedicated weekly sessions within Welsh Government.

Yours sincerely

Philip Evans
**Chair - Diabetes NSAG for Wales**

Appendix 1

1 The NHS will develop, implement and monitor strategies to reduce the risk of developing Type 2 Diabetes in the population as a whole and to reduce the inequalities in the risk of developing Type 2 Diabetes.

2 The NHS will develop, implement and monitor strategies to identify people who do not know that they have Diabetes.

3 All children, young people and adults with Diabetes will receive a service, which encourages partnership in decision making, support them in managing their Diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in the process.

4 All adults with Diabetes will receive high quality care throughout their lifetime, including support to optimise control of their blood glucose, blood pressure and other risk factors for developing complications of diabetes.

5 All children and young people with Diabetes will receive consistently high quality care and they, with their families and others involved in their care, will be supported to optimise the control of their blood glucose and their physical, psychological, intellectual, educational and social development.

6 All young people with Diabetes will experience a smooth transition of Diabetes care from paediatric to adult Diabetes Services, whether hospital or community-based, either directly via a young people's clinic. The transition will be organised in partnership with each individual and at an age appropriate to and agreed with them.

7 The NHS will develop, implement and monitor agreed protocols for rapid and effective treatment of Diabetic emergencies by appropriately trained healthcare professionals. Protocols will include the management of acute complications and procedures to minimise the risk of recurrence.

8 All children, young people and adults with Diabetes admitted to hospital, for whatever reason, will receive effective care of their Diabetes. Wherever possible, they will continue to be involved in decisions concerning the management of their Diabetes.

9 The NHS will develop, implement and monitor policies that seek to empower and support women with pre-existing Diabetes and those who develop Diabetes during pregnancy to optimise the outcomes of their pregnancy.

10 All young people and adults with Diabetes will receive regular surveillance for the long term complications of Diabetes.

11 The NHS will develop, implement and monitor agreed protocols and systems of care to ensure that all people who develop long-term complications of Diabetes receive timely, appropriate and effective investigation and treatment to reduce the risk of disability and premature death.

12 All people with Diabetes requiring multi-agency support will receive integrated health and social care.