

Written Response by the Welsh Government to the report of the Petitions Committee entitled: Petition P-04-682 - Routine Screening for Type 1 Diabetes in Children and Young People

While the Welsh Government cannot support the original petition given the agreed absence of evidence for the effectiveness of a population screening programme, I welcome the specific recommendations that have subsequently been made by the Petitions Committee. I am also grateful for the efforts of the petitioner, working with Diabetes UK Cymru, to improve awareness of type 1 diabetes among the public and healthcare professionals in Wales.

The importance of the early detection of type 1 diabetes is acknowledged in the Diabetes Delivery Plan for Wales. There are clear guidelines in place to support healthcare professionals in the investigation of suspected diabetes and the complications of diabetes are reported as part of the National Paediatric Diabetes Audit. The Children and Young People's Diabetes Network has done important work to develop a national referral pathway to support health boards to implement the guidance in a consistent way. Additional work by a number of important stakeholders is all being brought to bear; such as: health boards reporting and reviewing cases of suboptimal diagnosis, the awareness campaign led by Diabetes UK Cymru and the petitioner, the training available from the Primary Care Diabetes Society, as well as the guidance to health boards on point of care testing.

I am pleased to be able to accept or accept in principle all the recommendations made as they are very much in line with work already underway or completed. I have also given careful consideration to the merit of recommendation ten. While I agree the recommendation is well meaning, I am not wholly convinced it poses an effective means of reducing late diagnosis of type 1 diabetes and am conscious of the number of other childhood diseases that would also be similarly worthy of inclusion. It is important professionals working in educational settings are able to discharge their duty of care. In order to do this, the focus should be on safeguarding responsibilities and dealing correctly with health emergencies. However, I have accepted the recommendation in principle as we will continue to look for way to engage with appropriate staff where possible.

Detailed Responses to the report's recommendations are set out below:

Recommendation 1

The Welsh Government should seek to ensure that the "Four Ts" symptoms of type 1 diabetes are routinely asked when unwell children and young people present in primary care, and that appropriate diagnostic testing, for example through the use of finger prick blood glucose testing, is carried out immediately when symptoms which could be indicative of type 1 diabetes are present.

Response: Accept in principle

The Welsh Government endorses the recommendations of the National Institute for Health and Care Excellence (NICE) which guides healthcare professionals on the identification and investigation of suspected diabetes. This does not recommend all unwell children are asked about the symptoms of type 1 diabetes. Clinicians must use their discretion, based on their training and available guidance, to guide investigations of unwell children. This is consistent with Diabetes UK Cymru's evidence that finger prick testing should follow if any of the symptoms are present.

Health boards in Wales have routine processes for the dissemination of NICE guidance and clinicians are aware of their responsibilities in relation to such guidance. In addition, the referral pathway which has been issued to all health boards reinforces the criteria and approach to the assessment of suspected diabetes among children and young people. The Diabetes Delivery Plan for Wales also committed to a public awareness raising campaign, led by Diabetes UK Cymru as partners on the Diabetes Implementation Group, which has been delivered in conjunction with the petitioner.

Financial Implications – None

Recommendation 2

The Welsh Government should ensure that NICE guidance on diagnosis of type 1 diabetes is consistently implemented in NHS Wales. In particular by ensuring that primary care clinicians are aware of the Four T's symptoms of type 1 diabetes and the urgency of appropriate testing, and that cases of suspected type 1 diabetes are always referred for specialist care immediately.

Response: Accept

As described under recommendation one, a national referral pathway based on NICE guidance, as well as awareness materials developed by Diabetes UK Cymru, have been issued to all health boards. In parallel, health boards are reporting sub-optimal diagnoses as patient safety incidents to promote learning among healthcare professionals.

Financial Implications – None

Recommendation 3

The Welsh Government should seek assurances from health boards that appropriate blood glucose testing equipment is available in all relevant primary care settings, and that all GPs have access to equipment which can help to identify potential cases of type 1 diabetes upon presentation.

Response: Accept

The Welsh Government will seek assurance through a forum such as the Assistant Medical Directors for Primary Care and/or Point of Care Testing Network regarding the availability of glucose meters in primary care. However, guidance on point of care testing has already been issued to health boards

and this was recently reiterated as part of the dissemination of the referral pathway.

Financial Implications – None

Recommendation 4

The Welsh Government should explore, in partnership with professional bodies and health boards, how to ensure that health professionals, particularly GPs, can be supported to refresh and enhance their knowledge about type 1 diabetes in order to increase early diagnosis.

Response: Accept

As described under recommendation one, the Welsh Government has already written to health boards regarding the national referral pathway and in doing so highlighted the availability of awareness raising materials and e-learning for type 1 diabetes in children and young people.

Financial Implications – None

Recommendation 5

An e-learning module for type 1 diabetes should be rolled out across general practice, and other relevant professions, as soon as is practicable.

Response: Accept

The Primary Care Diabetes Society has an e-learning module on the diagnosis of type 1 diabetes in children and young people and this was promoted to health boards when the referral pathway was issued on 20 June.

Financial Implications – None

Recommendation 6

The Committee welcomes the work undertaken by the Children and Young People Wales Diabetes Network to develop a type 1 diabetes referral pathway for primary care. The pilot being carried out in Cardiff and the Vale University Health Board should be evaluated as a priority and quickly rolled out across Wales if it is demonstrated to be effective.

Response: Accept

The referral pathway has already been issued to all health boards in Wales. The Welsh Government will seek assurances from health boards that this is being adopted locally. Secondary care teams will be presenting the referral pathway to primary care colleagues in order to support its adoption.

Financial Implications – None

Recommendation 7

The Welsh Government should implement a means to monitor improvement with regard to diagnosis of type 1 diabetes, through a formal process of audit or other appropriate mechanism.

Response: Accept

The diagnosis of type 1 diabetes is monitored and reported through the National Paediatric Diabetes Audit.

Financial Implications – None

Recommendation 8

In cases where type 1 diabetes has only been diagnosed after the onset of Diabetic Ketoacidosis, healthcare organisations and professionals involved should be required to undertake a review of the case and learning from this should be widely shared.

Response: Accept

All organisations have policies in place to ensure all patient safety incidents where there has been a suboptimal case of diagnosis are reported and reviewed in order to aid learning and improvement and are shared with all clinicians involved.

Financial Implications – None

Recommendation 9

The Welsh Government should consider ways to highlight the symptoms of type 1 diabetes, and the urgency of seeking testing, in information routinely presented to parents of young children. This could include consideration of the sufficiency of information provided in the pregnancy book, personal child health record, and routine check-ups with professionals.

Response: Accept in principle

The provision of symptom information to parents during pregnancy or early years for such a relatively uncommon condition presents so long after childbirth is unlikely to support the earlier identification of type 1 diabetes. However, Diabetes UK Cymru has delivered a public awareness campaign, as committed to in the Diabetes Delivery Plan for Wales and this should help draw parents' attention to the relevant symptoms.

Financial Implications – None

Recommendation 10

The Welsh Government should work with health boards and other key partners to ensure that the Four Ts campaign is promoted in all appropriate settings, including primary care and also in early years/education setting.

Response: Accept in principle.

We are happy to continue working with partners to promote the Four Ts and have already included it as part of the referral pathway for healthcare professionals. However, in terms of promoting awareness in early years/education settings, we must be mindful that there is not always the

evidence to support the effectiveness of campaigns for the earlier identification of uncommon conditions such as type 1 diabetes. A recent study from New Zealand has shown no effect following a two year public information campaign. Nevertheless we will continue look for ways to ensure appropriate staff, including those working directly with children such as health visitors and school nurses, are aware of key resources issued by Diabetes UK and others, and of recommendations made by NICE.

Financial Implications – None

Vaughan Gething AM
Cabinet Secretary for Health and Social Services