

Petition P-04-682

Routine Screening for Type 1 Diabetes in Children and Young People

July 2018



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About the Committee

The Petitions Committee was established on 28 June 2016 to carry out the functions of the responsible committee set out in Standing Order 23.

Its role is to consider all admissible petitions that are submitted by the public. Petitions have to be about issues that the National Assembly had powers to take action on. The petitions process enables the public to highlight issues and directly influence the work of the National Assembly. Its specific functions are set out in Standing Order 23.

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Chair's foreword

This petition arose following the tragic loss of Peter Baldwin. Peter was 13 when he died as a result of the effects of type 1 diabetes. It goes without saying that the loss of a child is, thankfully, largely unimaginable for most people. The tremendous courage of Peter's family in seeking to use such awful circumstances to prevent the same situation happening to others should command enormous respect.

Prompt diagnosis is critical as the onset of type 1 diabetes can be extremely rapid. Peter was admitted to hospital in January 2015, having received a finger prick blood test from a rapid response paramedic. 24 hours earlier Peter had been examined by a GP who diagnosed a chest infection based on his symptoms, but without administering a blood test.

By the time Peter was admitted to hospital he was suffering from Diabetic Ketoacidosis, a potentially fatal condition which requires urgent treatment. Tragically, it was too late to save his life.

The Baldwin family, particularly Beth, Stuart and Lia, have courageously strived to ensure that the tragedy experienced by their family should lead to improvements in awareness and identification of type 1 diabetes in children.

The evidence they provided to the Petitions Committee led us to consider a wide range of issues and produce the recommendations in this report. In our view, these would assist the timely diagnosis and treatment of type 1 diabetes.

It is also notable how the Baldwin family have conducted their campaign in an extremely positive way. The petition has only been one aspect of their efforts and, alongside it, they continue to raise public awareness of the symptoms of type 1 diabetes and raise significant funds for Diabetes UK Cymru. They should be immensely proud.

I hope that the Committee's recommendations can help, in some small way, to support this work. I would like to offer our sincere condolences, respect and gratitude to the Baldwin family, and to everyone who has helped to honour Peter's memory in this way.

Recommendations

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..... Page 19

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..... Page 22

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..... Page 24

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..... Page 29

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..... Page 29

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..... Page 30

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..... Page 33

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..... Page 33

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.....Page 36

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 settings.....Page 36

1. The Petition

This report summarises the evidence considered by the Petitions Committee in relation to a petition received following the tragic death of Peter Baldwin from Cardiff. Peter was 13 when he died in January 2015 as a result of diabetic ketoacidosis arising from undiagnosed type 1 diabetes.

Background

1. The petition was submitted in 2015 through the National Assembly for Wales's online petitions system by Anthony Cook, Peter's Grandfather, and the Baldwin family.

"We call on the National Assembly for Wales to urge the Welsh Government to introduce routine screening for Type 1 Diabetes in children and young people.

In January of this year we tragically lost our beloved 13-year-old grandson, Peter Baldwin, to Type 1 diabetes that had been undetected until it was too late to save him. Peter was a well-loved and highly respected pupil at Whitchurch High School in Cardiff where he is greatly missed but for his family the hurt is unimaginable.

Our daughter Beth was recently presented with an award from The Pride of Britain for her fundraising efforts and for raising awareness of this terrible illness but with your help, and that of your friends and family we can really make a difference.

Please spare a couple of minutes to sign our petition calling on the Welsh Government to introduce a screening programme and to raise the profile of the need to check for Type 1 Diabetes in anyone presented to a health care professional with unexplained flu-like symptoms or general feeling of being unwell. The test involved is merely a finger prick or urine sample and takes less time than you have spent reading this paragraph; it also only costs pennies. It is our intention to make this test as routine within GP surgeries and clinics as temperature and blood pressure checks presently are.

Your signature on this petition really could help save lives and prevent further terrible loss within families.”¹

2. The petition gathered 2,570 signatures, whilst an associated petition to the UK Government also collected 5,347 signatures.² It was officially handed over the 4th Assembly Petitions Committee on 1 March 2016.

3. The Committee first considered the petition at a meeting on 8 March 2016. Information provided in advance of this by the Baldwin family included “Peter’s story” by way of background to the petition:



“Peter Baldwin turned 13 on 10th December 2014; he loved life, school and his friends. He was a fit, healthy teenager who had the world at his feet. As Christmas approached Peter got a winter cold which seemed to be worsening so we called the GP for advice and got an appointment on 31st December as by this time Peter was very unwell. The GP diagnosed a chest infection and gave us antibiotics. No finger prick blood test was offered or discussed. I explained that Peter was sleeping and drinking lots. We now know that these are two of the four symptoms of Type 1 diabetes.

24 hours later, at 4.30pm on New Year’s Day, we called the out of hours GP and explained we were very concerned about Peter who seemed to be deteriorating, with laboured breathing and a delirium. After insisting this was VERY URGENT we were transferred to 999 which was engaged for a short time. I, Beth Peter’s mum then asked for an ambulance, which I had to be very direct about, the operator kept asking if I deemed it necessary and was it that much of an emergency. Thank goodness I stuck to my guns (many at this point would’ve given in and thought they were wasting the callers time) the rapid response

¹ [P-04-682 Routine Screening for Type 1 Diabetes in Children and Young People](#)

² [Petition on Change.org](#)

paramedic arrived shortly [afterwards] and the very first thing he did after giving Peter some oxygen was prick his finger. He diagnosed Peter on the spot with Type 1 Diabetes; it took less than 30 seconds. The paramedic called an ambulance immediately and within less than 15 minutes we were in the resuscitation department in UHW [the University Hospital of Wales] and Peter was being given the right care.

Had the GP pricked Peter's finger we would have had a 24 hour head start & Peter's body would have had more chance to recover from the life-threatening state of diabetic ketoacidosis.

Please make GP/Healthcare professional testing for Type 1 Diabetes (finger prick) mandatory when presented with a child who has an illness that could be masking the symptoms of Type 1.³

4. During most of the Committee's consideration of the petition, the Baldwin family have been concerned with improving early diagnosis of type 1 diabetes and awareness of the condition amongst health professionals and the public, rather than on "routine screening" as described in the original petition text. As a Committee we have therefore primarily focused this report and our recommendations on these elements also.

5. Throughout our examination of these issues Peter's family, in particular his parents Beth and Stuart, his sister Lia and his grandparents, have provided us with extremely powerful evidence, information and personal testimony in support of the petition. They have also carried out a huge amount of fundraising and awareness-raising in his memory to support Diabetes UK Cymru.

6. The Committee would like to take this opportunity to place on record our sympathy, admiration and thanks to Peter's family and friends for their inspiring and selfless efforts to ensure that lessons are learnt from Peter's death and to try to prevent other young people and families facing similar tragedies in the future.

Type 1 Diabetes

7. Type 1 diabetes is an autoimmune condition where the pancreas does not produce insulin. Insulin is a hormone that the body needs to convert glucose from food into energy for use by cells within the body. Without insulin, glucose remains in the blood stream leading to high blood sugar levels. The symptoms of type 1 diabetes include going to the toilet a lot to pass urine, extreme thirst, feeling tired or lacking energy, and weight loss. These symptoms are known as the "4Ts":

³ [Petitioners to the Committee, 2 March 2016 \(PDF, 110KB\)](#)

- Toilet – Going to the toilet a lot, bed wetting by a previously dry child or heavier nappies in babies;
- Thirsty – Being really thirsty and not being able to quench the thirst;
- Tired – Feeling more tired than usual;
- Thinner – Losing weight or looking thinner than usual.⁴

8. There are approximately 1400 children with diabetes in Wales, the vast majority of which (96%) have type 1 diabetes.⁵ Incidence of type 1 diabetes is increasing by about 4% each year, and more quickly in children under five.⁶

9. Type 1 diabetes is most commonly diagnosed under the age of 15, although it can occur at any age. Evidence received from the Royal College of General Practitioners (RCGP) Wales stated that there are currently 187 children with type 1 diabetes for every 100,000 children under 15 years of age and the peak age of diagnosis is between 9-14 years.⁷

10. Type 1 diabetes symptoms can be mistaken for a range of common illnesses (such as viral or urine infections). The symptoms can also develop quickly (over a few days or weeks) and around a quarter of cases are not diagnosed until the child is in diabetic ketoacidosis (DKA), because diabetes was not detected at an earlier stage. This is a potentially fatal condition that occurs when blood sugar levels are so high that the body has become acidotic. DKA can result in breathing difficulties or coma and requires intensive medical intervention. It is the most common cause of death in children with diabetes.

11. The most recent data from the National Paediatric Diabetes Audit⁸ covering Wales and England was published in July 2017 (covering the period 2012-15). This showed that DKA at diagnosis occurred in 24% of new cases of type 1 diabetes. The overall rate was stable, although rates varied between countries and years, as shown by the following table:

⁴ Diabetes UK Cymru, 4 Ts campaign

⁵ Royal College of Paediatrics and Child Health, [National Paediatric Diabetes Audit 2015-16](#), February 2017 (PDF 1.17MB)

⁶ Juvenile Diabetes Research Foundation, [Type 1 diabetes facts and figures](#)

⁷ [Royal College of General Practitioners Wales to the Committee](#), 31 August 2017 (PDF 156KB)

⁸ Royal College of Paediatrics and Child Health, [National Paediatric Diabetes Audit Report 2012-15: Hospital Admissions and Complications](#), July 2017 (PDF 1.4MB)

	2012-13	2013-14	2014-15
England and Wales	22.5%	23.6%	23.9%
England	22%	23.9%	23.9%
Wales	30.7%	18.3%	24%

12. Children aged under 5 and those living in the most deprived areas had higher rates of DKA at diagnosis. Ethnicity is also a factor, with higher rates reported among black and minority ethnic groups.

2. Timeline of consideration by the Petitions Committee

13. The petition was considered for the first time on 8 March 2016 by the Petitions Committee in the 4th Assembly. The Committee considered an initial response from the then Welsh Government Minister for Health and Social Services, Mark Drakeford AM alongside further information from the Baldwin family, who described the overall aim of the petition as being:

“To reduce the number of children presenting with diabetic ketoacidosis (currently 500 per annum in the UK).”

14. They also explained that they were seeking to achieve several changes to improve the early identification of Type 1 diabetes in children. These included:

“In light of recently updated NICE guidance, we are calling for a mandatory duty for all GPs and healthcare professionals in a primary care setting to carry out the finger prick blood test for all children who present to them with an illness that could be masking Type 1.

[...]

The finger prick blood test provides an instant result and is incredibly low-cost.

Viruses and infections can mask the symptoms of Type 1 diabetes, exacerbating the condition with potentially fatal consequences. The symptoms are embodied in Diabetes UK’s campaign, the 4Ts (toilet/thirsty/tired/thinner). Identification of the symptoms is time critical and so we propose that healthcare professionals test in the following scenarios:

- If ANY of the 4T’S are present (on their own, in combination or all together);
- If the child is lethargic and has shallow breathing;
- If the child has a fever/chest infection/cold/ flu/virus or ANY common ailment.”

15. In addition to point of care blood glucose testing, the family set out a number of other changes they were seeking, including:

- Improved training for GPs and health care professionals on the dangers of misdiagnosis;
- A public health campaign to increase awareness of Type 1 Diabetes;
- A target of 100% participation in the National Diabetes Audit to support monitoring of testing for Type 1; and
- In the longer-term, screening of all babies at birth to see if they carry the antibodies that can increase the risk of Type 1 Diabetes.⁹

16. In anticipation of the Assembly elections that were coming up in May 2016, the Committee agreed to raise further questions with the Minister and to ask the Health Committee which would be established following the elections to consider including this issue in its work programme.

17. This request was considered by the Health, Social Care and Sport (HSCS) Committee early in the 5th Assembly. They sought further information in relation to type 1 diabetes from the Children and Young People's Wales Diabetes Network and, in February 2017, the Petitions Committee considered correspondence from the Chair of the HSCS Committee, Dr Dai Lloyd AM. This stated that a study was being conducted into the feasibility of a screening programme for type 1 diabetes in Germany and that the Committee would revisit the issue once the outcomes were known.¹⁰

18. In the meantime, the Petitions Committee agreed to gather further evidence on other issues being raised by the petitioners. The Committee gathered this evidence from the Baldwin family; the Cabinet Secretary for Health, Wellbeing and Sport, Vaughan Gething AM; health boards; professional bodies; and Diabetes UK Cymru.

19. On 11 July 2017 the Committee held an evidence session with Beth Baldwin, supported by Sara Moran and Libby Dowling from Diabetes UK. On 6 February 2018 the Committee held an evidence session with Vaughan Gething AM, now the Cabinet Secretary for Health and Social Services, to explore the issues and a range of possible solutions in detail.

⁹ [Petitioners to the Committee, 2 March 2016 \(PDF, 110KB\)](#)

¹⁰ [Chair of the Health, Social Care and Sport Committee to the Petitions Committee, 17 January 2017 \(PDF, 88KB\)](#)

20. The remaining sections of this report summarise the evidence received in relation to a number of key issues.

3. Diagnosis of type 1 diabetes

21. The Baldwin family's primary objective is to improve early diagnosis of type 1 diabetes in children. As outlined above, around a quarter of children with type 1 diabetes in Wales are currently diagnosed when they are already in DKA.

22. The first point of contact with the health service for most children with type 1 diabetes is likely to be their GP, as was the case with Peter Baldwin. However, this contact can also be with a health visitor, nurse or other community practitioner.

23. In her evidence to the Committee, Beth Baldwin described the importance of testing for type 1 diabetes whenever a child presents with symptoms typical of the disease:

“We call upon you, the National Assembly for Wales, to urge Welsh Government to introduce the four Ts as a routine question for primary care when children are presented ill to prevent another family going through this tragedy. You can introduce [a] protocol for type 1 testing and raise the profile to check for type 1 diabetes for anyone presented with illness.”¹¹

24. The Committee heard on a number of occasions, including from the Royal College of General Practitioners (RCGP), that Type 1 diabetes is a rare condition and that GPs and other primary health care professionals may only come across one new case during their careers.¹² However evidence we received also states that type 1 diabetes is one of the most common autoimmune conditions in children.

25. Given that patients with type 1 diabetes can deteriorate extremely quickly if the condition is untreated, the importance of timely diagnosis is clear. Evidence from Libby Dowling of Diabetes UK stressed this point from the perspectives of patients, their families and the NHS:

“So, not only is [DKA] life-threatening, but, even if the life is saved, it's an incredibly traumatic experience for a child and their family to be hooked up to drips, sometimes even ventilated. We're talking really intensive medical care here that might be necessary. It's not only incredibly traumatic for the child and family, but also incredibly expensive for the health service. Whereas, if you pick it up early, with a finger prick early on, then you can start a child on insulin injections

¹¹ Record of proceedings, 11 July 2017, para. 127

¹² Royal College of General Practitioners Wales to the Committee, 31 August 2017 (PDF 156KB)

quickly, you stop all that happening and you support them to manage their diabetes before they get very sick.”¹³

26. The Welsh Government’s Diabetes Delivery Plan for 2016-20 highlights the need for prompt diagnosis of type 1 diabetes to reduce the harm associated with DKA:

“This is imperative for children with possible type 1 diabetes; any child who is unwell and has any features of diabetes should have an urgent capillary blood glucose check and should be referred urgently (to be seen the same day) to specialist services if diabetes is suspected.”¹⁴

27. Several potential barriers to early diagnosis have been identified during the Committee’s consideration of the petition, including:

- low general awareness and recognition of type 1 diabetes amongst the public and health care professionals;
- deficiencies in staff knowledge or training; and
- lack of access to equipment in primary care, such as finger-prick blood glucose testing.

28. Giving evidence to the Committee alongside the Cabinet Secretary, Chris Jones (Deputy Chief Medical Officer for Wales) described how identifying type 1 diabetes can be difficult as the symptoms may be masked by another condition:

“(…) it is quite a difficult issue, and part of the complexity is the way people present and also understanding the urgency of the presentation, because I know in children, very often, when they do present, although the four Ts are present, often there’s an infection or some other condition that dominates the clinical picture and can distract.”¹⁵

Testing or screening children and young people

29. A key question is how early diagnosis of type 1 diabetes could be improved. The Baldwin family have consistently pushed for more routine use of blood tests for children and young people displaying symptoms which could be related to type 1. As previously described, the family’s focus has moved away from an initial

¹³ Record of proceedings, 11 July 2017, para. 143

¹⁴ Welsh Government, *Diabetes Delivery Plan for Wales 2016-2020*, May 2017

¹⁵ Record of proceedings, 6 February 2018, para. 200

call for screening towards ensuring that health care professionals respond quickly to give appropriate tests, and urgent treatment if required, to children with those symptoms:

“[...] we accept that a screening programme for Type 1 diabetes may not be feasible across a large population at present. We re-emphasise the aim of our campaign is for detection of Type 1 to take place as early as possible in PRIMARY CARE settings.”¹⁶

30. The RCGP, British Medical Association (BMA) Cymru and Diabetes UK Cymru all stated that a population-wide screening programme was not a feasible option at the current time. For example, the RCGP stated:

“Screening programmes involve testing populations for preclinical conditions. Screening is not appropriate for a symptomatic person or child as this is a diagnostic test. There are studies going on in the USA (Trialnet) looking at genetic markers in at risk populations but these are not proven and further research will need to be done before this is considered acceptable to fulfil the NHS population screening criteria.”¹⁷

31. Diabetes UK Cymru concluded that:

“The recommended way to action this within current systems is via testing for Type 1 diabetes in primary care if a child presents with the 4Ts (tired, thirsty, toilet, thinner) or unexplained symptoms.”¹⁸

32. As suggested by the petitioners, one way of seeking to improve early diagnosis could be to ensure that any child presenting with a symptom that could indicate type 1 diabetes should receive a finger-prick blood test.

33. However, the Cabinet Secretary wrote to the Committee in October 2017 to state that the Welsh Government did not consider that mandating finger prick testing in primary care would be possible or appropriate:

“[...] there is no feasible mechanism to legislate for the mandatory testing of all unwell children and asking of the four ‘T’ symptoms. Mandating would be very difficult to apply in practice and clinically inadvisable based on expert advice. In applying the prudent healthcare principles, I would be concerned about a significant number of

¹⁶ [Petitioners to the Committee](#), 6 June 2017 (PDF, 47KB)

¹⁷ [Royal College of General Practitioners Wales to the Committee](#), 31 August 2017 (PDF, 156KB)

¹⁸ [Diabetes UK Cymru to the Committee](#), 13 December 2016 (PDF, 260KB)

unnecessary referrals and investigations, as well as patient anxiety and ultimately avoidable harm. It will also utilise finite resources and mask referrals for those with genuine clinical urgency.”¹⁹

34. This being the case, the Committee considers that it is vital that appropriate diagnostic testing is carried out as early as possible on children and young people with symptoms that could be indicative of a condition which progresses as swiftly as type 1 diabetes. We note the Cabinet Secretary’s concern that mandating a specific test would be difficult in practice. However, we do not consider that finger prick blood glucose testing would result in significant numbers of unnecessary referrals or avoidable harm to patients, if it was supported by appropriate training and clinical judgement (which we cover in more detail elsewhere in this report).

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.

NICE guidance

35. Information the Committee received from the Welsh Government and health boards across Wales confirmed that GPs and other clinicians are expected to adhere to NICE clinical guidance on the diagnosis and management of type 1 diabetes in children and young people. This clearly references the “4Ts” symptoms and emphasises the importance of immediate referral of children suspected of having type 1 diabetes:

“1.1 Diagnosis

1.1.1 Be aware that the characteristics of type 1 diabetes in children and young people include:

- hyperglycaemia [high blood sugar]
- polyuria [frequent urination]
- polydipsia [excessive thirst]
- weight loss

¹⁹ [Cabinet Secretary for Health, Wellbeing and Sport to the Committee](#), 6 October 2017 (PDF, 210KB)

- excessive tiredness.

1.1.2 Refer children and young people with suspected type 1 diabetes immediately (on the same day) to a multidisciplinary paediatric diabetes team with the competencies needed to confirm diagnosis and to provide immediate care.”²⁰

36. From the health board responses it was not clear how consistent the awareness and implementation of NICE guidelines on the diagnosis and management of type 1 diabetes is across primary care in Wales. For example, Abertawe Bro Morgannwg University Health Board (ABMU) stated that GPs are expected to follow NICE guidelines and that steps were being taken to “raise awareness within Primary Care”, however they also acknowledged that “Arrangements do vary across the Health Board”.²¹ Other health boards did not specifically reference the NICE guidelines but stated their expectation that patients presenting with symptoms should be referred to specialist care on the same day.

37. Several health boards stated that there is no formal pathway for identifying type 1 diabetes in their area, but that this was in common with other NHS organisations across the UK. However, Cwm Taf University Health Board referred to a “newly diagnosed Type 1 admission pack which outlines the pathway” which had recently been implemented²² and some health boards also referred to their use of an All Wales DKA pathway.²³ Both relate to secondary rather than primary care.

38. The Baldwin family do not believe that NICE guidelines were followed in Peter Baldwin’s case, which led to a delay in the diagnosis and ultimately the treatment of his type 1 diabetes:

“Peter was unwell, had laboured breathing and was ‘flu like’. We attended our GP and told them that he was drinking lots of water, not eating, lethargic and was coughing. They diagnosed a chest infection, used a stethoscope, checked his glands and gave us antibiotics for him. The GP did not notice ketones on his breath or ask about any of the 4T’s symptoms of Type 1 diabetes (toilet, thirsty, thinner and tired). Had they

²⁰ National Institute for Health and Clinical Excellence (NICE), [Diabetes \(type 1 and type 2\) in children and young people: diagnosis and management](#), November 2016

²¹ [Abertawe Bro Morgannwg University Health Board to the Committee](#), 20 March 2017 (PDF, 65KB)

²² [Cwm Taf University Health Board to the Committee](#), 7 April 2017 (PDF, 101KB)

²³ Children and Young People’s Wales Diabetes Network, [Diabetic Ketoacidosis in Children: Integrated Care Pathway \(3rd edition\)](#), March 2016 (PDF, 1.8MB)

asked and pricked his finger, Peter would have had a 24 hour head start. The onset of Type 1 can be very quick. We now know Peter was already in DKA when we were at the surgery.”²⁴

39. During a short debate on screening for type 1 diabetes in primary care in Plenary on 6 December 2017, the Cabinet Secretary highlighted the challenge in ensuring a consistent approach among clinicians, and suggested that the focus of efforts should be on the implementation of NICE guidance on testing and referral.²⁵ In a letter to the Committee in October 2017 he concluded:

“The Diabetes Delivery Plan also emphasises to health boards the need to implement the National Institute for Health and Care Excellence recommended referral to specialist paediatric diabetes teams within 24 hours. Taken together, I am assured a proportionate level of focus and activity is in place to support NHS bodies in Wales to better identify, diagnose and treat children and young people with type 1 diabetes.”²⁶

40. The need for more consistent implementation of NICE guidance in a range of areas of healthcare has been identified in a significant number of Assembly committee inquiries over recent years.²⁷

41. Dr Chris Jones, the Deputy Chief Medical Officer for Wales, told the Committee that the Welsh Government was confident in the data it had about the implementation of guidance in relation to diabetes specifically:

“[...] I think we know, because we’ve had a NICE liaison group in place for some years now, that all organisations have quite robust mechanisms to share NICE guidance and raise awareness within their clinical communities. Clearly, we can’t monitor every single piece of NICE guidance because there’s such a lot of it, but, actually, in the area of diabetes care, there is actually quite considerable quality assurance against standards through the national clinical audits.

²⁴ [Petitioners to the Committee](#), 7 February 2017 (PDF, 210KB)

²⁵ Record of Proceedings, [6 December 2017](#), paras. 575-7

²⁶ [Cabinet Secretary for Health, Wellbeing and Sport to the Committee](#), 6 October 2017 (PDF, 210KB)

²⁷ Examples include the Health, Social Care and Sport Committee’s recent inquiries on suicide prevention, and on the use of antipsychotic medication in care homes. Also 4th Assembly Health and Social Care Committee inquiries on access to medical technologies, diabetes, stillbirths, venous-thromboembolism prevention.

[...] 100 per cent of general practitioner practices participate in the national diabetes audit [...] and all of our paediatric units participate in the national paediatrics diabetes unit too. So, it is one area where we do know more than in many other areas, in truth, about adherence to quality standards.”²⁸

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.

²⁸ Record of Proceedings, 6 February 2018, paras. 133-4

4. Availability of testing equipment

42. The petition calls for blood glucose testing to become more routine in primary care. The Baldwin family have pointed out that a finger prick blood test (or urine test) gives instant results and is a low-cost intervention. Immediate action can then be taken if the test indicates that diabetes may be present:

“I think all GPs need a monitor, and we know that pharmaceutical companies often give the monitors away for free because it’s the test strips that cost money and even they are pennies. We’re not talking about MRI scanners or anything here. This is a monitor that they give away for free—basic. If every single GP had one on the desk with the stethoscope and the temperature gauge and their normal equipment, it would be in their mindset, on the radar—check, check. It’s as simple as that.”²⁹

43. This point was reinforced by Diabetes UK Cymru:

“[...] every GP should have a blood glucose monitor. Certainly, there should be one in each surgery. We don’t think that’s the case, although we can’t be sure. No equipment audit has been undertaken in Wales. So, yes, the access to that equipment, and not just that, but, once they’ve got the equipment, the confidence in being able to use it, in interpreting the results, and in what action to take, depending on those results.”³⁰

44. In July 2017, the Committee wrote to health boards and a number of professional bodies to seek further information about policy and data on point of care blood glucose testing in primary care settings. The RCGP told us that point of care testing is routinely used in the assessment and management of diabetes in primary care, whilst accepting that:

“There may be scope to increase the use of point of care blood glucose testing in children, we feel that the use of this should be carefully considered in collaboration with other professional and clinical bodies.”³¹

²⁹ Record of Proceedings, 11 July 2017, para. 161

³⁰ Record of Proceedings, 11 July 2017, para. 146

³¹ Royal College of General Practitioners Wales to the Committee, 31 August 2017 (PDF, 156KB)

45. The Welsh Government confirmed that it does not hold data in relation to the number or percentage of GP surgeries with blood glucose testing equipment. However, the Government did “anticipate that every GP practice would have one” and would “hope that GPs would have that in their room”.³² The Cabinet Secretary committed to explore this issue further:

“I will ask the [Children and Young People Wales Diabetes] network to consider further the availability of glucose meters and electronic prompts for general practitioners.”³³

46. The following section of this report considers the development of a referral pathway for type 1 diabetes in primary care in more detail. However, it is worth noting that the Welsh Government considered that this would be likely to lead to additional assurance that GP practices would have appropriate access to testing equipment:

“An integral part of that pathway is whenever you suspect the diagnosis, you do undertake capillary blood glucose testing, which would require GPs to be able to do that using the equipment you describe. So, this care pathway, which is now being piloted, scrutinised and assessed in Cardiff and Vale—and this requires quite extensive training of general practitioners as well—would require GPs to have the equipment in place that you were discussing.”³⁴

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.

³² Record of Proceedings, 6 February 2018, para. 151

³³ Cabinet Secretary for Health, Wellbeing and Sport to the Committee, 6 October 2017 (PDF, 210KB)

³⁴ Record of Proceedings, 6 February 2018, para. 162

5. Awareness of health professionals

47. The level of training and awareness of type 1 diabetes amongst health professionals in general, and GPs in particular, has been central to the Committee consideration of the petition. The Baldwin family stated:

“[...] we would reiterate our focus on Primary Care and GPs/Health care professionals who are most often the first to see a child who is unwell, it is at this time that Type 1 is missed due to being masked by other common illness (chest infection/virus/flu) it’s critical that GPs/HCPs ask the questions to consider/discount Type 1 diabetes.”³⁵

48. The RCGP indicated that they would support efforts to increase awareness of type 1 diabetes amongst clinicians. In relation to current GP training, they stated that:

“The RCGP GP Training curriculum statements 3.04 and 3.17 include recognition of Paediatric emergencies (of which Diagnosis of Type 1 diabetes would be included) and the impact this has on the child and their family. Educational opportunities are provided both by RCGP and other agencies because there is recognition that it is important that GPs keep up to date with continued professional development, which includes the management of paediatric emergencies.”³⁶

49. The Royal College of Nursing (RCN) Wales stressed the vital role of other health professionals, including practice and school nurses, midwives and health visitors who “are uniquely placed to play a role in preventative healthcare and the promotion of public health amongst children and young people”. However, they expressed concern that:

“[...] the accessibility and opportunity to uptake education or training related to diabetes is highly variable, as is the financial support for, and release of, General Practice Nurses to undertake education.

“Currently, there are no agreed national standards for primary care education relating to diabetes [...] there can be significant variation in

³⁵ [Petitioners to the Committee](#), 6 June 2017 (PDF, 47KB)

³⁶ [Royal College of General Practitioners Wales to the Committee](#), 31 August 2017 (PDF, 156KB)

the identification of the educational needs of nursing staff within [General Practice and the independent sector].”³⁷

50. The Welsh Government’s Diabetes Delivery Plan sets out specific “key service actions” in this area, including:

- Health boards to ensure all key staff members have the knowledge to identify the risk factors and clinical features of diabetes and to undertake the appropriate diagnostic tests.
- The Diabetes Implementation Group to develop educational tools for healthcare professionals to support the detection and classification of diabetes.

51. However, it is not clear how consistent the approaches taken to promoting early diagnosis of Type 1 diabetes are across all health boards. In relation to the actions in the plan, the RCN has questioned how much progress has been made to date:

“[...] the Delivery Plan also states that having the right skills set in relation to population health needs assessment is essential, and that the paediatric diabetes network should work through primary care clusters to raise awareness and support identification of symptoms of type 1 diabetes. However, this is not yet evident within the primary care ‘Pace Setter’ or ‘Emerging Model’ programmes.”³⁸

52. It should also be noted that the actions in the plan are not specific to type 1 diabetes and, whilst type 1 overwhelmingly dominates cases of diabetes amongst children and young people, type 2 diabetes is much more prevalent overall and therefore is a more common feature of GP caseloads.

53. Several health boards provided information about specific actions being taken within their areas to raise awareness of type 1 diabetes in primary care and community settings. Aneurin Bevan University Health Board included examples of this, which included:

- regular teaching sessions with junior doctors (including GP trainees) to promote awareness of diabetes symptoms and the need for appropriate testing;

³⁷ Royal College of Nursing Wales to the Committee, 6 September 2017 (PDF, 168KB)

³⁸ Royal College of Nursing Wales to the Committee, 6 September 2017 (PDF, 168KB)

- awareness raising via Neighbourhood Care Networks (groups of GPs working with other health and care professionals to plan and provide services locally, also known as primary care clusters); and
- development of an online learning module.³⁹

54. The Committee heard that the “4Ts” are “frequently considered in the assessment of the unwell child” by GPs, but that these symptoms are not always present when a child presents with diabetes and can be masked by another acute conditions linked to the onset of diabetes. They can also be features of other conditions. However, the RCGP agreed:

“[...] that there needs to be increased awareness of diabetes and particularly ketoacidosis and the risks to children and young people for primary care clinicians.”⁴⁰

55. Diabetes UK Cymru supported the view that there are currently inconsistencies in the responses seen within primary care:

“We hear a lot from healthcare professionals in secondary care that incorrect action was taken. The wrong blood test was carried out, or even a blood test scheduled for the following week, or being told to come back in a week’s time, deferring it to a more junior colleague, who might not be available on that day.

[...] We do know more about services in secondary care, especially the answers that the committee has received from each health board, and those have been particularly insightful and they’ve been collated for the first time in Wales, which has been very, very enlightening for us. But the fact remains that most people present to their primary care services first, and that is where the grey area is, if you like, and the lack of standardisation and the approaches.”⁴¹

56. The charity has run an awareness campaign aimed at health care professionals, including an e-learning module containing video resources which provide a summary of the symptoms and can be used in group or cluster training for GPs.

³⁹ [Aneurin Bevan University Health Board to the Committee](#), 22 March 2017 (PDF, 423KB)

⁴⁰ [Royal College of General Practitioners Wales to the Committee](#), 31 August 2017 (PDF, 156KB)

⁴¹ Record of Proceedings, 11 July 2017, paras. 146-7

57. The Cabinet Secretary had also informed the Committee that development of an e-learning module was being considered:

“Consideration is also being given [by the Children and Young People’s Diabetes Network and the Diabetes Implementation Group] to making available a Primary Care Diabetes Society’s e-learning module and the potential for GP receptionist training on the symptoms of type 1 diabetes.”⁴²

58. He was supportive of a range of training initiatives during his evidence session with the Committee:

“[...] it is about healthcare professionals being properly trained, understanding the different things they need to consider—and we ask a lot of our healthcare professionals—and then pointing people in the right direction. That’s why you’ve got improvement work taking place; that’s why we were talking earlier about the e-learning model; that’s why we were talking earlier about the pilot taking place with 170 GPs in Cardiff and Vale; and it’s why we’re talking about the awareness-raising campaign that Diabetes UK are fronting.”⁴³

59. In addition to healthcare professionals, there has been some suggestion that other frontline staff should receive awareness training about type 1 diabetes, such as reception staff in GP surgeries. The Cabinet Secretary sounded a note of caution about this in his evidence to the Committee:

“There’s a challenge always about what we expect all the staff in a local practice to know. And that’s part of the point about awareness raising. There is something about wanting the healthcare professionals to know and understand, and what we can legitimately expect the receptionist staff to know as well, and how much, effectively, clinical knowledge and understanding we expect them to have.”⁴⁴

60. Diabetes UK Cymru explained what they would see as the desired outcome from improved training and awareness:

“What we really want to see happen as part of this is that GPs are asking the questions that they see the symptoms, see one or more of the

⁴² Cabinet Secretary for Health, Wellbeing and Sport to the Committee, 6 October 2017 (PDF, 210KB)

⁴³ Record of Proceedings, 6 February 2018, para. 227

⁴⁴ Record of Proceedings, 6 February 2018, paras. 174-83

symptoms, and carry out the finger-prick test. All four symptoms don't have to be present. It can be one or more, and we really want to see GPs being proactive in asking and probing—asking these questions that will draw out the answers from parents who might not be aware of the symptoms themselves.”⁴⁵

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.

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.

⁴⁵ Record of Proceedings, 11 July 2017, para. 164

6. Referral pathway

61. Responses from health boards in relation to their diagnosis and referral pathways for type 1 diabetes in children and young people indicated a lack of consistency.

62. A key development during the Committee's consideration of the petition has been work being done on a type 1 diabetes referral pathway for primary care, led by the Children and Young People Wales Diabetes Network. The Committee welcomes this as an extremely positive development.

63. The pathway emphasises that diagnosis of diabetes and the initiation of treatment in children and young people is a medical emergency and the speed of response required is very different to that for type 2 diabetes. It includes a focus on the Four Ts symptoms and emphasises point of care blood glucose testing where diabetes is suspected, in line with NICE guidance. The Committee was grateful to receive a copy of the pathway whilst it was undergoing scrutiny processes within Cardiff and Vale University Health Board in advance of a pilot exercise.

64. The Cabinet Secretary confirmed that it is the Welsh Government's intention that the pathway will be rolled out to all health boards following the pilot by Cardiff and the Vale University Health Board. The Committee heard that 170 GPs had received training by February 2018 and that an evaluation is due at the end of 2018 with a view to a national roll-out taking place after this.⁴⁶

65. However, the Baldwin family have expressed reservations that the pathway may only partially address their concerns because it will only apply once type 1 diabetes is suspected or a diagnosis has been made. The family's focus is on ensuring that the initial symptoms are acted upon, the relevant questions are asked and tests conducted.

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.

⁴⁶ Record of Proceedings, 6 February 2018, paras. 162-8

7. Monitoring

66. Diabetes UK Cymru told the Committee that there are currently knowledge gaps in relation to data gathering and performance monitoring, particularly in relation to primary care:

“Where the gaps are, really, is in further investigating primary care in terms of, you know—. We could easily, I think, look at how many tests are being carried out. We don’t have that information. A few of the health boards carry out a serious case review or a DATIX report when a child is diagnosed and it hasn’t gone as smoothly as it could have, or even when it’s gone well, they have that dialogue between secondary and primary care and that sort of thing can be monitored. But that’s where the gaps in our knowledge are at the moment.”⁴⁷

67. They also stated:

“There are a number of audits already that we use—established audits that we have a lot of data from, mainly the national paediatric diabetes audit, the NPDA (...) Certainly, we could benefit from, as I said, point of care testing in terms of reporting that. Monitoring referrals to secondary care could be done, and also the case reviews—so, any serious incident, in terms of reviewing that. We know of some excellent work in Cardiff and Vale health board being carried out by Dr Ambika Shetty, who’s a consultant paediatrician, to review that snippet of the pathway between primary and secondary care, and to really look at that under the microscope, and, as I said, go back for learning where it hasn’t gone to plan, and also praise it when it has gone right as well. So, there are a number of things that can be done that aren’t being done at the moment that would be of absolute benefit to this area.”⁴⁸

68. However, the Committee learned that existing monitoring and clinical audit processes focus upon care processes for patients following diagnosis, rather than in relation to the primary objective of the petition – to improve the recognition and diagnosis of type 1 diabetes. This was confirmed by the Deputy Chief Medical Officer, Dr Chris Jones, during an evidence session with the Cabinet Secretary:

⁴⁷ Record of Proceedings, 11 July 2017, para. 169

⁴⁸ Record of Proceedings, 11 July 2017, para. 188

“If I may just say, I think it’s probably fair to say that the audits cover probably more processes of care once the diagnosis is established because, obviously, the diagnosis of type 1 diabetes is a relatively unusual event in each GP’s life because it’s a relatively unusual condition. So, it would be very hard to have comparative information about those very tiny numbers. But certainly, the broader picture, the processes of care and the approach to diabetes care, is described.”⁴⁹

69. Whilst this is extremely important, the focus of the petition is on the period leading up to diagnosis. The Committee considers that further consideration should be given to how monitoring of performance and data in respect of diagnosis of type 1 diabetes – at national and health board level – could be done more consistently.

70. Two health boards (ABMU and Aneurin Bevan) noted in their responses to the Committee that in cases of late diagnosis and referral, such as when a child presents in DKA, it would be routine for the GP concerned to undertake a case review to identify any learning points.

71. The Cabinet Secretary confirmed that ensuring this took place across Wales was under active consideration:

“[...] the Children and Young People’s Diabetes Network, in conjunction with the Diabetes Implementation Group, is considering the potential to use Datix reporting of delayed diagnosis of type 1 diabetes. Datix is a national system all NHS bodies in Wales use to report adverse healthcare incidents and a report in this instance would trigger reflection and investigation of the case handling and learning for all concerned. This may be supported further by encouraging clusters (grouped primary care providers) to use this shared learning and highlight good practice.”⁵⁰

72. “Emergency admissions for hypoglycaemia and DKA” is identified as one of the key service performance indicators in relation to children and young people. However the most recent annual statement of progress on the Welsh Government’s diabetes delivery plan,⁵¹ published in April 2017, does not include

⁴⁹ Record of Proceedings, 6 February 2018, para. 145

⁵⁰ Cabinet Secretary for Health, Wellbeing and Sport to the Committee, 6 October 2017 (PDF, 210KB)

⁵¹ Welsh Government, Diabetes Annual Statement of Progress, April 2017 (PDF, 1.1MB)

any performance information relating to diagnosis of type 1 diabetes or admissions for DKA.

73. In relation to monitoring, the RCN told the Committee that:

“The impact and effectiveness of the delivery plan should be monitored carefully, with in-depth consideration of whether or not it is achieving the best possible outcomes from children in Wales.”⁵²

74. The Committee considers that there would be a benefit to adopting a more consistent approach to learning from instances of late diagnosis across all health boards.

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.

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.

⁵² Royal College of Nursing Wales to the Committee, 6 September 2017 (PDF, 168KB)

8. Public awareness

75. A perceived lack of public awareness of type 1 diabetes has been raised regularly during the Committee’s consideration of the petition. Diabetes UK Cymru told us:

“[...] there’s low awareness amongst the public. People aren’t aware of the symptoms. They’re not presenting to their GP, asking for these tests to be carried out.”⁵³

76. The BMA Strongly supported the need to improve general public awareness of the symptoms type 1 diabetes and suggested that investment should be prioritised in this direction:

“However, awareness raising, including enhancing knowledge of the ‘Four Ts’, cannot be realised by GPs alone. We would suggest that a sustained, properly-resourced awareness campaign featured in schools, community and healthcare settings – targeting parents and carers, teachers, school pupils of all ages, and wider health and social care professionals – is necessary.”⁵⁴

77. The Children and Young People’s Wales Diabetes Network’s letter to the Health, Social Care and Sport Committee highlighted Cardiff University’s recent Early Detection of Type 1 Diabetes in Youth (EDDY) study. The EDDY study looked at the feasibility of delivering a community educational intervention, aimed at raising awareness of the symptoms of type 1 diabetes among parents, teachers, and primary care health professionals. The Network’s letter (dated November 2016) stated that funding was being sought to extend the study in order to demonstrate whether such an intervention has an impact on DKA rates at diagnosis.⁵⁵

78. The Cabinet Secretary agreed that more could be done to raise awareness among the public and health professionals about the “Four Ts” symptoms (toilet, thirsty, tired, thinner), and commended the work carried out by Diabetes UK Cymru and the petitioner.⁵⁶ The Diabetes Delivery Plan commits to the Diabetes

⁵³ Record of Proceedings, 11 July 2017, para. 146

⁵⁴ [British Medical Association Wales to the Committee](#), 1 September 2017 (PDF, 384KB)

⁵⁵ [Children & Young People Wales Diabetes Network to the Chair of the Health, Social Care and Sport Committee](#), 16 November 2016 (PDF, 146KB)

⁵⁶ [Cabinet Secretary for Health, Wellbeing and Sport to the Committee](#), 6 October 2017 (PDF, 210KB)

Implementation Group developing an awareness campaign, in partnership with Diabetes UK, specifically to facilitate the early diagnosis of type 1 diabetes in children.

79. Diabetes UK Cymru provided further detail of their work in this area:

“Diabetes UK Cymru is currently working with Baldwin family and other families affected by late diagnosis to develop and deliver an awareness raising campaign targeting primary care staff, education staff and parents.

We note that the recently published Welsh Government Together for Health: A Diabetes Delivery Plan commits the Children & Young People’s Wales Diabetes Network (the Network) to a number of actions in this area.”⁵⁷

80. They also proposed that the symptoms of type 1 diabetes could be included in the personal child health record (the Red Book) provided to all new parents in Wales:

“For example, type 1 diabetes, it’s not in baby packs in Wales. It’s not in the red book that new mothers get. That’s only done very locally by our campaigners at grass-roots level speaking to their GP surgery and asking for the four Ts poster to be put in the pack. It’s really not driven centrally at all, unfortunately. Other conditions like meningitis: we all are aware of the symptoms. It’s never received that attention.”⁵⁸

81. The Cabinet Secretary questioned whether the focus should be on public awareness or professional awareness. This was on the basis that too many awareness raising campaigns can diminish the impact that they all have, and because of the relative rarity of type 1 diabetes:

“[...] it’s about what is the most effective way to do that. Through the life of this petition, I think there’s been a change from running a public awareness-raising campaign, which was one of the asks through the petition, to now recognising that it’s more effective to run that awareness-raising campaign with healthcare professionals. We’re talking about schools, of course, in the school nursing framework; we’ve

⁵⁷ [Diabetes UK Cymru to the Committee](#), 13 December 2016 (PDF, 260KB)

⁵⁸ Record of Proceedings, [11 July 2017](#), para. 157

got a range of things that people want to do. So, there are healthcare professionals in different settings.”⁵⁹

82. He also referred to the wider context of this:

“I would like everyone to be really aware of their own health and what they can do to improve it, but we have to start at the point that, actually, we still can’t get health messages about smoking, alcohol, exercise and diet consistently understood and acted on. To then say, in addition to those that we’re not doing as well on as we want to in persuading the public to make different choices, we’ll run condition-specific campaigns, I don’t think that actually is the best way to deploy our resources and I don’t think we’ll see the right improvement in health that we’d want to. That’s why we’ve chosen to focus attention and awareness-raising with healthcare professionals.”⁶⁰

83. However, Diabetes UK Cymru referred to their own campaigns, past and present, and the impact that they considered these to have had:

“Diabetes UK have just launched a campaign in June [2017], called the Know Type 1 campaign, which really does push the four T’s out there. Diabetes UK launched the four T’s campaign several years ago [...] and we know that awareness in the public went up from 9 per cent to 14 per cent at that time. So, it is doable. It is achievable. And I think Diabetes UK’s more recent campaign, which is funded by the Baldwin family, will go a long way in Wales into doing that, and we are evaluating it as well.”⁶¹

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.

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 settings.

⁵⁹ Record of Proceedings, ~~6 February 2018~~, para. 225

⁶⁰ Record of Proceedings, ~~6 February 2018~~, para. 227

⁶¹ Record of Proceedings, ~~11 July 2017~~, para. 151