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Dear Consultation Team,

Re: Consultation response on '*Modernising school attendance and admission registers and setting national thresholds for legal intervention.*'

On behalf of Cardiff University's School of Medicine, please find our response to the current consultation. We are submitting evidence from our quantitative research, '*Investigating the inter-relationship between diabetes and children's educational achievement*' and qualitative research, '*Steadfast: education outcomes in young people with diabetes*', which focuses on children living with Type 1 diabetes. The research has significant findings in relation to the impact of living with diabetes and pupil absence.

Despite diabetes being legally defined as a disability under The Equality Act 2010, we are finding from our research that many children with diabetes are experiencing discrimination because of their disability, which then impacts upon their attendance and therefore their school experience. Further, in the subset of children with diabetes who have the greatest challenges in maintaining blood sugars within the optimum range, we also see significantly worse attainment (in addition to much worse attendance) and so face a vicious circle of poor health, attendance, and attainment.

The Statutory Guidance '*Supporting pupils at school with medical conditions; statutory guidance for governing bodies and proprietors of academies in England*' (2015) exists to ensure that all children with medical conditions are supported in school. However, evidence from our research demonstrates that this is not being consistently implemented across the country, creating barriers for children and young people attending school and achieving their academic potential.

We would be happy to expand on the points covered in our response if it would be helpful. Likewise, if you have any queries regarding the response, please do not hesitate to get in touch.

Yours sincerely,

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Modernising school attendance and admission registers and setting national thresholds for legal intervention

Cardiff University response

Overview

Cardiff University has been funded to conduct this research by the UKRI Medical Research Council (MRC £395k), the UKRI Administrative Data Research UK (ADR UK £181k) and UKRI Data and Analytics Research Environments UK (DARE £238k). This research has been completed in partnership with Diabetes UK, the Royal College of Paediatrics and Child Health (RCPCH), NHS Digital, Health Quality Improvement Partnership (HQIP), University College London (UCL) and Swansea University.

The research used quantitative methods to identify and link individuals from the National Paediatric Diabetes Audit, National Pupil Database and Higher Education Statistics Agency datasets. Statistical modelling techniques were used to make findings about individuals and their schools and healthcare settings. Following the quantitative study, the research team held nineteen focus groups with over 70 children (aged 13-34) across the UK to discuss their experiences of the support they received in education settings and the impact on their school absence.

The findings of the quantitative research will be published shortly in the *Journal of Diabetes Care*, the world-leading clinical diabetes journal. The aim of the research was to understand the relationship between how childhood diabetes and diabetes management affected a child's experience of school. The link between diabetes developed in childhood and education is important because it relates to how well children do at school and what they will go on to achieve academically and into their future careers. Diabetes affects all aspects of a child's life, from family, friendships, and their self-esteem.

From our research findings, a key issue that emerged was levels of **pupil absence** due to (i) medical appointments related to the condition, (ii) illnesses as a result of living with diabetes, and (iii) missing continual short periods of time throughout the school day to manage their diabetes (for example to monitor blood glucose levels, to administer insulin, or to treat a hypoglycaemic or hyperglycaemic incident).

1. Key points

- **Diabetes is one of the most common chronic childhood illnesses in the UK, affecting 1 in 250 children.** There are two main types of diabetes which affect how insulin regulates blood glucose levels. This research focuses on Type 1 diabetes which is the most common form in childhood, arising from the destruction of the beta cells (which produce insulin). Children with Type 1 diabetes cannot produce any insulin. This means they must take insulin and check their blood sugar levels regularly throughout the day. A child with Type 1 diabetes must self-inject insulin regularly or use an insulin pump to keep their blood glucose levels within acceptable limits, depending on what they have eaten or physical activity.
- To manage their medical condition, **children living with diabetes will need to administer insulin by injection or pump four or more times a day**, plus monitor their blood glucose levels (by finger prick testing or continuous glucose monitors), especially around mealtimes and physical activity. Children who need to inject at school will need to bring in their insulin and injecting equipment. In most cases, the equipment will be an insulin pen device rather than a syringe. Those who use an insulin pump will deliver extra insulin via a cannula which sits under the skin. Children may wish to check their blood glucose levels and administer insulin privately; others may be comfortable injecting in public. Both situations should be allowed.
- **Children may need help with monitoring their blood glucose levels, injecting insulin, or managing their pumps.** Children living with diabetes will have varying levels of understanding or ability to independently manage their condition. They will be reliant upon the support and training of teachers in their school, particularly for younger children, children who are newly diagnosed and children with learning difficulties.
- **The medical impact on children living with Type 1 diabetes will primarily be through effects on their metabolic state.** Having abnormal glucose levels may lead to an impact on concentration levels in school or affect school attendance. If a child experiences a 'hypo' (hypoglycaemia, or low glucose levels in the blood), the child may start feeling shaky, become dizzy, tired or have blurred vision. This may happen if a child has had too much insulin, not eaten enough carbohydrate food, or been more active than usual. Hypos must be treated very quickly. Left untreated, the blood sugar will continue to fall, and the child could become unconscious or have a seizure. In contrast, children may experience a 'hyper'

(hyperglycaemia, or high glucose levels in the blood). This may happen when a child has missed an insulin dose, not taken enough insulin, had a lot of sugary or starchy food, or over-treated a hypo. In these situations, treatment may not be needed, or they may take an extra dose of insulin or drink plenty of water. More extreme variations in blood glucose levels may lead to hospital admissions through severe hypoglycaemia or hyperglycaemia, which, when linked with ketoacidosis, may lead to altered cerebral functioning and brain damage.

- **The social impact on children living with Type 1 diabetes** may also affect education, particularly through the stress arising from self-management. In contrast to most other childhood chronic health conditions, a high proportion of medication management is led by the child, especially in the teenage years. This is in contrast to most childhood health conditions where the child's clinical team manages the timing and dosage of medication. Medication needs to be administered throughout the school day, and glucose levels monitored. Children may feel self-conscious about their condition, or they may not have the maturity or knowledge to be able to manage it appropriately. In addition, their situation may be further exacerbated by not receiving the appropriate care and support from their school and teachers, which will negatively impact their health and well-being. These issues persist into higher education and may impact a young person's ability to leave home and live independently in order to attend university or college.

2. Research findings

Educational outcomes for children living with diabetes versus children without diabetes.

- Children living with diabetes are **absent from 9 additional sessions a year compared with children without diabetes** (the baseline rate for all children is 20 sessions). Sessions may be missed for medical appointments related to the condition or illnesses as a result of living with diabetes.
- Despite missing these additional sessions, on average, **children living with diabetes achieve the same levels of academic qualifications as children without diabetes.**
- Furthermore, **children living with diabetes are equally likely to attend higher education** as children without diabetes.

Educational outcomes by blood glucose levels.

The research used a blood test to measure the average blood glucose levels for the last two to three months (HbA1c levels).

- Children experiencing challenges managing their diabetes missed **15 additional sessions of school a year compared with children without diabetes**. Even children with levels of blood glucose associated with the best future health outcomes missed 7 additional sessions a year.
- Children experiencing the most significant challenges managing their diabetes achieved **5 grades lower at 16 years of age** than children without diabetes.
- This pattern continues into higher education; children experiencing challenges managing their blood glucose levels **are less than half as likely to attend University** compared to children without diabetes.

Despite diabetes being legally defined as a disability under The Equality Act 2010, we are finding from our research that many children are experiencing discrimination as a result of their disability, which then impacts upon their attendance and therefore their school experience and for children who are struggling to manage their diabetes their attainment.

The Statutory Guidance '*Supporting pupils at school with medical conditions; statutory guidance for governing bodies and proprietors of academies in England*' (2015) is intended to help governing bodies meet their legal responsibilities. The aim of the Guidance is to ensure that all children with medical conditions, in terms of both physical and mental health, are properly supported in school so that they can play a full and active role in school life, remain healthy and achieve their academic potential. Schools must make arrangements for supporting pupils at schools with medical conditions, and in meeting that duty, they must have regard to this Guidance. However, from our qualitative research study, '*Steadfast: education outcomes in young people with diabetes*', conducted in partnership with Diabetes UK, we have found that the Guidance is not being adequately implemented across the country, which is resulting in creating barriers to children and young people attending school. This work involved 19 focus groups with 70 children and young people aged 13-24 living with Type 1 diabetes. Emerging findings from the focus groups show that many of the children have experienced direct discrimination and unacceptable practices. To illustrate this, we have included a summary of their views and quotes from the children and young people.

- **Lack of awareness and training of teachers about children's medical needs**

Schools, teachers, and support staff are not routinely trained in supporting children with health conditions. Educating teachers to support children with diabetes occurs on an ad hoc basis through local diabetes clinics and as a result in inconsistent across the

country. Every school should have a medical conditions at school policy, which outlines the support and protection each child is entitled to, to manage their condition.

- **Lack of support in how to manage their condition.**

'I didn't get much support, and not many people tried to understand (well, not many of my teachers), and I didn't really know who to go to if I needed help in the school day'
Young person, 18

- **Lack of support around children's Individual Health Care Plans**

'My Mum's been working for years to try and get a care plan that was simple enough for the teachers to be able to understand. They still don't read it or pay any attention to it, then tell me what to do even though they don't know because they haven't read the plan'
Young person, 19

- **Children being penalised for their attendance record, despite absences being related to their medical condition**

'My attendance statistic report doesn't look great. My tutor commented that my predicted grades for science were a bit lower than my other grades because I'd missed more science lessons. He said maybe if your attendance was better, your grades would be better. But my attendance was because of my diabetes. So, it was like he was saying. "You know, if you handled your diabetes better, or if you didn't have diabetes, then you would be doing better in school", and it really frustrated me because he said something like that previously. My mum had challenged it, but he still put it, and I found it really frustrating, as I was having a really bad time and felt unwell with my diabetes.'
Young person, 18

'I've recently been getting high blood sugars overnight, enough to make me feel rubbish in the morning and that affects me. Being able to get out of bed but not mentally, like not being able to wake up properly. So that slows me down and I'm late for school. My teacher thinks I'm using my diabetes as an excuse to be late all the time and it's not'.
Young person, 16

'A lot of pressure was on more of attendance because, you know, if you drop below this amount of attendance, you can't go on the end of year trip. But if I had said to my teachers in advance, I've got an appointment on this day at this time I'll have to miss this lesson. They wouldn't count that as an authorised absence. So it just looked like I hadn't turned up, but really I was at an appointment.'
Young person, 16

'My mental health is worse because I've got diabetes. I've spent a lot of time not in school because of my condition. I think the way they handle attendance is horrible. They reward children for having 100% attendance and diminish others that don't. I understand that there are people that skip school for the fun of it, but there are people who aren't in school for real reasons and then not being allowed to go on school trips'.

- **Children missing education due to a lack of awareness and training**

Due to a lack of awareness, training, policies and procedures within the school, children have been prevented from fully participating in school.

- **Impact of living with diabetes on children and young people's mental health**

'In terms of mental health support, I feel like that's underestimated quite a lot. For me personally mental health is probably what's most damaging about diabetes. As a diabetic you have to make so many more decisions and considerations compared to someone who's not diabetic, which of course takes its toll on your mental health or your academic ability or your performance at work' **Young person, 18**

- **Lack of support during exam period**

Children and young people expressed concerns about the lack of support and awareness from teachers about their additional needs and how that impacted the exam period. For example, children were not given a private room to take their exam, not being given extra time to manage their diabetes, being questioned about why they were bringing in certain drinks and snacks, or not being allowed to have their phones (which link to their Glucose Monitoring Systems to manage their diabetes). Children spoke about how stressful the exam period was, in addition they then had to manage their diabetes during this time with little help from the school.

Conclusion

Our research found that children living with diabetes are absent from 9 additional sessions a year compared with children without diabetes. We are concerned that pupil attendance may be met with a punitive response from education, rather than seen as a welfare flag to show that a child may require increased support from their school and health teams. Particularly those children who are experiencing challenges in managing their diabetes that is resulting in them having higher levels of absence from school.