

Educational attainment and childhood onset type 1 diabetes

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Abstract

Objective

To quantify associations between educational outcomes with type 1 diabetes status and glycaemic management (HbA1c).

Research Design and Methods

A record linkage study of schools and higher (college) education datasets linked to national diabetes audits. The population includes all Welsh children attending school between 2009 and 2016, yielding eight academic cohorts with attainment data, including 263,426 children without diabetes and 1,212 children diagnosed with type 1 diabetes. Outcomes include standardised student attainment aged 16 years, higher education participation aged 18 years, and school absences aged 6 to 16 years.

Results

Comparison between children with type 1 diabetes and children without diabetes showed no strong evidence of associations for student attainment (+0.001 SD, CI -0.047 to 0.049, $p < 0.96$ $n=1,212$ vs 263,426) or higher education entry rates (OR=1.067, CI=0.919 to 1.239, $p < 0.39$ $n=965$ vs 217,191), despite nine more sessions of absence from school annually ($p < 0.0001$). However, attainment in children in the most optimal HbA1c quintile was substantially better than children without diabetes (+0.267 SD, CI 0.160 to 0.374, $p < 0.001$) while being worse than children without diabetes in the least optimal quintile (-0.395 SD, CI -0.504 to -0.287, $p < 0.001$). Attainment did not differ by duration of 'exposure' to diabetes based on age at diagnosis.

Conclusions

Despite greater school absences, being diagnosed with diabetes is not associated with educational attainment or entry into higher education, although attainment does vary by HbA1c levels, which may be explained in part (or wholly) by unobserved shared personal,

family, or socioeconomic characteristics associated with both success in education and effective glycaemic self-management.

Introduction

For children with Type 1 diabetes, frequent glycemic excursions outside the normal physiological range may result in the acute metabolic disturbances of hypoglycaemia, hyperglycaemia and ketoacidosis, which could impact educational attainment through impaired concentration, absence from school, or hospitalisation whilst efforts are made to correct the metabolic disturbance (1). Furthermore, recurrent episodes of hypoglycaemia may cause neuronal injury from neuroglycopenia and hyperglycaemia (especially in the context of ketoacidosis), may damage white matter, disrupt functioning of the blood-brain barrier, and cause cerebral oedema during episodes of ketoacidosis.

Having type 1 diabetes in childhood has been reported to lead to long term radiological differences in brain structure evident by early adult life (2). Additional studies suggest adverse effects of diabetes on several aspects of cerebral function, including intelligence quotient, spelling, reading and arithmetic (3; 4), spatial and verbal intelligence (5), memory (6; 7), attention (7; 8), and behaviour (9). Cognitive impairment, particularly in younger individuals with diabetes, has been reported (6; 7; 10-12). However, educational attainment is a much broader concept than these precisely defined cognitive measures and generating high-quality evidence of the impact of diabetes is more challenging. Some studies also used outcome measures that were not from high stakes tests (13; 14). High stakes tests refer to examinations or assessments which carry important consequences for the individuals taking the tests. For example, high stakes tests at the end of compulsory schooling will influence subsequent educational and employment prospects.(15). Such tests are often ‘standardised’, meaning there are specific rules and regulations involved in providing and completing the test allowing better comparison across individuals. Other limitations of the extant evidence included limited comparability across classes due to differences in teacher grading practices such as grade point averages (GPAs) (4) or using opportunistic samples with limited

generalisability (16). A systematic review identified only two high quality studies using the same Swedish dataset (17; 18), which showed a significant but substantively small reduction in mean final grades in those with diabetes. A more recent nationwide study from Scotland showed that those with diabetes experience greater absenteeism and learning difficulties but no difference in exams performance overall, although those in the least optimal HbA1c quintile did show significantly poorer attainment. This study was limited by the definition of academic achievement using qualifications over a range of levels gained during the last three years of secondary school categorised as low, basic, broad/general, or high attainment, with such data available for only three academic cohorts which reduced the analytical sample size. The study also did not compare young people with diabetes in the different HbA1c quintiles with the general population without diabetes.

Socioeconomic factors are also important to address when examining the relationship between diabetes, HbA1c and educational performance. Although a recent extensive study from Denmark by Skipper et al . (13) published after the systematic review was complete did not find reduced academic performance in children with diabetes, it did find an association between HbA1c status and educational performance. This association reduced substantially though not completely after adjustment for socioeconomic and personal/family factors including parental age, income, highest completed education, family structure, migrant status, and whether the parent had insulin-dependent diabetes.

In this study, we therefore aimed to evaluate the impact of diabetes on school absenteeism, high stakes assessment at the end of compulsory schooling (age 16) as well as progression to further education (age 19) in a large national cohort of young people diagnosed with diabetes in childhood in comparison to children who did not have diabetes. We also sought to utilise the repeated assessments made throughout school to take into account the duration of diabetes and also study the effects of socioeconomic status. Our working hypothesis was that

diabetes would have a negative association with educational outcomes, in view of the potential effects of low and high glucose levels and ill health on learning cited above.

Methods

Study population and datasets

The study population was children in Wales who were of compulsory school age from 2009 to 2016. This dataset had 18 academic year cohorts in total, with school absence data for all cohorts. Of these, eight academic year cohorts who were old enough to have measures of attainment in the high stakes testing at the end of compulsory schooling (aged 16 years), and six academic year school cohorts which could also be linked to follow through into higher education data (Table 1).

Educational datasets

The Welsh Government provided annual national administrative schools data for all children in Wales for 2009 to 2016. Separate files were provided for high stakes testing at the end of compulsory schooling, referred to as KS4 (Key Stage 4, ages 15 to 16 years). The ‘National Data Collection’ dataset provided attainment at the end of each of the earlier key stages, KS1 (ages six to seven years), KS2 (ages eight to eleven years), KS3 (ages 12 to 14 years).

Additional files were provided for school absence data (recorded annually), contextual data including special educational needs and a household measure of income deprivation.

Although the dataset included children educated outside of mainstream government schooling, including children attending private schools (2.2%), children attending pupil referral units (0.3%), and children educated at home (0.5%), these students have more limited attainment data, and their contextual data is not recorded centrally, and so could not be included in our models alongside children from government schools. The Higher Education Statistics Agency (HESA) provided higher education data for the whole of the UK from 2009 to 2017.

Diabetes datasets

The National Paediatric Diabetes Audit (NPDA) was established in 2003 to compare the care and outcomes of all children and young people with all types of diabetes receiving care from paediatric centres in England and Wales (19). Since 2013 this had population coverage of 95 to 97%. The Brecon Register was established in 1995 and records all childhood-onset diabetes diagnosed in Wales; it is known from capture-recapture studies to be 98% complete; this was used as the gold standard for case identification in data linkage. The National Diabetes Audit (NDA) for adults (aged 16+) (20) was provided by NHS Digital and is the annual audit of adults with all types of diabetes begun in 2003, with data extracted digitally from primary and secondary care sources.

Statistical analysis

We estimated multilevel models on three outcomes, attainment, absence, and higher education participation. We compared children with type 1 diabetes with the general population, using all individuals in the school cohorts without a diagnosis of diabetes as the reference category, excluding the small number of children with other types of diabetes. We use children without diabetes as the reference group (rather than the lowest HbA1c quintile) to provide a more stable and more easily interpretable basis for comparison. Models assume data was ‘missing at random’ and unbiased results obtained from complete case analysis.

Models of school absence used annual data, so we include pre-diagnosis person-years alongside person-years for children who are never diagnosed diabetes in the timeframe of our data. All models were fitted using a combination of iterative generalized least squares (IGLS) and Markov chain Monte Carlo (MCMC) computational procedure as implemented in the MLwiN software, called from Stata using the `runmlwin` command (21).

Outcome 1: Student Attainment

Student attainment was measured using the high stakes national standardised testing results at the end of compulsory schooling (age 16 years). The measure used was the total grade points score for each subject (grade A*=58 points, A=52, B=46, C=40, D=34, E=28) for the top eight subjects, including English and Maths. Values were standardised to a mean of zero and standard deviation of one within each academic year.

Outcome 2: Higher education participation

Progression to an undergraduate degree (in a higher education institution anywhere in the UK) for children from Welsh schools was obtained from HESA for six cohorts of Welsh school students. We modelled progression directly to higher education at the standard entry point - the year following the completion of further education (age 19 years) - to have consistent results across cohorts.

Outcome 3: School Absence

Student absence was recorded annually. Authorised and unauthorised absences were combined to give a measure of the total number of sessions (half-days) missed in an academic year. Where students moved schools in the middle of an academic year the two records for the year could not be easily reconciled, so all student-years containing such moves were excluded from models for this outcome.

Independent Variables

For each of the three outcomes we estimated two models. The first model comparing children with type 1 diabetes vs children without diabetes. The second model comparing children with diabetes grouped into five quintiles of HbA1c vs the children without diabetes reference category. Using all children without diabetes as the reference category in both models provides a clearer illustration of how the distribution of HbA1c effects maps onto the overall

binary effect of diabetes. Whether a child had diabetes was identified from the NPDA and NDA, the linkage was cross-checked with the gold standard diabetes register, the Brecon Register, and further comparison with prevalence estimates in GP records, prescriptions records, and hospital admissions inpatient data. Records of glycated haemoglobin (HbA1c) were obtained from the NPDA. From 2004 to 2012, the NPDA recorded a single value annually; from 2013, all HbA1c values were recorded (typically three measures p/a). For school absence models, we used the mean HbA1c for the academic year; for attainment and higher education, we used the mean HbA1c from the period from diagnosis to the end of compulsory schooling.

Confounding adjustment

We adjusted for pupil characteristics from the schools contextual data across all models; these included gender, academic cohort, academic year, household deprivation and special educational needs. Household deprivation is measured using a binary indicator for whether a family is eligible and claiming free school meals, typically for individuals from households with income below £16,190 (approximately USD 22,700) or receiving benefits indicative of similar levels of income poverty (22; 23). Special educational needs status was recorded as a binary measure for the most severe category of need since this was the only level that attracts additional funding and direct support. Claiming free school meals was used as a binary indicator of deprivation. We estimated multilevel models to account for the clustering of students in schools, and in the longitudinal models, the multilevel structure was repeated measures within-individuals nested within-schools. As a sensitivity analysis, we estimated four separate extensions to the models of attainment, (i) adjusting for age at diagnosis rather than quintiles of HbA1c to proxy ‘accumulated exposure’ to diabetes, (ii) adjustment for school absence, and (iii) adjustment for prior attainment at age 11 years (KS2) (iv) contrasting models with no adjustment for socioeconomic status with those using the free

school meals indicator of household deprivation and the ‘Welsh Index of Multiple Deprivation’ measure of neighbourhood deprivation. This measure is constructed from weighted indices across eight domains of deprivation (income, education, employment, health, access to services, housing, physical environment, and community safety) (24).

Results

Outcome 1: Attainment

Attainment in the high-stakes tests at the end of compulsory schooling (aged 16 years) was recorded for 263,426 individuals without diabetes and 1,212 individuals who were diagnosed with type 1 diabetes prior to completion of compulsory schooling (Table 1). Figure 1 shows attainment by whether a child had diabetes and HbA1c quintiles. No difference in the standardised points score was seen between children with and without diabetes (0.001 SD CI -0.047 to 0.049, $p < 0.957$). Compared with children without diabetes, children in the most optimal (lowest) HbA1c quintile 'HbA1c Q1' had 0.267 SD (0.160 to 0.374, $p < 0.001$) higher attainment, whereas children in the least optimal (highest) HbA1c quintiles 'HbA1c Q5' had -0.395 SD (-0.504 to -0.287, $p < 0.001$) lower attainment. To aid interpretation, we also consider estimates for the same models using the unstandardised raw points totals for the outcome. Using those raw scores, the children without diabetes have predicted attainment of 297.9 points (e.g. 4x C grades 4x D grades), whereas the most optimal HbA1c quintile was predicted 321.3 points (e.g. 8x C grades), and the least optimal HbA1c quintile 263.1 (e.g. 7x D grades 1x E grade).

Outcome 2: Higher (college) education participation

For modelling entry to higher education, we had data from six complete cohorts of school students including 217,191 children without diabetes and 965 children who were diagnosed with type 1 diabetes prior to completion of compulsory schooling. Figure 2 shows progression to higher education by whether a child had diabetes and HbA1c quintiles. Progression to higher education was not different between children with or without diabetes (OR=1.067, 0.919 to 1.239, $p < 0.393$), equivalent to predicted rates of progression to higher education of 23.5% for children with diabetes compared to 22.4% for children without

diabetes. Compared with children without diabetes, children in the most optimal HbA1c quintiles were 1.703 (1.257 to 2.307, $p < 0.001$) times more attend higher education, and in the least optimal HbA1c quintiles 0.412 (0.258 to 0.656, < 0.001) times as likely to attend higher education, equivalent to predicted progression rates of 33.0% in the most optimal HbA1c quintile vs 10.6% in the least optimal.

Outcome 3: School absence

School absence was recorded for 18 cohorts of students, including 617,890 individuals without diabetes with 2,605,835 person-years of school attendance, and 2,067 individuals diagnosed with type 1 diabetes prior to completion of compulsory schooling, with 1,902 person-years prior to diagnosis and 6,874 person-years after diagnosis (Table 1). Figure 3 shows school absence by whether a child had diabetes and HbA1c quintiles. Children with diabetes were absent for 8.8 (8.045 to 9.463, < 0.001) more sessions than children without diabetes. Children in the most optimal HbA1c quintiles missed 6.7 (5.563 to 7.842, $p < 0.001$) more sessions per year, whereas children in the least optimal HbA1c quintiles missed 14.8 (13.532 to 15.998, < 0.001) more sessions per year than children without diabetes. Children with diabetes could miss up to six sessions per year due to routine diabetes-related health appointments; however, it is unlikely that all routine appointments would fall on school days or that children attend all the appointments they should. We estimate that the average student would miss between two to three sessions per year due to routine diabetes-related appointments, and so even for the most optimally managed children with diabetes, there is substantial excess absence over and above that accounted for by routine appointments. Some of that excess absence is due to unauthorised absence (truancy), accounting for 8% of absence in the most optimal three HbA1c quintiles, rising to 18% in the least optimal HbA1c quintile.

Sensitivity analysis

Figure 4 shows that the age (schooling period) in which a child is diagnosed with type 1 diabetes appears to make no difference to their final attainment at age 16. Supplemental Figure 1 shows that after adjustment for school absence, children with diabetes have better overall attainment than children without diabetes (0.076 SD, CI 0.032 to 0.120, $p < 0.001$), and the association with HbA1c quintile is attenuated but still present (0.258 SD, CI 0.160 to 0.355, $p < 0.001$ in the most optimal HbA1c quintile; -0.182 SD, CI -0.281 to -0.083, $p < 0.001$ in the least optimal quintile). Supplemental Figure 2 shows that adjusting for prior attainment leads to a marginally significant negative difference in progress for children diagnosed with diabetes in secondary school compared with those without diabetes (-0.088 SD, CI -0.176 to < 0.001 , $p < 0.050$). For the models HbA1c quintiles rather than binary diabetes status, however, we see a substantial change after adjusting for prior attainment, with an attenuation of 69% of the estimate for the most optimal quintile and 37% for the least optimal quintile, although the pattern of decreasing attainment by HbA1c quintiles remains. Supplemental Figure 3 shows the extent to which family socioeconomic measures account for both educational outcomes and HbA1c levels. We estimated a variation on the model of age 16 attainment by HbA1c quintiles, firstly including no measures of socioeconomic status, then a second model which includes household socioeconomic status (eligible and claiming free school meals) and an additional neighbourhood measure of deprivation, the Welsh Index of Multiple Deprivation. In the model which does not adjust for socioeconomic status, the HbA1c quintiles estimates range from -0.478 ($P < 0.001$) for the least optimal HbA1c quintile to 0.293 ($P < 0.001$) for the most optimal HbA1c quintile. When we adjust for both measures of socioeconomic status, the estimates for HbA1c quintiles range from -0.390 ($P < 0.001$) for the least optimal HbA1c to 0.258 ($P < 0.001$) for the most optimal HbA1c. Overall, adjusting for socioeconomic status attenuates the HbA1c effects by 18% for the least optimal HbA1c

quintile. In addition, we observe that for children living in the most deprived households, only 11% have mean HbA1c levels in the most optimal quintile, with 37% having HbA1c levels in the least optimal quintile.

Discussion

Key findings

Our data indicate that in a national population of young people diagnosed with type 1 diabetes before the end of compulsory schooling, compared to the remainder of their contemporaries, having diabetes was not associated with any difference in high stakes exam attainment at age 16 years (Figure 1), despite a mean of 8.8 additional school sessions missed annually (Figure 3). Indeed, after adding adjustment for school absence, children with diabetes overall actually had better attainment than children without diabetes (Supplemental Figure 1). Moreover, the odds of young people progressing to higher education was also no different between people with and without diabetes (Figure 2). Importantly, duration of diabetes was also not associated with reduced academic performance (Figure 4).

By contrast, breaking down the type 1 diabetes cohort by mean HbA1c levels attained between diagnosis and the end of compulsory schooling revealed major differences with children without diabetes (Figure 1). Attainment at age 16 years in children in the most optimal HbA1c quintile was over one-quarter of a SD (4 grades) higher than their peers without diabetes, whereas the attainment in the least optimal quintile was almost two-fifths SD (5 grades) lower. Where the value of an additional grade (e.g. moving from 8 grade Bs across the top 8 subjects to 7 grade Bs and 1 grade A) in undiscounted earnings over the working lifetime is estimated to be £23,000 (approximately \$31,500), equivalent to three-quarters of the average full-time annual salary in the UK in 2019 (25).

Furthermore, the pattern of attainment according to HbA1c quintile was replicated on higher education entry (Figure 2), with the most optimal HbA1c quintile group exceeding the achievement of the general population, being 1.7 times more likely to attend higher education, whereas the least optimal HbA1c quintile were 0.4 times as likely to attend higher

education. In other words, those with the most optimal HbA1c quintile were almost three-fold more likely to attend higher education than the least optimal HbA1c quintile, with predicted probabilities of 33.0% vs 10.6 % (using reference values for independent variables).

These findings are consistent with those of Fleming et al. and previous publications in this area. However, they substantially extend these observations by using robust high stakes examinations as outcomes and replicating these findings at college entry, an important stage in impact for the future. In addition, by using children without diabetes as the reference group, our models emphasise that the gradient in attainment by HbA1c levels arises from both overperformance and underperformance. In other words, the most optimal HbA1c quintile appears to overachieve compared to the general population, whereas the least optimal HbA1c quintile very substantially underachieve.

The overachievement of children in the lowest HbA1c quintile compared to their peers without diabetes seems unlikely to be explained by a “beneficial” effect of diabetes and raises the possibility that the marked gradient in educational achievement by HbA1c is due to factors unrelated to glucose levels, such as socioeconomic and familial factors. Consistent with these observations, the age (schooling period) in which a child is diagnosed with diabetes, and hence the amount of ‘exposure’ to diabetes accrued before testing, made no difference to their final attainment at age 16 years (Figure 4). In addition, a marked gradient in HbA1c by deprivation was observed in our data, with children living in the most deprived households over three times more likely to have an HbA1c in the highest quintile as compared to the lowest HbA1c quintile. When we adjusted for socioeconomic status in our analysis, we saw an 18% improvement in the achievement of children in the highest HbA1c quintile. Skipper et al. observed a substantially greater attenuation of the HbA1c gradient in attainment after adjustment (13). However, our socioeconomic adjustments did not include the family factors used by Skipper et al., which included elements such as parental

educational attainment (a proxy for parental IQ), single-parent families and immigrant status and which resulted in even greater attenuation of the gradient by HbA1c in their analysis than we observed (13). To account for this, in contrast to previous analyses, we were able to adjust for prior educational attainment for those diagnosed aged 11-16. This identifies any change in an individual child's educational trajectory before and after diagnosis. Since parental and child IQ would not be expected to change over time and other family factors will be constant in most cases, a change in educational trajectory following the diagnosis of diabetes is less likely to be the result of socioeconomic factors on educational attainment, and an approximate upper bound on the direct (biological) diabetes factors. Following this adjustment, we see attenuation of 69% of the estimate for the most optimal quintile and 37% for the least optimal quintile (Supplementary Figure 2), consistent with a major effect for family factors. Adjustment for school absence rates (more than twice as high in the highest HbA1c quintile) also attenuated the effect of HbA1c quintile (Supplementary Figure 1), although this could include absence related to glucose related ill-health in addition to socioeconomic factors.

Taken together, our sensitivity analyses suggest there may be socioeconomic and family factors that are associated with both high HbA1c and poor educational attainment. However, they do not exclude a direct effect on high or low glucose levels on cognitive function as a contributory factor, as even after all our adjustments, a gradient of achievement by HbA1c quintile remained, although substantially attenuated. In addition, after adjustment for educational trajectory before diagnosis of diabetes (prior attainment), children with diabetes overall did show a small reduction of educational attainment of 0.08SD compared to the children without diabetes (supplemental Figure 2).

Strengths and weaknesses of the study

Strengths of our study include the robust nationwide population with type 1 diabetes studied, defined using national audit data validated using a national register; the high-quality attainment outcome, summarising standardised attainment across the top eight subjects in the high stakes assessment at the end of compulsory schooling; and the large sample size, both cross-sectionally and in terms of the number of academic-year cohorts. In particular, our paper utilised high stakes examinations, with replication for university admissions, both key determinations of an individual's future economic performance and prosperity. In addition, we were able to utilise an individual's age of onset of diabetes and multiple high stakes tests throughout school, enabling us to also explore the impact of "time at risk" from diabetes. A potential weakness of our study is that we average each individual's HbA1c measures over a year (for school absence models) or the whole school lifecourse since diagnosis (for attainment and progression to university measures). This 'averaging out' will mask periods of high HbA1c, particularly where those periods were short, even though they may have potentially large impacts on education, health, and other outcomes. Further, because this study uses administrative data, we are limited in the variables available as contextual factors. Most importantly there are likely to be omitted variables such as levels of parental support, that are correlated with HbA1c levels and educational outcomes. Finally, the time period for our study (from 2009-16) includes many changes in treatment, including more stringent glycaemic targets, more intensive insulin regimens, insulin pumps and continuous glucose monitoring. These changes may account both for some of the differences in educational outcomes between individuals (which may be further correlated with socioeconomic status) and differences between our findings and estimates from other studies using earlier cohorts. In addition, we only have complete contextual and attainment data for the children who

attend mainstream government schooling (97%) and so are not able to comment on the 3% that are educated at private schools, at home or in other modes, including pupil referral units

Our paper substantially advances the literature by resolving the controversy over whether there is any overall negative effect of diabetes on education as it has both high stakes testing and replicates further by including university admission. It also utilises repeated assessments over time, enabling us to explore the impact of longer duration of disease. It is reassuring that neither of these factors was associated with adverse educational outcomes.

Implications

We believe that our analysis of the comparison between children with type 1 diabetes and their peers without diabetes has important implications for interpretation. Fleming et al. concluded that “children with type 1 diabetes fare worse than their peers in respect of education and health outcomes”, and previous publications refer to effects of type 1 diabetes across many cognitive domains. Our data strongly indicates that there is no overall negative effect of diabetes on educational performance, even in those with a longer duration of diabetes. Furthermore, an effect of blood glucose concentrations on cognition is not consistent with the apparent “overperformance” of children with more optimal HbA1c levels that we report or the very small or insignificant differences in overall attainment of children with diabetes that are a consistent finding in our data and other well-matched cohorts (17; 18; 26). Indeed the lack of difference in attainment in the population of children with diabetes overall is all the more remarkable given that they miss a third more school sessions, and we have previously shown that they have a persistent excess of hospital admissions (1).

We believe our findings have several important implications for improving outcomes for children with type 1 diabetes and other chronic diseases. Firstly, health care professionals can reassure parents that (on average) a diagnosis of diabetes or its duration should not

substantially affect the learning of the child (27). Secondly, our data raise the possibility that intensified glycaemic management per se will have a limited effect on improving educational outcomes in those with the least optimal HbA1c. Rather, less optimal HbA1c levels identify children in whom more intensive educational and clinical support should be considered. Furthermore, our data suggest that those more likely to experience earlier onset of long-term complications of diabetes due to greater glycaemic exposure are also more likely to have low educational attainment. This “double jeopardy” would be expected to have a major adverse socioeconomic impact with lower earnings potential compounded by long-term sickness and disability. Thus, efforts to improve glycaemic management as well as to delay or prevent the onset of diabetes (28), especially in those most likely to have less optimal diabetes management, may help reduce the additional burden of early onset diabetes-related complications on top of the consequences of lower educational attainment, or at least delay these until individuals are more financially secure.

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Author contributors

- RF, CD, JG, & AS developed the research question and designed the study.
- RF conducted the data analysis.
- JW, HR, JR & PT supported the information governance and processing data for linkage.
- DK, AS & PT provided methodological support.
- All authors contributed to the data interpretation.
- JG & CD provided mentorship and clinical insight.
- RF, JG, & CD drafted the manuscript.
- All authors contributed to revision of the manuscript and approved the final version to be published.
- RF & CD are responsible for the overall content as guarantors.
- "The corresponding author RF attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted."

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Conflicts of interest statement

We declare no competing interests.

Patient and other consents

Identifiable variables for linkage of health datasets (NHS number, name, date of birth, postcode, gender) were shared under a Section 251 exemption from the common law duty of confidentiality awarded by the UK Health Research Authority Confidentiality Advisory Group. Identifiable variables for linkage of non-health datasets (name, date of birth, postcode, gender) were shared separately under the Digital Economies Act with supporting qualifications agreed with data providers. The data protection legal basis for processing personal data (GDPR & Data Protection Act) was Article 6(1) (e), processing necessary for the performance of a task carried out in the public interest. Probabilistic assignment of the linkage field was performed by NHS Wales Informatics Service, and data linkage and analysis was conducted within the SAIL platform. Diagrams summarising the flows and linkages are provided on the project website, along with the fair processing notices and other relevant agreements.

Data sharing statement

- All individual-level de-identified linked datasets will be made available after the publication of this paper alongside the code used to prepare and analyse the data.
- Data will be available for any research application with direct benefit to health and social care that meets the approvals of the data providers and data processors.
- Data access is subject to approval to (i) the SAIL IGRP process for access to the data in the SAIL gateway, (ii) approval by data providers, (iii) approval by HRA CAG; however, the key information governance challenge (the precedent for flowing identifiers for linkage) and technical challenge (data linkage) for creating the dataset is made available freely to other researchers.
- At present documentation for the data is still limited. There are data dictionaries for the schools data only; we hope to provide fuller documentation during 2022.

Patient and Public Involvement and Dissemination

PPI meetings, including adult patients, parents, members of the public and a range of diabetes practitioners, were used to get feedback on the linkage of confidential patient information without consent, the modelling design, and interpretation of results. Views of child patients were obtained through focus groups with young people and individual meetings with a child and their carers after clinic appointments. Dissemination to patients with diabetes will be conducted using a summary in the National Paediatric Diabetes Audit annual publication.

References

1. Sayers A, Thayer D, Harvey JN, Luzio S, Atkinson MD, French R, Warner JT, Dayan CM, Wong SF, Gregory JW. Evidence for a persistent, major excess in all cause admissions to hospital in children with type-1 diabetes: results from a large Welsh national matched community cohort study. *BMJ Open* 2015;5:e005644-e005644
2. Pell GS, Lin A, Wellard RM, Werther GA, Cameron FJ, Finch SJ, Papoutsis J, Northam EA. Age-related loss of brain volume and T2 relaxation time in youth with type 1 diabetes. *Diabetes Care* 2012;35:513-519
3. Ryan C, Longstreet C, Morrow L. The effects of diabetes mellitus on the school attendance and school achievement of adolescents. *Child Care Health Dev* 1985;11:229-240
4. McCarthy AM, Lindgren S, Mengeling MA, Tsalikian E, Engvall J. Factors Associated With Academic Achievement in Children With Type 1 Diabetes. *Diabetes Care* 2003;26:112-117
5. Perantie DC, Lim A, Wu J, Weaver P, Warren SL, Sadler M, White NH, Hershey T. Effects of prior hypoglycemia and hyperglycemia on cognition in children with type 1 diabetes mellitus. *Pediatr Diabetes* 2008;9:87-95
6. Gaudieri PA, Chen R, Greer TF, Holmes CS. Cognitive Function in Children With Type 1 Diabetes: A meta-analysis. *Diabetes Care* 2008;31:1892-1897
7. Desrocher M, Rovet J. Neurocognitive correlates of type 1 diabetes mellitus in childhood. *Child Neuropsychol* 2004;10:36-52
8. Parent KB, Wodrich DL, Hasan KS. Type 1 diabetes mellitus and school: a comparison of patients and healthy siblings. *Pediatr Diabetes* 2009;10:554-562
9. McCarthy AM, Lindgren S, Mengeling MA, Tsalikian E, Engvall JC. Effects of Diabetes on Learning in Children. *Pediatrics* 2002;109:e9-e9
10. Naguib JM, Kulinskaya E, Lomax CL, Garralda ME. Neuro-cognitive Performance in Children with Type 1 Diabetes—A Meta-analysis. *J Pediatr Psychol* 2009;34:271-282

11. Blasetti A, Chiuri RM, Tocco AM, Giulio CD, Mattei PA, Ballone E, Chiarelli F, Verrotti A. The effect of recurrent severe hypoglycemia on cognitive performance in children with type 1 diabetes: a meta-analysis. *J Child Neurol* 2011;26:1383-1391
12. He J, Ryder AG, Li S, Liu W, Zhu X. Glycemic extremes are related to cognitive dysfunction in children with type 1 diabetes: A meta-analysis. *Journal of diabetes investigation* 2018;9:1342-1353
13. Skipper N, Gaulke A, Sildorf SM, Eriksen TM, Nielsen NF, Svensson J. Association of Type 1 Diabetes With Standardized Test Scores of Danish Schoolchildren. *JAMA : the journal of the American Medical Association* 2019;321:484-492
14. Cooper MN, McNamara KA, de Klerk NH, Davis EA, Jones TW. School performance in children with type 1 diabetes: a contemporary population-based study. *Pediatr Diabetes* 2016;17:101-111
15. Marchant GJ. What is at stake with high stakes testing? A discussion of issues and research. 2004;
16. Vetiska J, Glaab L, Perlman K, Daneman D. School attendance of children with type 1 diabetes. *Diabetes Care* 2000;23:1706-1707
17. Dahlquist G, Kallen B. School performance in children with type 1 diabetes-a population-based register study. *Diabetologia* 2007;50:957-964
18. Persson S, Dahlquist G, Gerdtham UG, Steen Carlsson K. The impact of a childhood onset of type 1 diabetes on higher education and labour market outcomes. *Diabetologia* 2013;1):S22-S23
19. National Paediatric Diabetes Audit, Royal College of Paediatrics and Child Health. Annual report 2018-19: Care processes and outcomes. 2020;
20. Health and Social Care Information Centre. National Diabetes Audit, 2017-18 Report 1: Care Processes and Treatment Targets. 2019;
21. Leckie G, Charlton C. runmlwin - A Program to Run the MLwiN Multilevel Modelling Software from within Stata. *Journal of Statistical Software* 2013;52:1-40
22. Ilie S, Sutherland A, Vignoles A. Revisiting free school meal eligibility as a proxy for pupil socio-economic deprivation. *British Educational Research Journal* 2017;43:253-274
23. Taylor C. The reliability of free school meal eligibility as a measure of socio-economic disadvantage: Evidence from the millennium cohort study in Wales. *British Journal of Educational Studies* 2018;66:29-51

24. Statistics for Wales (Welsh Government). Welsh Index of Multiple Deprivation 2011 Summary Report. Welsh Government Cardiff, 2011
25. Department for Education. GCSE attainment and lifetime earnings. 2021;
26. Fleming M, Fitton CA, Steiner MF, McLay JS, Clark D, King A, Lindsay RS, Mackay DF, Pell JP. Educational and Health Outcomes of Children Treated for Type 1 Diabetes: Scotland-Wide Record Linkage Study of 766,047 Children. *Diabetes Care* 2019;42:1700-1707
27. Amillategui B, Calle JR, Alvarez MA, Cardiel MA, Barrio R. Identifying the special needs of children with Type 1 diabetes in the school setting. An overview of parents' perceptions. *Diabet Med* 2007;24:1073-1079
28. Dayan CM, Korah M, Tatovic D, Bundy BN, Herold KC. Changing the landscape for type 1 diabetes: the first step to prevention. *The Lancet (British edition)* 2019;394:1286-1296

Tables and figures

Table 1: Descriptive statistics for the model samples for each of the three outcomes

	18 education cohorts with linked diabetes and school absence data. Born 1993 to 2010.		8 education cohorts with linked diabetes and student attainment data. Born 1993 to 2000.		6 education cohorts with linked diabetes, schools, and higher education data. Born 1993 to 1998.	
	Children without type 1 diabetes	Children with type 1 diabetes	Children without type 1 diabetes	Children with type 1 diabetes	Children without type 1 diabetes	Children with type 1 diabetes
Number of Individuals	617,890	2,067	263,426	1,212	217,191	965
(Percentage of individuals)	(99.7%)	(0.3%)	(99.5%)	(0.5%)	(99.6%)	(0.4%)
Number of person-years	2,605,835	8,776	-	-	-	-
(Percentage of person-years)	(99.7%)	(0.3%)	-	-	-	-
Number of schools	1,830	1,024	276	229	653	240
Number of females	302,121	998	129,780	566	106,294	448

(Percentage of persons who are female)	(48.9%)	(48.3%)	(49.3%)	(46.7%)	(48.9%)	(46.4%)
Special Educational needs statement (SEN)	56,458	233	6,954	56	8,986	60
(Percentage of person-years.)	(2.2%)	(3.2%)	(2.6%)	(4.6%)	(4.1%)	(6.2%)
Free school meals (FSM)	471,916	1,271	39,407	203	33,204	157
(Percentage of person-years)	(18.1%)	(18.5%)	(15.0%)	(16.7%)	(15.3%)	(16.3%)

Figure 1: Conditional models of standardised educational attainment score by whether a child has type 1 diabetes (binary and HbA1c quintiles).

Figure 2: Conditional models of progression to higher education by whether a child has type 1 diabetes (binary and HbA1c quintiles).

Figure 3: Conditional models of school absence by whether a child has type 1 diabetes (binary and HbA1c quintiles).

Figure 4: Sensitivity analysis showing models of standardised student attainment by binary type 1 diabetes status and the type 1 diabetes sample broken down by age of diagnosis rather than HbA1c quintiles.