

DR MICHAEL J SAMPSON (Orcid ID : 0000-0002-1433-2319)

DR HELEN R MURPHY (Orcid ID : 0000-0001-6876-8727)

DR KHIN SWE MYINT (Orcid ID : 0000-0002-2490-8342)

Article type : Research Article

Title: Diabetic Medicine

Created by: Maria Hale

Email proofs to: khinswe.Myint@nnuh.nhs.uk

Copyright: Diabetes UK

Article no.: DME-2017-00731

Article type: Research Article

Short title/Authors running head: *Experience of young people with Type 1 diabetes at UK universities* • J. Kellett et al.

Research: Care Delivery

Young people's experiences of managing Type 1 diabetes at university: a national study of UK university students

J. Kellett¹, M. Sampson¹, F. Swords¹, H. R. Murphy³, A. Clark², A. Howe², C. Price³, V. Datta⁴ and K. S. Myint⁵

¹Norfolk and Norwich University Hospitals NHS Foundation Trust, Clinical Research and Trials Unit, ²Norwich Medical School, Faculty of Health and Medical Sciences, and ³University Medical Centre, University of East Anglia, and Departments of ⁴Paediatrics and ⁵Diabetes and Endocrinology, Norfolk and Norwich University Hospitals NHS Foundation Trust, Norwich, UK

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/dme.13656

This article is protected by copyright. All rights reserved.

What's new?

- This national survey is unique and captured data from approximately one-third of all students with Type 1 diabetes at UK universities.
- Current diabetes care systems for university students are not functioning well, resulting in poor glycaemic control (25% higher HbA_{1c}, 63% increased difficulty in diabetes management), diabetes complications that interrupt studies (43% frequent hypoglycaemia) and excess hospital admissions (25%).
- Higher risk groups were female students (hypoglycaemia, depression, etc.) and those who had moved healthcare providers (higher HbA_{1c}, hypoglycaemia, ketoacidosis and hospital admissions).
- Despite these challenges, 91% never/rarely contacted university support services.
- There is scope for a national approach to improving the focus care pathway.

Abstract

Aim Little is known about the challenges of transitioning from school to university for young people with Type 1 diabetes. In a national survey, we investigated the impact of entering and attending university on diabetes self-care in students with Type 1 diabetes in all UK universities.

Methods Some 1865 current UK university students aged 18–24 years with Type 1 diabetes, were invited to complete a structured questionnaire. The association between demographic variables and diabetes variables was assessed using logistic regression models.

Results In total, 584 (31%) students from 64 hospitals and 37 university medical practices completed the questionnaire. Some 62% had maintained routine diabetes care with their home team, whereas 32% moved to the university provider. Since starting university, 63% reported harder diabetes management and 44% reported higher HbA_{1c} levels than before university. At university, 52% had frequent hypoglycaemia, 9.6% reported one or more episodes of severe hypoglycaemia and 26% experienced diabetes-related hospital admissions. Female students and those who changed healthcare provider were approximately twice as likely to report poor glycaemic control, emergency hospital admissions and frequent hypoglycaemia. Females were more likely than males to report stress [odds ratio (OR) 4.78, 95% confidence interval (CI) 3.19–7.16], illness (OR 3.48, 95% CI 2.06–5.87) and weight management issues (OR 3.19, 95% CI 1.99–5.11) as barriers to self-care. Despite these difficulties, 91% of respondents never or rarely contacted university support services about their diabetes.

Conclusion: The study quantifies the high level of risk experienced by students with Type 1 diabetes during the transition to university, in particular, female students and those moving to a new university healthcare provider.

<H1>Introduction

There are an estimated 25 357 young people aged under 24 years old with Type 1 diabetes in the UK [1]. Type 1 diabetes is associated with increased risk of long-term complications, and increased morbidity and mortality [2–5]. Much of this excess risk can be mitigated by achieving and maintaining optimal glycaemic control [6]. Optimal glycaemic control requires frequent blood glucose monitoring and active insulin dose titration tailored to dietary intake and physical activity, which is always complex and challenging, especially during times of

change such as puberty and adolescence, when a marked deterioration in glycaemic control is common [7,8].

Young people with diabetes go through many transitions: from paediatric to adult diabetes services; from a family support structure to independent living; from school to university, or on to the world of employment. During the transition from paediatric to adult services, many lose contact with their local diabetes team, increasing the risk of poor metabolic control and emergency hospital admission [9–11], poorer educational and vocational outcomes [12], and mortality [13]. The importance of transitional care in the UK is emphasized in national policy, [14,15] but the risk associated with the later transition from home to university for many young adults has been a neglected area.

The transition from home to university is a period of tremendous change for all young people, with particular challenges for those with a long-term health condition. A new home environment, lack of parental involvement, irregular timetables, risk-taking behaviours, contraception issues, alcohol and peer pressure all have substantial impacts on diabetes self-care [16–21]. A lack of continuity in diabetes care as students move away from home can also undermine healthcare professionals' ability to meet young adults' needs [22,23].

Although 43% of school leavers in the UK now attend university [24], there is little research on the experiences of students with Type 1 diabetes. The aim of this study was to investigate the experiences of university students with Type 1 diabetes and to describe the impact of this transition on their diabetes care and self-management.

<H1>Methods

<H2>Questionnaire design

The questionnaire was designed to investigate the experiences of young people with Type 1 diabetes studying at university (Doc. S1). It included a broad range of questions on diabetes

management at university, diabetes problems since university, experiences of healthcare services, and advice and support at university. Demographic data included gender, current age, ethnicity, age at diagnosis, home and university town, current year of study, and residence during holidays and term time. The questionnaire was developed by the study team (including practitioners based in university medical practices and diabetes specialist services). Additional input was provided by the project advisory group [including diabetes specialists and researchers, university general practitioners (GPs) and Diabetes UK], current and recent university students and their families, via Diabetes UK online networks. The questionnaire was first piloted with a small group of students at a local university and refined further where required. It contained 45 questions that were divided into six sections (personal and university details, diabetes management, diabetes experience and communication with healthcare professionals). Respond formats were mixture of single and multiple choices and different scale. It allowed free text for comments (Doc. S1).

<H2>Data collection

Some 91 hospitals and 88 GP practices located on university campuses or affiliated to a nearby university were invited to participate in the study by distributing questionnaires to university students, aged 18–24 years, with Type 1 diabetes. In total 64 hospitals (51 in England, six in Scotland, four in Northern Ireland, three in Wales) and 37 university medical practices (31 in England, six in Scotland) sent the study questionnaire and participant information sheet to eligible patients between June 2013 and June 2014. The sample comprised 1865 students identified by their healthcare team as eligible. Participants who completed the questionnaire returned it either directly to the central study team via a freepost envelope or completed the survey online. Information publicising the study was also placed on key website networks (e.g. Diabetes UK) and via university student support services.

NHS ethical approval was obtained from the NRES Committee East Midlands – Leicester (12/EM/0165). Research and development approval to conduct the research was given by individual participating hospital trusts in England and Wales, primary care trusts in England, health boards in Scotland and health and social care trusts in Northern Ireland from where the students would be recruited.

<H2>Data analysis

Demographic variables and outcomes were summarized using numbers and percentages for categorical factors and mean and standard deviation (SD) for continuous factors. The association between demographic variables (gender, age, diagnosis before or during university, lived away from home, used an insulin pump and home or university healthcare provider) and the experience of diabetes problems at university [HbA_{1c} > 59 mmol/mol (7.5%), HbA_{1c} > 76 mmol/mol (9.1%), harder perceived self-management, more than three hypoglycaemia episodes per week, severe hypoglycaemia, diabetes-related hospital admissions and retinal complications] were assessed using logistic regression models adjusting for all the demographic variables listed above. The association between demographic variables and issues affecting glycaemic control was also assessed using the same modelling approach. The analysis was conducted using IBM Statistics SPSS 22 for Windows. The open-ended comments were subjected to basic content analysis in NVivo software 10 to categorize and summarize the data.

<H1>Results

<H2>Sample characteristics

Some 584 (31%) students with Type 1 diabetes completed the questionnaire (335 by post, 249 online), with more female than male respondents (64% and 36%) (Table 1). Mean age

was 20 years (SD 2.0) and mean age at diabetes diagnosis was 11 years (SD 5.0), with the vast majority (87%) diagnosed before university. Most lived away from home during term time and used multiple daily injections of insulin.

<H2>Student experiences of healthcare services

Regardless of where in the UK students were studying, 62% (360) continued with their home diabetes healthcare team, whereas 32% (187) moved to their university healthcare team (6.3% were unknown). Of those students who had moved healthcare provider, 40% reported reduced access to dieticians, 35% had problems obtaining prescriptions during holidays and 33% reported reduced access to diabetes education (Table S1). However, 53% rated the university clinic location as better, and indicated better access to specialist nurses and GP services (48% and 47% respectively) compared with home.

On average, students had attended a diabetes clinic 2.9 times (SD 1.98) in the past 12 months. Almost a third (30%) had missed at least one clinic appointment in the previous 12 months; the main reasons included a clash with their university timetable (33%), unable to travel to an appointment at home (18%) or forgot appointment (16%). Some 35% of students had not received at least one component of the annual diabetes review (Table S2). This was highest for the foot check, where 20% had not received an examination in the past 12 months. No associations were found between missed annual reviews and any particular demographic variables (Table S3).

A majority of students with diabetes (> 75%) had seen a diabetes specialist consultant, retinal screener, diabetes specialist nurse and GP regarding their diabetes in the past 12 months (Table 2). However, fewer than half had seen a dietitian, just over one third had seen a podiatrist and only 8.4% had seen a psychologist. Over half of respondents reported that they would not know how to access psychological help.

<H2>Changes in glycaemic control since starting university

One-third of students did not know their HbA_{1c} level (Table 3). Of the 390 students (67%) who did report their HbA_{1c} level, the mean was 68 mmol/mol (SD 19) (8.4% with SD 4). Since starting university, just under one half of respondents (44%) reported that their HbA_{1c} value was much or slightly worse, whereas just under one quarter (22%) reported that it was much or slightly better. Some 28% of students also reported that the number of missed insulin doses had increased since they started university. In terms of managing their diabetes at university compared with at home, nearly two-thirds (63%) perceived it to be much or slightly harder, whereas 9.7% reported that it was much or slightly easier.

<H2>Hypoglycaemia and diabetes complications

At university, 287 (52%) students reported having three or more hypoglycaemia episodes per week, with 53 (9.6%) reporting severe hypoglycaemia needing assistance; 86 (16%) had ketoacidosis and 56 (10%) had diabetes-related hospital admissions other than ketoacidosis. Some 68 (12%) had diabetes eye problems and 50 (9.1%) had a urine test showing protein (Table S4). Compared with male students, female students at university were significantly more likely to report a higher HbA_{1c} measurement, more perceived difficulty with diabetes self-care, three or more hypoglycaemia episodes per week and diabetes eye problems (Fig. 1).

Compared with students who kept their home specialist team, students who moved their healthcare team while at university were significantly more likely to report a higher HbA_{1c} level, three or more hypoglycaemia episodes per week, emergency admissions for ketoacidosis and other diabetes-related hospital admissions (Fig. 2). Students who used insulin pumps and those diagnosed while at university were less likely to report a higher

HbA_{1c} measurement (Table S5). No significant differences were found between age/year of study and diabetes problems at university.

<H2>Perceived barriers to optimal self-management

Respondents were asked whether a range of factors had had an impact on their ability to manage their diabetes while at university, rating each from 1 (no impact) to 5 (high impact) (Table S6). The main factors impacting on diabetes self-management were stress, irregular meals, the type of food and drink consumed, lack of structure and routine, and university timetables.

The issues that had the most impact on optimal diabetes self-care (rated 4 or 5) were compared with a range of factors (Table S7). Females were more likely than males to report stress [odds ratio (OR) 4.78, 95% confidence interval (CI) 3.19–7.16], general illness (OR 3.48, 95% CI 2.06–5.87), weight management (OR 3.19, 95% CI 1.99–5.11), depression (OR 2.54, 95% CI 1.49–4.33), less parental supervision (OR 1.88, 95% CI 1.17–3.02), university timetables (OR 1.82, 95% CI 1.23–2.70), lack of routine (OR 1.70, 95% CI 1.15–2.49) and meal irregularity (OR 1.57, 95% CI 1.07–2.30) as having a big impact on their diabetes self-management. Students who had moved away from home to live independently had a bigger concern about a lack of parental supervision (OR 2.66, 95% CI 1.17–6.07) and alcohol (OR 2.78, 95% CI 1.36–5.68). Older students (aged 21) were more likely than younger students (aged 18) to have concerns about food and drink at university (OR 2.43, 95% CI 1.16–5.06), university timetables (OR 2.35, 95% CI 1.07–5.15), stress (OR 2.55, 95% CI 1.23–5.28), sports/exercise (OR 5.32, 95% CI 1.93–14.7), socializing (OR 2.9, 95% CI 1.07–4.92), weight management (OR 7.6, 95% CI 2.16–26.8) and alcohol (OR 2.49, 95% CI 1.12–5.55). Students who were diagnosed at university had concerns about their ability to regulate meal times (OR 1.99, 95% CI 1.14–3.45), food and drink at university (OR 1.81, 95% CI 1.12–2.85) and

exercise/sport (OR 2.02, 95% CI 1.13–3.59) (Table S7). Conversely, they reported better HbA_{1c} (Table S5) and less frequently missed clinic appointments (OR 0.29, 95% CI 0.14–0.62) (Table 3).

Compared with students who kept their home specialist team, those who had moved their healthcare team while at university reported a higher impact of alcohol (OR 1.7, 95% CI 1.15–2.52), sports/exercise (OR 1.65, 95% CI 1.09–2.49) and weight management (OR 1.59, 95% CI 1.04–2.45). Changing healthcare team had a greater impact on students using insulin pumps (OR 2.12, 95% CI 1.25–3.58).

<H2>Information, support and advice

The majority of students had received specific diabetes management information on hypoglycaemia (88%), alcohol (84%), exercise (79%), ketone testing (79%), driving (77%) and sickness advice (69%) (Table S8). By contrast, fewer students had received information specific to young persons' health: 22% received information on sexually transmitted infections or substance use and 25% on mental health/depression; 50% of females received information on contraception and 39% on pregnancy care and diabetes. Specific information related to starting university such as registering with a new GP and accessing university student support services were also received by a majority of students (64.9% and 62%, respectively). However, 50% of students had not received any information on how to access specialist hospital care while at university. Some 45% of respondents also reported inadequate information on changing the timing of insulin with a changing routine, who to contact in an emergency while at university (42%), how to apply for additional financial support (41%), and how to obtain extra support for exams and coursework (40%) (Table S8). While at university the main source for support or advice for students were their parents and family (38% contacted very often or often), followed by their diabetes specialist nurse and

diabetes consultant (22% and 17%, respectively, contacted very often or often), (Table S9).

In total, 91% reported never or rarely contacting university student support services for advice or support. The main method of communication between students and their healthcare team was via telephone (57%) or letter (41%), although 32% were also in touch via email. When asked how they would prefer to communicate with their healthcare team nearly two-thirds (61%) reported that email would be their preferred option, followed by telephone (47%).

<H1>Discussion

In this national survey of university students with Type 1 diabetes, we have shown that the transition from home to university is a challenging and high-risk time for young people with Type 1 diabetes. Dedicated (on the campus) GP-led university medical services were available in only some universities. Students at many universities had to make their own arrangement to register with nearby GPs. A majority of students were under the care of a hospital specialist diabetes team either in their home town or closer to the university. Some 58% of students never contacted their GP for diabetes advice. Advanced technology (insulin pump, continuous glucose monitoring) and specific self-management skills such as carbohydrate counting require specialist skill. It was likely that students were more comfortable discussing these issues directly with their specialist teams. Two-thirds of university students reported that diabetes self-management became more challenging, with almost half experiencing deteriorating glycaemic control and recurrent hypoglycaemia since starting university. Two particular groups of students (females, and those who had moved to a university healthcare provider) were at much higher risk.

Missing clinic appointments is an issue among young people and has been shown in other chronic illnesses, e.g. childhood cancer survivors [25]. Accessibility and lack of flexibility (evening/weekends and or dedicated youth clinics) also contributed to missing appointments.

Female students had a higher hypoglycaemia risk, struggled with erratic meals and routines, and had more issues with general illness, stress, depression and weight management.

Previous research that has looked at gender differences in health outcomes among university students, found that male students reported more health-risk behaviours than female students [26], whereas females reported more weight management issues and total stressors than males [27]. There is little research available specifically on gender differences among university students with diabetes, but research from a wider population suggests this strong gender inequality is also apparent in the health of young people with Type 1 diabetes at university. A recent meta-analysis found that females were at increased relative risk of all-cause mortality, cardiovascular disease, stroke and renal disease [28]. If diabetes is less well controlled among females than males at this stage in their lives, one could argue for more targeted support and awareness of these gender differences at this young age.

Students who moved healthcare provider at university were also at higher risk. Kipps *et al.*

[29] also reported that some students who were away at university but maintained contact with specialist care in their home town had better clinic attendance. The reasons for this were unclear, but may, in part, be related to students who were having problems (actual or perceived) at university actively seeking to move their healthcare provider. There may have been delays in accessing care at university or establishing relationships with a new team.

These findings demonstrate the increased risk for those moving their healthcare provider at university and add to existing research on transitional care. Garvey *et al.* [30] found that those who cited moving/relocation as the most important reason for transition were more likely to report gaps in care exceeding 6 months. However, in our study, there was no clear

evidence of deterioration in access to support in students who had moved healthcare provider.

Indeed, students reported easier access to specialists, diabetes nurses and prescriptions, and better communication when they moved to a service closer to their university.

However, a high percentage of students kept their specialist diabetes care with their home team and half of students had not received any information on how to access specialist diabetes hospital care while at university. In addition, many missed their clinic appointments due to clashes with university schedules or were not able to go back home to see their specialists. Although most students received some diabetes self-management information, targeted and age-appropriate information on contraception, pregnancy, alcohol, mental health, coping strategies to deal with changing routines, university responsibilities and lifestyles, and accessing National Health Service (NHS) services at home and university were commonly lacking.

Students who were newly diagnosed at university experienced more challenges with their university lifestyle (not able to have regular meals, type of food and sports). However, they reported better glycaemic control and missed clinics less frequently than those who were diagnosed prior to attending university. The effect of the honeymoon phase of diabetes, during which patients required very low doses of insulin, might explain their good glycaemia control. It could, however, also be due to their better engagement with healthcare professionals for their diabetes self-management, presumably with less direct parental supervision.

It was surprising to find that older students have more issues with their diabetes management. This age group likely included 'mature students' who had more complicated life commitments with busy timetables, social isolation (less likely to live in university halls) and greater personal responsibility. Older students were also likely to be more concerned with the

financial burden of being a student as well as their future career prospects on leaving university.

Previous research comparing the health behaviours of young adults with and without Type 1 diabetes found that both engaged in risky behaviours, such as alcohol consumption, binge drinking and smoking, and experienced similar levels of psychological well-being [31].

However, having diabetes was associated with lower life satisfaction and lower life purpose over time, compared with peers without diabetes. Comparing first-year university students with chronic illnesses with first-year students who were considered healthy, Herts *et al.* [32] found that students with either physical or mental chronic illness had lower health-related Quality of Life scores and higher loneliness scores than their healthy peers. Yet few first-year students with a chronic illness sought support from their college. Increased university student support may improve knowledge and diabetes self-care, yet only a small number of students in this study sought additional support at university. Students with Type 1 diabetes are required to declare their 'disability' on the UK university application form. This factor likely contributed to the young person not accessing a student support service as they perceived having diabetes was not being disabled. Knowledge of diabetes in student support services varied and was sometimes suboptimal because focus was more on physical disabilities and mental illness, rather than other chronic diseases.

This national study is the first to explore diabetes care for UK university students from the perspective of young people. The study has limitations, particularly selection bias, with only 31% of invited participants returning completed questionnaires. Because of the recruitment method, the characteristics of the non-responders are unknown. We also had a preponderance of female respondents (approximately two-thirds) and this potential bias should be borne in mind when considering the findings, although we did carefully adjust our analyses for

confounding demographic factors. Data were self-reported and we have no independent verification of self-reported HbA_{1c} levels.

In conclusion, our findings suggest that there are significant acute and long-term clinical risks and failures in diabetes care for students attending UK universities. The study findings highlight the need for a national approach to improve the care pathway for these young adults living away from home, with a need to focus on care for female students and those who move healthcare teams. We recommend developing a common national pathway for young people with diabetes who transition to universities. The pathway could include upskilling students' knowledge of their diabetes self-management with a focus on dealing with risky behaviour, along with information on accessing health care, examination and financial support. In addition, a pathway to support healthcare professionals with guidance and information is important for care of this at-risk group. The authors are committed to working collaboratively with leading national diabetes organizations, i.e. Diabetes UK, JDRF and NHS England (diabetes), to establish those pathways. The role of student support services in actively developing peer support groups and support networks across the university could be explored. Very little was known about other chronic disease management in universities, this study may provide platform for unifying other chronic disease management at universities.

Funding sources

This research was funded by Diabetes UK (Grant Reference Number 11/0004360). The views expressed are those of the authors and not necessarily those of the NHS, Diabetes UK or the Department of Health. Diabetes UK were represented on the project steering group and were involved in the questionnaire design and publicising the study via their website. The funder had no involvement in the collection, analysis, and interpretation of data; in the writing of the manuscript; or in the decision to submit the article for publication. The sponsor for the

project was the Norfolk & Norwich University Hospitals NHS Foundation Trust. The sponsor had no involvement in study design; in the collection, analysis, and interpretation of data; in the writing of the report; or in the decision to submit the article for publication.

Competing interests

None declared.

Acknowledgements

The authors would like to acknowledge the contribution of the project steering group members (Dr Carlo Acerini, Dr Fiona Hayes, Professor Fiona Poland, Professor Lee Shepstone, and Katie Simon) who provided advice and support to the research. The authors would also like to thank the participating sites for their assistance with recruiting the students.

Author contributions

KSM and MJS designed the study, interpreted the data, and wrote the report. JK collected, analysed, interpreted the data, and wrote the report. AC analysed the data and edited the report. FS, AH, CP, HM and VD designed the study and edited the report. All authors had full access to all of the data and can take responsibility for the integrity of the data and the accuracy of the data analysis. All authors drafted different sections of the article and critically revised the article for intellectual content. All authors approved the version to be published. KSM acts as the guarantor for the paper. KSM confirms full access to all the data in the study and has final responsibility for the decision to submit for publication.

References

- 1 National Paediatric Diabetes Audit/ Royal College of Paediatrics and Child Health. *National Paediatric Diabetes Audit Report 2013–14 Part 1: Care Processes and Outcomes*. March 2015. Available at <http://www.rcpch.ac.uk/system/files/protected/page/Revised%20Sept%202014%20NPA%20Report%201%20FINAL.pdf> Last accessed 9 January 2017.
- 2 Secrest AM, Becker DJ, Kelsey SF, LaPorte RE, Orchard TJ. All-cause mortality trends in a large population-based cohort with long-standing childhood-onset type 1 diabetes: The Allegheny County type 1 diabetes registry. *Diabetes Care* 2010; **33**: 2573–2579.
- 3 Soedamah-Muthu SS, Fuller JH, Mulnier HE, Raleigh VS, Lawrenson RA, Colhoun HM. All-cause mortality rates in patients with type 1 diabetes mellitus compared with a non-diabetic population from the UK general practice research database, 1992–1999. *Diabetologia* 2006; **49**: 660–666.
- 4 Lind M, Svensson A-M, Kosiborod M, Gudbjörnsdottir S, Pivodic A, Wedel H *et al.* Glycemic control and excess mortality in type 1 diabetes. *N Engl J Med* 2014; **371**: 1972–1982.
- 5 Laing SP, Jones ME, Swerdlow AJ, Burden AC, Gatling W. Psychosocial and socioeconomic risk factors for premature death in young people with type 1 diabetes. *Diabetes Care* 2005; **28**: 1618–1623.
- 6 DCCT Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *N Engl J Med* 1993; **329**: 977–986.
- 7 Morris AD, Boyle DI, McMahon AD, Greene SA, MacDonald TM, Newton RW. Adherence to insulin treatment, glycaemic control, and ketoacidosis in insulin-

dependent diabetes mellitus. The DARTS/MEMO Collaboration. Diabetes Audit and Research in Tayside Scotland. Medicines Monitoring Unit. *Lancet* 1997; **350**: 1505–1510.

8 Thompson CJ, Cummings F, Chalmers J, Newton RW. Abnormal insulin treatment behaviour: a major cause of ketoacidosis in the young adult. *Diabet Med* 1995; **12**: 429–432.

9 de Beaufort BC, Jarosz-Chobot P, Frank M, de Bart J, Deja G. Transition from pediatric to adult diabetes care: smooth or slippery? *Pediatr Diabetes* 2010; **11**: 24–27.

10 Frank M. Factors associated with non-compliance with a medical follow-up regimen after discharge from a paediatric diabetes clinic. *Can J Diabetes Care* 1996; **20**: 13–20.

11 Pacaud D, Yale JF. Exploring a black hole: transition from paediatric to adult care services for youth with diabetes. *Paediatr Child Health* 2005; **10**: 31–34.

12 Maslow GR, Haydon A, McRee AL, Ford CA, Halpern CT. Growing up with a chronic illness: social success, educational/vocational distress. *J Adolesc Health* 2011; **49**: 206–212.

13 Bowen M, Henske J, Potter A. Health care transition in adolescents and young adults with diabetes. *Clinical Diabetes* 2010; **28**: 99–106.

14 NHS Diabetes. *Quality Standard of Transition*, 2013. Available at <https://diabetes-resources-production.s3-eu-west-1.amazonaws.com/diabetes-storage/migration/pdf/Quality%2520standards%2520for%2520transition.pdf> Last accessed

- 15 NHS Diabetes. *Diabetes Transition: Assessment of Current Best Practice and Development of a Future Work Programme to Improve Transition Process For Young People With Diabetes*, August 2012. Available at <http://www.diabetes.org.uk/Documents/nhs-diabetes/paediatrics/diabetes-transition-report.pdf> Last accessed 9 January 2017.
- 16 Hill S, Gingras J, Gucciardi E. The lived experience of Canadian university students with type 1 diabetes mellitus. *Can J Diabetes* 2013; **37**: 237–242.
- 17 Eaton S, Williams R, Bodansky HJ. University students with diabetes. *Diabet Med* 2001; **18**: 940–942.
- 18 Ramchandani N, Cantey-Kiser JM, Alter CA, Brink SJ, Yeager SD, Tamborlane WV *et al.* Self-reported factors that affect glycaemic control in college students with type 1 diabetes. *Diabetes Educ* 2000; **26**: 656–666.
- 19 Wdowik MJ, Kendall PA, Harris MA. College students with diabetes: using focus groups and interviews to determine psychosocial issues and barriers to control. *Diabetes Educ* 1997; **23**: 558–562.
- 20 Balfe, M. Diets and discipline: the narratives of practice of university students with type 1 diabetes. *Sociol Health Ill* 2007; **29**: 136–153.
- 21 Balfe M. Healthcare routines of university students with Type 1 diabetes. *J Adv Nurs* 2009; **65**: 2367–2375.
- 22 Dovey-Pearce G, Hurrell R, May C, Walker C, Doherty Y. Young adults' (16–25 years) suggestions for providing developmentally appropriate diabetes services: a qualitative study. *Health Soc Care Community* 2003; **13**: 409–419.
- 23 Allen D, Cohen D, Robling M, Hood K, Lane C. *The Transition From Paediatric to Adult Diabetes Services: What Works, For Whom and in What Circumstances?* Final report. NIHR Service Delivery and Organisation Programme 2010. Available at

http://www.netscc.ac.uk/hsdr/files/project/SDO_FR_08-1504-107_V01.pdf Last accessed 9 January 2017.

- 24 Department for Business, Innovation & Skills. *Participating Rates in Higher Education: Academic Years 2006/2007–2012/2013* (Provisional), 28 August 2014. Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/347864/HEIPR_PUBLICATION_2012-13.pdf Last accessed.
- 25 Klosky JL, Cash DK, Buscemi J, Lensing S, Garces-Webb DM, Zhao W *et al.* Factors influencing long-term follow-up clinic attendance among survivors of childhood cancer: *J Cancer Surviv* 2008; **2**: 225–232.
- 26 Pengpid S, Peltzer K. Gender differences in health risk behaviour among university students: an international study. *Gender Behav* 2015; **13**: 6576–6583.
- 27 Smith SS, Smith Carter J, Karczewski S, Pivarunas B, Suffoletto S, Munin A. Mediating effects of stress, weight-related issues, and depression on suicidality in college students. *J Am Coll Health* 2015; **63**: 1–12.
- 28 Huxley HR, Peters SAE, Mishra GD, Woodward M. Risk of all-cause mortality and vascular events in women versus men with type 1 diabetes: a systematic review and meta-analysis. *Lancet Diabetes Endocrinol* 2015; **3**: 198–206.
- 29 Kipps S, Bahu T, Ong K, Ackland FM, Brown RS, Fox CT *et al.* Current methods of transfer of young people with Type 1 diabetes to adult services. *Diabet Med* 2002; **19**: 649–654.
- 30 Garvey KC, Finkelstein JA, Laffel LM, Ochoa V, Wolfsdorf JI, Rhodes ET. Transition experiences and health care utilization among young adults with type 1 diabetes. *Patient Prefer Adherence* 2013; **7**: 761–769.

- 31 Palladino DK, Helgeson VS, Reynolds KA, Becker DJ, Siminerio LM, Escobar O. Emerging adults with Type 1 diabetes: a comparison to peers without diabetes. *J Pediatric Psych* 2013; **38**: 506–517.
- 32 Herts KL, Wallis E, Maslow G. College freshmen with chronic illness: a comparison with healthy first-year students. *J Coll Stud Dev* 2014; **55**: 475–480.

FIGURE 1 Risk of poor glycaemic control in female students. Adjusted OR (95% CI) calculated for gender, age, whether living at home or away, whether diagnosed at university or before, whether moved healthcare at university and whether on insulin injection or pump.

FIGURE 2 Risk of poor glycaemic control in with change of healthcare provider. Adjusted OR (95% CI) calculated for gender, age, whether living at home or away, whether diagnosed at university or before, whether moved healthcare at university and whether on insulin injection or pump.

<H1>Supporting Information

Table S1 Diabetes services for students who had moved their healthcare at university compared with home.

Table S2 Number (%) of students who had missed annual tests in the past 12 months.

Table S3 Missed clinics and tests within the last 12 months.

Table S4 Diabetes problems before and during university.

Table S5 Diabetes problems experienced since starting university.

Table S6 Issues affecting the ability to achieve good self-care at university.

Table S7 Issues affecting glycaemic control at university.

Table S8 Number (%) of students who received information before starting university.

Table S9 Frequency of contact for support or advice regarding diabetes at university.

Doc. S1 Student questionnaire.

Table 1 Student demographics

| | Number (%) |
|--------------------------------------|------------|
| Age | |
| 16–18 | 59 (10) |
| 19 | 147 (25) |
| 20 | 134 (23) |
| 21 | 112 (19) |
| 22–27 | 130 (22) |
| Gender | |
| Male | 211 (36.2) |
| Female | 372 (63.8) |
| Diabetes diagnosis | |
| Before university | 505 (86.5) |
| During university | 79 (13.5) |
| Family history of Type 1 diabetes | |
| Close relative with Type 1 diabetes | 103 (17.6) |
| No family history of Type 1 diabetes | 481 (82.4) |
| Year of study | |
| First | 160 (28.3) |
| Second | 167 (29.5) |
| Third | 166 (29.3) |
| Fourth | 60 (10.6) |
| Fifth or over | 13 (2.3) |
| Residence during term time | |
| Living at home | 91 (15.6) |
| Moved away | 474 (81.2) |
| Unknown | 19 (3.3) |
| Diabetes management | |
| Insulin injection | 438 (78.1) |
| Insulin pump therapy | 123 (21.9) |

Specialist healthcare provider at university

| | |
|--------------------------------|------------|
| Moved healthcare to university | 187 (32.0) |
| Healthcare stayed at home | 360 (61.6) |
| Unknown | 37 (6.3) |
| UK region (by university town) | |
| Scotland | 62 (10.6) |
| Wales | 23 (3.9) |
| Northern Ireland | 13 (2.2) |
| East Midlands | 49 (8.4) |
| East of England | 38 (6.5) |
| London | 33 (5.7) |
| North East | 24 (4.1) |
| North West | 62 (10.6) |
| South East | 25 (4.3) |
| South Central | 44 (7.5) |
| South West | 59 (10.1) |
| West Midlands | 36 (6.2) |
| Yorkshire and Humber | 95 (16.3) |
| Unknown | 21 (3.6) |

Table 2 Students contact with diabetes healthcare professionals over the past 12 months

| | Contact with HCP | | | | |
|--------------------------------|------------------|-----------------------|--------------------|------------|---------------|
| | <i>N</i> | Within last 12 months | Over 12 months ago | Never | Not needed/NA |
| Diabetes specialist consultant | 528 | 482 (91.3) | 29 (5.5) | 10 (1.9) | 7 (1.3) |
| Retinal screening specialist | 531 | 470 (88.5) | 40 (7.5) | 17 (3.2) | 4 (0.8) |
| Diabetes Specialist Nurse | 528 | 450 (85.2) | 49 (9.3) | 14 (2.7) | 15 (2.8) |
| GP | 526 | 396 (75.2) | 53 (10.1) | 52 (9.9) | 25 (4.8) |
| Practice nurse | 512 | 334 (65.2) | 42 (8.2) | 85 (16.6) | 51 (10.0) |
| Dietician | 529 | 241 (45.6) | 201 (38.0%) | 59 (11.1) | 28 (5.3) |
| Podiatrist | 521 | 184 (35.3) | 93 (17.9%) | 204 (39.1) | 40 (7.7) |
| Psychologist | 512 | 43 (8.4) | 44 (8.6) | 333 (65.0) | 92 (18.0) |

Data are given as *n* (%). HCP, healthcare provider; NA, not applicable.

Table 3 Student perceptions of glycaemic control and diabetes care since starting university

| | Number (%) |
|---|------------|
| Current HbA _{1c} level | |
| ≤ 58 mmol/mol (≤ 7.5%) | 131 (22.4) |
| 59–75 mmol/mol (7.5–9%) | 165 (28.3) |
| 76–108 mmol/mol (> 9–12%) | 76 (13.0) |
| ≥ 109 mmol/mol (> 12%) | 18 (3.1) |
| Unknown | 94 (33.2) |
| Change in HbA _{1c} level | |
| Much worse | 49 (9.2) |
| Slightly worse | 184 (34.7) |
| Same | 120 (22.6) |
| Slightly better | 88 (16.6) |
| Much better | 30 (5.6) |
| Not sure | 60 (11.3) |
| Changes in the number of missed injections | |
| Increased | 155 (28.0) |
| No change | 345 (62.4) |
| Decreased | 33 (6.0) |
| N/A | 20 (3.6) |
| Changes in diabetes self-management/self-care | |
| Much harder | 89 (16.3) |
| Slightly harder | 255 (46.8) |
| Same | 148 (27.2) |
| Slightly easier | 41 (7.5) |
| Much easier | 12 (2.2) |

