Letter

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Variations in diabetes transition care for children and young people: a national survey

The National Service Framework for Children and Young People highlights the importance of effective transition care for people with chronic conditions such as diabetes [1]. Previous research has reported deficiencies in the transition to adult services, and poorly planned care in the process is associated with increased risk of non-adherence to treatment and loss to follow-up, leading to serious long-term consequences [2,3]. We write to report on the Association of Children's Diabetes Clinicians (ACDC) national survey on current national diabetes transition care in the UK. The aim of the survey was to review current variations in transition care for diabetes which includes all types of diabetes.

All diabetes units caring for children and young people in England, Wales, Scotland and Northern Ireland and those submitting data to the National Paediatric Diabetes Audit during the period 2018–2019 (n = 175) were identified and invited, via email to the clinical leads, to complete a short questionnaire relating to their current diabetes transition care service between January and March 2020 (Appendix S1).

Responses were received from 125 units (72%) from England and Wales, together with five from Scotland and four from Northern Ireland. Variations in transition care service are shown in Table 1 for England and Wales. We have not included the analyses for Scotland and Northern Ireland because of the small numbers of surveys received.

The survey showed that 92% of units have joint transition clinics, defined by outpatient clinics that are led by both the paediatric diabetes and adult diabetes teams. Only 22% had a transition nurse and 46% had a clinical psychologist within the diabetes teams. Only 58% of units provided written information about the transition process and 53% had a structured transition education programme. There was significant variability across diabetes services in terms of how transition is planned. Following transition to adult services, the non-attendance rate significantly deteriorated in every network. In England, 94% of units were receiving best practice tariff, and 60% would consider reducing best practice tariff to support a national 19–25 tariff.

The national mandated best practice tariff for diabetes stipulates that each provider unit must have a clear policy for transition to adult services. This national survey highlights that significant regional variation in diabetes transition care exist despite the best practice tariff for diabetes in England. Variations in care were also reported in the recent National Paediatric Diabetes Audit for 2018/2019, where considerable variation in HbA_{1c} outcomes amongst children and young people with Type 1 diabetes persists between paediatric units, even after case-mix adjustment. Those living in more deprived areas had higher risk of retinopathy and albuminuria, and were found to require more psychological support and had higher HbA_{1c} levels [4].

The transition phase from paediatrics to adult services is a critical period and the results of the survey show that almost every region reported a higher incidence rate of non-attendance following completion of the transition to adult-oriented services. Studies have reported that many young people with long-term conditions such as diabetes may show delays in psychosocial development and also increased prevalence of mental health difficulties, including depression, anxiety and eating disorders compared to their peers and access to mental health and psychological services are crucially important [2]. Access to mental healthcare was highly variable even within paediatric diabetes units, as reported. It is important that provider organizations and commissioners adopt a system-wide approach to ensure that good practice is adopted during the transition phase from children's and adults' services. This includes the provision of psychological services and structured transition education programmes which recognize the changing developmental needs of young people with chronic conditions who transition, as psychological and social difficulties are common among those with long-term conditions [5].

Collaboration between paediatric and adult services is important in supporting young people with their transition process; the process needs to be person-centred and a good rapport between the teams developed to motivate the young person to feel empowered in managing their diabetes effectively. There is an important role for commissioners to fund transition services adequately, in addition to funding children's diabetes services through the current best practice tariff for paediatric diabetes [6].

The NHS long-term plan aims to reduce the variation in the quality of diabetes care services delivered [7]. However, it is clear that inequalities and regional variations in care still exist for children and young people with type 1 diabetes in the UK. A national mandate with adequate funding should be implemented for transition services in diabetes which are person-centred and also tailored for psychosocial development rather than a process of transfer of care. More collaboration with adult services could help us better understand what makes for better transition and service user experiences.

Table 1 Response to the national survey on transition care service in England and Wales

Regions (England and Wales)	Number of units (%) returning survey	Units receiving BPT, %	Number of units (%) with joint transition clinic	Mean age of child at transition fully to adult team, years	Mean age of child at time of being introduced to adult team, years	Mean child age at time that discussion about transition occurs, years	Mean number of joint transition clinics per year by region	Units that would consider reducing BPT to create national 19–25 tariff, %	Mean HbA_{1c}*, mmol/mol (%)	*Median HbA_{1c}, mmol/mol (%)
East Midlands	8/10 (80)	100	100	18.5	16.0	15	4	50	62 (7.8)	59 (7.5)
East of England	12/17 (71)	88	100	18.5	16.5	15	6	42	65 (8.1)	61 (7.7)
London and South East	19/40 (48)	94	100	18.5	16.0	14	8	53	65 (8.1)	62 (7.8)
North East and North Cumbria	8/11 (64)	100	80	18.0	15.0	14	7	80	64 (8.0)	62 (7.8)
North West	21/21 (100)	95	100	18.5	16.0	13.5	8	75	65 (8.1)	63 (7.9)
South Central	13/14 (93)	85	84	18.5	16.5	14	4	60	62 (7.8)	60 (7.6)
South West	9/11 (82)	100	89	18.5	16.5	13.5	4	80	64 (8.0)	61 (7.7)
West Midlands	14/19 (74)	100	70	18.5	16.0	13.5	6	53	65 (8.1)	63 (7.9)
Yorkshire and Humber	13/18 (72)	92	100	18.5	15.5	14.5	5	46	65 (8.1)	62 (7.8)
Wales	8/14 (57)	NA	100	18.0	16.0	15.5	4	N/A	65 (8.1)	62 (7.8)

Regions (England and Wales)	Units with specialist transition nurse, %	Units with a clinical psychologist within teams, %	Units providing written information about transition, %	Units with structured transition education programme, %	Mean 'did-not-attend' rate per year transition clinics 16–19, %	Mean 'did-not-attend' rate per year (in the first year) after final transition to adult services, %
East Midlands	37	50	38	25	7	28
East of England	25	38	43	62	16	22
London and South East	25	56	56	43	22	43
North East and North Cumbria	0	40	40	60	18	29
North West	27	45	61	58	23	32
South Central	8	60	69	61	17	28
South West	22	45	55	66	19	26
West Midlands	22	57	71	42	18	27
Yorkshire and Humber	38	38	76	61	16	26
Wales	15	25	75	45	17	25

BPT, best practice tariff.
*HbA_{1c} data were obtained from the National Paediatric Diabetes Audit 2018/2019.

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References

1 *National Service Framework for Children, Young People and Maternity Services*. London: Department for Education and Skills, Department of Health, 2004.

2 *National Service Framework for Long-term Conditions*. London: Department of Health, 2005.

3 Garvey KC, Foster NC, Agarwal S, DiMeglio LA, Anderson BJ, Corathers SD *et al*. Health Care Transition Preparation and Experiences in a U.S. National Sample of Young Adults With Type 1 Diabetes. *Diabetes Care* 2017; **40**: 317–324.

4 Royal College of Paediatrics and Child Health (2020), National Paediatric Diabetes Audit. RCPCH London. Available at https://www.rcpch.ac.uk/work-we-do/quality-improvement-patient-safety/national-paediatric-diabetes-audit. Last accessed 15 April 2020.

5 Bennett DL, Towns SJ, Steinbeck KS. Smoothing the transition to adult care. *Med J Aust* 2005; **182**: 373–374.

6 Department of Health Transition. *getting it right for young people: Improving the transition of young people with long term conditions from children to adult health services*. London: Department of Health, 2006.

7 Alderwick H, Dixon J. The NHS long term plan. *BMJ* 2019; **364**: l84.

