

Lost in transition? Access to and uptake of adult health services and outcomes for young people with type 1 diabetes in regional New South Wales

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Young people with type 1 diabetes mellitus (T1DM) experience major life transitions in their late teens, around the time they lose access to paediatric health services. Subsequent poor engagement and early loss of contact with adult services has been linked to poorer self-management and outcomes.¹

Adult diabetes services vary across geographical settings, but there has been little study of these different treatment models and their outcomes for transitioning young people. After puberty, microvascular complications increase, and continuing surveillance and optimal diabetes control are essential.²⁻⁴ Regional services are more likely to be general practitioner-led, with varied access to multidisciplinary specialists. Resource and staffing constraints are generally more pronounced in regional areas and there are few transition programs.⁵ Abrupt transfer of young people with T1DM from paediatric services to unfamiliar adult systems without structured preparation does little to encourage engagement.^{1,2,6-8}

Adult diabetes services focus on self-management skills and avoidance of long-term complications, often predominantly targeting the majority population of older people with type 2 diabetes. Young people may not have the organisational skills needed to navigate the health care system,⁹ may experience difficulties,^{1,10} and may fail to connect or quickly lose contact with adult services.² This has been linked with poorer self-management and diabetic control, resulting in early development of complications.⁴ Dedicated transition services have demonstrated improved outcomes.¹¹

Given the increasing incidence of T1DM and high associated mortality,¹² but a lack of information about service models, their uptake and outcomes, we audited the case notes of young people with T1DM in the state capital, a major city and a regional area of New South Wales to compare planned and unplanned service contacts and key diabetes-related indicators.

METHODS

Study hypothesis and objectives

We hypothesised that youths with T1DM in regional areas cannot access an equivalent

ABSTRACT

Objective: To document diabetes health services use and indices of glycaemic management of young people with type 1 diabetes from the time of their first contact with adult services, for those living in regional areas compared with those using city and state capital services, and compared with clinical guideline targets.

Design, setting and subjects: Case note audit of 239 young adults aged 18–28 years with type 1 diabetes accessing five adult diabetes services before 30 June 2008 in three geographical regions of New South Wales: the capital (86), a city (79) and a regional area (74).

Main outcome measures: Planned (routine monitoring) and unplanned (hospital admissions and emergency department attendance for hypoglycaemia or hyperglycaemia) service contacts; recorded measures of glycated haemoglobin (HbA_{1c}), body mass index (BMI), and blood pressure (BP).

Results: Routine preventive service uptake during the first year of contact with adult services was significantly higher in the capital and city. Fewer regional area patients had records of complications assessment and measurements of HbA_{1c}, BMI and BP across all audited years of contact (HbA_{1c}: 73% v 94% city, 97% capital; $P < 0.001$). Across all years, regional area patients had the highest proportion of HbA_{1c} values $> 8.0\%$ (79% v 62% city, 56% capital) and lowest proportion $< 7\%$ (4% v 7%, 22%) (both $P < 0.001$). Fewer young people made unplanned use of acute services for diabetes crisis management in the capital (24% v 49% city, 50% regional area; $P < 0.001$). In the regional area, routine review did not occur reliably even annually, with marked attrition of patients from adult services after the first year of contact.

Conclusion: Inadequate routine specialist care, poor diabetes self-management and frequent use of acute services for crisis management, particularly in regional areas, suggest service redesign is needed to encourage young people's engagement.

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adult model of diabetes care after they lose eligibility to well resourced paediatric diabetes outreach services around the age of 18 years, and that this is associated with poorer diabetes control compared with youths in urban areas. We documented their health service use and indices of management, and compared them with those of cohorts attending city and state capital diabetes services, and with clinical guideline targets.

Study settings and subjects

Services were based in an ambulatory diabetes clinic at Royal Prince Alfred Hospital, Sydney (capital), the Young People's Clinic run by Hunter New England (HNE) Area Diabetes Service in Newcastle (city), and three HNE regional country towns 2–6 hours by road from Newcastle (regional area).

We aimed to audit similar-sized groups in each setting. Inclusion criteria were: a diag-

nosis of T1DM, age of 18–28 years at audit, and contact with an adult service before 30 June 2008. Young people with T1DM in the capital and city were identified through clinic records. In the regional area, additional sources were required, including hospital records, a diabetes register managed by a Division of General Practice, personal records of local GPs and diabetes nurse educators (DNEs), and pathology records.

Data collection

Data were extracted during 2008 from medical files of each individual up to the study end date of 30 June 2008 by three investigators (LP, JSD and a research nurse) using a standard and previously tested form. Data extraction training included duplicate extraction to check reliability. Data spanned 1–10 years depending on the subject's age at 30 June 2008 and date of first contact with adult services. "First year" was defined as the first

12 months after the initial contact with adult services (start date varied for each person). "All years" was defined as time from initial contact until the end date of 30 June 2008. Extracted data included demographics; planned contacts with health care professionals; hospital admissions and emergency department (ED) presentations for events attributable to hypoglycaemia or hyperglycaemia; commencement on subcutaneous insulin infusion pumps; complications assessment for retinopathy, nephropathy and neuropathy; indices of glycaemic management — glycated haemoglobin (HbA_{1c}), blood pressure (BP) and body mass index (BMI) — and episodes of hypoglycaemia requiring assistance. Acute service use where diabetes may have complicated management but was not the main presenting problem (eg, presentations for infection) was excluded.

Glycaemic management findings were compared with World Health Organization recommended targets:

- HbA_{1c}: target, <7%; borderline, 7%–8%; poor, >8%;
- BP: target, systolic <130 mmHg; diastolic <80 mmHg;
- BMI (male): target, <25 kg/m²; borderline, 25–27 kg/m²; poor, >27 kg/m²;
- BMI (female): target, <24 kg/m²; borderline, 24–26 kg/m²; poor, >26 kg/m².¹³

Statistical analysis

Statistical analyses were performed using SPSS for Windows, version 17 (SPSS Inc, Chicago, Ill, USA), with a 5% level of significance. Where family-wise tests indicated significant difference (reported in tables), pair-wise tests with Bonferroni correction ($P < 0.017$) were applied (reported in text). χ^2 or Fisher exact tests were used for categorical data; one-way analysis of variance and Student's *t* test, or Kruskal–Wallis H and Wilcoxon Mann–Whitney tests were used for ordinal and interval data.

Retention of young people in contact with services was calculated in two ways: 1) all study subjects eligible by age in each location at each time point; and 2) all those eligible by age minus those whose subsequent ongoing non-attendance suggested they had permanently relocated (we could not verify whether those who ceased attending had moved away).

Ethical considerations

The audit was part of a broader study for which approval was granted by relevant health services and university human

1 Demographic and clinical characteristics of 239 young people with type 1 diabetes mellitus in selected regional, city and state capital health services in New South Wales, 2008*

	Regional (n = 74)	City (n = 79)	Capital (n = 86)	P
Female	32 (43%)	42 (53%)	40 (47%)	0.554
Aboriginal or Torres Strait Islander	8	1	1	
Age at audit, mean (SD) years	23.1 (2.7)	21.4 (2.0)	23.7 (3.0)	<0.001
Age at first contact with adult services, mean (SD) years	20.1 (2.4)	18.3 (1.4)	21.0 (2.9)	<0.001
Years of adult service use, median (IQR)	2.8 (1.9–4.6)	3.2 (2.1–5.1)	2.2 (1.2–4.9)	0.385
Duration of diabetes, median (IQR) years	12 (7–17)	11 (8–14)	10 (4–14)	0.040
Diagnosed in 2 years before audit	5	0	17	
Diagnosed as adult	11	0	28	
Moved into area as adult	5	0	0	
BMI > 25 kg/m ² in first year [†]	20 (27%)	36 (46%)	41 (48%)	
HbA _{1c} in first year of contact with adult services, median (IQR)	9.4% (7.9%–11.0%)	8.7% (7.7%–10.1%)	8.4% (7.2%–10.2%)	0.032
Insulin pump started in first year	2	5	10	

IQR = interquartile range. BMI = body mass index. HbA_{1c} = glycated haemoglobin. * Figures are number or number (%) of subjects unless otherwise indicated. † For both sexes.

research ethics committees; ethics committee approval was not required for this component. Local Audit Office approvals were granted.

RESULTS

Characteristics of service users

We identified 286 young people aged 18–28 years at 30 June 2008 and audited the records of 240 (84%). We audited records of all eligible subjects in the regional area ($n = 74$), after excluding 27 young people identified in records of paediatric services but for whom no record of contact with adult services was found. To obtain similar-sized groups in each area, we randomly sampled 80 young people from the city clinic database of 108; one patient who died from diabetic ketoacidosis before adult service uptake was audited but excluded from analysis ($n = 79$, 73%). Of the 104 eligible subjects in the capital, we audited all available case notes ($n = 86$, 83%). Across all settings, most patients (200/286, 70%) had attended paediatric services. Demographic and clinical characteristics of the 239 young people included in our analyses are shown in Box 1.

Planned adult service use

Recorded contact with doctors and DNEs differed significantly between groups in both

the first year and all years (Box 2; all $P < 0.001$). For annual complications screening in the first year, seven (9%), 12 (15%) and 38 (44%) of the regional, city and capital subjects, respectively, had all three assessments of retinal, renal and foot health. Proportions having each assessment were significantly higher in the capital ($P < 0.001$) (Box 2). In both the first year and all years, total planned service use was significantly lower in the regional area than in the city and capital ($P < 0.001$). Recorded service contacts in the two urban areas did not differ significantly in either period. Significantly more missed appointments were recorded in the city in the first year: in the regional, city and capital cohorts, 18, 43 and 14 people missed 34, 86 and 18 appointments, respectively. This pattern held across all years (Box 2).

Both methods of examining retention of young people's contact with services demonstrated marked early attrition in the regional cohort, with better longer-term retention of the capital cohort (Box 3). Numbers were small but, for example, 13, 7 and 12 young people appeared to still be resident in regional, city and capital areas, respectively, in Year 7, with 8, 2 and 10 of these young people in contact with their services that year.

Monitoring glycaemic control

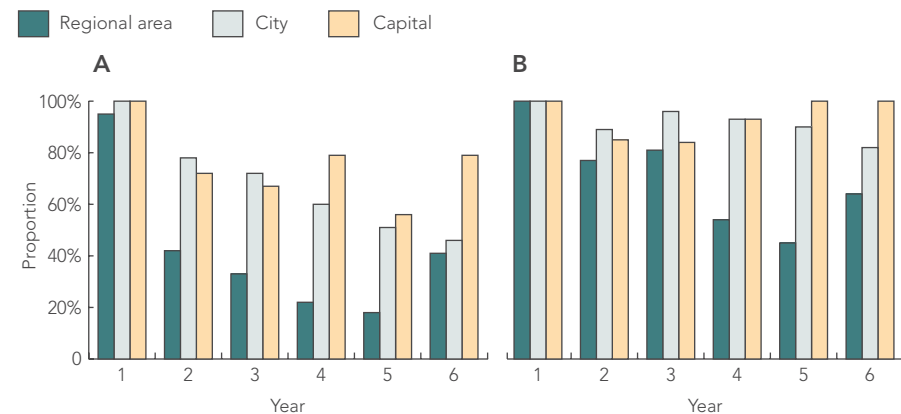
Routine monitoring of indices of glycaemic management (BMI, BP, HbA_{1c}) was recorded

2 Recorded planned health service contacts of 239 young people with type 1 diabetes mellitus a) during their first year and b) during all years of contact with adult health services*

Recorded service contacts	Regional (n=74)	City (n=79)	Capital (n=86)	P
a) First year				
Consulted a doctor	28 (38%)	77 (97%)	77 (90%)	<0.001
Consultations with doctor, median (IQR)	0 (0–1)	3 (1–4)	2 (1–3)	<0.001
Consulted a DNE	55 (74%)	77 (97%)	81 (94%)	<0.001
Consultations with DNE, median (IQR)	1 (0–3)	3 (2–4)	4 (1–7)	<0.001
Consulted a dietitian	44 (59%)	55 (70%)	55 (64%)	0.420
Consultations with dietitian, median (IQR)	1 (0–1)	1 (0–2)	1 (0–2)	0.213
Retinal assessment	20 (27%)	17 (22%)	49 (57%)	<0.001
Renal function assessment	30 (41%)	21 (27%)	50 (58%)	<0.001
Foot check	12 (16%)	22 (28%)	43 (50%)	<0.001
Any planned service contacts,† median (IQR)	4 (2–8)	9 (6–12)	10 (5–15)	<0.001
Missed one or more appointments	18 (24%)	43 (54%)	14 (16%)	<0.001
b) All years (range, 1–10 years)				
Consulted a doctor	38 (51%)	78 (99%)	80 (93%)	<0.001
Consultations with doctor, median (IQR)	1 (0–2)	5 (3–10)	3 (2–6)	<0.001
Consulted a DNE	60 (81%)	78 (99%)	81 (94%)	<0.001
Consultations with DNE, median (IQR)	2 (1–4)	5 (3–11)	6 (3–16)	<0.001
Consulted a dietitian	54 (73%)	64 (81%)	65 (76%)	0.484
Consultations with dietitian, median (IQR)	1 (0–2)	2 (1–3)	1 (1–3)	0.046
Retinal assessment	23 (31%)	42 (53%)	58 (67%)	<0.001
Renal function assessment	39 (53%)	49 (62%)	60 (70%)	<0.001
Foot check	17 (23%)	50 (63%)	50 (58%)	<0.001
Any planned service contacts,† median (IQR)	7 (3–12)	17 (9–33)	16 (9–34)	<0.001
Missed one or more appointments	30 (41%)	69 (87%)	32 (37%)	<0.001

IQR = interquartile range. DNE = diabetes nurse educator. * Figures are number or number (%) of subjects unless otherwise indicated. † Consultations with doctor, DNE, dietitian, podiatrist or ophthalmologist. ◆

3 Proportions of young people contacting adult health services at least once a year in each of the first 6 years of contact, estimated in two different ways



A: The total eligible according to their age at each time point. B: Those eligible by age but excluding those thought to have moved away from the area. ◆

significantly less frequently for regional than urban young people, in both the first year and all years ($P < 0.001$) (Box 4). At least

one HbA_{1c} reading was recorded for 199 of the 239 service users (83%) in their first year of contact with an adult service, with

these individuals having between one and seven measurements. In the first year, 20 (27%), 68 (86%) and 64 (74%) of the regional, city and capital subjects, respectively, had all three measurements of HbA_{1c}, BP and BMI recorded.

Unplanned acute service use for hypoglycaemia or hyperglycaemia

Overall, there was significantly less unplanned service use for hypoglycaemia or hyperglycaemia by the capital cohort compared with the regional cohort in the first year ($P = 0.010$) and compared with both the regional ($P = 0.002$) and city ($P < 0.001$) cohorts in all years (Box 4). However, across all years, there were significantly more ED presentations in the city compared with the regional area ($P = 0.014$) or the capital ($P < 0.001$), with significantly fewer episodes of hospital admission in the capital than elsewhere ($P = 0.011$ v city, $P = 0.001$ v regional area).

Indices of glycaemic management

Median HbA_{1c} values in the first year were 9.4%, 8.7% and 8.4% in the regional area, city and capital, respectively (Box 1). Comparing values with targets recommended by the World Health Organization,¹³ all areas had substantial numbers of recorded HbA_{1c} values indicative of borderline or poor glycaemic control, but there was a consistent pattern in the first year and all years of better HbA_{1c} values among the capital cohort compared with generally poorer control among young people in the regional area (Box 5). Of a total of 467 HbA_{1c} measurements retrieved for all three cohorts for the first year, 62 (13%) were <7%, 111 (24%) were 7%–8%, and 294 (63%) were >8%. A similar pattern was seen with the 1202 measurements retrieved across all years, of which 161 (13%) were <7%, 307 (26%) were 7%–8%, and 734 (61%) were >8%. In all years, the regional cohort had significantly more recorded values >8% and fewer <7% than the capital cohort (both $P < 0.001$). Substantial proportions of all cohorts nevertheless experienced at least one hypoglycaemic event requiring assistance (Box 4).

DISCUSSION

This study is the first in Australia to examine disparate facets of care for young people with T1DM beyond the age of eligibility to use paediatric services. Different service configurations and resources in the three geographical settings were reflected in clear

4 Recorded glycaemic management and unplanned acute service use for hypoglycaemia or hyperglycaemia of 239 young people with type 1 diabetes mellitus a) during their first year and b) during all years of contact with adult health services*

	Regional (n=74)	City (n=79)	Capital (n=86)	P
a) First year				
HbA _{1c} documented	46 (62%)	72 (91%)	81 (94%)	<0.001
HbA _{1c} assessments, median (IQR)	1 (0–2)	3 (1–4)	2 (1–3)	<0.001
Blood pressure (BP) documented	31 (42%)	73 (92%)	70 (81%)	<0.001
BP assessments, median (IQR)	0 (0–1)	3 (1–4)	1 (1–2)	<0.001
BMI documented	34 (46%)	70 (89%)	77 (90%)	<0.001
BMI assessments, median (IQR)	0 (0–1)	3 (1–4)	2 (1–4)	<0.001
Hypoglycaemic episodes requiring assistance	8 (11%)	12 (15%)	14 (16%)	0.285
Admitted to hospital [†]	26 (35%)	18 (23%)	11 (13%)	0.027
Hospital admission episodes [†]	43	32	11	0.001
Attended ED [†]	4 (5%)	11 (14%)	6 (7%)	0.458
ED attendance episodes [†]	5	19	8	0.122
Total unplanned service attendees [‡]	28 (38%)	26 (33%)	15 (17%)	0.046
Total unplanned service use episodes [‡]	48	51	19	0.007
b) All years (range, 1–10 years)				
HbA _{1c} documented	54 (73%)	74 (94%)	83 (97%)	<0.001
HbA _{1c} assessments, median (IQR)	1 (0–3)	5 (2–10)	4 (2–7)	<0.001
BP documented	39 (53%)	75 (95%)	75 (87%)	<0.001
BP assessments, median (IQR)	1 (0–1)	5 (3–10)	3 (1–6)	<0.001
BMI documented	42 (57%)	72 (91%)	79 (92%)	<0.001
BMI assessments, median (IQR)	1(0–2)	5 (2–11)	3 (2–7)	<0.001
Hypoglycaemic episodes requiring assistance	14 (19%)	17 (22%)	21 (24%)	0.449
Admitted to hospital [†]	32 (43%)	29 (37%)	17 (20%)	<0.001
Hospital admission episodes [†]	82	79	19	0.004
Attended ED [†]	10 (14%)	24 (30%)	7 (8%)	0.010
ED attendance episodes [†]	29	56	11	<0.001
Total unplanned service attendees [‡]	37 (50%)	39 (49%)	21 (24%)	<0.001
Total unplanned service use episodes [‡]	111	135	30	<0.001

HbA_{1c} = glycated haemoglobin. IQR = interquartile range. BMI = body mass index. ED = emergency department. * Figures are number or number (%) of subjects unless otherwise indicated. † For hypoglycaemia or hyperglycaemia. ‡ All hospital admissions and ED attendance for hypoglycaemia or hyperglycaemia. ◆

patterns across the audited period. There was limited access to adult services and contact with specialist staff in the regional area, with many young people not receiving any reviews each year. Acute hospital services were used for crisis management in all settings, but much less frequently in the capital. Despite elevated HbA_{1c} values in all areas, many young people experienced episodes of severe hypoglycaemia. Service practices limited our ability to identify loss to contact between paediatric and adult services, but attrition from adult services appeared to be around 50% by 5 years, and

was significantly greater in the regional area.

Similar disparities in care for rural residents have been reported from the United States.¹⁴ Many health services report resource constraints, and the particular difficulties of regional and rural areas — widely dispersed populations and health centres, limited transport and greater difficulty attracting specialist personnel — are well known. The urban services we studied had larger target populations, more specialist staff, and clinics in the public health care system capable of undertaking all or most

complications screening. By contrast, as previously reported,^{5,15} regional diabetes services had fewer resources, heavier reliance on GPs and limited access to specialists. Distance and geographical socioeconomic factors have been acknowledged as major issues in access to diabetes services, and strong predictors of attendance.²

Our findings contrast with a report of paediatric patients in NSW, which found no difference in the metabolic control of rural and urban children (median HbA_{1c}, 8.2% in both).¹⁶ Median HbA_{1c} values in our three cohorts, particularly in the regional area, were substantially higher, highlighting the challenges of chronic disease self-management in early adulthood¹ and the deterioration in control that occurs when young people leave the comprehensive paediatric rural outreach clinics.

Overall, we found that recorded routine service delivery fell short of that advocated in national and international guidance.^{4,13,17} National recommendations stipulate no less than 3–4 reviews per year for adolescents;⁴ adult T1DM guidelines have not been established, but we found that not even annual review was always achieved in the regional area. Potentially avoidable acute service use for crisis management represents opportunity costs that could be invested to redesign services to better meet the needs of this group.

All three settings showed evidence of poor glycaemic control. The capital service had the greatest proportion of recently diagnosed users, whose “honeymoon phase” values may have contributed to greater numbers of HbA_{1c} readings within target ranges. However, our findings are comparable with other studies of adolescents and young adults from Australia and elsewhere.^{3,11,18} The risk of progression to severe diabetic retinopathy in the Diabetes Control and Complications Trial follow-up study was reduced by 78% in the group originally treated intensively, demonstrating the longer-term value of good control.¹⁹ Services should consider ways to make access easier for young people and to maintain contact, as this provides the best chance of achieving better control, given that deterioration in diabetes indices around this age seems common.¹ The poor retention rates demonstrated in our study and others indicate this is not occurring.^{2,7,20}

Our findings suggest a likely mix of developmental characteristics of youth and system failures of current service models to engage, retain and support these young people. The Newcastle and Sydney services

5 Comparison of young people's glycaemic management audit data from the first year and all years of contact with adult health services (to 30 June 2008) with World Health Organization recommended targets^{13*}

	Period	Regional	City	Capital	P
Blood pressure (mmHg)					
< 130/80 [†]	First year	34 (81%)	83 (40%)	106 (80%)	<0.001
	All years	53 (74%)	245 (47%)	342 (84%)	<0.001
≥ 130/80	First year	8 (19%)	124 (60%)	26 (20%)	<0.001
	All years	19 (26%)	281 (53%)	66 (16%)	<0.001
Body mass index (kg/m²)					
< 25 (men), < 24 (women) [†]	First year	26 (43%)	106 (48%)	117 (54%)	<0.001
	All years	43 (44%)	262 (47%)	215 (45%)	<0.001
25–27 (men), 24–26 (women)	First year	11 (18%)	54 (24%)	43 (20%)	0.022
	All years	16 (16%)	163 (29%)	81 (17%)	0.001
> 27 (men), > 26 (women)	First year	24 (39%)	61 (28%)	55 (26%)	0.156
	All years	39 (40%)	135 (24%)	178 (38%)	0.060
HbA_{1c}					
< 7% [†]	First year	6 (8%)	18 (9%)	38 (20%)	0.002
	All years	6 (4%)	39 (7%)	116 (22%)	<0.001
7%–8%	First year	14 (18%)	53 (27%)	44 (23%)	0.005
	All years	24 (17%)	168 (31%)	115 (22%)	<0.001
> 8%	First year	58 (74%)	129 (65%)	107 (57%)	0.001
	All years	112 (79%)	332 (62%)	290 (56%)	<0.001

HbA_{1c} = glycated haemoglobin. * Figures are number (%) of total recorded values for each index of glycaemic management. † WHO recommended target. ◆

included specialised clinics for young adults, and all centres stated they were proactive in following up patients who failed to attend. However, neither strategy appears to have solved the retention problem. More important may be the manner in which clinics are run. Transitional services that address young people's priorities and life-style requirements can sustain users' engagement with services, lower drop-out rates, improve uptake of educative and preventive services,^{21,22} and improve diabetic control.^{8,11} Innovative examples such as the Maestro Project in Canada,²² which used a case management approach to service coordination and social educational networking, have shown this is achievable for young people in regional areas.

Our study has some limitations. The sample sizes of our groups were small, and a documentation audit only shows what was recorded and may not reflect user and stakeholder experiences. Any service redesign would need to take into account what service users say would be useful to help them achieve better long-term diabetes control. Auditing was particularly problematic where regional service records were fragmented and hard to access, and in general practice.

Although our study found key indices of diabetes management were poor in all settings, there was substantially lower access to and uptake of routine monitoring and preventive services in regional compared with urban settings. In regional areas, adolescents transfer from multidisciplinary "one-stop shop" paediatric outreach clinics to very differently configured adult diabetes services, and attrition is high. Coaching is needed to prepare young people for these changes, as well as improvements in service coordination and appointment of case managers to help them navigate adult care. Specialist diabetes health care professionals are in short supply, and GPs need to be supported to develop T1DM expertise. Our findings do not support continuance of the status quo and suggest service reconfiguration is needed, to ensure equity of access for the small but increasing numbers of young people with T1DM in regional Australia and to achieve acceptable outcomes for all Australians with T1DM.

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COMPETING INTERESTS

None identified.

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