

# 'The Lost Tribe': a study of transition care in Lothian

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## Abstract

**Aims:** The management of a chronic disease is challenging during the transition to adulthood. This study examined the follow-up status, glycated haemoglobin (HbA<sub>1c</sub>) and complication rates in 18–23 year olds with type 1 diabetes mellitus in the Royal Infirmary Edinburgh (RIE) and Roodlands Hospital, Haddington (RHH).

**Methods:** Subjects were identified by date of birth using Scottish Care Information - Diabetes Collaboration. Follow-up status, median HbA<sub>1c</sub>, albumin:creatinine ratio, and complications were recorded for the last year of adolescent follow-up and years 1–5 from transition.

**Results:** 100 subjects were studied; 77 from RIE (39 female) and 23 from RHH (7 female). RIE and RHH respectively lost 20.8% and 34.8% to follow-up. Median HbA<sub>1c</sub> at RIE fell from 85 mmol/mol to 77 mmol/mol by year 4 and, at RHH, from 79 mmol/mol to 65 mmol/mol by year 4. These HbA<sub>1c</sub> changes were potentially driven by patients lost to follow-up, who had higher baseline HbA<sub>1c</sub> (RIE: 91 mmol/mol; RHH: 90 mmol/mol). 12 patients had microalbuminuria after transition to adult care. Retinopathy was recorded in 36% at year 5. There were 0.23 diabetes-related hospital admissions per subject per year and no recorded deaths.

**Conclusions:** High losses to follow-up are worrying. Those with higher HbA<sub>1c</sub> appear most at risk. Complication and admission rates are high, underlining the importance of engagement with patients during transition.

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**Key words:** type 1 diabetes, transition, best clinical care, complications, adolescence

## Introduction

Adolescence is a period of physical, emotional and social change. Type 1 diabetes is commonly diagnosed in childhood<sup>1</sup> so that those affected face adolescence with the added stress of managing a chronic condition. The risk of poor control, disengage-

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## Abbreviations and acronyms

ACR	albumin:creatinine ratio
DKA	diabetic ketoacidosis
DSN	diabetes specialist nurse
GP	general practitioner
HbA <sub>1c</sub>	glycated haemoglobin
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
RCPE	Royal College of Physicians of Edinburgh
RHH	Roodlands Hospital Haddington
RIE	Royal Infirmary of Edinburgh
SCI-DC	Scottish Care Information - Diabetes Collaboration
SIGN	Scottish Intercollegiate Guidelines Network
SSGCDY	Scottish Study Group for the Care of Diabetes in Young people

ment with services and developing complications is greater at this time and services must provide appropriate support.<sup>2,3</sup>

The differences in approach between paediatric and adult services can be problematic. While growing up and taking on responsibility is a gradual process, the change from family-focused paediatric care to self management in the adult clinic can be more sudden. Most centres offer transition clinics to help navigate this change.

Both NICE and SIGN advise a structured transition with involvement of adult and paediatric services.<sup>4,5</sup> The RCPE "Think Transition" document highlights issues with chronic disease management during transition.<sup>6</sup> The SSGCDY surveyed current transition services in NHS boards across Scotland (Table 1).<sup>6</sup>

In Lothian, the diabetes transition clinics are run jointly by paediatric and adult teams. Clinics offer 3-monthly follow-up as standard, with 6-weekly follow-up when needed. A dedicated DSN is attached to the clinics and appointments are offered repeatedly despite non-attendance. Adult services differ between sites. The RIE runs five diabetes clinics per week and treats over 1500 adults with type 1 diabetes, with standard follow-up appointments every 6–7 months at the time of this study. RHH in East Lothian holds a diabetes clinic twice weekly, with 230 adults with type 1 diabetes, and can accommodate 4-monthly follow-up appointments if necessary. No further routine appointments are sent after two consecutive missed clinics, but the patient's GP is informed and the patient is also usually written to directly to encourage re-engagement.

NHS Lothian follows accepted guidance during adolescence, but there is currently no dedicated service for those who have recently transitioned from the adolescent clinic. The transition from childhood to young adulthood does not cease at the age of

**Table 1** Transition services across Scotland for adolescents with type 1 diabetes<sup>6</sup>

	Numbers		Specialised transfer			Age Transfer	Guidelines			Age band	Type of clinics			Upper age
	Paediatric clinic	Transfers	Yes/No	Across HB	Similar		Available	Local	Nat.		Transition	No appoint.	Joint clinic	
<b>Ayrshire &amp; Arran*</b>	100–200	10–20	Y	Y	N	16–18	N	N	N	N	Y	>4	Y	>18
<b>Fife</b>	100–200	10–20	Y	Y	Y	12–16	N	N	N	N	Y	>4	N	>20
<b>Forth Valley</b>	100–200	10–20	Y	Y	Y	12–16	N	N	N	N	Y	>4	Y	>18
<b>Glasgow</b>	>200	>20	Y	N	N	12–16	N	N	N	Y	Y	1	N	
<b>Grampian**</b>	100–200	10–20	Y	Y	N	12–16	N	N	N	N	Y	>4	N	>20
<b>Highland***</b>	100–200	10–20	Y	Y	N	16–18	N	N	N	Y	N		N	>18
<b>Lanarkshire</b>	>200	10–20	Y	N	N	16–18	N	N	N	N	N		Y	>18
<b>Lothian</b>	>200	>20	Y	Y	N	12–16	Y	Y	N	Y	Y		Y	>18
<b>Tayside</b>	>200	10–20	Y	Y	N	>18	Y	Y	N	Y	Y	1	N	>18

\* Royal Alexandra Hospital: Different arrangements for Inverclyde (5–10 transfers per year, no joint clinics) and Oban & Lochgilphead (>5 transfers per year), no joint clinics

\*\* Orkney and Shetland: No specific arrangements (>5 transfers per year at 18 years age)

\*\*\* Western Isles: No specific arrangements (>5 transfers per year)

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18 and the risk of disengagement continues beyond this age. We wished to study the follow-up and outcome data from patients in the first few years after transition to assess whether this should be a focus for future service development.

## Aims

The primary aim of this study of transition was to examine the following outcomes: the proportion of patients under active follow-up; HbA<sub>1c</sub>; the prevalence of microvascular complications; and the number of hospital admissions. Comparing the above parameters between the RIE and RHH clinics, given the different frequency of follow-up in their respective adult clinics, was a secondary study aim.

We also set out to study the following outcomes in those who became pregnant during the study period: booking HbA<sub>1c</sub>; pregnancy outcome; documentation of contraception advice; pre-conception folic acid treatment.

## Methods

This was a retrospective cohort study conducted in 2012, using participants identified from the SCI-DC network at RIE and RHH. Inclusion criteria were type 1 diabetes and date of birth between August 1 1989 and August 1 1994. Participants with less than 12 months of adolescent clinic data and those who had not yet attended an adult clinic were excluded from the study. Follow-up status was recorded as “current” if the last clinic appointment had been kept; “lost to follow-up” if non-attendance had continued for ≥12 months and two appointments were missed; and “moved away” if this reason was recorded for non-attendance.

Median HbA<sub>1c</sub> was calculated for the final year of adolescent clinic attendance and annually thereafter for up to 5 years of adult clinic follow-up. ACR and retinopathy screening results were recorded pre- and post-transition, using the most recent result. Hospital admission and mortality data were obtained for all patients, regardless of follow-up status, from hospital com-

puterised records (TRAKCare®). The reason for admission was obtained from discharge letters.

Pregnancy data collected from SCI-DC and TRAKCare® included booking HbA<sub>1c</sub>, folic acid prescription and outcome of pregnancy. A review of previous letters was undertaken to examine documentation of pre-conception advice.

## Results

Although 205 patients met age criteria, only 100 (77 from RIE; 23 from RHH) were eligible for inclusion. Follow-up data were available for between 1 and 5 years at both sites with mean follow-up of 2.5 years at RIE and 2.6 years at RHH.

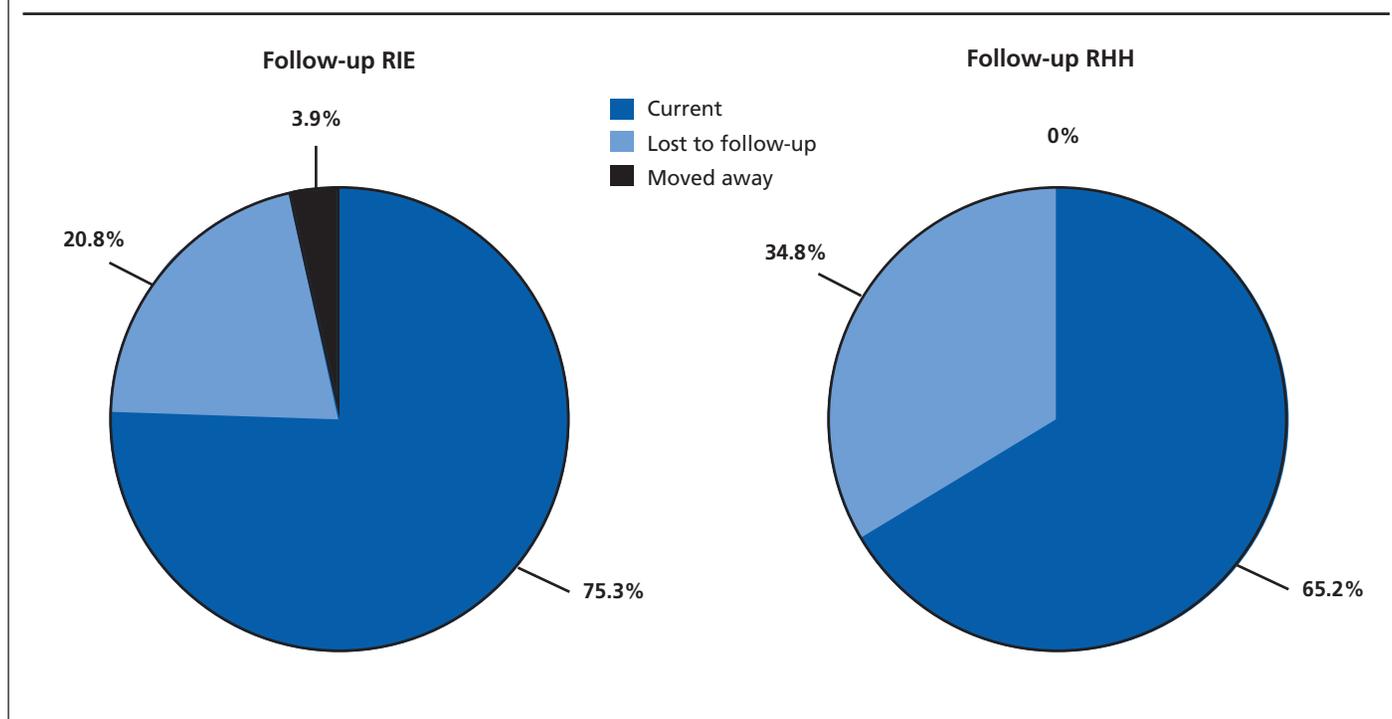
Of the 89 excluded RIE patients, 64% had moved to Edinburgh from outside Lothian and 23% were diagnosed in adulthood, so that no adolescent data were available. For 8% seen at both RIE and RHH, data were recorded at the site of the most recent clinic attended. A further 2% had not yet attended adult services, 2% never attended clinic and 1% remained in adolescent care due to complex needs. Of the 16 excluded RHH patients, 38% were diagnosed at age >18 years, 19% were still in transition, 6% had moved from elsewhere and another 6% remained in adolescent care due to complex needs. The final 31% were analysed in the RIE group due to contact with both sites.

## Follow-up status

At RIE, 20.8% were lost to follow-up with 3.9% recorded as “moved away”. RHH had no patients moving away and 34.8% were lost to follow-up (Figure 1).

## Glycaemic control

Median (range) HbA<sub>1c</sub> at RIE fell from 85 (52–138) mmol/mol in the adolescent clinic to 77 (48–121) mmol/mol at year 4 of adult follow-up (Table 2). Similarly, RHH patients had a median (range) HbA<sub>1c</sub> of 79 (58–111) mmol/mol in the adolescent clinic which

**Figure 1.** Follow-up status at Royal Infirmary Edinburgh (RIE) and Roodlands Hospital Haddington (RHH)**Table 2** Glycaemic control from adolescent to adult clinic, Royal Infirmary Edinburgh

All subjects	Adolescent (n=77)	Year 1 (n=69)	Year 2 (n=47)	Year 3 (n=23)	Year 4 (n=18)	Year 5 (n=1)
Median (range) HbA <sub>1c</sub> (mmol/mol)	85 (52–138)	83 (53–138)	80 (50–121)	73 (62–103)	77 (48–121)	68
<b>Current patients</b>	<b>(n=55)</b>	<b>(n=50)</b>	<b>(n=31)</b>	<b>(n=20)</b>	<b>(n=16)</b>	<b>(n=1)</b>
Median (range) HbA <sub>1c</sub> (mmol/mol)	83 (52–138)	83 (55–138)	79 (64–121)	72 (62–103)	72 (48–121)	68
<b>Lost to follow-up</b>	<b>(n=22)</b>	<b>(n=19)</b>	<b>(n=17)</b>	<b>(n=3)</b>	<b>(n=2)</b>	<b>(n=0)</b>
Median (range) HbA <sub>1c</sub> (mmol/mol)	91 (54–119)	91 (53–132)	93 (50–119)	76 (76–98)	85 (78–92)	No data

**Table 3** Glycaemic control from adolescent to adult clinic, Roodlands Hospital Haddington

All subjects	Adolescent (n=23)	Year 1 (n=18)	Year 2 (n=13)	Year 3 (n=9)	Year 4 (n=6)	Year 5 (n=3)
Median (range) HbA <sub>1c</sub> (mmol/mol)	79 (58–111)	78 (50–102)	77 (55–130)	68 (64–97)	65 (58–73)	81 (52–92)
<b>Current patients</b>	<b>(n=14)</b>	<b>(n=13)</b>	<b>(n=9)</b>	<b>(n=7)</b>	<b>(n=6)</b>	<b>(n=3)</b>
Median (range) HbA <sub>1c</sub> (mmol/mol)	75 (58–111)	73 (50–102)	69 (55–107)	68 (64–97)	65 (58–73)	81 (52–91)
<b>Lost to follow-up</b>	<b>(n=9)</b>	<b>(n=5)</b>	<b>(n=4)</b>	<b>(n=2)</b>	<b>(n=0)</b>	<b>(n=0)</b>
Median (range) HbA <sub>1c</sub> (mmol/mol)	90 (68–101)	91 (78–100)	101 (78–130)	75 (65–85)	No data	No data

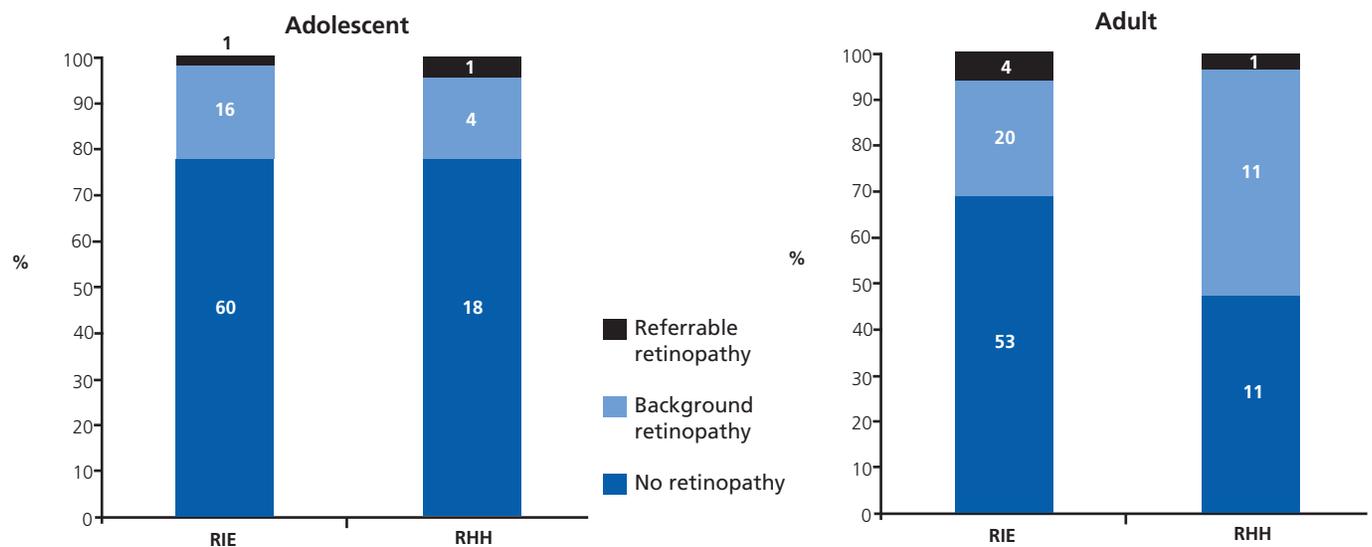
fell to 65 (58–73) mmol/mol at year 4 (Table 3).

Median HbA<sub>1c</sub> fell from 83 mmol/mol to 68 mmol/mol at year 5 in those remaining under follow-up at RIE. Patients who were lost to follow-up had higher baseline median HbA<sub>1c</sub> (91 mmol/mol), falling to 85 mmol/mol at year 4. In a similar analysis at RHH, current patients' median HbA<sub>1c</sub> fell from 75 mmol/mol to 65 mmol/mol at year 4. Those lost to follow-up had a median

baseline HbA<sub>1c</sub> of 90 mmol/mol which peaked at 101 mmol/mol at year 3. Numbers fell each year from adolescence and no data were available for those lost to follow-up at years 4 and 5 at RHH, and year 5 at RIE.

#### Microvascular complications

Microalbuminuria was recorded in 11 (14.2%) adolescents at RIE

**Figure 2.** Retinopathy outcomes in patients at Royal Infirmary Edinburgh (RIE) and Roodlands Hospital Haddington (RHH)

Values are total number of patients in each group

and one (4.3%) at RHH. After transition, nine (11.7%) RIE patients and two more RHH patients had persistent microalbuminuria. Retinopathy was established in 22% of adolescents at both sites and 36% had changes identified on screening in the first 5 years after transition (Figure 2).

### Hospital admissions

There were 55 diabetes-related admissions involving 23 patients in the RIE cohort; 56% of admissions were for DKA and 25% were for hyperglycaemia and gastrointestinal upset. One patient was admitted with a Charcot foot and the remainder presented with hypoglycaemia. About one-fifth (21.8%) of admissions involved patients who were lost to follow-up. Four admissions among RHH patients were all for DKA; three involved patients not attending clinic. No deaths were recorded. Overall there were 0.23 diabetes-related admissions per subject per year.

### Pregnancy

Eight patients across either site became pregnant and delivered healthy babies, but two of these patients also had a miscarriage. Pre-conception advice was documented in 62.5% of cases but only one patient took pre-conceptual folic acid. Median (range) booking HbA<sub>1c</sub> was 89 (50–111) mmol/mol.

### Discussion

The results of this study give a stark reminder of the risks faced by young adults with type 1 diabetes. Worryingly, a fifth of RIE patients and over a third of RHH patients were not under active follow-up just 5 years after transition. Median HbA<sub>1c</sub> appeared to improve each year after transition; however, analysis of HbA<sub>1c</sub> according to follow-up status revealed a different pattern: those lost to follow-up had a higher baseline HbA<sub>1c</sub>, which remained



### Key message

- Young adults with type 1 diabetes are at risk of early complications and loss to follow-up after moving from adolescent to adult care

poor, while HbA<sub>1c</sub> gradually improved at both sites in those under regular review. A number of patients were excluded because of incomplete data, largely associated with young adults starting higher education or employment at RIE (there was less movement of patients at RHH, consistent with its more rural setting).

Microvascular complications were prevalent at a young age, suggesting that loss to follow-up may contribute to significant morbidity in early adulthood. Hospital admissions were significant with a high proportion of DKA. Admissions in those lost to follow-up should provide an opportunity to re-engage with the service. It is worrying that one patient developed a Charcot foot at this stage.

Pre-conception advice was only documented in 62.5% of pregnancies. Adherence to folic acid supplementation was poor and median booking HbA<sub>1c</sub> was high, suggesting that these pregnancies were probably unplanned. Pregnancy advice needs to be consistently delivered to all females of childbearing age with type 1 diabetes.

### Conclusions

A significant proportion of young people with type 1 diabetes

lose contact with health services at a time when control may deteriorate and complications may develop. There are multiple complex reasons for this disengagement, but one factor may be the change in management style from paediatric to adult care at a time when patients may not be ready to self-care independently.

In Lothian, we are examining options to increase engagement with the service, including use of online resources and opportunistic reviews by our in-patient diabetes and liaison psychiatry teams during acute admissions. Emphasis must be given to advice on contraception. Furthermore, specific clinics are being established for patients who have recently moved from the adolescent clinic with input from a dedicated DSN for young adults. We will re-audit this service in 2–3 years.

**Conflict of interest** None

**Funding** None

## References

1. Scottish Diabetes Survey Monitoring Group. Scottish Diabetes Survey 2012. <http://www.diabetesinscotland.org.uk/Publications>
2. Peters A, Laffel L. Diabetes care for emerging adults: Recommendations for transition from paediatric to adult diabetes care systems. American Diabetes Association Transitions Working Group. *Diabetes Care* 2011; **34**:2477-85. <http://dx.doi.org/10.2337/dc11-1723>
3. Crawley R, Wolfe I, Lock K *et al*. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child* 2011; **96**:548-53. <http://dx.doi.org/10.1136/adc.2010.202473>
4. National Institute for Health and Care Excellence. Clinical Guideline 15. Type 1 diabetes: diagnosis and management of type 1 diabetes in children, young people and adults. July 2004, updated December 2014
5. Scottish Intercollegiate Guidelines Network. Section 5.3.7. Guideline 116: Management of Diabetes. March 2010
6. The Royal College of Physicians of Edinburgh Transition Steering Group. Think Transition: Developing the essential link between paediatric and adult care. Royal College of Physicians 2008. <http://www.cen.scot.nhs.uk/files/160-think-transition-edinburgh.pdf>

# Casting Course for the Diabetic Foot 2015



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- The course aims to standardise care and improve clinical outcomes for patients presenting with a neuropathic diabetic foot complications
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Course cost is £425.00  
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