RESEARCH

We mind your step: understanding and preventing drop-out in the transfer from paediatric to adult tertiary endocrine healthcare

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This paper forms part of a special series collated by the European Reference Network on Rare Endocrine Conditions, celebrating its fifth year. The guest editors for this section are Violeta Iotova, Jérôme Berherat, and George Mastorakos.

Abstract

Introduction: Transition from paediatric to adult endocrinology can be challenging for adolescents, their families and healthcare professionals. Previous studies have shown that up to 25% of young adults with endocrine disorders are lost to follow-up after moving out of paediatric care. This poses a health risk for young adults, which can lead to serious and expensive medical acute and long-term complications.
Methods: In order to understand and prevent dropout, we studied electronic medical records of patients with endocrine disorders. These patients were over 15 years old when they attended the paediatric endocrine outpatient clinic (OPC) of our hospital in 2013–2014 and should have made the transfer to adult care at the time of the study.
Results: Of 387 adolescents, 131 had an indication for adult follow-up within our university hospital. Thirty-three (25%) were lost to follow-up. In 24 of them (73%), the invitation for the adult OPC had never been sent. We describe the failures in logistic processes that eventually led to dropout in these patients.
Conclusion: We found a 25% dropout during transfer from paediatric to adult tertiary endocrine care. Of all dropouts, 73% could be attributed to the failure of logistic steps. In order to prevent these dropouts, we provide practical recommendations for patients and paediatric and adult endocrinologists.

Key Words
- transition to adult care
- adolescent
- young adult
- paediatrics
- endocrinology

Endocrine Connections (2022) **11**, **e220025**

Introduction

Improved diagnostics and treatment options have increased the life expectancy of children with genetic and/or congenital disorders (1). As a result, more and more patients with childhood-onset chronic conditions are making the transfer from paediatric care (PC) to adult care (AC) (2, 3). The entire dynamic process in which the

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paediatric patient is guided towards AC is called 'transition', whereas 'transfer' is the moment when the patient leaves PC and AC takes over. The transfer of adolescents from PC to AC is a crucial but vulnerable step in the care of adolescents with a chronic disorder (4, 5). Previous studies have shown that up to 25% of young adults with endocrine disorders are lost to follow-up after moving out of paediatric care (6, 7, 8). Research among adolescents with congenital adrenal hyperplasia (CAH) even shows that 3 years after the transfer to AC, 50% of the patients with CAH were no longer under medical supervision (9). Suboptimal management of the disorder and non-attendance to the adult outpatient clinic (OPC) appointments can lead to poor compliance and undertreatment. This can cause an increase in (co)morbidity and even mortality (10, 11). In order to understand the high dropout rate, it is important to identify critical factors for the transfer process. Once identified, new interventions targeting these critical factors can be developed. Several researchers have investigated transition, but only a small number focused specifically on transition and transfer in endocrine disorders (12, 13, 14).

Research groups from different countries have tried to define successful transition and to describe measurable and modifiable indicators. Essential elements within transition care have been identified (15, 16) and translated into so-called transition success indicators (TSI) (17). Three frequently used TSI are (a) presence or absence at the first appointment, (b) the number of missed consultations in AC after the first appointment and (c) the number of post-transfer emergency room (ER) visits and/or hospital admissions related to the chronic disorder (18, 19).

In order to understand the dropout rate in our centre, we have performed a retrospective cohort study among patients who (should have) made the transfer from paediatric to adult endocrinology. The primary outcome of this study was the dropout rate among adolescents 2 years after transfer. The secondary outcome was the correlation between the dropout rate and the before mentioned TSI.

Materials and methods

The study was approved by the Medical Ethics Review Committee of the Erasmus Medical Centre.

Study design and participants

For this retrospective cohort study, we have analysed electronic medical records (EMR), with a focus on three TSI: (1) presence or absence at the first appointment in AC, (2) the number of missed consultations in AC, after the first appointment and (3) the number of visits to the emergency room and/or hospital admissions (related to the chronic endocrine disorder) in the 2 years after transfer to AC.

Inclusion criteria

We included patients who were treated at Erasmus MC-Sophia department of Paediatric Endocrinology between 1 January 2013 and 31 December 2014, who were over 15 years old at that time and who had an indication for adult endocrine follow-up. Indication for endocrine follow-up was dependent of the type of endocrine disorder and the clinical evaluation of the paediatric endocrinologist.

Exclusion criteria

We excluded patients who participated in a pilot to improve transition, as they did not follow the regular transition process. We also excluded patients with intellectual disability (ID). For patients with an ID, transition in our centre is different. During a regular check at the PC, patients and caregivers meet with the transition coordinator, who maintains contact with the caregivers for further appointments. Based on information from the referring paediatrician and caregivers, the transition coordinator determines the composition of the multidisciplinary team present at the first AC visit.

Data collection from medical records

From the EMR, we collected baseline characteristics: gender, year of birth, endocrine disorder, year of (planned) transfer and information on whether the adolescent has made the transfer and to where. For adolescents who made the transfer within the Erasmus Medical Centre, we scored presence or absence at first appointment (TSI 1), number of missed consultations in AC after the first appointment (TSI 2) and the number of visits to the emergency room and/or hospital admissions (TSI 3). TSI 1 was scored as 'presence' or 'absence'. TSI 2 was scored as '0 missed consultations', '1–2 missed consultations' or '>2 missed consultations'. TSI 3 was scored as 'no emergency room visits/hospital admissions', '1–2 emergency room visits/hospital admissions' or '>2 emergency room visits/hospital admissions'. Loss to follow-up ('dropout') was defined as absence of adult endocrine care visits for a period of >2 years after planned transfer.

Patient data

All data from the EMR were collected in a coded manner, using respondents' numbers. The respondent numbers

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were assigned by, and only accessible for, the researcher and the principal investigator. To increase the reliability of this study, a total sample approach was chosen.

Statistical analysis

Chi-squared tests (for trend), or Fisher exact test if the expected count was less than 5, were used to examine associations between the different TSI. Similarly, the associations between TSI and dropout, age at transfer and gender were explored. Only for exploration of TSI 2 with age at transfer a Spearman's rho was used. A P-value < .05 was considered statistically significant. Categorical variables are represented as percentages, and continuous variables as means and s.d. All analyses were performed using SPSS Statistics 25.

Results

Three hundred and eighty-seven (198 male/189 female) patients were over 15 years old when they attended the paediatric endocrine OPC of our hospital in 2013–2014. The process of inclusion and exclusion is illustrated in Fig. 1. Diagnoses of the adolescents are shown in Table 1. Of 387 adolescents, 161 (42%) did not need adult endocrine follow-up because paediatric endocrine care was only puberty- or growth-related. Of the 226 patients who had an indication for adult follow-up, 46 did not enter regular transition because they participated in a pilot to improve transition ($n = 10$), had an intellectual disability and transferred to ID-care ($n = 28$) or died ($n = 8$, mostly cancer-related). Another 49 patients were referred to another hospital or to the general practitioner.

The remaining 131 patients should have made the transfer towards AC within the Erasmus Medical Centre by the time of the start of this study. Of this 'internal transition cohort', the mean age at the time of transfer towards AC was 17.7 (s.d. 1.2) years. There was a slight female predominance (58% females vs 42% males).

Transition success indicators

TSI 1: Presence at first AC appointment

Of the total internal transition cohort of 131 patients, 75% (98 patients) were present at the first AC appointment. Of the males, 78% were present vs 73% of the females. Of five patients, who were under 16 years old at the time of transfer, three (60%) did not attend the first AC appointment vs 22% of those in the age group 16–18 years and 29% in the group over 18 years old (Table 2).

TSI 2: Missed AC consultations after first appointment

After presence at the first consultation, 14 patients (11%) still missed one or two appointments in AC. Five patients (4%) even missed more than two appointments but eventually visited the OPC. Thirty-three patients (25%) did not attend the adult endocrine OPC for more than 2 years after the last appointment at the paediatric OPC. They were

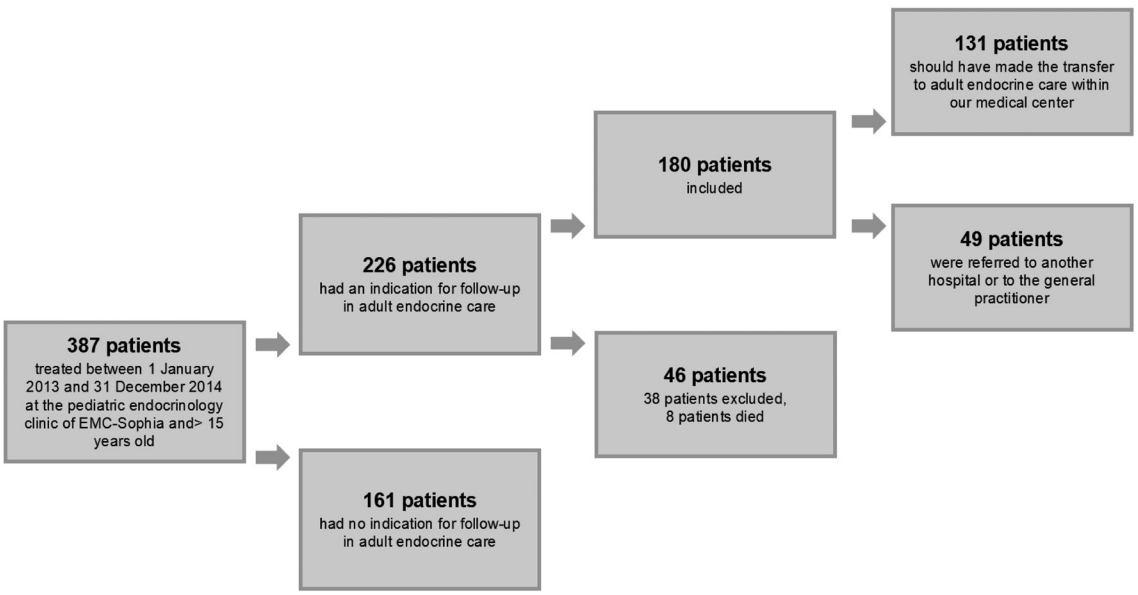

Figure 1
Inclusion and exclusion process.

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Table 1 Diagnoses of included patients (n = 180).

Adrenal	*n*	Thyroid	*n*	Gonads	*n*	Pituitary	*n*	Other	*n*
Addison's disease	8	Graves' disease	6	Oligo-/amenorrhoea	4	Congenital pituitary anomaly	15	Polyglandular syndrome	1
17a-OH hydroxylase deficiency	1	Congenital hypothyroidism	6	Complete androgen insensitivity syndrome (CAIS)	4	(Pan) hypopituitarism	4	Fanconi anaemia	2
Hyperandrogenism	1	Multinodular goitre	2	Polycystic ovary syndrome (PCOS)	9	Central adrenal insufficiency	1	Follow-up after (chemo-) radiation	25
Congenital adrenal hyperplasia (CAH) salt loosing type	9	Hemi- or total thyroidectomy	3	Sex chromosome mosaicism	2	Diabetes insipidus	4	Hypophosphatemic rickets	2
Congenital adrenal hyperplasia (CAH), non-salt loosing type	4	Hashimoto thyroiditis	2	Hypogonadotropic hypogonadism	3	Growth hormone deficiency	2	McCune-Albright syndrome	1
DAX1 gene mutation	1	Toxic thyroid adenoma	1	Kallmann syndrome	1	Prolactinoma	4	Multiple endocrine neoplasia syndrome type 2A	4
				Ovotesticular disorder of sex development	1	Childhood-onset craniopharyngioma	6	Genetic obesity	4
				Partial androgen insensitivity syndrome (PAIS)	1	Septo-optical dysplasia	2	Childhood-onset osteopenia	1
				Premature ovarian failure	2			X-linked osteoporosis	2
				Klinefelter syndrome	5			Von Hippel-Lindau disease	1
				Turner syndrome	19				
				Vanishing testes	2				
				XXYY syndrome	1				
				17-beta-HSD-deficiency	1				
Total	24		20		55		38		43

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Table 2 Transition success indicators according to gender and age of participants.

	TSI 1			TSI 2				TSI 3		
	Present at first AC appointment	Not present at first AC appointment	*p* (gender) 0.45	No missed AC consultations after first appointment	One or two missed AC consultations after first appointment	More than two missed AC consultations after first appointment	Lost to follow-up	*p* (gender) 0.57	No ER visits or hospital admissions after transfer	More than two emergency room visits / hospital admissions after transfer	*p* (gender) 0.45
Gender											
Males	40	11		27	9	2	13		51	0	
Females	58	22		52	5	3	20		79	1	
Total	98	33		79	14	5	33		130	1	
Age at transfer to AC			*p* (age) 0.74					*p* (age) 0.12			*p* (age) 0.16
<16	2	3		1	0	0	4		5	0	
16–18	76	22		26	2	3	14		45	0	
>18	20	8		52	12	2	15		80	1	
Total	98	33		79	14	5	33		130	1	

Correlation between TSI 1 and 2: $P < 0{,}001$, correlation between TSI 1 and 3: $P = 0{,}80$, correlation between TSI 2 and 3: $P = 0{,}64$.

classified as dropouts. Diagnoses of patients who dropped out are shown in Table 3. A comparison with the diagnoses of the patients who did not drop out is shown in Fig. 2.

TSI 3: ER visits or hospital admissions after transfer

Of the total internal transition cohort, one patient had visited the emergency room and was hospitalized more than two times in the 2 years after the transfer. This female patient, who had Addison's disease and complex psychosocial background, did not adhere to hydrocortisone stress instructions and suffered adrenal crises during several school exams and other stressful events. For the remaining 130 patients (99%), no emergency care visits or hospitalizations in our hospital were reported in the first 2 years after the transfer.

Presence at the first appointment at AC was associated with the presence at subsequent appointments ($P < 0.001$). There was no significant association between the other TSI (Table 2).

Baseline characteristics of patients who dropped out did not differ significantly from the patients who did not drop out. Of the patients who dropped out, the mean age at the time of transfer was 17.3 years (S.D. 1.2) and 61% were females. For the patients who did not drop out, the mean age at the time of transfer was 17.9 years (S.D. 1.2) and 61% were females.

To find the cause for the 25% dropout, we checked several logistic processes. This revealed that of 33 dropouts, 24 patients (73%) had not received an invitation for the AC appointment, although the paediatric endocrinologist had written in the medical record that an AC appointment should be made. Of these 24 patients, 8 (33%) did not have any comment about follow-up in the medical file. In another 8 (33%), a comment in the EMR ('transfer to AC') was present, but there was no letter of referral in the EMR. In 7 patients, there was a letter of referral, but the AC appointment had never been made. In 1 case, the letter of referral was made and read, but the AC appointment was not made.

Discussion/conclusion

In this single-centre study, we observed a 25% dropout rate during transition from paediatric to adult endocrine care. The high dropout of 25% is in accordance with previous studies (6, 7, 8). Remarkably, in 73% of dropouts, the invitation for the AC appointment had not been sent. This strongly suggest that logistic failures are responsible for a large part of the dropouts.

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Table 3 Diagnoses of patients who dropped out (n = 33).

Adrenal	*n*	Thyroid	*n*	Gonads	*n*	Pituitary	*n*	Other	*n*	Total
Hyperandrogenism	1	Multinodular goitre	1	Oligo-/amenorrhoea	3	Congenital abnormality of the pituitary	1	Follow-up after chemotherapy/ irradiation chemoradiation	9	
		Hashimoto thyroiditis	1	Polycystic ovary syndrome (PCOS)	3	(Pan)Hypopituitarism	1	Genetic obesity	2	
				Ovotesticular disorder of sex development	1	Childhood-onset craniopharyngioma	1			
				Partial androgen insensitivity syndrome (PAIS)	1					
				Klinefelter syndrome	4					
				Turner syndrome	3					
				17-beta-HSD-deficiency	1					
Total	1		2		16		3		11	33

We assessed three previously defined TSI, being (a) presence or absence at the first appointment, (b) the number of missed consultations in AC after the first appointment and (c) the number of post-transfer ER visits and/or hospital admissions related to the chronic disorder.

The first TSI, presence at first AC appointment, is an important TSI (16, 20, 21) which is significantly associated with future appointment attendance. A quarter of the adolescents in our transition cohort was not present at the first appointment.

The second TSI was the number of missed consultations after the first appointment. Four in every ten adolescents (40%) missed more than one appointment after the first. Most of them did not return at all and were lost to follow-up. This is important as estimated no-show costs in the general Dutch population are around 300 million euros a year (22). Reducing missed appointments might lead to reduction of healthcare costs, which is an important topic in healthcare.

The third TSI, emergency care visit and/or hospitalization in the first 2 years after transfer, is considered an important indicator of disease management quality (20, 21, 23, 24). However, in our study, hospitalization turned out to be so rare that it was not considered a useful TSI in our cohort. Low hospitalization rate was probably due to the fact that our transition cohort consisted of patients with endocrine disorders. Many chronic endocrine conditions, such as hypogonadism, will not directly lead to an emergency care visit or hospitalization in the case of suboptimal management.

The transition from PC to AC is known for its high risk of dropout and poor overall health outcomes in various chronic disorders (25, 26, 27, 28, 29). Many patients are unaware of the importance of long-term follow-up (30), which can lead to non-attendance and finally dropout. Therefore, in order to improve the transition process, it is important to inform patients and caregivers of the possible adverse consequences of non-attendance.

Apart from informing patients and caregivers, it is crucial to identify factors related to dropout. Therefore, gender, age of transfer and medical diagnosis were compared between the 33 patients who dropped and the 98 patients who did not. Furthermore, we assessed the role of logistic issues.

Female gender has previously been associated with low dropout rates (8). However, in the patients who were lost to follow-up in the current cohort, the percentage of females (60%) was comparable to that in the total study sample. This suggest that women do not go to through transfer any better or worse than men do.

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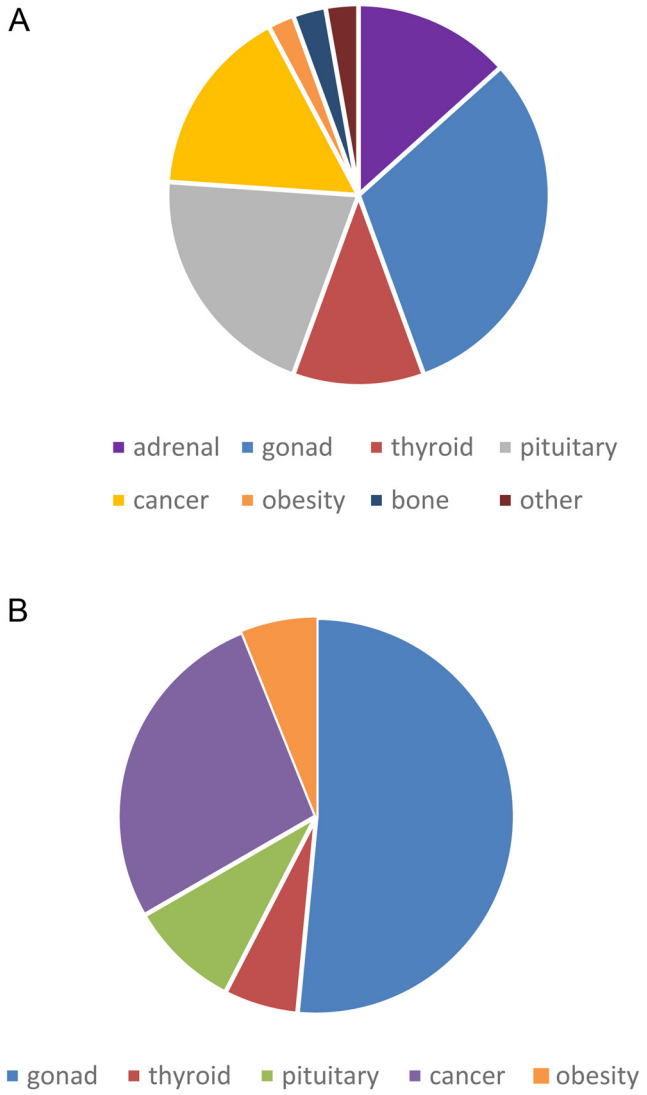

Figure 2
Medical diagnosis for patients who successfully made the transfer to adult endocrine care (A) and for patients who dropped out (B).

There is no consensus about the optimal timing of transition (31). Adolescents and young adults (AYA) have indicated that they are transition-ready between 17 and 40 years old, with the majority preferring the age of 18–24 for transfer (32, 33). This age is sometimes reported as the 'ideal age' for transfer (33). One study states that early transfer from the PC to the AC is associated with worse disease control (34). However, others recommend starting the transition process much earlier, beginning at the age of 12 (35). In our study, the mean age at transfer to AC of those who dropped out was 17.3 (S.D. 1.2, range 15–20) years, which is within the 'ideal range'. Age was not different between those that did and did not drop out.

It seemed that there were more gonadal disorders, more cancer and less pituitary disorders among the patients who eventually dropped out (Fig. 2). However, patient numbers were too small to draw any firm conclusions.

When trying to find an explanation for the missed appointments, it was striking that in 73% of dropouts, the first appointment at AC was never planned even though the paediatric endocrinologist had written 'ready for transfer' in the EMR and/or written a letter of referral. When looking in detail, there are some crucial steps in the logistics of transition which could explain part of the dropout. After the paediatric endocrinologist and patient decide that the patient is ready for transfer, the paediatric endocrinologist writes a letter of referral. This letter must be sent and delivered to the adult endocrinology department. The letter must be read by the adult endocrinologist, who then asks the secretary to make an appointment for the patient. The invitation for the appointment must be sent and delivered at the patient's home address. In our cohort, in 33% (8/24) of the dropouts the process already failed at the first step; there was no 'ready for transfer' comment in the EMR about follow-up. We neither could find any comments about communication with the patient nor did we find any missed appointments at paediatric care. In another 33%, there was a 'ready for transfer' comment in the EMR, but no letter of referral was written. In 29% (7/24), the letter of referral was written, but the appointment was not made by AC. In one case, the letter of referral was written by the paediatric endocrinologist and read by adult endocrinologist, but the AC appointment was not made. Apparently, patients nor caregivers had taken any action to inform the hospital of the fact that they had not received an appointment.

Although, in the current article, logistic causes of dropout seemed most prevalent, psychosocial aspects of transition are evenly important. Appointing a transition coordinator can help to focus more on the psychosocial and logistic issues in order to improve transition (36, 37, 38, 39, 40, 41, 42, 43).

At the time of this study, there was no protocolled handover process in the transition from PC to AC. There was no standard shared consultation with both the paediatric and adult endocrinologist. Communication about the transfer of the patient from the PC to the AC mostly took place through a letter of referral. In 2017, we changed this approach and launched a Young Adults Clinic (YAC) in our centre. As soon as a patient is ready for transfer to the AC, the paediatric endocrinologist schedules an appointment for the YAC. During this shared consultation with paediatric and adult endocrinologists, patient and caregivers meet the AC providers. During the appointment, the patient receives the contact details

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of the transition coordinator, who is the primary point of contact and ensures that follow-up appointments are made and kept. The first appointment at AC takes place within 6 months. If necessary, telephone/virtual appointments are used in the meantime to maintain contact with the patient and to prevent loss in follow-up. Although launching a specialized transition clinic or appointing a transition coordinator can help to improve transition, this is often not feasible (for example due to budget limitations). If there is no physical room to organize a specialized transition outpatient clinic, virtual consultations might be an option. Also, the following three practical recommendations should already help to prevent dropouts due to failure of logistic steps.

First, the paediatric endocrinologist should make a telephone appointment with the patient a few months after the last visit to make sure an appointment with the adult endocrinologist was made and received. Secondly, the adult endocrinologist should carefully read the letters from the paediatric endocrinologist to see if action is required. Ideally, there should be direct communication between paediatric and adult endocrinologists, independent of the formal medical correspondence. Thirdly, the patient, parents or caregivers should be instructed to alarm the hospital when they do not receive an invitation for the adult OPC.

In summary, we found a 25% dropout during transfer from paediatric to adult tertiary endocrine care. Almost two-thirds could be attributed to failure of practical, logistic steps. We provide practical recommendations for patients and paediatric and adult endocrinologists that require relatively little effort and may prevent these dropouts.

Declaration of interest
The authors declare that there is no conflict of interest that could be perceived as prejudicing the impartiality of the research reported.

Funding
This publication has been supported by Endo-ERN, which is co-funded by the European Union's 3rd Health Programme (CHAFEA Framework Partnership Agreement No 739527).

Statement of ethics
The study was approved by the Medical Ethics Review Committee of the Erasmus Medical Centre.

Author contribution statement
K D wrote the first draft of the manuscript and did the statistical analysis. A J v d L and L d G were responsible for the conception and design of the study. J B and K D were responsible for data collection. All authors were involved in data interpretation, revision of the manuscript, and final approval of manuscript.

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Received in final form 7 March 2022
Accepted 22 April 2022
Accepted Manuscript published online 22 April 2022