

Training needs in adolescent and young adult health and transition in UK paediatric and adult higher specialist trainees in endocrinology and diabetes

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Abstract

Background: There is a concern that medical training contains insufficient emphasis on adolescent and young adult health and transition. Clinicians working in diabetes and endocrinology across paediatric and adult services need to have the skills to work effectively with this age group. The aim of the present survey was to ascertain the current state of training of paediatric and adult trainees in endocrinology and diabetes in the UK.

Methods: A questionnaire assessing training in adolescent and young adult health was developed using existing questionnaire formats. An online survey was disseminated to UK trainees in paediatric and adult endocrinology and diabetes through the Young Diabetologists and Endocrinologists Forum (YDEF), the British Society of Paediatric Endocrinology and Diabetes (BSPED), and the Society for Endocrinology (SfE) to assess access and quality of adolescent and young adult health and transition training.

Results: 146 responses were received from 97 adult trainees, 38 paediatric trainees with a special interest and 11 paediatric sub-specialty trainees. All grades were represented from across the UK. Training in adolescent and young adult health and transition was rated as minimal or non-existent (65%); this was more marked in endocrinology (76%) than in dia-

betes (42%). The major barriers to achieving this experience and training were perceived to be limited clinic time and lack of training. Trainees reported unmet training needs, with paediatric trainees reporting higher learning needs despite reporting more exposure and training. Both seniority and number of clinics attended positively impacted on reported training experience.

Conclusions: This survey has highlighted the need for improvements in training in adolescent and young adult health. Trainees from paediatric and adult backgrounds feel under-trained and under-prepared to deliver this care. Given the importance of improving outcomes in adolescents and emerging adults with long-term conditions, this issue merits urgent attention.

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Introduction

The 2012 annual report from the Chief Medical Officer of the UK National Health Service ('Our Children Deserve Better: Prevention Pays') identified the importance of working to improve outcomes for young people with long-term conditions, stating that "caring for young people is everybody's business".¹ Transition, a period during which young people with long-term conditions move from paediatric to adult services, was one of the areas highlighted.

Clinicians working in endocrinology and diabetes are expected to manage transition from paediatric to adult services to ensure the continuation of high quality endocrine and diabetes care for young people. It is widely recognised that delivering effective transition is a challenge for health care professionals.²⁻⁵ Providing an optimal service remains challenging, despite increasing national guidance on organisation of transition and transfer and the recognition that young people can be lost from the system.^{6,7}

Evidence exists of suboptimal outcomes in diabetes and endocrinology. Two UK studies demonstrated that 50% of young people with congenital adrenal hyperplasia were lost to follow up during transition from paediatric to adult services, or failed to engage fully with their long term care despite a high risk of

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morbidity and mortality.^{8,9} Studies in people with type 1 diabetes have demonstrated loss to follow up during transition,¹⁰ although we know that there is a 7-fold increased risk of mortality in young women aged 15–34 years when compared with their peers without diabetes,¹¹ and an increased predisposition to developing diabetic ketoacidosis.¹²

The period of adolescence is critical in terms of shaping a person's future use of health services and likelihood of long term engagement. It is essential that clinicians caring for people during this important phase of life are appropriately trained to deliver this care. The essence of care of adolescents and young adults differs from that of children and older adults, with a need to recognise the influence of biopsychosocial development, to employ differing consultation dynamics and skills, and the need to deal with both young person and parents or carers, while addressing confidentiality and communication issues.^{13–15} Previous studies of clinicians in gastroenterology and rheumatology have identified that lack of training is one of the barriers to achieving good clinical care for young people.^{5,16}

We therefore aimed to investigate the provision of training in adolescent and young adult health and transition for higher specialist trainees in paediatric and adult endocrinology and diabetes.

Methods

An online questionnaire was developed using previous questionnaire formats using Google forms. A link to the survey was distributed throughout the UK to all trainees in paediatric and adult endocrinology and diabetes in 2013–2014 via the Young Diabetologists and Endocrinologists Forum (YDEF), the Society for Endocrinology (SfE), and the British Society of Paediatric Endocrinology and Diabetes (BSPED). Paediatric trainees are subdivided into those who train as subspecialists in paediatric endocrinology and diabetes, and those who train in general paediatrics with an interest in diabetes and endocrinology (with an emphasis on training in diabetes). Email reminders were issued monthly over a 5-month period (September 2013–January 2014).

The following sections were included in the questionnaire:

About you and your region

Respondents were asked about their background (adult, paediatrics with special interest [PwSI] or paediatric sub-specialty trainees), age, gender, stage of training (Year 1 to Year 5 of higher specialist training) and geographical region of work.

About your training

Respondents were asked to rate their training and clinical exposure in adolescent and young adult health and transition overall, in diabetes, and in endocrinology as non-existent, minimal, average, good or excellent. They were also asked about formal training received and to rate it using the same scale. Respondents also estimated the number of adolescent, young adult or transition clinics they had attended during the course of their higher specialist training to date.

About your practice

Respondents were asked to rate the barriers that they had

experienced in working with adolescent and young adult patients, based on recognised barriers from previous studies.^{17,18} The barriers were rated from 1 to 5 with 1 representing the least significant and 5 the most significant barrier.

About your training needs

Respondents were asked if they had any training needs with regard to the care of young adults and adolescents or transition overall and also focussing on specific areas of adolescent and young adult care. The specific areas were identified from a survey of healthcare professionals working in rheumatology.⁵ Respondents were also asked to rate their training need in the specific areas from 1 to 5 with 1 representing the lowest level of need and 5 the highest level of need.

An option to add free text responses or explanations at several points was provided in the survey. Results were collated and analysed using Microsoft Excel/Numbers for Mac.

Results

Responses were received from 146 trainees: 97 adult trainees (21% response rate), 38 PwSI (61% response rate) and 11 paediatric subspecialty trainees (69% response rate). Forty-one percent of respondents were male. All levels of higher specialist training were represented (20 first-year, 23 second-year, 25 third-year, 35 fourth-year and 41 fifth-year or beyond). Trainees from a paediatric background tended to be in the later stages of training, as may be expected following completion of general paediatric registrar training. Respondents from an adult background were geographically spread throughout the UK, with a higher response rate from West Midlands, East Midlands and London regions. PwSI were working throughout the UK, with highest response rates from Yorkshire and

Figure 1. Experience of training in the care of adolescents and young adults with diabetes and endocrine conditions

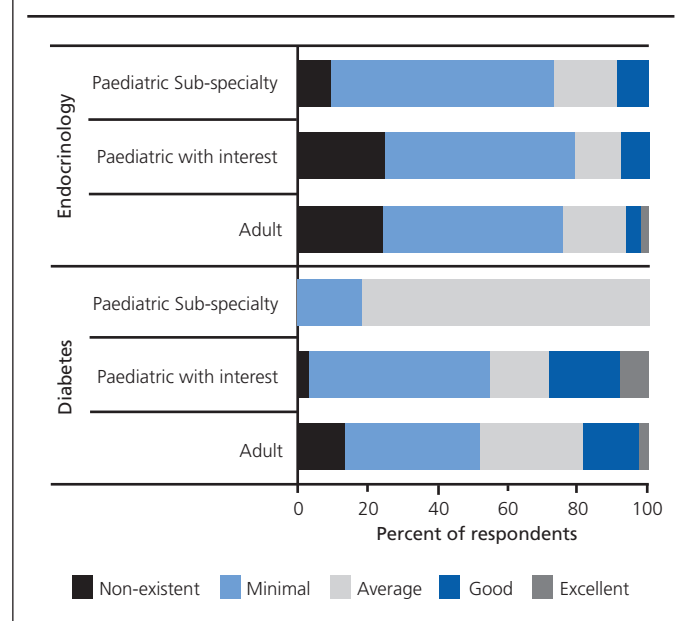
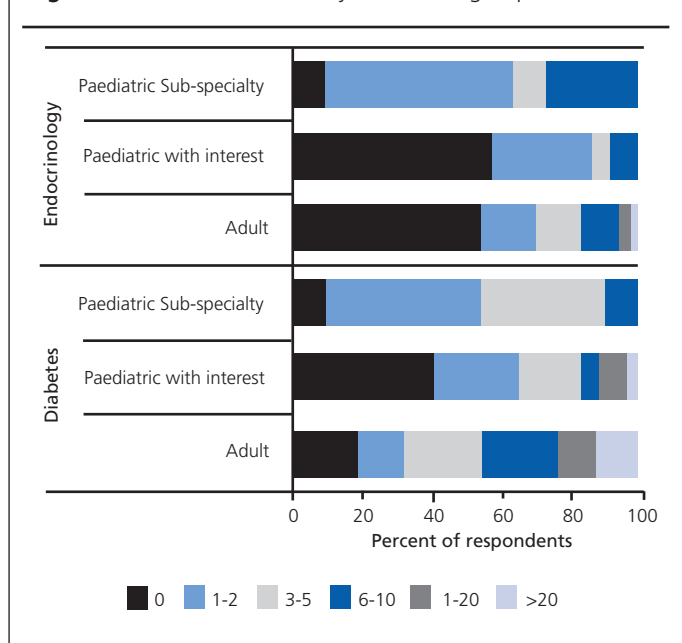
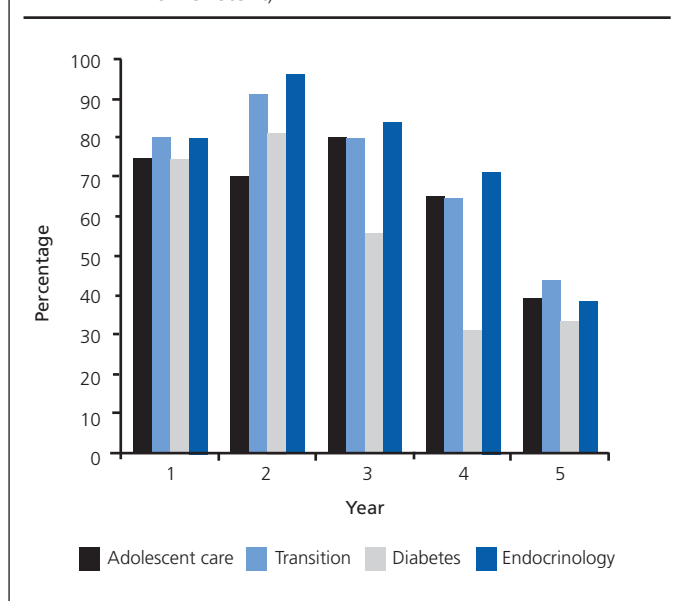


Figure 2. Clinic attendance by trainee subgroup**Figure 3.** Experience of training by year of training (expressed as percentage rating training as minimal or non-existent)

London. Paediatric sub-specialty trainees were smaller in number, with the majority from West Midlands.

Current training

Overall, 65% of trainees rated their training in adolescent and young adult health and transition as minimal or non-existent. This was more problematic for all trainees in endocrinology (76%), compared with diabetes (42%). Paediatric sub-specialty trainees reported better training experience in diabetes, with only 18% rating

their training as minimal and 82% as average; 55% of PwSI and 52% of adult trainees rated their diabetes training as minimal or non-existent (Figure 1).

Forty-seven percent of respondents reported no formal training (defined as lectures, tutorials, courses or e-learning) in adolescent and young adult health or transition either as undergraduates or postgraduates. Five percent had received some form of undergraduate training, and 43% some postgraduate training; 11% had used e-learning methods such as the Adolescent Health Project¹⁹ (5% of trainees reported more than one method of formal training).

Overall, more trainees attended adolescent/young adult/transition clinics in diabetes than in endocrinology (Figure 2), though numbers of clinics attended remained small. There was less exposure to endocrinology clinics, with 55% of adult trainees and 58% of PwSI never having attended any. Paediatric sub-specialty trainees reported more clinic exposure in general, with only 9% not having managed to attend either a diabetes or endocrinology clinic.

When experience of adolescent and young adult training was subdivided by year of specialty training, senior trainees were more satisfied with their training, particularly in diabetes (Figure 3). Only 14% of final year adult trainees reported their diabetes training as minimal or non-existent. Clinic attendance was also associated with improved perception of experience in respondents from all training backgrounds, with a marked reduction in the number rating their training as minimal or non-existent when they had attended more than 10 diabetes clinics. As only five trainees had attended more than 10 clinics in endocrinology, a similar benefit could not be confirmed (Figure 4). The number of clinics attended increased with each successive year of training.

Barriers to working effectively with adolescents

Trainees reported that limited clinic time and lack of training in issues specific to adolescent and young adult health were the most significant barriers to working effectively with adolescents (mean rating 4/5).

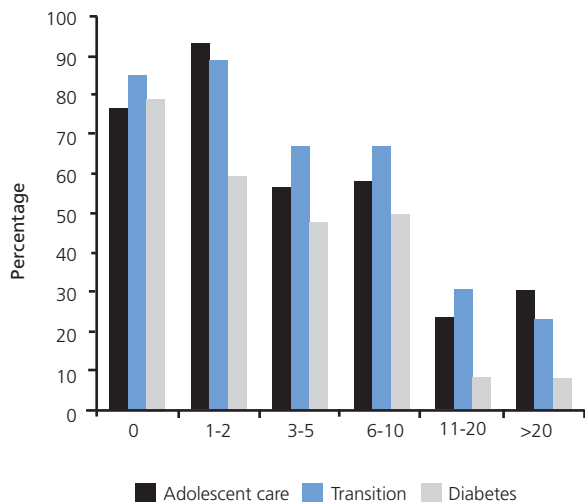
Training needs

Most adult trainees reported training needs (90% in endocrinology and 77% in diabetes), while 95% of PwSI had training needs in endocrinology, and 87% in diabetes. All paediatric sub-specialty trainees reported training needs in both endocrinology and diabetes. Respondents reporting no training needs tended to be more senior, though some junior trainees in their first 2 years of higher specialist training reported no training needs.

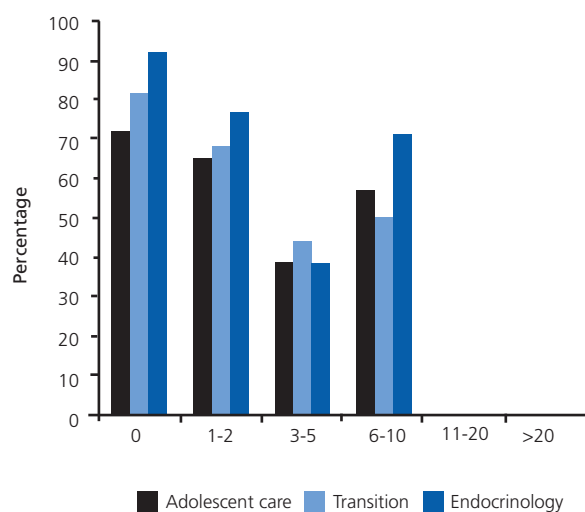
Trainees were then asked to state whether they had received training in 17 domains of adolescent and young adult diabetes and endocrinology training, and whether they considered themselves to have outstanding training needs in these domains. Paediatric trainees averaged 37% training across domains compared with 23% for adult trainees. More than half of paediatric trainees had received training in 5/17 domains including interpersonal skills, alcohol, drugs and smoking, legislative issues, diabetes and growth and puberty, but more than half of adult trainees had received training in two condition-specific domains only: diabetes, and growth

Figure 4. Experience of training by clinic attendance (expressed as percentage rating training as minimal or non-existent). A. Diabetes, B. Endocrinology

a) Diabetes



b) Endocrinology



and puberty. Domains (5/17) recording the lowest training in paediatric trainees (<25%) were knowledge of benefits available, independent living issues, vocational issues, interagency services and transition and transfer. For adult trainees, additional domains (11/17) with the lowest training were available resources, psychosocial issues, educational issues, mental health, interpersonal skills and alcohol, drugs and smoking. Table 1 summarises these findings, and illustrates that all trainees recognised that further training in nearly all domains would fulfil their requirements, with paediatric

Table 1 Training received (percent of respondents) and training needs (mean score out of 5 with SD) relating to issues specific to adolescence/young adults

| Subject area | Adult trainees | | Paediatric trainees | |
|---|--------------------|----------------|---------------------|----------------|
| | Training received? | Training need? | Training received? | Training need? |
| Transition & transfer | 16% | 3.21 (1.4) | 20% | 3.49 (1.4) |
| Resources available | 10% | 3.22 (1.3) | 26% | 3.88 (1.2) |
| Interagency services | 1% | 3.09 (1.5) | 12% | 3.57 (1.3) |
| Benefits available | 1% | 2.85 (1.5) | 2% | 3.61 (1.4) |
| Legislative issues | 33% | 2.92 (1.3) | 65% | 3.51 (1.1) |
| Growth & puberty | 77% | 3.28 (1.1) | 90% | 3.24 (1.1) |
| Childhood endocrine problems in adolescence | 41% | 3.27 (1.3) | 37% | 3.71 (1.2) |
| Diabetes in adolescence | 58% | 3.23 (1.2) | 65% | 3.59 (1.0) |
| Alcohol, drugs and smoking | 22% | 2.86 (1.2) | 59% | 3.57 (1.3) |
| Healthy eating & exercise | 26% | 2.90 (1.1) | 43% | 3.45 (1.1) |
| Sexual health | 36% | 2.90 (1.1) | 47% | 3.37 (1.2) |
| Psychosocial issues | 12% | 3.07 (1.3) | 29% | 3.63 (1.3) |
| Adolescent mental health | 17% | 3.04 (1.3) | 39% | 3.71 (1.1) |
| Education issues | 14% | 3.04 (1.3) | 29% | 3.47 (1.2) |
| Vocational issues | 4% | 2.72 (1.2) | 10% | 3.49 (1.2) |
| Independent living | 3% | 2.65 (1.3) | 4% | 3.43 (1.3) |
| Interpersonal skills | 20% | 3.04 (1.3) | 55% | 3.45 (1.2) |

Box 1. Qualitative experiences of training in adolescent and young adult care

“I think overall training in adolescent endocrinology is poor and I would have liked more opportunities”

“Any such training was patchy...guidance on how to gain such training and knowledge was very poor.”

“This group would benefit significantly from specialists who were well trained as the burden of their disease will be significant.”

“I feel my exposure is limited and is not adequate to arm me enough in dealing with challenging adolescents”

“No formal training in adolescent health especially in communication skills e.g. motivational interviewing... unsure about transition to adult clinic and how it is best done”

“Most paediatric endocrine and diabetes conditions will require adult endocrinology management...the sooner Specialist Registrars understand the nature of adolescent health, the better it is for the patients and their future disease management, also, it will make the transition smoother for the receiving team too”

sub-specialty trainees reporting higher mean training need scores in most domains, despite a higher percentage having received training.

Trainees commented on their experience and training in adolescent and young adult health and transition. Some of these comments are shown in Box 1. The general theme was that training was not sufficient to equip them with the necessary skills to manage this particular age group, and trainees are not sure how to improve upon this experience.

Discussion

Senior clinicians in the specialty of diabetes and endocrinology recognise that the standards of care required to support adolescents and young adults accessing their care are not being achieved. Discussions and work are in progress locally and nationally to improve this care. This survey of higher specialist trainees in endocrinology and diabetes has highlighted that, even during the training years, perceived experience of training is minimal to non-existent, and thus transition training requires further development. Paucity of training appears to be more evident in endocrinology compared with diabetes, but also in generic aspects of adolescent and young adult health and transition. Trainees expressed strong feelings about this gap in their training and stated that they would be more equipped to manage this group of patients appropriately if training was more accessible.

The adult training curriculum in endocrinology and diabetes²⁰ specifies competencies in adolescent and young adult issues, with a greater focus in diabetes. Competencies include knowledge and awareness of the biological, psychological and social factors that may impact on diabetes, the importance of transition from paediatric services, and adopting a patient-centred, non-judgemental approach. There is, however, no real explanation or guidance as to how to gain or assess this experience. There is a lack of emphasis on adolescents and young adults in the endocrinology section, which concentrates more on knowledge of pubertal and growth disorders, though it does make specific mention of the complexities in managing congenital adrenal hyperplasia. The general paediatric curriculum²¹ makes repeated reference to 'adolescents' in most sections of the curriculum, with increased emphasis on the interplay between biological, psychological, emotional and social aspects, though the term is often embedded in the phrase 'babies, children and adolescents' which may detract from these aspects of care specifically during adolescence. There is, however, an additional section of the curriculum devoted to 'Adolescence' with mention of substance use, mental health, safeguarding and development. The European paediatric sub-specialty endocrinology curriculum²² emphasises the essential interface between paediatric and adult specialists, but there is no mention in either the adult or paediatric special interest curriculum²³ of liaison between paediatric and adult services, which would seem to be critically important in achieving quality care through transition and transfer for young people. The paediatric special interest curriculum²³ does not make any reference to adolescents or young adults. A future review of the paediatric and adult diabetes and endocrinology UK training curricula should focus on the specific area of transition in adolescents and young adults and ensure that the curricula are compatible and seamless.

There was a correlation between the number of clinics attended and the rating for experience of training. More advanced year of training and attending more than 10 clinics was associated with greater satisfaction with training. Surprisingly, all of the paediatric trainees and some senior adult trainees had failed to attend 10 or more clinics. In the adult trainee cohort, the five trainees who had attended more than 10 endocrinology

clinics all reported training to be average or better. In earlier versions of the training curriculum, attendance at 10 adolescent/young adult or transition clinics was required in order to be deemed competent at dealing with adolescents and young adults. The present study suggests that a return to this quantitative method, with a stated target of more than 10 clinics to attend throughout training, may well dramatically improve trainee satisfaction and confidence in dealing with this group of patients. This has not been examined in previous studies to our knowledge.

All trainees reported unmet needs in the training domains specified in this survey. Importantly, they also felt that, if these needs were met, they might be better equipped to deal with the specialised needs of this population who are frequently neglected by health services. It is also interesting to note that paediatric trainees received more training in issues specific to adolescence, averaging 37% across 17 domains compared with 23% in adult trainees, although in only 5/17 had over 50% received training compared with 2/17 in adult trainees. Areas covered in paediatric but not adult training were interpersonal skills, alcohol, drugs and smoking and legislative issues. Despite receiving more training, paediatric trainees also reported greater learning needs than the adult trainees. Paediatric trainees therefore seem to be more aware of the need for training in these areas, and perhaps more emphasis needs to be placed on this being a focus in the adult endocrinology and diabetes curriculum. Additionally, there was a much higher response rate to the survey from paediatric trainees, suggesting that they are generally more engaged with this issue.

Young people attending endocrinology or diabetes clinics may not see any other health care professionals on a regular basis. There is an opportunity to positively influence many aspects of their health service use and their attitudes to generic issues such as healthy eating and exercise, sexual health, substance use and mental health. The rate of obesity among adolescents has tripled during the last 30 years,²⁴ sexually transmitted infection rates are increasing and alcohol use is increasingly common among this population.²⁵ Clinicians dealing with young people regularly are well placed to help influence these and other issues that affect them, yet the trainees we surveyed reported unmet training needs in many relevant domains. It has been shown that, typically, half of a young person's needs are overlooked during a consultation, and half are undisclosed, and that traditional didactic consultation techniques are not effective for this population.²⁶ The clinical condition is often not the main focus for the young person, so an awareness of the complexities of adolescence is critical to providing appropriate care for young people. In addition, the consequences of inadequately managed transition or adolescent and young adult care are far reaching, including adverse social and educational outcomes, improper use of NHS services with repeated non-attendance, increased acute care and out of hours attendance, and loss to follow up with deterioration of clinical parameters.

Trainees are expected to achieve a wide range of competencies during their training. There are also the significant competing



Key messages

- Improving outcomes for adolescents and young adults with long-term conditions is vitally important
- Trainees in endocrinology & diabetes from both paediatric and adult training backgrounds feel their training is lacking, leaving them under-prepared for dealing with this age group
- Number of young person's clinics attended positively impacts on training experience
- This gap in training requires urgent attention

demands of service provision versus training, resulting in trainees not being able to attend specialist clinics. In adult and PwSI trainees, the requirement to cover acute and general wards is well recognised as a barrier to specialist training and often cited as one of the difficulties in acquiring adequate specialty-related experience. A lack of consultants trained in adolescent and young adult health is another barrier to trainees achieving adequate training, with some respondents commenting that their experience relied hugely on the enthusiasm of one particular consultant. Young people have highlighted that continuity of care by fewer health care professionals is important and also that having others (trainees, students) observing a consultation is seen as a barrier to communication.²⁷ These issues must be considered when developing curricula to ensure training opportunities are not restricted. Paediatric diabetes and paediatric endocrinology services are also organised in very different ways, with diabetes having undergone an intensive national peer review process and with additional funding being injected through the best practice tariff for all up to age 19 years. In contrast, endocrinology operates in a less streamlined fashion, with more variability in provision, although a national audit is presently being undertaken to ascertain what endocrinology transition services look like across the UK. These service delivery factors may affect access to training for both paediatric and adult trainees, and may help to explain why access to diabetes training appears to be more satisfactory in this survey.

The development of paediatric and adult diabetes and endocrinology curricula must carefully consider ways of providing seamless training whilst overcoming perceived barriers to training. It is perhaps noteworthy that adolescent and young adult health training may facilitate the development of many generic skills that are relevant to endocrinology, to diabetes, to general (internal) medicine and general paediatric care. Based on these data, we recommend a review of the curricula for both paediatric and adult trainees in parallel and that consideration should be given to a return to a stated minimum number of clinics to attend during the training programme. Additional ways for trainees to acquire generic adolescent and young adult competencies should be explored through case-based discussion with designated trainers, the use of e-learning such as the Adolescent

Health Project,¹⁹ trainee-targeted workshops at national training days, and collaborative sessions between paediatric and adult trainees.

In summary, the survey has demonstrated a gap in training with 40% of senior paediatric and adult trainees in endocrinology and diabetes reporting minimal or non-existent training in adolescent and young adult health, and the majority of trainees reporting unmet training needs. An urgent review of training is required if the speciality is to meet the needs of this population.

Conflict of interest None declared

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- the data will be automatically added to the **national data in anonymised form**
- we can provide **easy-to-complete paper proformas** for use in clinic if preferred

Please remember: - the more data, the more complete our understanding of this new treatment will be
- all contributors will be listed in publications arising from data submission