Safe Transition to Young adult Life (STYLe) through a restructured adolescent and young person diabetes transitional service

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Article points

1. Today's lifestyles require a modern approach to chronic disease management.
2. The restructure of the young person service in conjunction with the paediatric team has been beneficial.
3. Young people with type 1 diabetes need access to support when it is convenient for them.
4. Consultations led by the young person have helped them develop responsibility for their diabetes.
5. Flexible access may result in longer-term reduction of admissions and non-attendance, and increase engagement.

Key words

- Autonomy
- Service redesign
- Transition
- Type 1 diabetes
- Young people

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Transitioning from paediatric to adult diabetes services is notoriously difficult, due to change of staff and the challenging nature of engaging young people and adolescents (YPs) at a time in their lives that is already demanding, both emotionally and physically. Traditional NHS methods have usually involved didactic teaching methods, which may not be applicable to this niche group. Safe Transition to Young adult Life (STYLe) is an initiative developed by Portsmouth (Adult) Diabetes Department in early 2013 to ease transition of YPs with type 1 diabetes from paediatric to adult services, through a restructured YP diabetes transitional service. The aim of restructuring was to encourage independence, autonomy and adoption of responsibility by YPs for their own diabetes through person-led consultations and flexible access to diabetes services. Social media focus groups provided a platform to develop new ways of thinking. As a result, risky behaviours are addressed in non-judgemental ways with various educational techniques to ensure that young people with diabetes remain safe. Parents are included in the transition process to enable them to voice opinions, fears and frustrations while allowing the young person to maintain independence. Feedback has been positive and "do not attend" rates and diabetic ketoacidosis admissions have decreased.

Safe Transition to Young adult Life (STYLe) is an initiative developed by Portsmouth (Adult) Diabetes Department in early 2013 to ease the transition of young people and adolescents (YPs; age range 10–19 years [WHO, 2014]) with type 1 diabetes from paediatric to adult services, through a restructured YP diabetes transitional service. This article describes the process used to restructure the service.

The previous service was arguably disjointed, so the decision was taken to develop a dedicated young person team and a strategy to achieve a structured smooth transition from paediatric to adult services. The need to move away from traditional didactic models of care and consider alternative approaches to suit today's modern lifestyles was paramount. "A red rag to a bull" comes to mind when dictating what YPs should be doing with their health care: we therefore based our thinking on person-led consultations and flexible access to services.

Background

Adolescence is a distinct developmental life stage between childhood and adulthood that encompasses physical, psychological and social changes. This time period forces the young person to learn how to manage separation, choice, independence and loss. How young people respond to these changes during this time can have a significant impact on their lives (Royal College of Nursing; RCN, 2013a).

Before the restructure, Portsmouth's YP diabetes transitional service lacked a clear process to introduce YPs into the adult service. Involvement of parents was variable and information provided to

YPs with diabetes was arguably patchy, leaving them uncertain as to whether they would receive robust support through their challenging years. Spencer et al (2014) studied the impact of environmental factors on self-management. One of the themes to emerge was the "suspicion of parents" as to what care would be provided by an adult service – a theme already acknowledged by Fleming et al (2002).

Didactic consultation techniques are rarely effective forms of communication for young people (Stewart, 1995). Typically, half of patient concerns are overlooked by the healthcare professional (HCP) and 50% are undisclosed by the YP. It is, therefore, unsurprising that the desired outcomes are not achieved when the goals set relate to professional needs rather than to the YP with the chronic condition. Discussing their diabetes management may not be a priority for YPs, whereas understanding how to have a tongue pierced safely may be.

Risk taking with regard to health is inevitable among YPs, but this age group is more likely to engage in risky behaviours, such as drug taking, eating disorders or early sexual debut, if they have a chronic condition (Suris et al, 2008). Transitioning coincides with the stresses of becoming a maturing person. While coping with these pressures, YPs must also keep their diabetes under control. These emotional and physical demands make them more susceptible to non-adherence as they have a strong need for acceptance and a tendency to live in the moment (Fleming et al, 2002; RCN, 2013a).

Portsmouth transitional diabetes team noted that their "do not attend" (DNA) rates (40–50%) were predominantly accounted for by YPs, and screening uptake was variable without defined methods of following up results. Analysis of admissions by review of case notes also reflected a combination of optimal care along with non-engagement of this vulnerable group.

Aims and objectives

Based on the above evidence, the aim of the service redesign was to provide a planned, structured, cohesive YP-centred transition service led by a dedicated multiprofessional team to support young people in a way that was acceptable to them and their lifestyles. We wanted YPs to develop confidence in using the services by developing good relationships with HCPs, as failure to do so may set patterns for long-term poor use of services. Focus groups set up suggested that YPs and their parents lacked confidence in the adult services regarding continuity and the level of care that could be provided.

A correlation has been found between effective physician–patient communication and improved health outcomes (Stewart, 1995). Our wish was to allow YPs to take increased responsibility for their health and exercise autonomy in consultation discussions. While encouraging freedom and honesty in lifestyle choices, the HCP endeavours not only to remain non-judgemental with regard to risk-taking behaviours but also to support YPs with diabetes in understanding how to approach the inevitable risks safely.

Initial objectives thus were:

- To ensure that admissions secondary to diabetic ketoacidosis (DKA), especially those due to non-compliance or non-engagement, decreased.
- To ensure that DNA rates decreased.
- To engage YPs by creating flexible and suitable access to the team, including virtual contact.
- To provide continuity of staff to enhance rapport and understanding between YPs and HCPs.
- To enable the YP to feel comfortable in attending the adult diabetes centre by providing a safe, friendly environment.
- To support increasing maturity through person-led consultations.
- To support parents through the transition phase.
- To ensure that routine screening is completed within appropriate time periods and abnormal results are followed up.

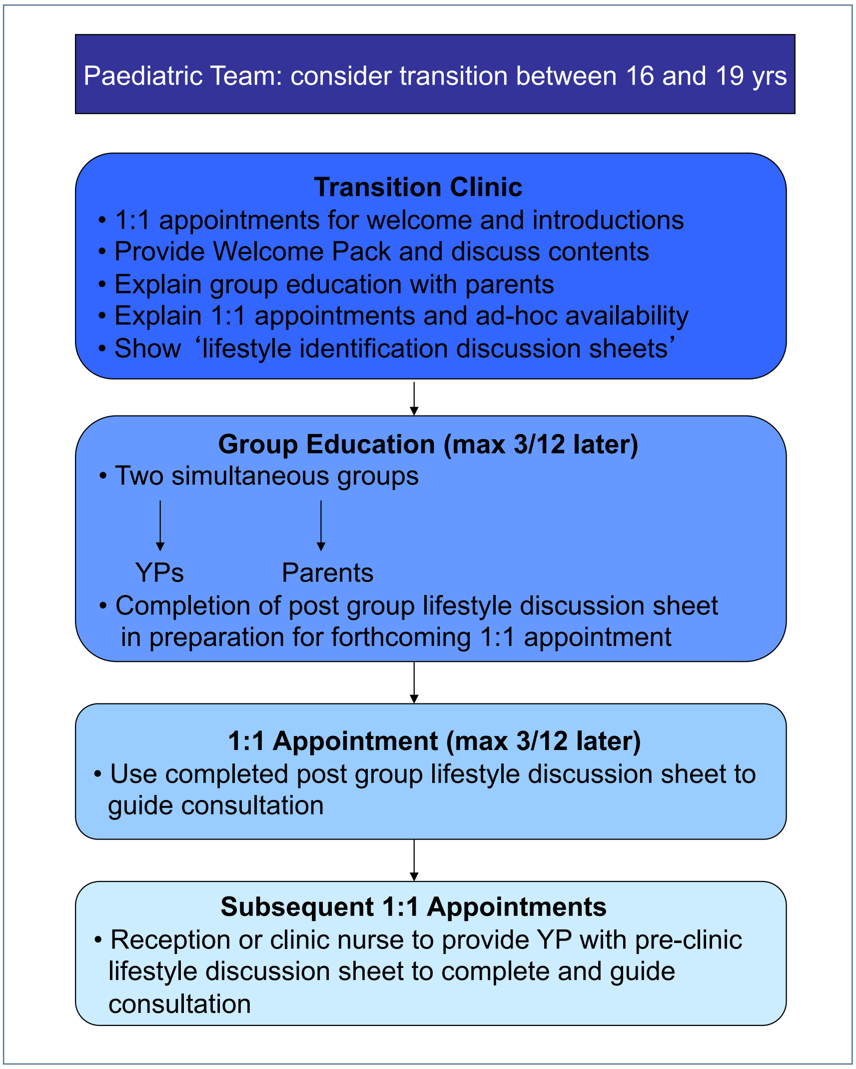
Further longer-term objectives are to reduce end-organ damage, such as retinal bleeds and rate of nephropathy.

In Oxford's Renal Transplant Unit, a similar restructure (Harden et al, 2012) resulted in a significant reduction in lost transplants, owing to an effective transition period. Lessons learnt are largely transferable to other YPs with chronic conditions. In contrast, a diabetes transition survey by Garvey et al (2012) showed that pre-transition HbA_{1c} levels significantly influenced post-transition levels, although the service itself did not appear to promote improvements in HbA_{1c}. It was concluded that more robust preparation strategies and handoffs between paediatric and adult care were needed.

Page points

1. The aim of the service redesign was to provide a planned, structured, cohesive young person and adolescent (YP)-centred transition service led by a dedicated multiprofessional team to support young people in a way that was acceptable to them and their lifestyles.
2. We wanted YPs to develop confidence in using the services by developing good relationships with healthcare professionals, as failure to do so may set patterns for long-term poor use of services.
3. Young people and adolescents are more likely to engage in risky behaviours, such as drug taking, eating disorders or early sexual debut, if they have a chronic condition such as diabetes.
4. While encouraging freedom and honesty in lifestyle choices, the healthcare professional endeavours not only to remain non-judgemental with regard to risk-taking behaviours, but also to support young people with diabetes to understand how to approach the inevitable risks safely.

Figure 1. The restructured young person and adolescent (YP) diabetes transitional service process.



Method

The paediatric and adult diabetes teams met to identify any perceived shortfalls in the transition service and develop agreement on how to move forward. Social media focus groups with YPs provided a platform to develop new ways of thinking. From this, the following strategies were developed to ease transition of YPs with diabetes from the paediatric service to the adult service.

1. Transition preparation clinic

Joint handover from the "familiar" paediatric team to the "unfamiliar" adult team is undertaken in what could be described as a transition preparation clinic. The prospect of transition is a daunting process, moving from the "safe" to the unknown (Spencer et al, 2014). YPs with diabetes are identified as ready to transition by the paediatric team. This decision is based on factors such as social set-up and time of life (e.g. not at exam times) rather than age alone.

In a 1:1 appointment the paediatric team "handover" and introduce the YP to the adult team (*Figure 1*). The YP's parents remain in the waiting room to gently sow the seed of the young person attending appointments alone. One of the adult team welcomes the parents in the waiting room before entering the consultation. Halfway through, parents are invited to join the consultation.

This consultation is driven purely by engaging the YP and informing them about how the adult service works. The YP's diabetes is barely discussed, if at all: the aim is simply to build trust. Gaining insight into the YP as an individual and their daily life allows the beginnings of understanding what emotional support they have, any difficulties they are encountering and how best to meet their needs in the future (RCN, 2013a). The RCN (2013a) also acknowledges that a happy medium is for the parents to have the opportunity to enter the consultation part way through.

A comprehensive information pack is also provided with age-appropriate information, such as attending festivals and having a tattoo, to highlight methods of approaching young adult lifestyles safely. This pack also contains information on staff members, what the adult service offers in terms of educational packages, equipment and a type 1 diabetes reference manual for "recapping" (*Figure 2*).

Portsmouth paediatric diabetes care is conducted on a 1:1 basis. However, once the YPs have transitioned, adult educational packages (such as basal bolus conversions, intensive insulin management and pump therapy) are conducted in groups over several weeks. For the vast majority this is alien territory, and so the purpose and benefits of group settings are explained.

2. Group session

Parents also require support for the increasing maturity of the YP and may need privacy to air their concerns (RCN, 2013a). The next appointment offered is a group session providing information on risky lifestyle behaviours. These behaviours are addressed in a non-judgemental way with various education techniques, to ensure that YPs with diabetes remain safe. Each PowerPoint slide lists three points to highlight the main safety issues. These slides are kept simple to promote discussion and are presented in a relaxed manner.

The parents are also invited to receive the same information, but in an adjoining room. Separating parent and young person again starts the process of developing independence while also promoting freedom of speech, and allows both parties to voice opinions, fears and experiences freely (*Figure 1*).

3. Identifying topics for discussion

To maximise diabetes control, YPs must participate effectively in their own medical care (Greenfield et al, 1988). Before each appointment the YP is given a lifestyle identification discussion sheet to mark which topics they would like to discuss during the consultation (*Figure 3*). This promotes person-led consultations to encourage young people to speak out about their needs, wishes and priorities.

Feedback from this new approach has been highly positive, and assigning dedicated staff to this young adult age group to offer flexible follow-ups has resulted in reduced DNA and admission rates. A similar strategy employed by Greenfield et al (1988) showed that patients were twice as effective as controls in eliciting information they required from the physician, leading to behaviour change.

4. Business cards and flexible appointments

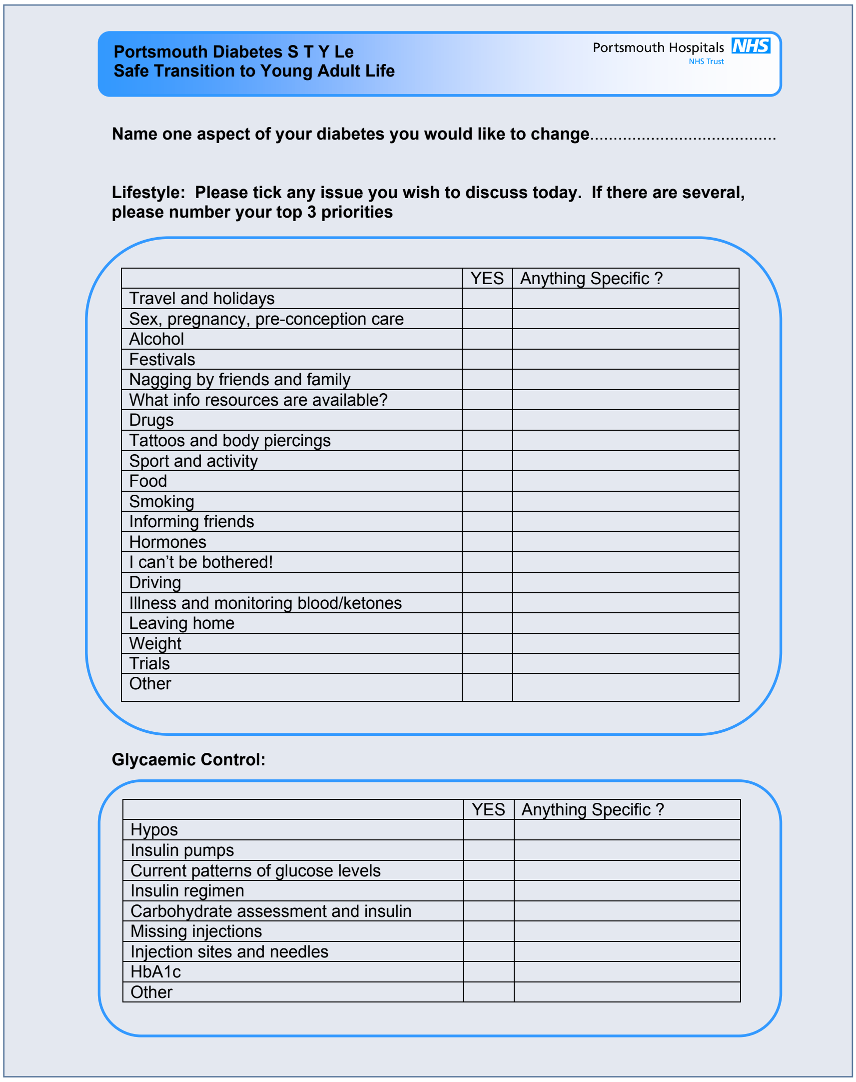
It has been suggested that YPs with diabetes prefer to reply to texts or emails at their convenience, rather than answer telephone calls. We therefore designed business cards with email addresses, a text number and telephone numbers. These were distributed to the YPs with diabetes to increase the availability of HCPs in a way that is more suited to the needs of young people. In addition, *ad-hoc* flexible appointments are made for those who find attending a routine clinic unsuitable for various reasons, e.g. does not fit in with their college days – a tip suggested by the RCN (2013a).

5. DSN clinic at Portsmouth University

Portsmouth University is approximately six miles from the Queen Alexandra Hospital. Many students

Figure 2. Examples of information leaflets included in the Welcome Pack.

Figure 3. Pre-clinic lifestyle identification discussion sheet.



Portsmouth Diabetes S T Y Le
Safe Transition to Young Adult Life

Portsmouth Hospitals NHS
NHS Trust

Name one aspect of your diabetes you would like to change.......................................

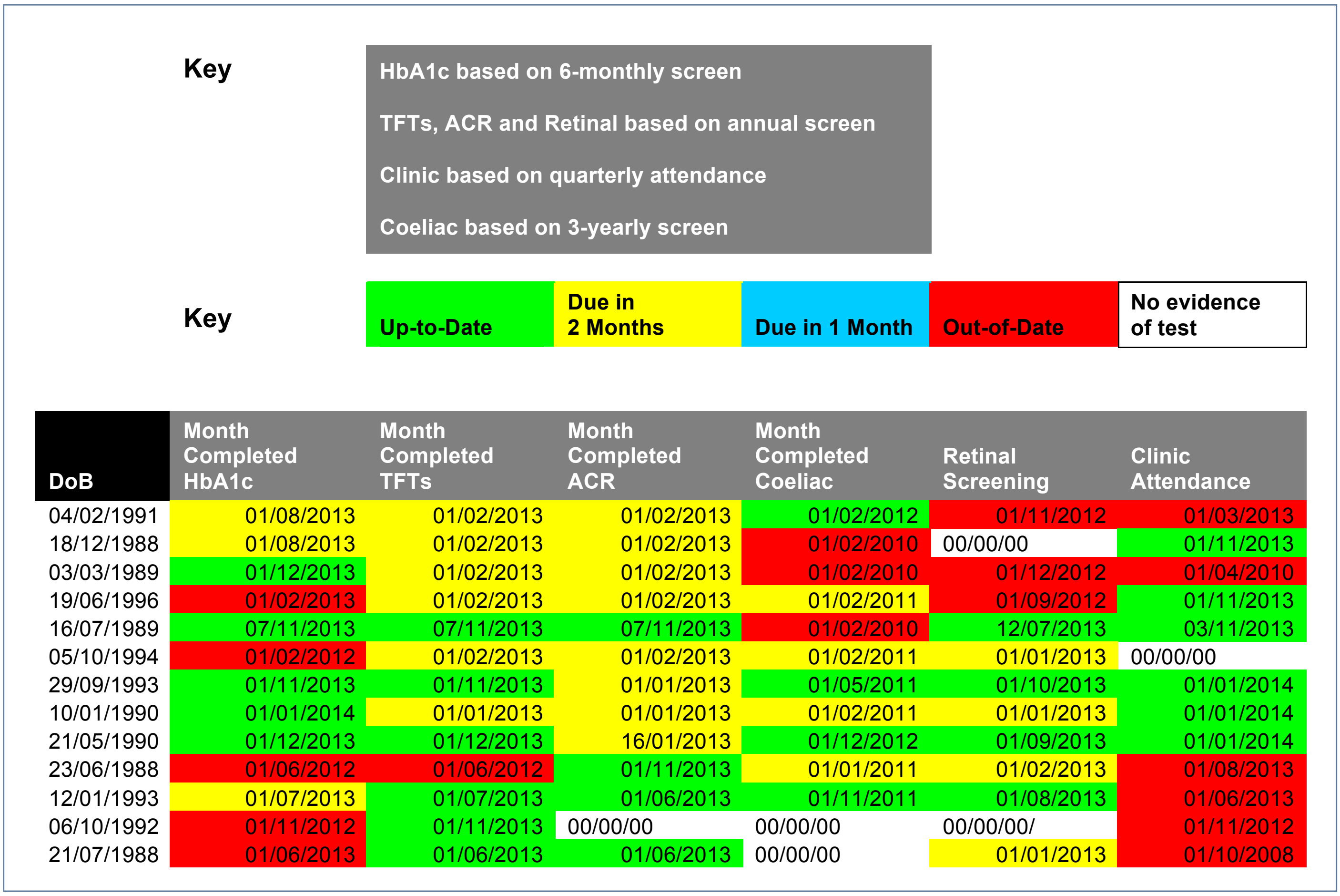
Lifestyle: Please tick any issue you wish to discuss today. If there are several, please number your top 3 priorities

	YES	Anything Specific ?
Travel and holidays		
Sex, pregnancy, pre-conception care		
Alcohol		
Festivals		
Nagging by friends and family		
What info resources are available?		
Drugs		
Tattoos and body piercings		
Sport and activity		
Food		
Smoking		
Informing friends		
Hormones		
I can't be bothered!		
Driving		
Illness and monitoring blood/ketones		
Leaving home		
Weight		
Trials		
Other		

Glycaemic Control:

	YES	Anything Specific ?
Hypos		
Insulin pumps		
Current patterns of glucose levels		
Insulin regimen		
Carbohydrate assessment and insulin		
Missing injections		
Injection sites and needles		
HbA1c		
Other		

Figure 4. Screenshot of Excel Screening Tracker (ACR=albumin:creatinine ratio; DoB=date of birth; TFTs=thyroid function tests).



Key

HbA1c based on 6-monthly screen
TFTs, ACR and Retinal based on annual screen
Clinic based on quarterly attendance
Coeliac based on 3-yearly screen

Key

Up-to-Date	Due in 2 Months	Due in 1 Month	Out-of-Date	No evidence of test

DoB	Month Completed HbA1c	Month Completed TFTs	Month Completed ACR	Month Completed Coeliac	Retinal Screening	Clinic Attendance
04/02/1991	01/08/2013	01/02/2013	01/02/2013	01/02/2012	01/11/2012	01/03/2013
18/12/1988	01/08/2013	01/02/2013	01/02/2013	01/02/2010	00/00/00	01/11/2013
03/03/1989	01/12/2013	01/02/2013	01/02/2013	01/02/2010	01/12/2012	01/04/2010
19/06/1996	01/02/2013	01/02/2013	01/02/2013	01/02/2011	01/09/2012	01/11/2013
16/07/1989	07/11/2013	07/11/2013	07/11/2013	01/02/2010	12/07/2013	03/11/2013
05/10/1994	01/02/2012	01/02/2013	01/02/2013	01/02/2011	01/01/2013	00/00/00
29/09/1993	01/11/2013	01/11/2013	01/01/2013	01/05/2011	01/10/2013	01/01/2014
10/01/1990	01/01/2014	01/01/2013	01/01/2013	01/02/2011	01/01/2013	01/01/2014
21/05/1990	01/12/2013	01/12/2013	16/01/2013	01/12/2012	01/09/2013	01/01/2014
23/06/1988	01/06/2012	01/06/2012	01/11/2013	01/01/2011	01/02/2013	01/08/2013
12/01/1993	01/07/2013	01/07/2013	01/06/2013	01/11/2011	01/08/2013	01/06/2013
06/10/1992	01/11/2012	01/11/2013	00/00/00	00/00/00	00/00/00/	01/11/2012
21/07/1988	01/06/2013	01/06/2013	01/06/2013	00/00/00	01/01/2013	01/10/2008

rely on bus services, have little disposable cash and do not know the area if Portsmouth is not their home town. It was noted that this group of individuals were missing out on diabetes services, perhaps waiting until the holidays to visit their own diabetes centre, although this may be past the time of need.

A DSN clinic was therefore set up. It runs within the Portsmouth University GP Surgery, which out-of-area students register with. The clinic runs monthly in term times, thus avoiding the need for travel and additional cost to the student.

6. Excel screening tracker program

A system has been developed, using Excel, to highlight when blood tests are in date, due in 2 months, or out of date, to track when routine screening is due. The system automatically colour codes the dates when the last screening tests were completed, and changes colour according to when the next test is due. During clinics the system can be running in the background and check each individual screening progress in alphabetical order (*Figure 4*).

Results

The transitional clinic and routine 1:1 YP clinic attendance levels were monitored. These show that the DNA rate, which had varied from 40% to 50%, dropped to 10–15% in the 10 months following the service restructure. Acute admissions secondary to DKA – a common reason for admission in this group – were also monitored. Results show that these decreased by 11% over the same period.

Specific educational sessions were set up for primary care emergency admission teams to teach them to identify the clues that will help to avoid admissions, while also giving them information regarding access to the inpatient diabetes team and adolescent diabetes team.

Patient satisfaction levels identified from a post-transition clinic satisfaction questionnaire completed by both YP and parent, and verbally from students, are high for both hospital and university settings. Particular appreciation has been noted for easy access to the hospital team on a virtual basis (email/text messaging).

Since the lifestyle identification discussion sheet was introduced, consultations have been guided by the individual and conversations have flowed. Patient evaluation of the sheet included the following comments:

> *"I didn't know I needed to know about tattoos."*
>
> *"Good prompt as I often forget what I want to ask."*
>
> *"Allows proper discussion of my topics rather than just being noted at the end."*
>
> *"Useful that the doctor could see what I wanted to talk about."*
>
> *"It seems like we are finally in charge!"*

Conclusions

The journey of a young person with type 1 diabetes is laden with challenges, especially when transitioning from paediatric to adult services. It is the responsibility of physicians to ensure that the journey is as smooth as possible.

The initiatives and changes in service described above have been based on the recommendations of young people with type 1 diabetes, rather than HCPs assuming or dictating what is right or wrong. The initial results show a positive and encouraging trend, which it is hoped will continue.

The results reported here (patient satisfaction, DNA rates and admission rates) are short-term improvement markers, which need to be sustained. We look forward to seeing the results of longer-term outcomes, such as a reduction in end-organ damage (e.g. retinal bleeds and nephropathy). These data are being monitored by the unit. In the diabetes world and beyond, the development of person-focused services can help to deliver outcomes that should indicate whether the service is good or not. The initial signs look positive.

Adult diabetes services tend to work in rigid structures dictated by tradition, but YPs in the modern world need services that are more responsive and receptive to the idea of virtual contacts and the use of social media, such as Twitter, with flexible access to these services.

Our experience has been that if one genuinely lets the young person with diabetes be in charge, there exists the opportunity to make changes within current resources to help that person on their journey.

This strategy could be replicated in the wider diabetes community, as none of the changes needed extra money or investment, but were achieved using existing staff and resources in a different manner, i.e. one that provided consistent team members and continuity, allowing greater rapport to be built with the YP. Restructure of the service has required time, patience and a lot of engagement with young people with diabetes to understand their frustrations with the system. It is up to HCPs to find a way past the myriad of NHS rules, fixed ways of working and traditional ways of delivering clinics, and question whether it helps the YP with diabetes.

For the future it seems appropriate to investigate the correlation between pre- and post-transition HbA_{1c} levels. If deterioration is seen, more robust preparation strategies and post-transition care should be explored.

A limitation of the restructured YP diabetes transitional service is that there is no psychology input within the adult diabetes service; community access is also limited. Psychology input is widely appreciated and thought to be invaluable within chronic disease management (RCN, 2013b). Portsmouth's YP transitional service is striving to gain psychology support and does recognise its importance. Negotiations with local commissioners to address this issue are ongoing, and the team is hopeful that it will soon be resolved.

Additionally, although the YP service has dedicated staff, they have yet to undertake any formal training to facilitate transition or work with the YP age group. The RCN (2013b) is calling for HCPs working with young people in this age group to access specific training, so this may be something to consider for the future.

Conducting clinics specifically for the university student population is believed to be unique, and there appears to be little or no published research in this area. These clinics therefore seem to be the "tip of the iceberg", suggesting that much work is required for this small group of students/YPs with diabetes temporarily living away from home. ■

"In the modern world, young people and adolescents with diabetes need services that are more responsive and receptive to the idea of virtual contacts and the use of social media, such as Twitter, with flexible access to these services."

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