

ENHIDE telehealth support for 148 disengaged young adults with type 1 diabetes: a pilot study – rationale and study design

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Abstract

Disengaged young adults with type 1 diabetes are vulnerable to poor health outcomes. Potentially 20% of those aged 16–30 years could be included in this category. East and North Herts Clinical Commissioning Group (CCG) commissioned the East and North Herts Institute of Diabetes and Endocrinology (ENHIDE) to pilot an innovative model of care in August 2016. Young adults aged 16–30 were offered an alternative model of tailored care, with access to a young adult support worker and specialist nurse. Inclusion in the project was based on fulfilling at least one of the following criteria:

- **Acute admission with diabetic ketoacidosis or hypoglycaemia**
- **Non-attendance for retinal screening**
- **Non-attendance at clinics on at least two consecutive occasions**
- **Persistent HbA_{1c} levels >75 mmol/mol**
- **Non-attendance for routine laboratory measures of glycaemia and renal function**
- **Multidisciplinary team review stating need for more flexible care**

We invited 148 young adults to participate in the project. Of these, 118 have been recruited after the initial contact, markedly exceeding the 10% take-up rate set by the CCG. The project will evaluate changes in emergency admissions, attendance for routine biochemical tests and retinal screening, changes in glycaemic control and quality of life measures at 6 and 12 months after entry to the project

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Background

Clinical management and self-care of young adults with type 1 diabetes is challenging. There is an evident need for effective transitional care of those aged 16–19 years, but also recognition of issues with transfer of care to adult services.^{1–3} There are more adults aged 19–30 with type 1 diabetes – including those who have developed their condition after the age of paediatric care – than those aged 16–19.¹

Several studies have clearly demonstrated the multifaceted nature of issues that impact on attendance at clinics for young adults, adherence to self-care, hospitalisation with diabetic ketoacidosis (DKA), high levels of HbA_{1c} and early onset complications, most notably retinopathy. These include psychosocial factors such as socioeconomic status, parental separation and lack of family cohesiveness, unemployment, and psychological and mental health factors including eating disorders and substance abuse.^{4,5} In addition, there is clear evidence that a proportion of young adults living with type 1 diabetes do not find current models of care provide services they wish to access.⁶

Less engaged patients have poor glycaemic control, the highest rates of DKA admissions and non-attendance at clinics, and the greatest incidence of complications.^{7,8} Certain models using non-direct face-to-face communication using Skype and text-based support have provided benefits such as better clinical attendance and potentially fewer emergency admissions.^{9–13} These services have been offered to all patients attending diabetes clinics rather than selected patients with poor clinic attendance.⁹

Despite recent advances in diabetes care and more intensified insulin regimens, much higher levels of HbA_{1c} than are desirable persist.^{14–16} Furthermore, psychological interventions designed to help young people with type 1 diabetes have achieved disappointing results in respect of engagement, HbA_{1c} attainment and improved quality of life measures.¹⁷

By definition, it might be difficult to identify factors that account for dissatisfaction with standard care. However, this has recently been explored in a semi-structured interview with 29 young people with type 1 diabetes⁶ who fulfilled any of the following criteria: no HbA_{1c} test in preceding 12 months, non-attendance for retinal screening in the preceding 18 months, no contact with the specialist diabetes team for 12 months, or two or more hospital admissions with DKA in the past 2 years.

The themes that emerged were:

- Feeling overwhelmed by having and managing type 1 diabetes
- Experience of bereavement
- Feeling different to peers without type 1 diabetes
- Trust previously broken by a health professional
- Embarrassment at discussing menstruation, personal issues and being examined by male doctors
- Length of time and inconvenience attending clinic appointments
- Concern they were being 'blamed' for ineffective self-management

In East and North Hertfordshire there are approximately 800 people with type 1 diabetes aged 16–30. Surveys of our transition and young adult clinics in 2014 recorded a 23% drop-out rate after 2 years follow-up.¹⁸ In 2016 there were 52 young adults aged 16–30 with at least one DKA admission over an 18-month period identified from Hospital Episode Statistics. The last recorded median value of HbA_{1c} available in 49 cases was 93 mmol/mol. Eighteen of these were disengaged from regular care. Our DKA admission rates equate to a 4.3% annual event frequency, in line with UK and international reports, with the highest incidence being amongst those aged 18–24.^{8,19,20}

The East and North Herts Diabetes Retinal Screening programme in 2016 identified 66 young adults aged 16–30 who had not attended retinal screening. This is a serious concern, given the link with variable engagement and the recognition that the incidence of sight-threatening retinal disease and blindness is especially high below the age of 40.^{14,15}

The ENHIDE Young Adult Telehealth Pilot Study

The 2-year project was designed to enable at least 12 months review of the impact of supported care on the outcome measures. The East and North Herts Clinical Commissioning Group (CCG) provided financial support for the core personnel and for IT support. The project was set up in August 2016, with full recruitment of the team by the end of October 2016.

Outline of patient selection

The project was designed to provide an alternative care model for those identified as 'disengaged'. This categorisation is not a binary definition in that young adults with diabetes can engage with certain aspects of routine care on an intermittent basis.

Consequently, inclusion in the telehealth service for individuals aged 16–30 was based on meeting at least one of the following criteria in the 2 years prior to project entry:

- Admission with diabetic ketoacidosis or hypoglycaemia
- Non-attendance for retinal screening
- Non-attendance at diabetes clinics on at least two consecutive occasions
- Persistent HbA_{1c} levels >75 mmol/mol
- Non-attendance for routine laboratory measures of glycaemia and renal function
- Multidisciplinary team review stating the need for a more flexible system of supported care.

Young adults aged 16–30 years in East and North Herts were identified from outpatient and inpatient hospital registers, the Diabetes

Retinal Screening register and individual patients identified from GP practice registers. All 55 general practices in East and North Herts were invited to participate. GP practices were informed about the project via a GP bulletin. The CCG made practices aware of the project time scales, aims and objectives and offered a financial incentive (£200) for participation.

Young adults aged 16–30 admitted with DKA and/or hypoglycaemia were prioritised for immediate entry along with potential disengaged cases from specialist diabetes services. All general practices were contacted to create a cross-referenced list enabling updates of those currently registered at the practice with type 1 diabetes aged 16–30. This enabled documentation on whether individuals had changed practices, or had been admitted to other acute units within the preceding 2 years, and helped identify lack of key biomedical data within the preceding 2 years. We also identified additional psychosocial, employment information and other issues.

Young adults who no longer lived in the East and North Herts catchment area were excluded from consideration to participate in the study.

The telehealth team

The telehealth project team comprised two consultant diabetologists who provided a total of two sessions weekly for this project, two Band 7 diabetes specialist nurses (DSNs) who provided a total of five full days a week, a half-time project manager and a whole-time young adult support worker (YASW).

Development of the young adult telehealth protocol

The telehealth team initially identified three pilot practices from three separate localities in East and North Herts. A detailed baseline proforma (Figure 1), which included an individualised care plan, was completed and agreed by the telehealth team. All young adults identified for the project were invited to participate by letter (Figure 2) which was tailored to their individual needs. Those still under transitional care were invited to participate by the paediatric department.

We trialled methods of delivering the invitation: attached alongside the repeat insulin prescription, hand delivered to home addresses or via the Practice Nurse. The young adult was given 5 days to 'opt out' of the project before the team made contact.

We asked primary care and young adults from the three 'pilot' practices for suggested changes to this process. Subsequently we hand delivered invitations to the home addresses. This gave the team the opportunity to speak to the young adults in person if they were at home, and the process was repeated 8–12 weeks later if no contact had been achieved.

Ongoing project delivery

After initial contact, participants were asked to complete a 'Problem Areas in Diabetes' (PAID) Questionnaire used in the DAWN study²¹ and eight questions from The Diabetes Wellbeing Questionnaire used by the National Paediatric Diabetes Network (Figure 3).

Day-to-day support was provided by the DSNs and the YASW. After initial input, the consultant role remained supervisory, other

Figure 1. Proforma for baseline data collection

<h2 style="text-align: center;">TeleHealth Young Adult (Baseline Form)</h2>		Addressograph	
		Name:	
		Date of Birth:	
		Gender: Male <input type="checkbox"/> Female <input type="checkbox"/>	
		NHS Number:	
		Hospital Number:	
Practice Name.....		Date diagnosed:	Date Completed:
Patient Care managed by: Acute Care <input type="checkbox"/> Primary care <input type="checkbox"/> Community Team <input type="checkbox"/>			
Safeguarding Issues? *Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/> *State			
Weight:		BMI:	
Reasons for inclusion on the Telehealth project?			
Admitted to hospital with a diabetes emergency within the past 2 years? DKA <input type="checkbox"/> Hypo <input type="checkbox"/> *Other <input type="checkbox"/> *state.....			Yes <input type="checkbox"/> No <input type="checkbox"/>
Attended an annual diabetes eye check?			Yes <input type="checkbox"/> No <input type="checkbox"/>
Diabetes blood test taken in the past 15 months?			Yes <input type="checkbox"/> No <input type="checkbox"/>
Micro albuminuria tested in the past 15 months?			Yes <input type="checkbox"/> No <input type="checkbox"/>
Not attended 2 consecutive appointments for diabetes clinics (in hospital or community diabetes service) in last 2yrs or discharged.			Yes <input type="checkbox"/> No <input type="checkbox"/>
HbA1c higher than 75 mmol/mol?			Yes <input type="checkbox"/> No <input type="checkbox"/>
Would benefit from a more flexible means of supporting diabetes care?			Yes <input type="checkbox"/> No <input type="checkbox"/>
Psychosocial Domestic Status:			
Under Paed Clinical Psychology/CAMHS? Offered <input type="checkbox"/> Under <input type="checkbox"/> Declined <input type="checkbox"/> N/A <input type="checkbox"/> NK <input type="checkbox"/>			
Comments:			
Under IAPT/Adult Psychiatry? No <input type="checkbox"/> Offered <input type="checkbox"/> Under <input type="checkbox"/> Declined <input type="checkbox"/> N/A <input type="checkbox"/> NK <input type="checkbox"/>			
Comments:			
Social status? Living with parents <input type="checkbox"/> Living with single parent <input type="checkbox"/> Living alone <input type="checkbox"/> Parents Divorced <input type="checkbox"/>			
Parents Separated <input type="checkbox"/> Living with friends/House Share <input type="checkbox"/> No Fixed Abode <input type="checkbox"/>			
Divorced <input type="checkbox"/> In a relationship <input type="checkbox"/> Living with partner <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Single <input type="checkbox"/> Widowed <input type="checkbox"/>			
At School/Uni? Yes <input type="checkbox"/> No <input type="checkbox"/>		Working? *Yes <input type="checkbox"/> No <input type="checkbox"/> *If Yes Occupation	
Exercise? Low <input type="checkbox"/> Moderate <input type="checkbox"/> High <input type="checkbox"/>		Alcohol? None <input type="checkbox"/> < 5 units <input type="checkbox"/> 6-15 units <input type="checkbox"/> > 16units <input type="checkbox"/>	
(Within the last 2 yrs) Smoking? Yes <input type="checkbox"/> Previous smoker <input type="checkbox"/> Never <input type="checkbox"/> N/K <input type="checkbox"/>			
Driving? Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/>		DVLA informed on Insulin <input type="checkbox"/> N/K <input type="checkbox"/> Recreational Drugs? Yes <input type="checkbox"/> No <input type="checkbox"/> N/K <input type="checkbox"/>	
Additional Information			
.....			
.....			
.....			

Continued ...

Figure 1. Proforma for baseline data collection (continued)

Patient Tests/Results:		
1.	HbA1c a) Checked in past 15 months? Yes <input type="checkbox"/> No <input type="checkbox"/>	b) Result..... c) Date: MM / YY d) Rising <input type="checkbox"/> Variable <input type="checkbox"/> Stable <input type="checkbox"/> Improving <input type="checkbox"/> Low –Normal <input type="checkbox"/> No previous results to grade <input type="checkbox"/> e) Treatment.....N/a <input type="checkbox"/>
2.	eGFR a) Checked in past 15 months? Yes <input type="checkbox"/> No <input type="checkbox"/>	b) Result <60 Yes <input type="checkbox"/> No <input type="checkbox"/> c) Result..... d) Date: MM / YY e) Deteriorating <input type="checkbox"/> Variable <input type="checkbox"/> Stable <input type="checkbox"/>
3.	ACR a) Checked in past 15 months? Yes <input type="checkbox"/> No <input type="checkbox"/>	b) Result >10 Yes <input type="checkbox"/> No <input type="checkbox"/> c) Result..... d) Date: MM / YY e) Deteriorating <input type="checkbox"/> Variable <input type="checkbox"/> Stable <input type="checkbox"/>
4.	Blood Pressure: a) Checked in past 15 months? Yes <input type="checkbox"/> No <input type="checkbox"/>	b) Result..... c) Date: MM / YY d) <130/75 Yes <input type="checkbox"/> No <input type="checkbox"/> N/a <input type="checkbox"/> e) Treatment..... N/a <input type="checkbox"/>
5.	Lipids a) Checked in past 15 months? Yes <input type="checkbox"/> No <input type="checkbox"/>	b) Date: MM / YY c) Total Cholesterol d) HDL..... e) Non HDL..... f) Treatment.....N/a <input type="checkbox"/>
6.	Feet a) Checked in past 15 months? Yes <input type="checkbox"/> No <input type="checkbox"/>	b) Date: MM / YY c) Under Podiatry Y <input type="checkbox"/> N <input type="checkbox"/> NK <input type="checkbox"/> d) Neuropathy Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/> e) Peripheral Vascular Disease Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/> f) Ulceration Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>
7.	Eyes a) Checked in past 15 months? Yes <input type="checkbox"/> No <input type="checkbox"/>	b) Date: MM / YY c) Retinopathy Yes <input type="checkbox"/> No <input type="checkbox"/> d) Eye Right <input type="checkbox"/> Left <input type="checkbox"/> Both <input type="checkbox"/> e) Background Retinopathy <input type="checkbox"/> Maculopathy <input type="checkbox"/> Proliferative Retinopathy <input type="checkbox"/> f) Under Ophthalmology Yes <input type="checkbox"/> No <input type="checkbox"/>
8.	Hypo Enquiry a) Checked in past 15 months? Yes <input type="checkbox"/> No <input type="checkbox"/>	b) Recent Hypos Yes <input type="checkbox"/> No <input type="checkbox"/> c) Severe Acute Hypoglycaemic Episode in last yearNK <input type="checkbox"/>
9.	Offered structured education? Yes <input type="checkbox"/> No <input type="checkbox"/> NK <input type="checkbox"/>	b) Attended Education *Yes <input type="checkbox"/> No <input type="checkbox"/> c) *If Yes, IDAC <input type="checkbox"/> DAFNE <input type="checkbox"/> BERTIE <input type="checkbox"/> Carb Counting <input type="checkbox"/> *Other <input type="checkbox"/>
10.	Any Pre Conception care counselling? *Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/>	If Yes, any comments.....
11.	Recent admission to hospital with foot problem?	Yes <input type="checkbox"/> No <input type="checkbox"/>
12.	Recent admission to hospital NOT diabetes related?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Who will make initial engagement with the patient? Consultant <input type="checkbox"/> GP practice <input type="checkbox"/> DSN <input type="checkbox"/> PDSN <input type="checkbox"/> Youth Worker <input type="checkbox"/> Psychology <input type="checkbox"/> Other <input type="checkbox"/> Name of person.....		
Telehealth DSN:		

IDAC – Insulin Dose Adjustment Course

DAFNE – Dose Adjustment for Normal Eating

BERTIE – Beta Cell Education Resources for Training in Insulin and Eating

Continued ...

Figure 1. Proforma for baseline data collection (continued)

'Problem Areas in Diabetes' questionnaire completed?	Yes <input type="checkbox"/> No <input type="checkbox"/>
'Wellbeing in Diabetes' questionnaire completed?	Yes <input type="checkbox"/> No <input type="checkbox"/>

Young adult agreed priorities

Criteria to demonstrate improvement <ul style="list-style-type: none"><input type="checkbox"/> Avoidance of hospital admissions<input type="checkbox"/> Improve mental well being<input type="checkbox"/> Obtain HbA1c < 75 mmol/mol<input type="checkbox"/> Attend annual diabetes eye check<input type="checkbox"/> Have bloods taken<input type="checkbox"/> Have micro albuminuria taken<input type="checkbox"/> Improve engagement with HCP via clinics/telehealth Other information
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Figure 2. Invitation to participate

East and North Hertfordshire NHS Trust

Your contact details:

Name: _____

Address: _____

Home telephone number: _____

Mobile number: _____

E-mail address: _____

Please check the above contact details that we have for you. If they are wrong, please let us know.

If they are correct but you do not wish us to make contact with you for an initial discussion, please phone or text us on 01438 xxxxxx within the next five working days of receiving this leaflet.

We very much hope we can support you going forward!

Other useful contact details:

Young adult support worker, Lister Hospital ☎ 01438 xxxxxx



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ENHIDE
 East and North Herts Institute of Diabetes and Endocrinology

Patient Information
 Helping you live better with diabetes
 TeleHealth Young Adult Service





Diabetes TeleHealth Team
 'Here to support YOU'

Dear _____

Thanks for picking up your insulin prescription.

 We wanted to let you know that we are providing a new service for those aged 16-30 who need a more flexible way of supporting diabetes self-care. We will tailor this support to **your** individual needs.

Are you struggling with your diabetes?

We recognise how difficult it can be sometimes to live with diabetes and manage it in your day to day educational or working life, as well as your social life. You might need specific diabetes related advice to deal with working hours, exams, sport, stress, eating out, holidays and many other issues that may arise. 

New methods to contact you regarding your diabetes

The ENHIDE (East and North Herts Institute of Diabetes and Endocrinology) TeleHealth team are here to help in a way that suits you, without clinic appointments if you prefer. We'll be looking to use **Skype, text and phone call** support, and to find times and settings for contact that work for you and us. 

The team providing this service is led by two consultants with the support of a 'young adult support worker' and a dedicated 'diabetes specialist nurse' that you can have regular contact with.

We have a range of new support systems in place to help you better self-care for diabetes. We can direct you to a range of local health and social services, if necessary, regarding work and available resources such as claiming relevant benefits and accessing mental health support if required.

All young people being offered this new support have been identified from GP records as we want to provide this service alongside your primary care team.

We feel that this service could be of particular benefit to you as:

- you have been admitted to hospital with a diabetes emergency within the past two years.
- you have not been able to attend the diabetes eye check for over 12 months.
- you have not had a blood and urine diabetes health check in the past 12 months.
- you have been unable to attend your last two appointments for diabetes clinics and have been discharged in line with the Trust policy.
- your last measure of diabetes control (HbA1c) has been high and we want to provide additional help to reduce the risk of development and progression of complications.
- we feel you would benefit from a more flexible means of support with your diabetes self-care.

We collaborated with the retinal screening team to offer more flexible screening times at weekends and evenings, offering DSN review to coincide with the time of eye screening.

The DSNs and YASW used text, telephone and Skype communication with young adults who requested such support. The timings for access were mutually agreed, enabling contacts at week-end and outside working hours.

Clinical support from the DSNs enabled conversion to peakless basal insulin such as Degludec, use of meters with apps, and readier access to downloading blood glucose readings using DIASEND. A subgroup of individuals with recurrent DKA and/or no record of blood glucose monitoring were selected by the DSNs to have FreeStyle Libre Flash glucose monitoring for a minimum of 1 month to better support self-care, recognition of glycaemia, and need for more effective use of insulin to match carbohydrate intake. This enabled the DSNs to support changes to insulin regimens where nocturnal hypoglycaemic events were documented, or enable carbohydrate counting with insulin bolus advisors.

Use of smart phone applications such as 'Carbs and Cals' was encouraged. Dietetic support was offered through a 3-hour carbohydrate counting course or through more structured education.

All data and contacts were captured on our diabetes data management system after initial baseline documentation was captured using a standardised proforma (Figure 1). Hospital admissions of those included in the study were identified through the Diabetes Outreach Team.

Monthly case reviews by the project team were established to assess adherence to the programme. Quarterly HbA_{1c} measurements were arranged if individual patients were agreeable. Information on the clinical impact and engagement of the patient throughout the project life-cycle was recorded at 6 and 12 months after inception, enabling direct comparison with baseline data to monitor project success.

The original CCG support was contingent on attainment of the key performance indicators in those recruited in this pilot study. These included:

- The proportion of the young adults taking up the offer of support: a minimum of 10% set as a goal
- Baseline and post service changes in individualised care plan improvements
- Ambulance call-outs for young adults with hypoglycaemia reduced by 20%
- Reduction in DKA admissions by 20%

than review of cases admitted with ketoacidosis or hypoglycaemia. Consultant reviews were offered at patients' request. In addition to the goals the patient wished to achieve by being part of the project, an individual care plan was also agreed by the team.

The key role for the YASW was to help participants navigate around medical, social and employment services, to ensure access for support for low-grade mood disorders provided by Hertfordshire County Council and national services such as the 'Big White Wall' and Samaritans, and to improve access to cognitive behavioural therapy. Individuals requiring behavioural support were identified based on responses to the PAID or Wellbeing questionnaires. Services were accessed by self-referral or via the project team. In addition, the YASW provided moral support and basic diabetes advice, and access to smoking cessation programmes (Table 1).

The YASW and the DSNs had discussion with the mental health team to ensure access to clinical psychology and/or psychiatric care for complex mental health issues.

Figure 3. Young Adult Wellbeing Patient Questionnaire

Patient Name:	Completion Date:		Interview Date:		
	Not a problem	Minor Problem	Moderate Problem	Somewhat serious Problem	Serious Problem
1. Not having clear and concrete goals for your diabetes care?	0	1	2	3	4
2. Feeling discouraged with your diabetes treatment plan?	0	1	2	3	4
3. Feeling scared when you think about living with diabetes?	0	1	2	3	4
4. Uncomfortable social situations related to your diabetes care (e.g., people telling you what to eat)?	0	1	2	3	4
5. Feelings of deprivation regarding food and meals?	0	1	2	3	4
6. Feeling depressed when you think about living with diabetes?	0	1	2	3	4
7. Not knowing if your mood or feelings are related to your diabetes?	0	1	2	3	4
8. Feeling overwhelmed by your diabetes?	0	1	2	3	4
9. Worrying about low blood sugar reactions?	0	1	2	3	4
10. Feeling angry when you think about living with diabetes?	0	1	2	3	4
11. Feeling constantly concerned about food and eating?	0	1	2	3	4
12. Worrying about the future and the possibility of serious complications?	0	1	2	3	4
13. Feelings of guilt or anxiety when you get off track with your diabetes management?	0	1	2	3	4
14. Not "accepting" your diabetes?	0	1	2	3	4
15. Feeling unsatisfied with your diabetes physician?	0	1	2	3	4
16. Feeling that diabetes is taking up too much of your mental and physical energy every day?	0	1	2	3	4
17. Feeling alone with your diabetes?	0	1	2	3	4
18. Feeling that your friends and family are not supportive of your diabetes management efforts?	0	1	2	3	4
19. Coping with complications of diabetes?	0	1	2	3	4
20. Feeling "burned out" by the constant effort needed to manage diabetes?	0	1	2	3	4
21. There have been changes in my usual eating patterns or appetite	0	1	2	3	4
22. I have been feeling more sad / lower in mood than usual	0	1	2	3	4
23. I have been worrying or feeling nervous more than usual	0	1	2	3	4
24. I have found things at home more difficult than usual	0	1	2	3	4
25. I have found doing school / college work more difficult than usual	0	1	2	3	4
26. I have found getting on with friends / other pupils / students more difficult than usual	0	1	2	3	4
27. I have found doing what is needed to look after the diabetes more difficult than usual e.g. injections, blood tests, carb counts etc	0	1	2	3	4
28. I am worried about how we are coping as a family	0	1	2	3	4

Table 1 Local and national support services signposted by young adult support worker

Local services	National services
FRANK Adolescent Drugs and Alcohol Service Herts (online drugs advice)	Diabetes UK
Mind in Mid Herts (mental health support)	JDRF (online type 1 diabetes support)
IFST (Intensive Family Support Team)	Carbs and Cals (online, books and APPS)
Youth Connexions (mental health, sexual health, education and employment support)	Young Minds (child and adolescent mental health support)
YMCA (support with health and wellbeing, homelessness, family support, training, education and youth work)	Self-harm UK (online support)
The Wellbeing Service Herts (mental health support)	Kooth (children, adolescent online counselling support)
Rapid Assessment Interface and Discharge (RAID) (mental health in patient liaison service)	Samaritans (Helpline)
LGBT*Q in Hertfordshire (lesbian, gay, bisexual, trans and questioning support, advice and events)	Beat (beating eating disorders)
A-Dash (Adolescent & Alcohol Service Herts)	Brook (eating disorder support)
Sexual health clinics	British Dyslexia Association (online support)
Herts Young & Homeless	Change 4 Life (exercise & diet)
Herts CAMHS (Child Adolescent Mental Health Service)	
Dyslexia Herts	Rethink Mental Health (online support)
Herts Help (range of different support)	Sane (mental health helpline)
Smoke Free Hertfordshire	PALMS (positive behaviour, autism, learning disability and mental health)
Herts Sunflower (Herts domestic abuse helpline)	The Big White Wall (online counselling)

- Improved quality of life measures
- Feedback on patient experience

The project did not commence without challenges:

- Only 70% of the 55 practices expressed interest in supporting the project and providing additional information on patients who met the project criteria; the response was lower from those practices on the fringes of the CCG catchment area.
- Contact details in acute and primary care information systems were not always up to date, raising concern that those considered disengaged may not have received regular communication both prior to and during the initial phase of the pilot study. This became apparent in approximately 40% of cases when a successful second home visit with direct contact identified changes in mobile phone numbers.
- Absence of blood testing often reflected lack of willingness to wait in lengthy queues in the pathology department.
- Face-to-face contact was limited to certain locations on grounds of safety and data protection.

Current status

Initially the project anticipated there would be 200 eligible young adults from the start of recruitment in October 2016. At completion of recruitment in September 2017, 148 young adults not under acute care elsewhere fulfilled criteria for participation.

The majority (n=120) were on basal bolus insulin regimens, 23 were on 1–3 daily injections using pre-mixed and rapid acting



Key messages

- Young adults with type 1 diabetes are frequently disengaged from current models of care
- A new tailored approach for their care is being piloted in 118 out of 148 suitable people, reflecting a high level of initial interest
- Over a 1-year follow-up period we will evaluate impact on hospitalisation, take-up of routine laboratory blood and urine testing and retinal screening, metabolic control and quality of life

insulin and five were on insulin pumps. Overall, 80% (n=118) responded to the invitation to participate in the project, which was staggered over the period from October 2016 to September 2017. Data capture at 6 and 12 months after initiation will enable review of the project outcomes towards the end of 2018.

The ENHIDE young adult telehealth pilot project was designed as a collaborative exercise between primary and specialist care. We have demonstrated in the establishment of the programme that this is both feasible and necessary. If successful, the economic cost per case supported (less than £1000 annually covering the salary costs of the

telehealth team) would be measured against the short-term benefits from reduced unscheduled hospital admissions and better use of clinic appointments, and the potential longer-term savings through reduced diabetes complications.

Conflict of interest: None

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Diary dates 2019

- 6 February** ABCD Yorkshire Regional Diabetes Event
York Racecourse
<https://abcd.care/events/abcd-yorkshire-regional-diabetes-event>
- 13 February** 4th Joint Meeting of ABCD and the Renal Association
NEC, Birmingham
<https://abcd.care/events/4th-joint-meeting-abcd-renal-association>
- 14 February** Obesity Update 2019
Royal College of Physicians, London
<https://www.bioscientifica.com/event-management/our-events/obesity-update-2019/>

- 16 May** ABCD DTN-UK Meeting 2019
Loughborough University
<https://abcd.care/events/abcd-dtn-uk-meeting-2019>
- 16/17 May** ABCD Spring Meeting
Loughborough University
<https://abcd.care/events/abcd-spring-meeting-2019>

For other meetings see <https://www.abcd.care/events>