East and North Hertfordshire NHS Trust
ENHIDE
East and North Herts Institute of Diabetes and Endocrinology

ENHIDE Young Adult Telehealth Project

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Diabetes Telehealth Team

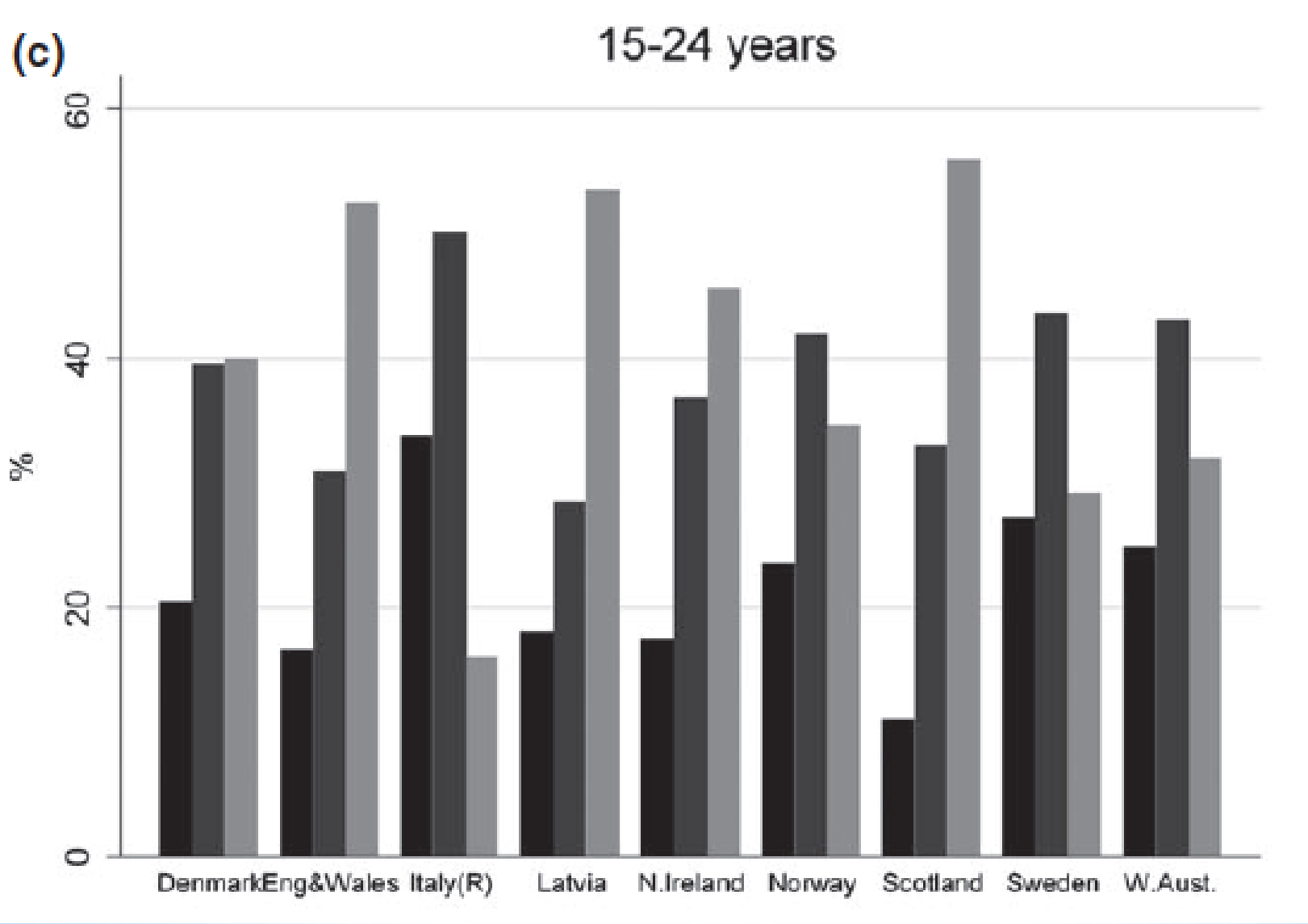
T1 DM care is challenging

- NDA 2014-15 findings in England (and ENH) :
- Completion of 8 care processes 40% (35%)
- HbA1c < 58 mmol/mol (< 7.5%) 31% (34%)
- Offered structured education 33% (35%)

Why is T1 DM care challenging (especially in young adults)?

- 150 standards in NICE T1DM guidelines !!
- These include diagnosis, CYP care , pumps , CGMS , education , hypo awareness , other AI screening , psychology , pregnancy , microvascular and macrovascular complications , emergency care , exercise , driving , occupational and higher education issues
- Target HbA1c now set at 48 mmol/mol (6.5%)

Comparing HbA1c outcomes across Europe



McKnight et al, Diabet Med 2015

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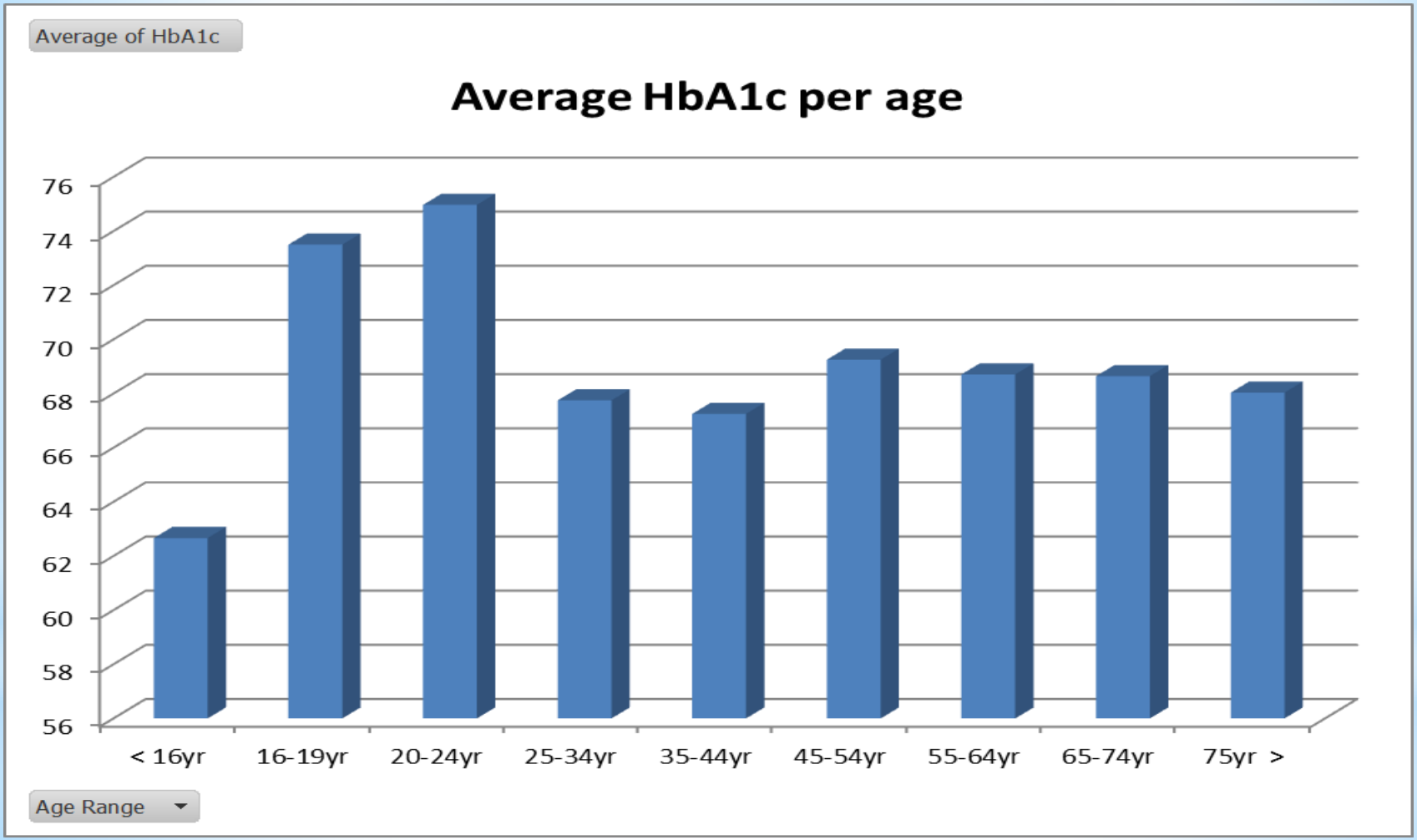

Limitations of structured education using psychological techniques- CASCADE study

- In children and adolescents with established T1DM
- No impact on HbA1c at 12 and 24 months
- Low uptake , high cost
- Previous studies of psychological interventions in those with poor control found no impact

- Christie et al . BMJ Open , 2016

SDRN 2011-Retinopathy in Young People

- Retinal screening DNA rates :
- 15-30% aged 16-19 and 25-38% aged 20-25
- Referable retinopathy after DRS :
- 4.5% aged 15-25 and 8.2%* aged 25-34
- *Highest of all age categories

Beyond Transition – Club 18-30

- Higher prevalence in 18-30 than < 18 yrs old
- NDA registrations T1DM were 8% < 15 , 6.5% 16-20 and 14% 20-30
- Many T1DM diagnosis aged > 18 never under paediatric care
- BpT operates till age 19 then .. !

ENHIDE Transfer Audit

- Audit of 77 T1DM transferred from transition to adult care in 2006-12
- Delays in YAC appointments , high DNA rates
- 20% lost to follow up at transfer
- 2016 review – 25 of these 77 cases aged 22-28 years old remain disengaged

What do disengaged young adults with T1DM want ?

- For HCP to understand their individual issues that hinder engagement - **don't make assumptions !**
- Individualised person-centred care planning
- Relationship building and needs-based assessment
- Problem solve difficulties in self-management
- ? Peer support – mentoring through transition
- Telehealth support and appts, inc out of hours
- Proactive information – issues, events, developments
- Young adult support worker to navigate through the system
- Avoid negative directive consultations and offer gender appropriate care if requested
- DUK 2016 Meeting healthcare needs of young people with type 1 diabetes

Type 1 Diabetes in ENH

- ? Estimated 2600 with T1DM ? 800 aged 16-30
- Currently 1342 under acute specialist care of whom 413 (31%) aged 16-30
- Potentially 200 (48%) of these were identified from records initially and considered ‘disengaged’

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Young Adult

Telehealth Project

East and North Hertfordshire CCG Map

- Ashwell
- Baldock
- Courtenay House
- Orford Lodge
- Portmill
- Regal Chambers
- Knebworth & Marymead
- Birchwood
- Garden City
- Nevells Road
- Sollershott
- Whitwell

- Puckeridge
- Buntingford Medical Centre
- Orchard
- Castlegate
- Hanscombe House
- Wallace House
- Ware Road
- Watton Place
- Haileybury College
- Hailey View
- Amwell Street
- Park Lane
- Church Street
- Dolphin House
- The Maltings
- The Limes

- Bedwell Medical Centre
- Canterbury Way
- Chells Way
- King George
- Manor House
- Shephall Way
- St Nicholas Health Centre
- Stanmore Medical Group
- Symonds Green Health Centre

- Church Street
- Parsonage
- South Street
- The Health Centre
- Central Surgery

- Burvill House
- Lister House
- Potterells Medical Centre
- Wrafton House
- Bridge Cottage
- The Garden City
- Hall Grove
- Peartree Lane
- Spring House

- The Maples
- Cromwell and Wormley
- High Street
- Stockwell Lodge
- Warden Lodge
- Cuffley and Goffs Oak
- Abbey Road
- Stanhope

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Disengaged - Young Adults

Young Adult

Objective

- Contact with a member of the health care team via the Young adult support worker or DSN.
- Improved attendance for clinics
- Improved attendance for routine blood tests and other screening tests – including retinal screening.
- Reduction in hospital admissions with DKA – all DKA admissions reviewed by project consultants.
- Improved patient experience.
- At least 10% Engagement

Getting Started

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Young Adult

- Identifying patients for inclusion (initial estimate 250 pts)
- Criteria for inclusion
  - Admitted with DKA,
  - Not attended Retinal Screening,
  - No Bloods or Micro albuminuria taken in last 15mths,
  - Not attended 2 consecutive appointments,
  - Hba1c higher than 75mmol/mol,
  - Benefit from a more flexible approach
- Contacting the practice for engagement
- Practice meetings / discussions for further knowledge on patient history
- Invite leaflet sent out to patient (includes process to 'Opt out')
- Baseline form completed on patient
- Wellbeing and DAWN questionnaire completed
- 6 month follow up form completed
- Final 12 month form completed

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Young Adult

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 **07585 328751** or **07585 328754** 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 ☎ 07585 328750

Date of publication: January 2017
Author: Diabetes/Enhide
Reference: Version: 01
Review Date: January 2020

www.enherts-tr.nhs.uk

You can request this information in a different format or another language.

East and North Hertfordshire NHS
NHS Trust

Patient Information

Helping you live better with diabetes

TeleHealth Young Adult Service

ENHIDE
East and North Herts Institute of Diabetes and Endocrinology

Diabetes TeleHealth Team

'Here to support YOU'

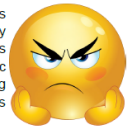
Dear _____

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.

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Young Adult

TeleHealth Young Adult

(Baseline Form)

Addressograph
Name:
Date of Birth:
Gender: Male ☐ Female ☐
NHS Number:
Hospital Number:

Practice Name..... **Date diagnosed:** ...../...../..... **Date Completed:** ...../...../.....

Patient Care managed by: Acute Care ☐ Primary care ☐ Community Team ☐

Safeguarding Issues? *Yes ☐ No ☐ N/A ☐ *State .....

Weight: **BMI:**

Reasons for inclusion on the Telehealth project?

Admitted to hospital with a diabetes emergency within the past 2 years? DKA ☐ Hypo ☐ *Other ☐ *state.....	Yes ☐ No ☐
Attended an annual diabetes eye check?	Yes ☐ No ☐
Diabetes blood test taken in the past 15 months?	Yes ☐ No ☐
Micro albuminuria tested in the past 15 months?	Yes ☐ No ☐
Not attended 2 consecutive appointments for diabetes clinics (in hospital or community diabetes service) in last 2yrs or discharged.	Yes ☐ No ☐
HbA1c higher than 75 mmol/mol?	Yes ☐ No ☐
Would benefit from a more flexible means of supporting diabetes care?	Yes ☐ No ☐

Psychosocial Domestic Status:

Under Paed Clinical Psychology/CAMHS? Offered ☐ Under ☐ Declined ☐ N/A ☐ NK ☐
Comments: .....

Under IAPT/Adult Psychiatry? No ☐ Offered ☐ Under ☐ Declined ☐ N/A ☐ NK ☐
Comments: .....

Social status? Living with parents ☐ Living with single parent ☐ Living alone ☐ Parents Divorced ☐

Parents Separated ☐ Living with friends/House Share ☐ No Fixed Abode ☐

Divorced ☐ In a relationship ☐ Living with partner ☐ Married ☐ Separated ☐ Single ☐ Widowed ☐

At School/Uni? Yes ☐ No ☐ **Working?** *Yes ☐ No ☐ ***If Yes Occupation** .....

Exercise? Low ☐ Moderate ☐ High ☐ **Alcohol?** None ☐ < 5 units ☐ 6-15 units ☐ > 16units ☐

***(Within the last 2 yrs)* Smoking?** Yes ☐ Previous smoker ☐ Never ☐ N/K ☐

Driving? Yes ☐ No ☐ N/K ☐ DVLA informed on Insulin ☐ N/K ☐ **Recreational Drugs?** Yes ☐ No ☐ N/K ☐

Additional Information .....
.....
.....
.....

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Young Adult

Patient Tests/Results:

1. **HbA1c a) Checked in past 15 months?** Yes ☐ No ☐ **b) Result**..... **c) Date:** MM / YY
d) Rising ☐ Variable ☐ Stable ☐ Improving ☐ Low –Normal ☐ No previous results to grade ☐
e) Treatment.....
.....
.....N/a ☐

2. **eGFR a) Checked in past 15 months?** Yes ☐ No ☐ **b) Result <60** Yes ☐ No ☐
c) Result..... **d) Date:** MM / YY **e)** Deteriorating ☐ Variable ☐ Stable ☐

3. **ACR a) Checked in past 15 months?** Yes ☐ No ☐ **b) Result >10** Yes ☐ No ☐
c) Result..... **d) Date:** MM / YY **e)** Deteriorating ☐ Variable ☐ Stable ☐

4. **Blood Pressure: a) Checked in past 15 months?** Yes ☐ No ☐ **b) Result**.....
c) Date: MM / YY **d) <130/75** Yes ☐ No ☐ N/a ☐
e) Treatment.....
.....N/a ☐

5. **Lipids a) Checked in past 15 months?** Yes ☐ No ☐ **b) Date:** MM / YY
c) Total Cholesterol ..... **d) HDL**..... **e) Non HDL**.....
f) Treatment.....
.....N/a ☐

6. **Feet a) Checked in past 15 months?** Yes ☐ No ☐ **b) Date:** MM / YY
c) Under Podiatry Y ☐ N ☐ NK ☐ **d) Neuropathy** Yes ☐ No ☐ NK ☐
e) Peripheral Vascular Disease Yes ☐ No ☐ NK ☐ **f) Ulceration** Yes ☐ No ☐ NK ☐

7. **Eyes a) Checked in past 15 months?** Yes ☐ No ☐ **b) Date:** MM / YY
c) Retinopathy Yes ☐ No ☐ **d) Eye** Right ☐ Left ☐ Both ☐
e) Background Retinopathy ☐ **Maculopathy** ☐ **Proliferative Retinopathy** ☐
f) Under Ophthalmology Yes ☐ No ☐

8. **Hypo Enquiry a) Checked in past 15 months?** Yes ☐ No ☐
b) Recent Hypos Yes ☐ No ☐ **c) SAHE in last year** .....**NK** ☐

9. **Offered structured education?** Yes ☐ No ☐ NK ☐ **b) Attended Education** *Yes ☐ No ☐
c) *If Yes, IDAC ☐ Daphne ☐ BIDEC ☐ Carb Counting ☐ *Other ☐ .....

10. **Any Pre Conception care counselling?** *Yes ☐ No ☐ N/A ☐
If Yes, any comments.....

11.	Recent admission to hospital with foot problem?	Yes ☐ No ☐	
12.	Recent admission to hospital NOT diabetes related?	Yes ☐ No ☐	

Who will make initial engagement with the patient? Consultant ☐ GP practice ☐ DSN ☐ PDSN ☐
Youth Worker ☐ Psychology ☐ Other ☐ Name of person.....

Telehealth DSN:

Karen Moore-Haines/Telehealth Project/Jan 17/v9

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Young Adult

Practice Engagement

- Excellent engagement from practices identifying young adults suitable for the project.
- Focused initially on the localities closer to the Lister and New QE2 hospital.
- Approximately 1-5 patients included in the project, per practice.

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Young Adult

Figures to date:	Total
Total Number of 'Young Adults' reviewed	**341**
Reviewed and not included	**160**
Currently identified Young Adults for Project	**181**
Total number of 'Young Adults' sent invite leaflet	**181 (100%)**
Patients removed from Telehealth	**16 (9%)**
Total number of patients to 'Opt out'	**5 (2%)**
Total number of patients who have had initial engagement & baseline proformas	**81 (51%)**

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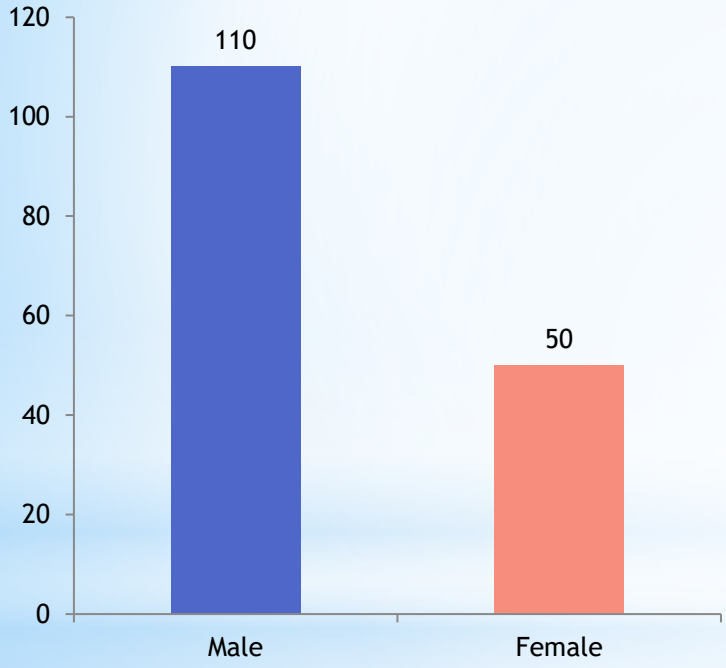
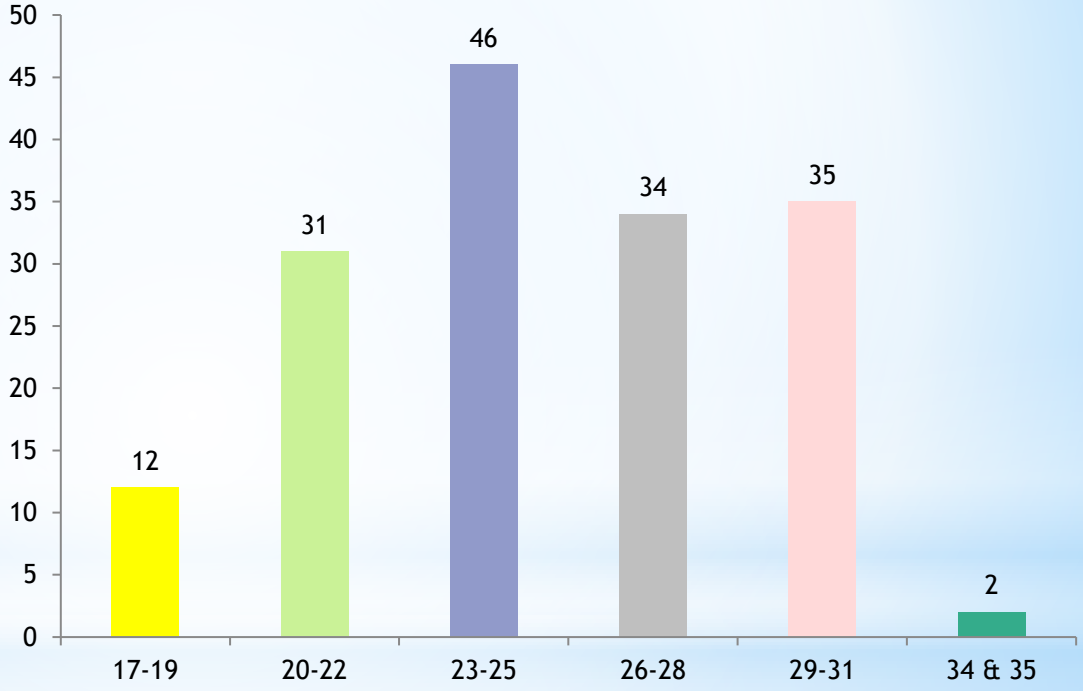
Young Adult

Gender



Age



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Young Adult

Key Messages to date:

- Very low number of patients 'Opting out' of the project (2%)
- Very positive response so far from YA's who are keen to re-engage.
- Increasing uptake in medical technologies and carb counting course, 28 patients out of 81 (35%)
- Patients are very keen to communicate via text and phone, a few interested in using Skype or Skype messaging. Some have shown interest in 'Whats App' but current Trust policy does not allow this technology.

Role of the Telehealth DSN

- Offer a flexible approach to patient management
- Agree patients priorities
- Agree clinical criteria for improvement
- Improve engagement with HCP
- Use of different methods of communication
- Use of apps
- 3hr carbohydrate awareness course
- Access to newer insulins
- Offer flash glucose monitoring (Libre) or Dexcom CGMS
- Use of Diasend for remote consultation

Initial summary of patients needs / requirements

- Patients want face to face consultations at times convenient to them
- A general feeling of low morale
- Diabetes is not top of their agenda
- Interested in new technology
- Large proportion of patients with mental health needs
- High proportion of disengaged patients following transition
- Issues with appointments – trust cancellation policy

- Wanting a cure for Diabetes!!

Role of the Young Adult Support Worker

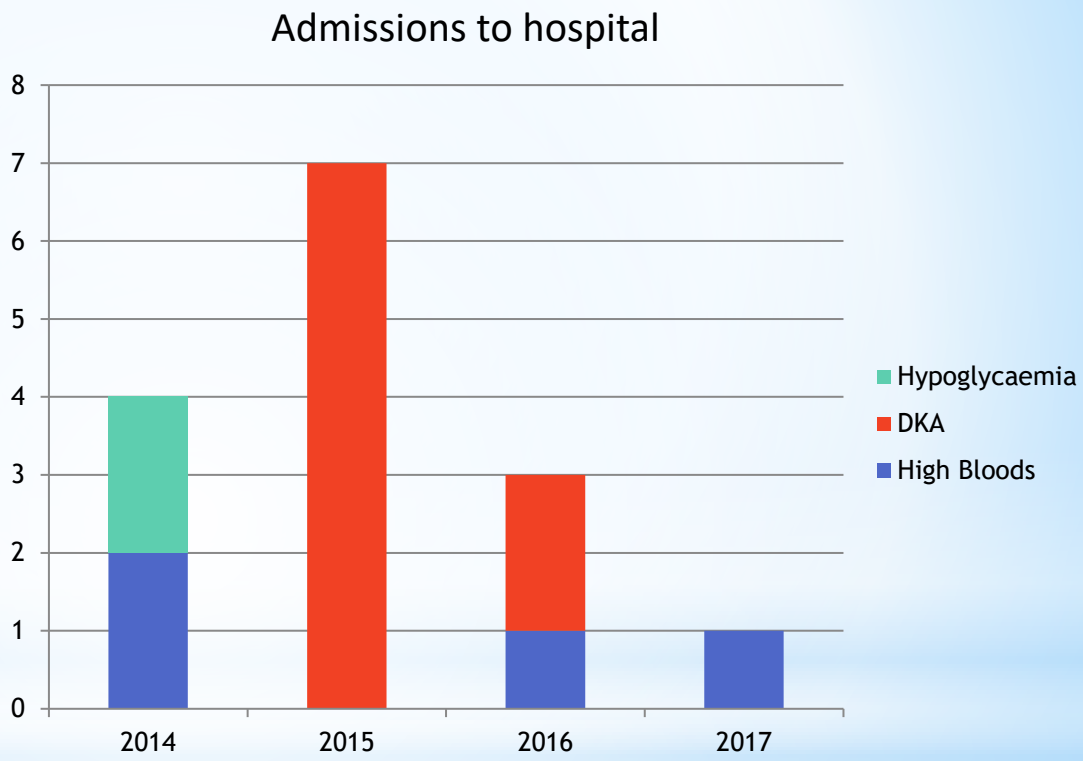
- To work holistically with young people.
- Provide a support service focusing on everyday lifestyles.
- Ensure patients are aware of current support aimed at young adults provided by the local county council, NHS Trust such as Diabetes education programs .
- Ensure patients are aware of current support aimed at young adults provided by national based support such as Diabetes UK and JDRF.
- Assisting with self-help approaches with diet control, glucose monitoring, clinic appointments and emotional support.
- Signpost young adults to appropriate services and assists with completing forms and making contact with services on behalf of the young adult, if appropriate.

- **Communication with the Young Adults to the YA Support Worker will be via phone calls, text messaging, SKYPE, email and face to face contact.**

Case Study – Young Adult Support Worker

Pre Telehealth

- Diagnosed diabetes in 2013
- Single parent
- Minimal family support
- Poor mental health
- Year of diagnoses HbA1c 65mmol
- 5 months later 95mmol
- HbA1c levels between 65 – 118mmol
- 2014 – 2017 – 15 admissions



Post Telehealth

- 2017 – 1 admission (January pre telehealth)
- Post telehealth 83mmol
- No admission & full engagement

Any Questions?