Type 1 Diabetes in Children and Young Adults (0-25yrs)

Presented by:
Joint Children and Young Adults Diabetes Workstream

Welcome

Candice Ward – CDEP Lead,

Cambridge Diabetes Education Programme

Housekeeping

Please do take the opportunity to say “Hi” via the chat box

If you wish to ask a question, please use the Q&A session.

If you have any technical issues, please leave and join again.

This webinar will be recorded and shared widely

Webinar Speakers

Dr Fulya Mehta – National Clinical Lead Diabetes in Children and Young Adults, NHS England

Verity Hawkes – Senior Project Manager, National Diabetes Programme, NHS England

Dr Reza Zaidi – Young Adult Advisor, Consultant Diabetologist

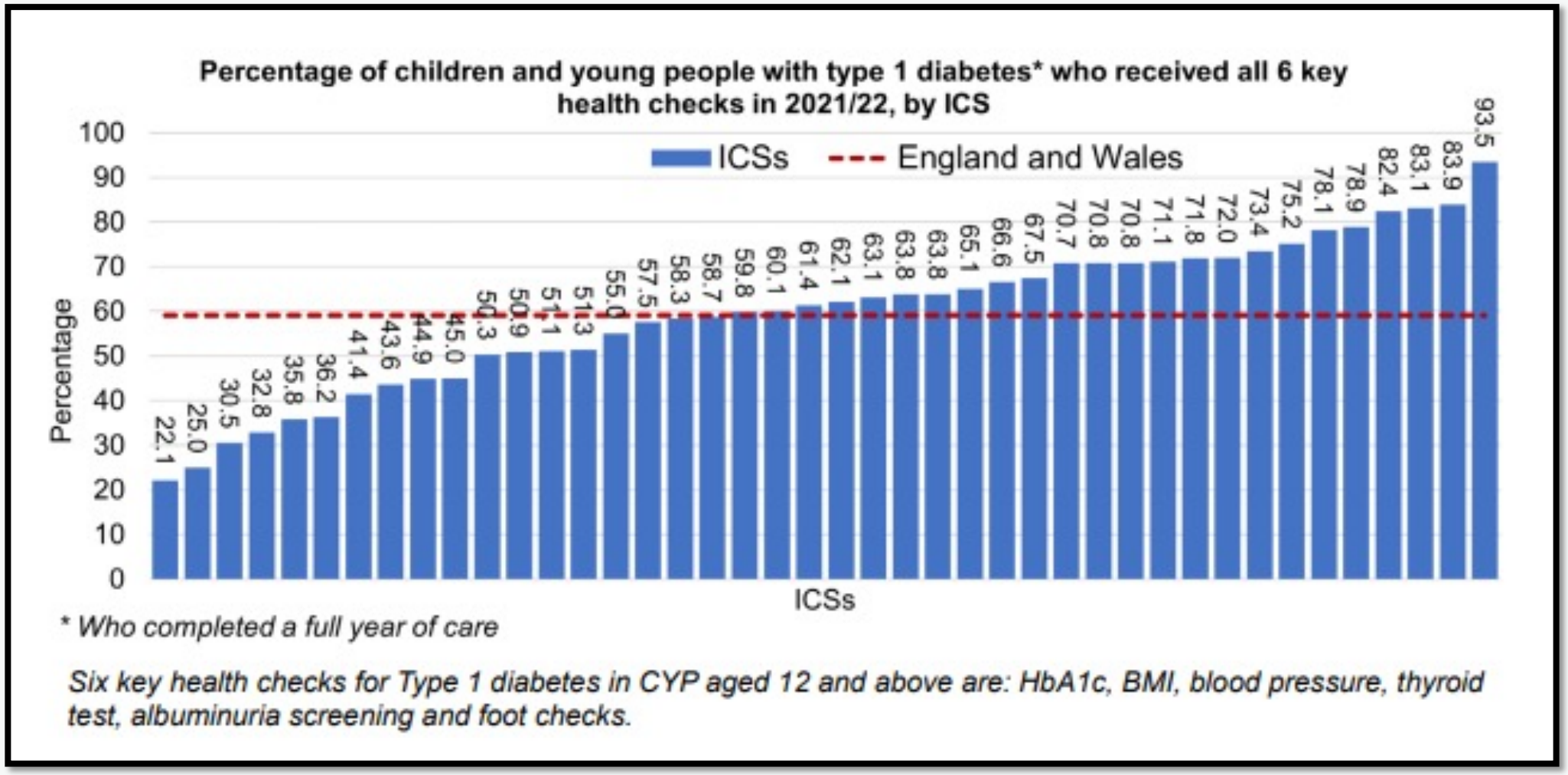
Data Insights

Verity Hawkes, NHS Diabetes Programme

Data Headlines

- There were 58,925 people aged 0-25 years with Type 1 diabetes registered in the National Diabetes Audit in 2021/22, and 31,349 children and young people were cared for within paediatric diabetes units.
- There has been an increase in the incidence of Type 1 diabetes in children since the COVID-19 pandemic.
- Average HbA1c levels (a key marker of blood sugar management) in paediatrics have improved over the past decade. However, levels are still higher than the NICE treatment targets.
- Inequalities in outcomes exist between groups of the population (by age, ethnicity and socioeconomic deprivation).
- There is also variation in care and outcomes across the country, between NHS trusts and Integrated Care Systems.

Data Insights: Unwarranted Variation



NPDA, 2021/22

Support for Quality Improvement

Key Sources of Data

Where to find your local data:

Source	Data included	Geography	Dashboard links
National Paediatric Diabetes Audit (NPDA)	Data for those cared for by paediatric units, up to age 24 years	Region, ICB, Unit	NPDA Online (rcpch.ac.uk)
National Diabetes Audit (NDA)	Data on those registered with diabetes from both primary and secondary care settings	Region, ICB and Sub ICB	NDA Core Annual Dashboard, NDA Core Quaterly Dashboard & NDA Type 1 Dashboard
Adolescent and Young Adults' (AYA) Audit	Data on demographics, care and outcomes for people with Type 1 diabetes aged 15-25yrs	Region and ICB	AYA dashboard
CYP Transformation Dashboard	DKA admissions in those aged 0-25 years	ICB and Trust	NHS England applications (model.nhs.uk) (requires registration)

National Diabetes Audit dashboards

Welcome to the National Diabetes Audit dashboard hub. This page provides links to a number of interactive data visualisation tools containing data relating to provision of care and services for people with diabetes.

These visualisations are mainly produced in Microsoft Power BI at present and allow users to interact with the data available.

National Diabetes Audit Core Annual Dashboard

This dashboard presents local data on care process completion and treatment target achievement, as well as participation and registration information.

→

National Diabetes Audit Core Quarterly Dashboard

The core quarterly dashboard provides care process and treatment target information using primary care data for England. It is refreshed 4 times throughout the audit period. This dashboard also includes several post-COVID pandemic service recovery metrics.

→

Adolescent and Young Adult Type 1 Diabetes Dashboard

This dashboard presents data related to the audit of care provision during the period when young people with diabetes move from paediatric to adult based clinical care.

→

National Diabetes Audit Young People with Type 2 Diabetes Dashboard

This dashboard presents local data on the characteristics, care process completion and treatment target achievement of young people (aged under 40 years old) with type 2 diabetes.

→

Publication, Part of National Diabetes Audit, Adolescent and Young Adult Type 1 Diabetes

Adolescent and Young Adult Type 1 Diabetes Audit (AYA), 2017-21

Publication Date: 16 Jun 2022
Geographic Coverage: England, Wales
Geographical Granularity: Country, Regions
Date Range: 01 Jan 2017 to 31 Mar 2021

Content:

Click on the → next to the pages below to access that area of the dashboard.

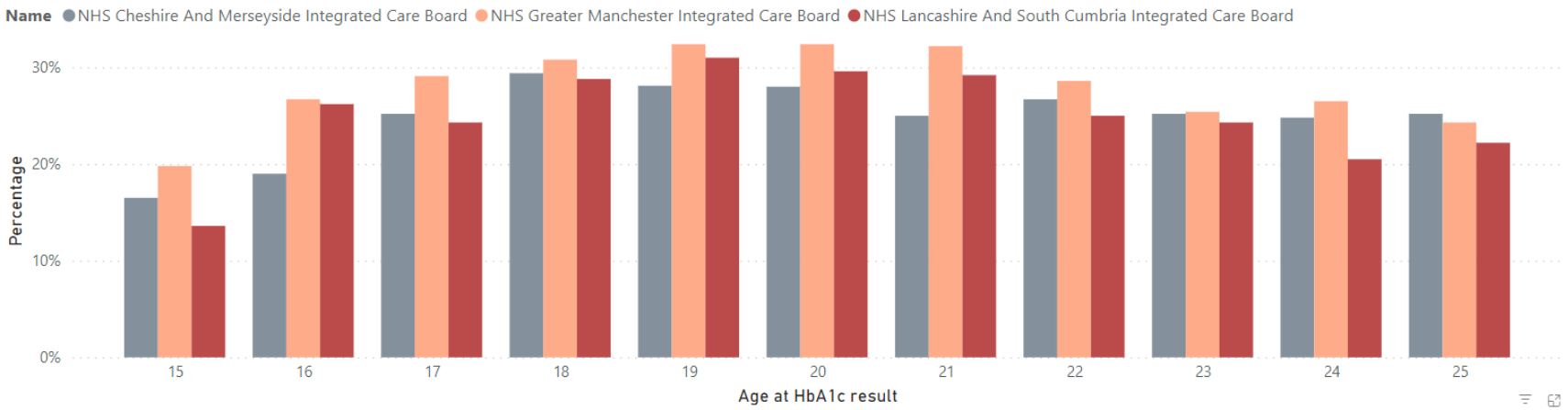
- → Definitions
- → Additional Information
- → Search for ICS
- → Demographics - ICS/Region/Country
- → BMI by Age - ICS/Region/Country
- → Average HbA1c by Age - ICS/Region/Country
- → HbA1c Measures by Age - ICS/Region/Country
- → Care Processes by Age - ICS/Region/Country
- → DKA and Insulin Pump by Age - ICS/Region/Country

NDA Adolescent and Young Adult Type 1 Diabetes Report

HbA1c Measures by Age - ICS/Region/Country

NHS Digital · RCPCH · NPDA · NHS Wales GIG Cymru · HQIP · Diabetes UK

Select Level: (Select First)	Select Country:	Select Region(s):	Select ICS(s):	Select Measure:	Select Age(s):
ICS	England	North West	Multiple selections	HbA1c > 86 mmol/mol	All



Age	15			16			17			18			19
Name:	Numerator	Denominator	%	Numerator	Denominator	%	Numerator	Denominator	%	Numerator	Denominator	%	Num
NHS Cheshire And Merseyside Integrated Care Board	70	425	16.5%	100	525	19.0%	150	595	25.2%	175	595	29.4%	
NHS Greater Manchester Integrated Care Board	100	505	19.8%	140	525	26.7%	160	550	29.1%	165	535	30.8%	
NHS Lancashire And South Cumbria Integrated Care Board	40	295	13.6%	85	325	26.2%	90	370	24.3%	115	400	28.8%	

NPDA Results Online

RCPCH Royal College of Paediatrics and Child Health
Leading the way in Children's Health

NPDA Results Online

- Home
- Unit Data
- CCG/LHB Data
- ICS Data
- Network Data
- NHS Region Data
- Outlier Data
- Longitudinal Data
- Annual Reports
- Help / FAQs
- Report a glitch

Unit Data

(Please select your criteria below)

Audit Measures: Key care process completion breakdown (all)

Chart Type:

Primary Unit/Hospital: Royal Cornwall Hospital

2nd Unit/Hospital: Select a second Unit/Hospital (OPTIONAL)

3rd Unit/Hospital: Select a third Unit/Hospital (OPTIONAL)

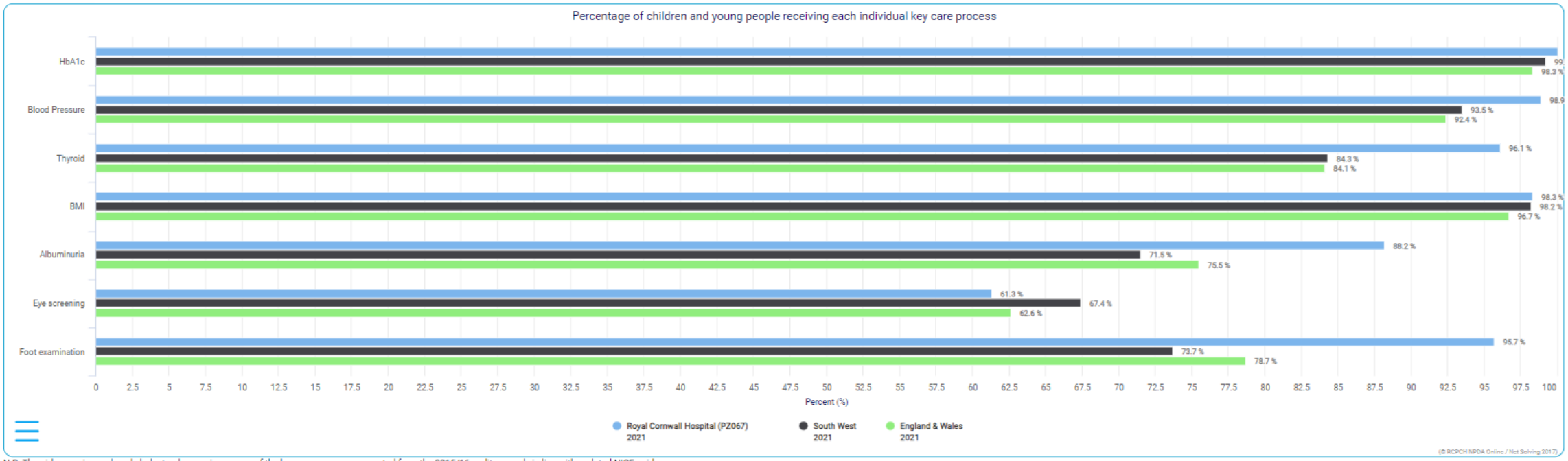
4th Unit/Hospital: Select a fourth Unit/Hospital (OPTIONAL)

Data year range from: 2021-22 To Data year: 2021-22

ALSO DISPLAY:

☑ Region Average ☑ National Average

Help View Chart



N.B. Thyroid screening replaced cholesterol screening as one of the key care processes reported from the 2015/16 audit onwards in line with updated NICE guidance

DKA Dashboard

Select your location

Region: (All) | Integrated Care Board: (All) | Provider: (All) | Clear filter

Select your Ketoacidosis Indicator

Indicator name: Diabetic Ketoacidosis emergency admissions (all) | Financial year: 2023/24 | Age group(s): (All)

Diabetic Ketoacidosis emergency admissions (all)

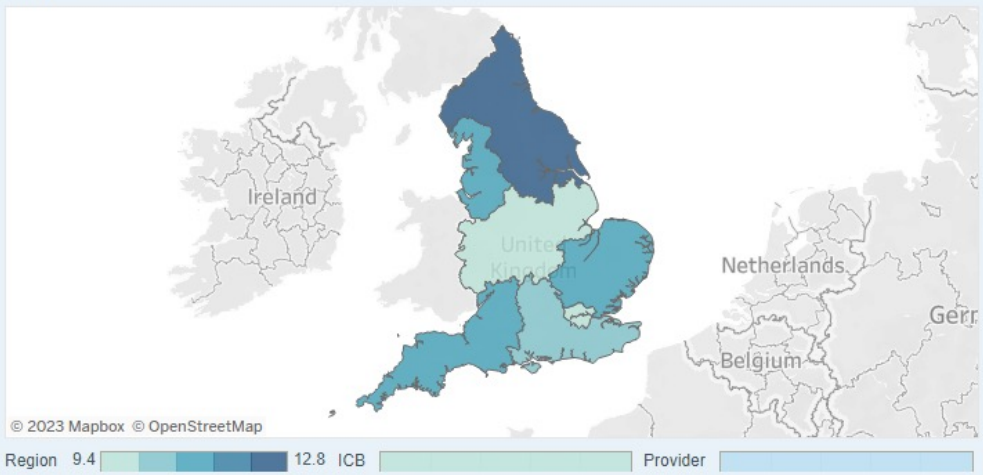
National: 10.6 per 100k (FY 2023/24)

Age group: All, Context selected: Region

Context selector: Region | ICB | Provider

Benchmarking ⓘ Select a Bar in the benchmarking chart to highlight the location in the Map and Time series.

Map ⓘ



Select your Ketoacidosis Indicator

Indicator name: Diabetic Ketoacidosis emergency admissions with a new diabetic diagnosis

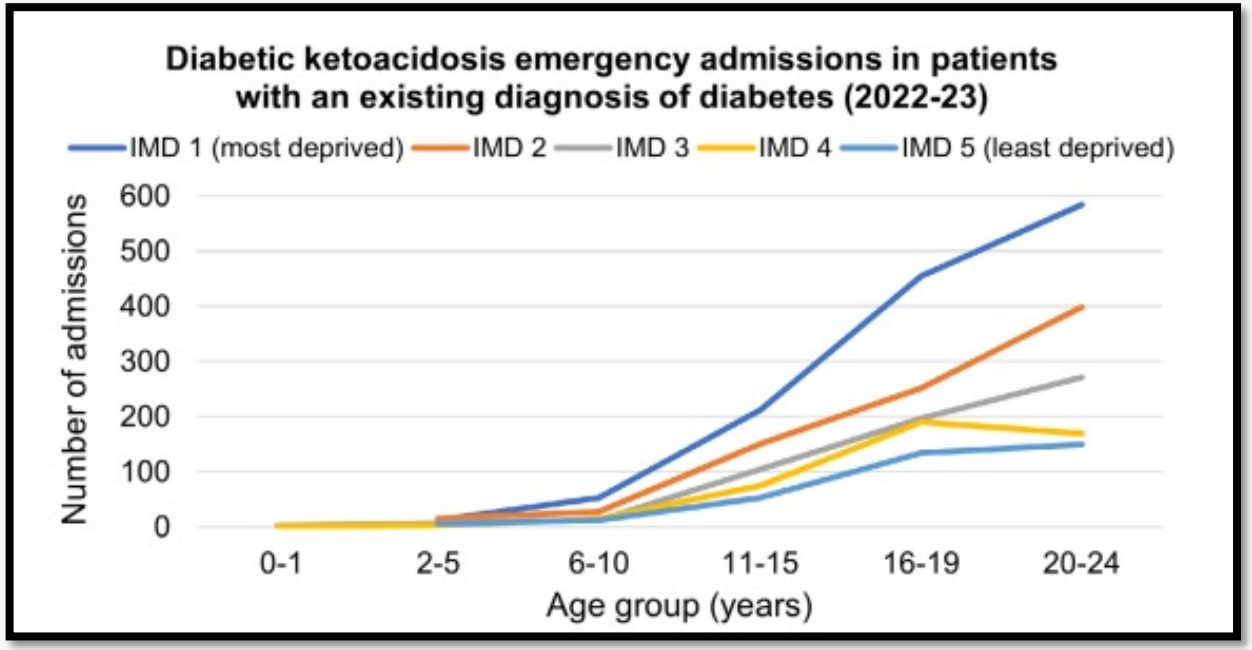
- Diabetic Ketoacidosis emergency admissions (all)
- Diabetic Ketoacidosis emergency admissions with a new diabetic diagnosis
- Diabetic Ketoacidosis emergency admissions with an existing diabetic diagnosis

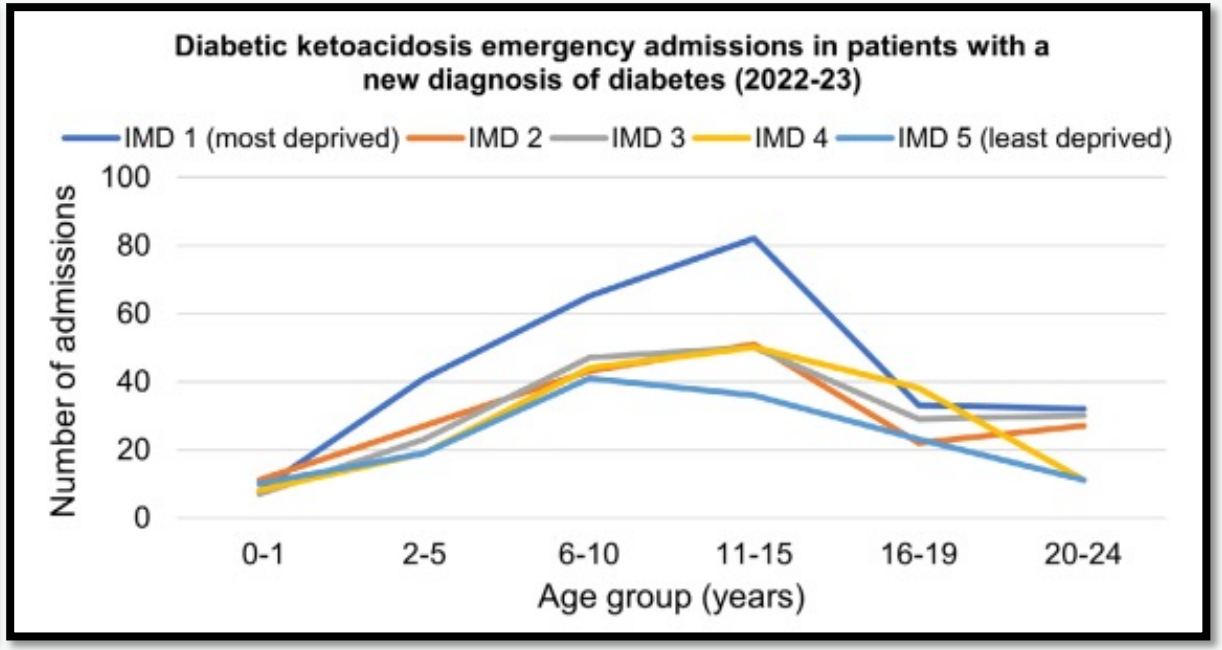
Diabetic ketoacidosis (DKA)

Dr Fulya Mehta - National Clinical Lead for Children and Young Adults

Data Insights: Hospital Admissions

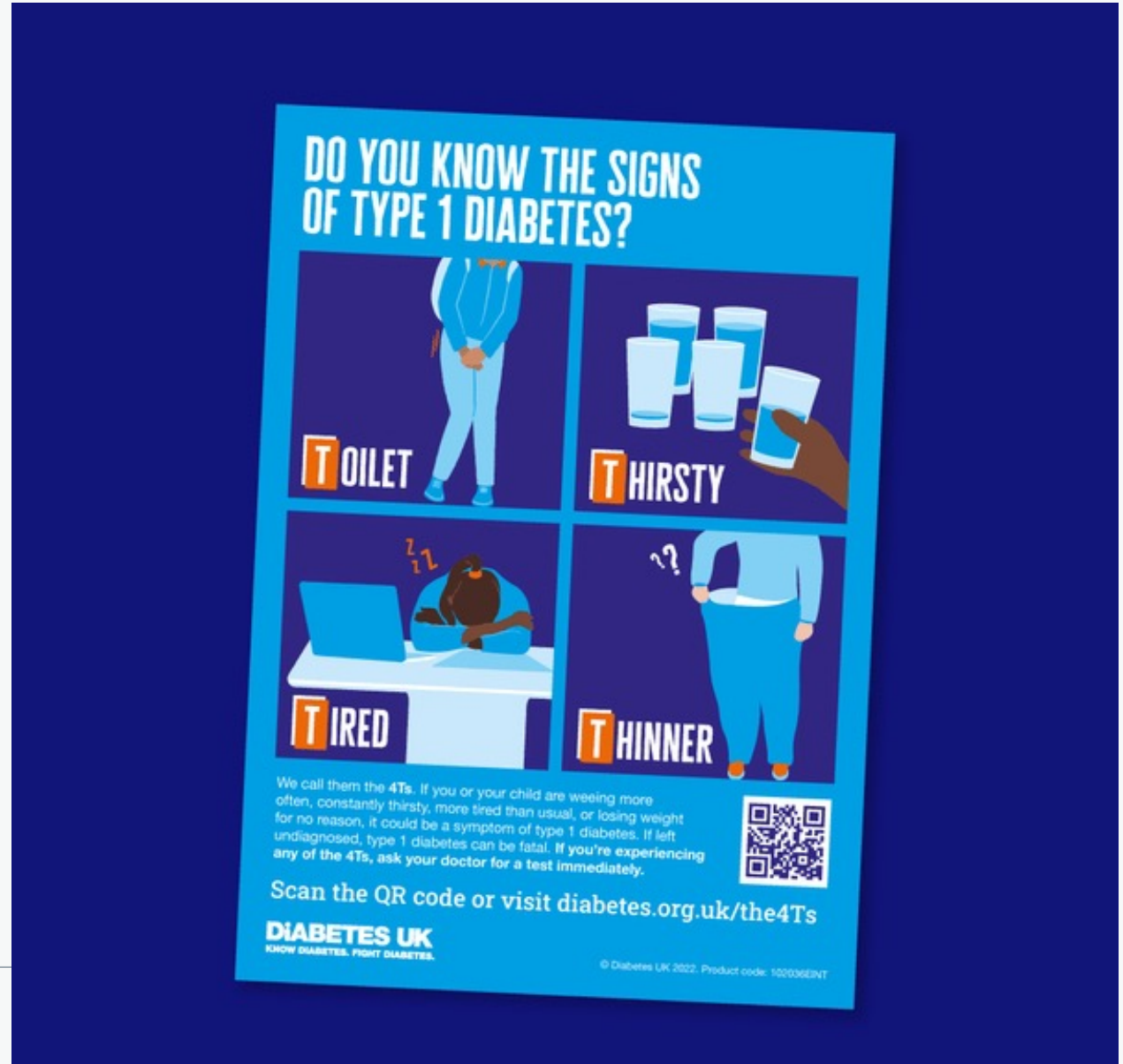
Diabetic ketoacidosis (DKA) admissions





Identifying Type 1 Diabetes

DIABETES UK
KNOW DIABETES. FIGHT DIABETES.



Identifying Type 1 Diabetes and DKA

- In addition to the 4T's also think about diabetes in children with:
  - Recurrent oral thrush
  - Persistent nappy rash

- Children with suspected diabetes should have a finger prick blood glucose test on a blood glucose meter. All GP practices should ensure they have a blood glucose meter available

- Blood glucose levels >11mmol/l indicates diabetes. Transfer immediately to hospital for further assessment.

- Children who have developed DKA may show the following additional symptoms:
  - Sleepy or confused
  - Deep sighing breathing
  - Abdominal pain
  - Vomiting
  - Breath that smells fruity (pear drops)

Preventing DKA at Diagnosis

E-learning Tool

A short e-learning tool has been developed by a working group as part of the National Children & Young People's Diabetes Network aimed at primary care health professionals

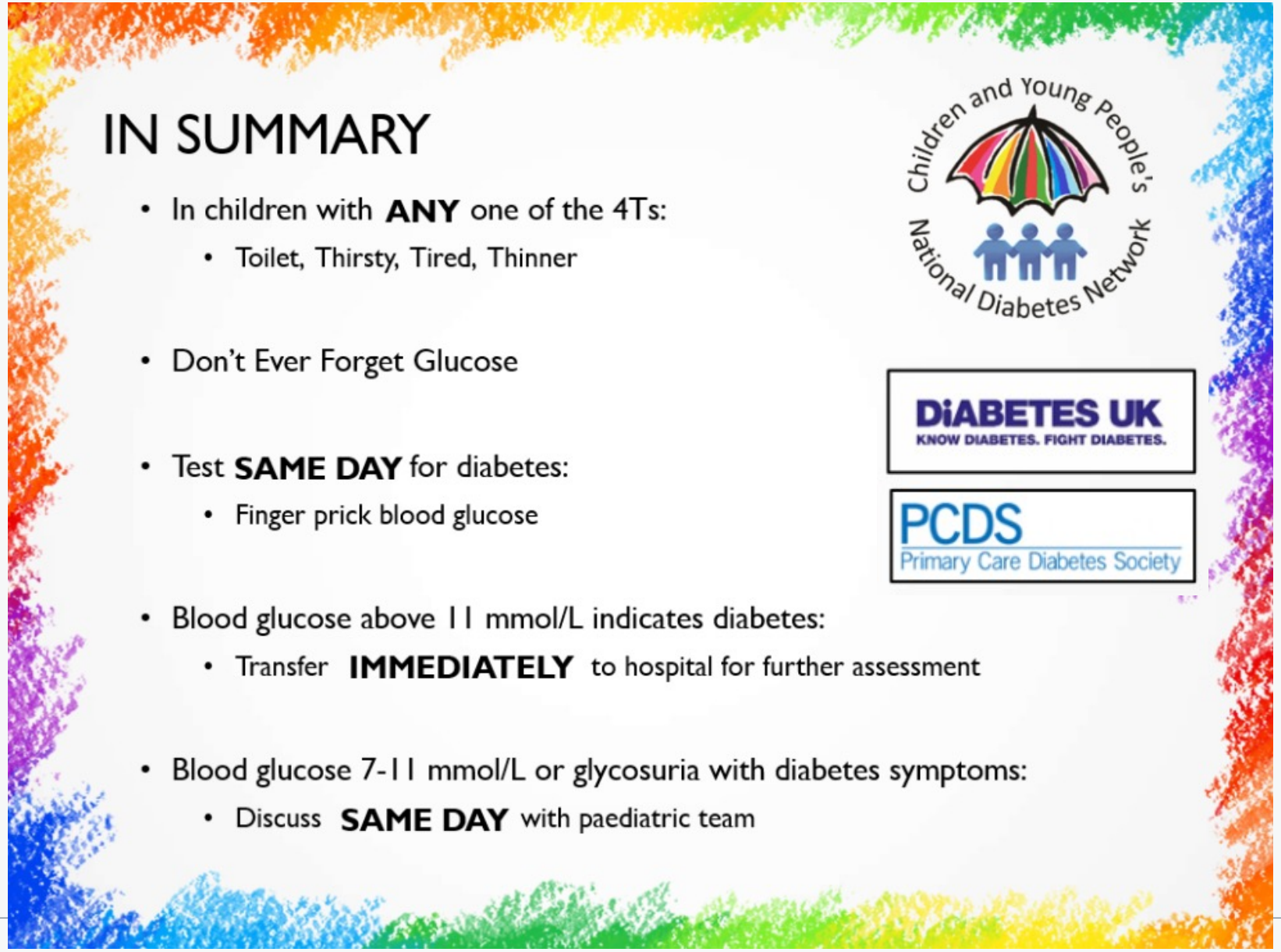
Learning objectives:

- Recognition of the symptoms of type 1 diabetes in children
- What to do when type 1 diabetes is suspected
- Importance of prompt diagnosis to avoid DKA
- Reasons why the diagnosis might be delayed or missed

The e-learning tool plays as a slideshow and it takes around 5 minutes to read.

Link: [Short e-learning tool - National Network (cypdiabetesnetwork.nhs.uk)]

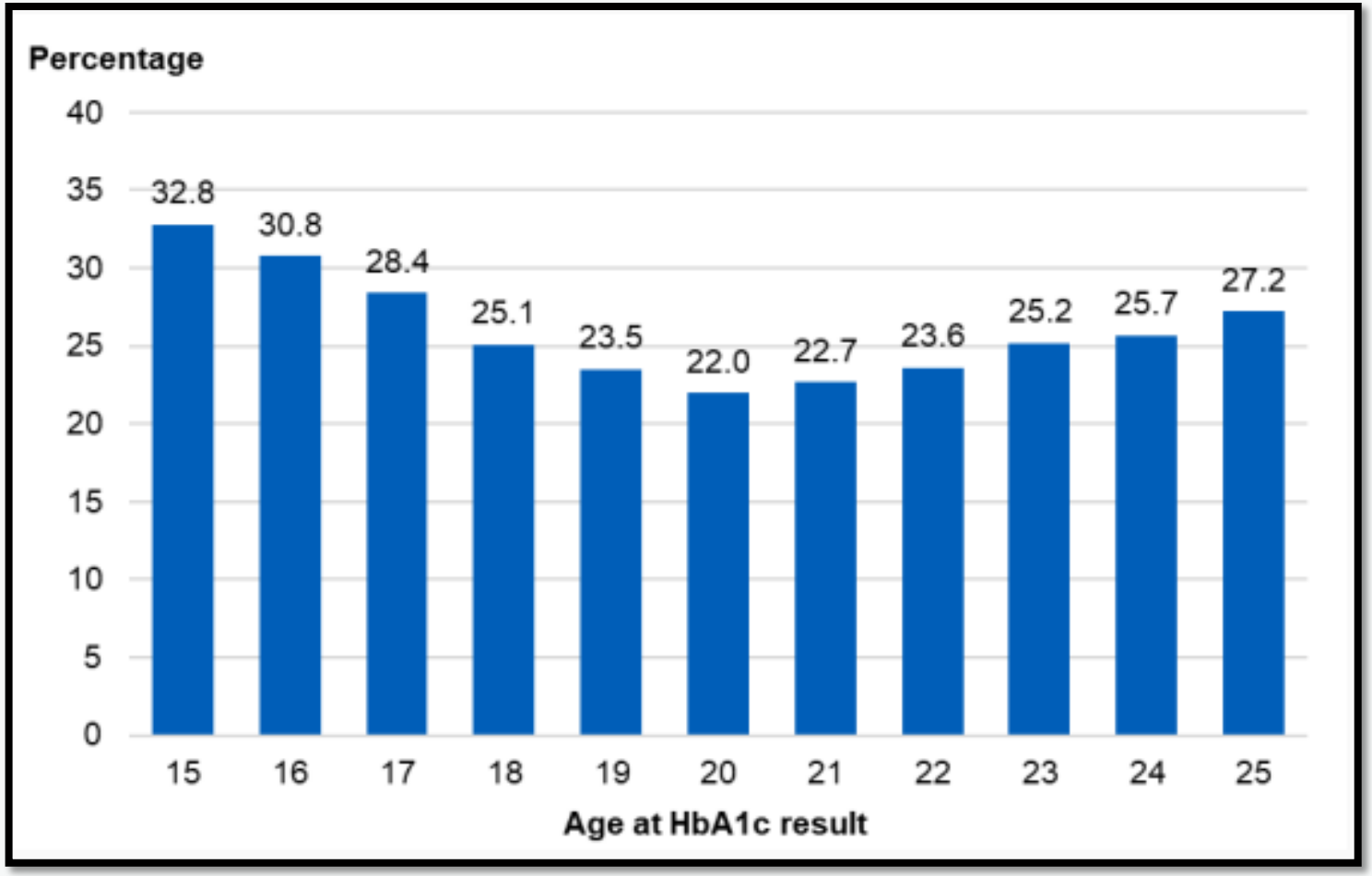
Key messages



Key Considerations for Transition and Young Adult Care

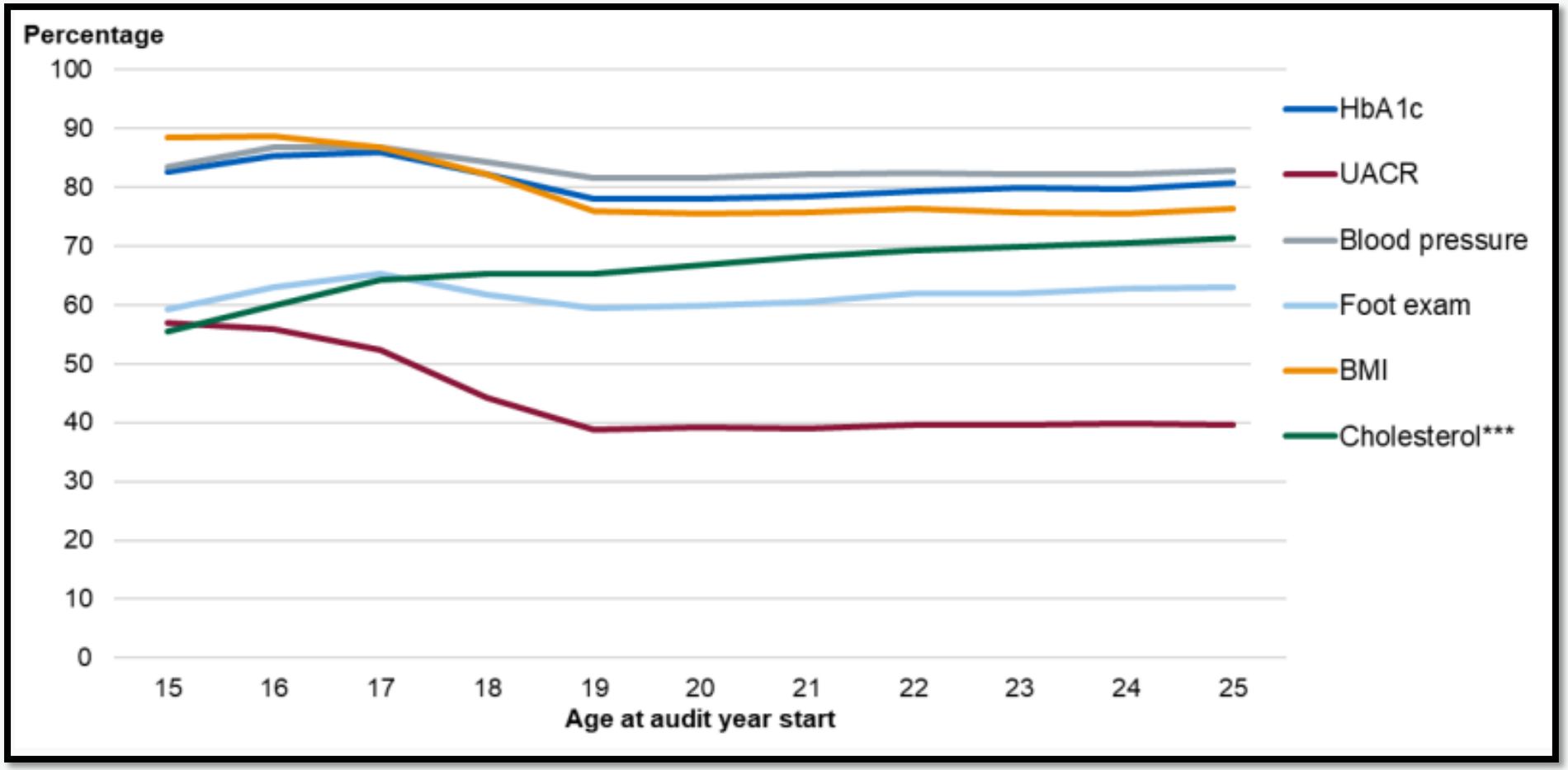
Dr Reza Zaidi, Young Adult Advisor,
Consultant Diabetologist

Data Insights: Adolescence and Young Adults



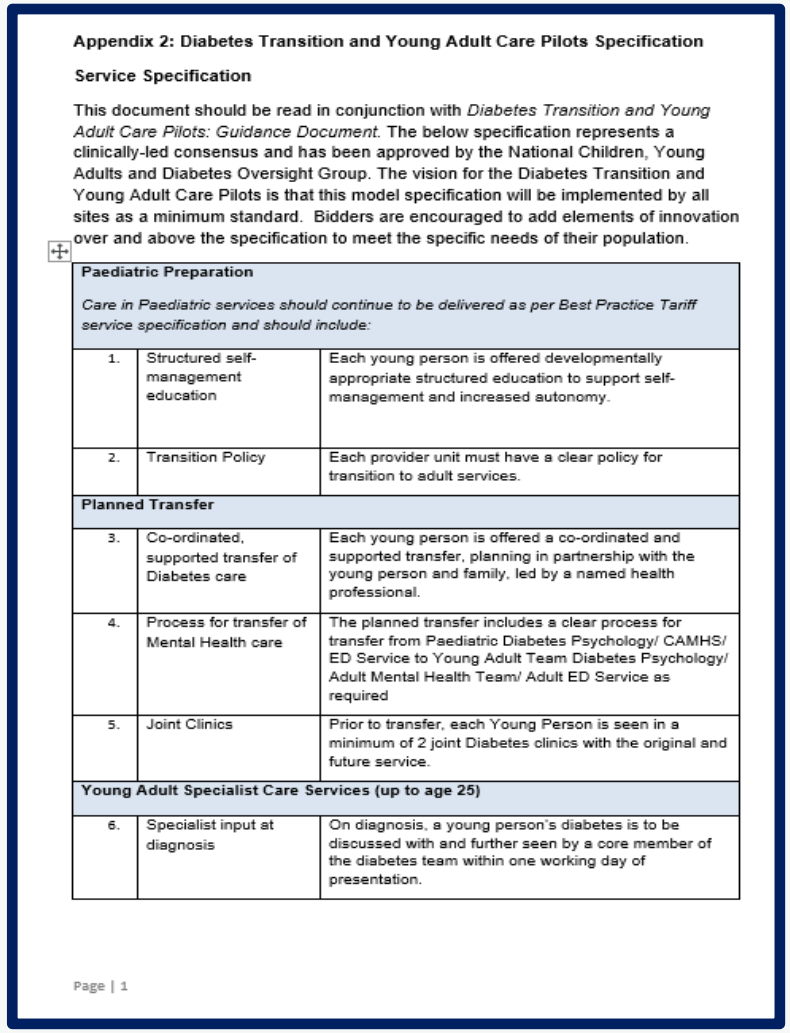
Percentage of adolescents and young adults with type 1 diabetes achieving HbA1c ≤ 58 mmol/mol by age at HbA1c result, England, 2017-21

Data Insights: Adolescence and Young Adults



Care process completion rates in adolescents and young adults with type 1 diabetes, by age at audit year start, England, 2017-21

Transition and Young Adult Care (16-25yrs) Pilot Programme



Appendix 2: Diabetes Transition and Young Adult Care Pilots Specification

Service Specification

This document should be read in conjunction with *Diabetes Transition and Young Adult Care Pilots: Guidance Document*. The below specification represents a clinically-led consensus and has been approved by the National Children, Young Adults and Diabetes Oversight Group. The vision for the Diabetes Transition and Young Adult Care Pilots is that this model specification will be implemented by all sites as a minimum standard. Bidders are encouraged to add elements of innovation over and above the specification to meet the specific needs of their population.

Paediatric Preparation		
Care in Paediatric services should continue to be delivered as per Best Practice Tariff service specification and should include:		
1.	Structured self-management education	Each young person is offered developmentally appropriate structured education to support self-management and increased autonomy.
2.	Transition Policy	Each provider unit must have a clear policy for transition to adult services.
Planned Transfer		
3.	Co-ordinated, supported transfer of Diabetes care	Each young person is offered a co-ordinated and supported transfer, planning in partnership with the young person and family, led by a named health professional.
4.	Process for transfer of Mental Health care	The planned transfer includes a clear process for transfer from Paediatric Diabetes Psychology/ CAMHS/ ED Service to Young Adult Team Diabetes Psychology/ Adult Mental Health Team/ Adult ED Service as required
5.	Joint Clinics	Prior to transfer, each Young Person is seen in a minimum of 2 joint Diabetes clinics with the original and future service.
Young Adult Specialist Care Services (up to age 25)		
6.	Specialist input at diagnosis	On diagnosis, a young person's diabetes is to be discussed with and further seen by a core member of the diabetes team within one working day of presentation.

Page | 1

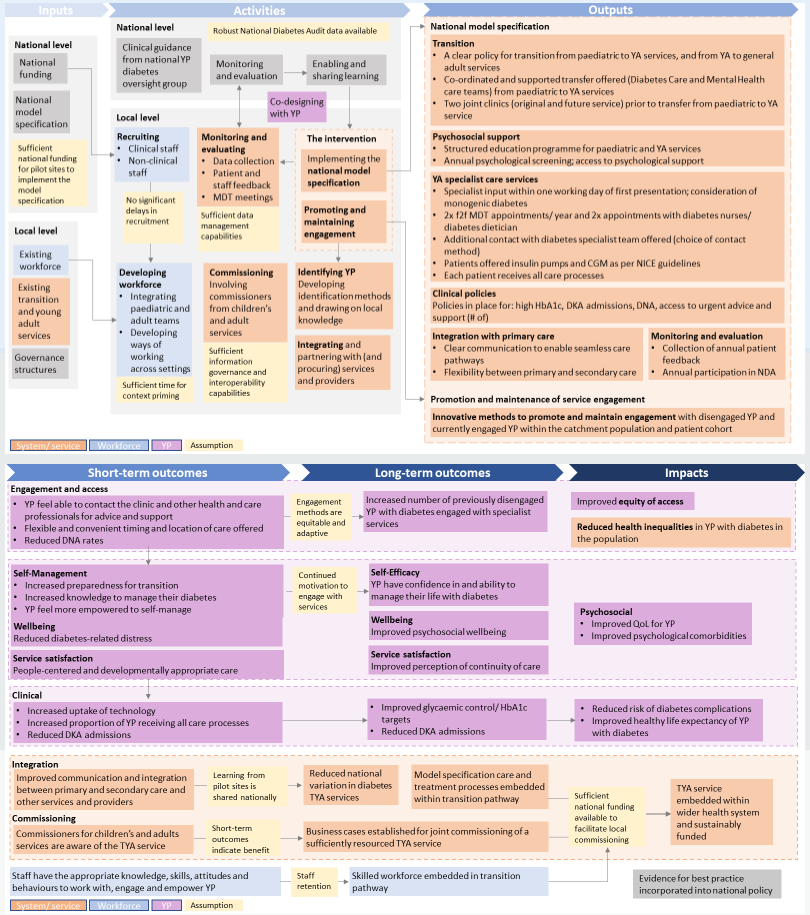
- Lack of a clear evidence base around what works to improve engagement and outcomes between the ages of 16 - 25.
- Specification developed with minimum requirements around;
  - Paediatric preparation
  - Planned Transfer
  - Young Adult Specialist Care Services
  - Whole population focus – integration with primary care
- Funding for 15 sites with a requirement to implement specification plus additional innovative approaches to improving engagement.
- Services expected to run until March 25, with evaluation report expected Spring 25.
- Evaluation expected to support sustainability of services established in the pilots, as well as inform broader learning and improvement across the country outside of funded sites

Pilot Evaluation Approach

Evaluation objectives | Theory of Change and Evaluation Framework | Data collection tools | Evidence

1. Impact evaluation
- Engagement
- Clinical outcomes
- Wellbeing and experience

2. Process evaluation
- Feasibility
- Replicability
- Scalability



MDS

Patient survey

Staff fieldwork

YP fieldwork

Formative learning via COP

What works

Inform commissioning and investment decisions

Potential scaling-up

Approaches to Improve Service Engagement

Working with integrated community service

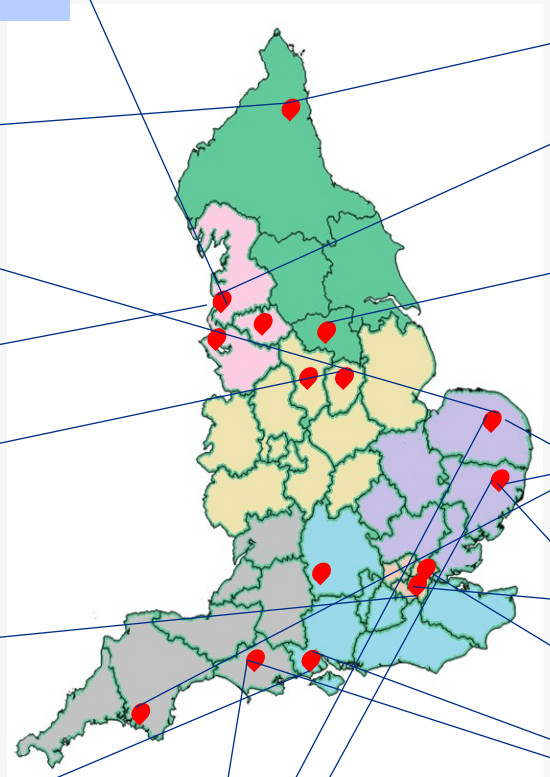
Liaison with local Universities to identify and support students moving to the area

Referral pathway from DKA hospital admissions to the YA service

More flexible clinic timing

Patient centred clinical reviews (pre clinic Q's)

Dedicated Instagram account for YA clinic caseload



Focus groups to co-deign young adult Type 2 diabetes service model

Clinics outside of hospital settings

Structured 'unable to contact pathway' (UTC- PW)

Regular peer support groups and events

Youth workers

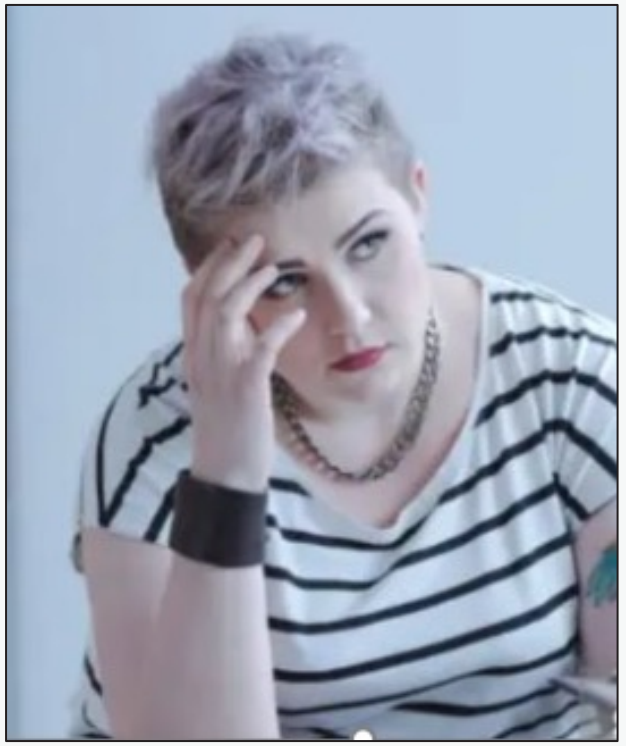
Mental Wellbeing – Key considerations

1 in 3 adolescents and young adults with type 1 diabetes experience **diabetes distress**

Young adults with type 1 diabetes are **twice as likely to be diagnosed with a psychiatric disorder**, especially eating, mood, anxiety and behaviour disorders, compared to peers without diabetes

Type 1 Diabetes Disordered Eating (T1DE) increases rates of complications and can lead to a three-fold increase in risk of death

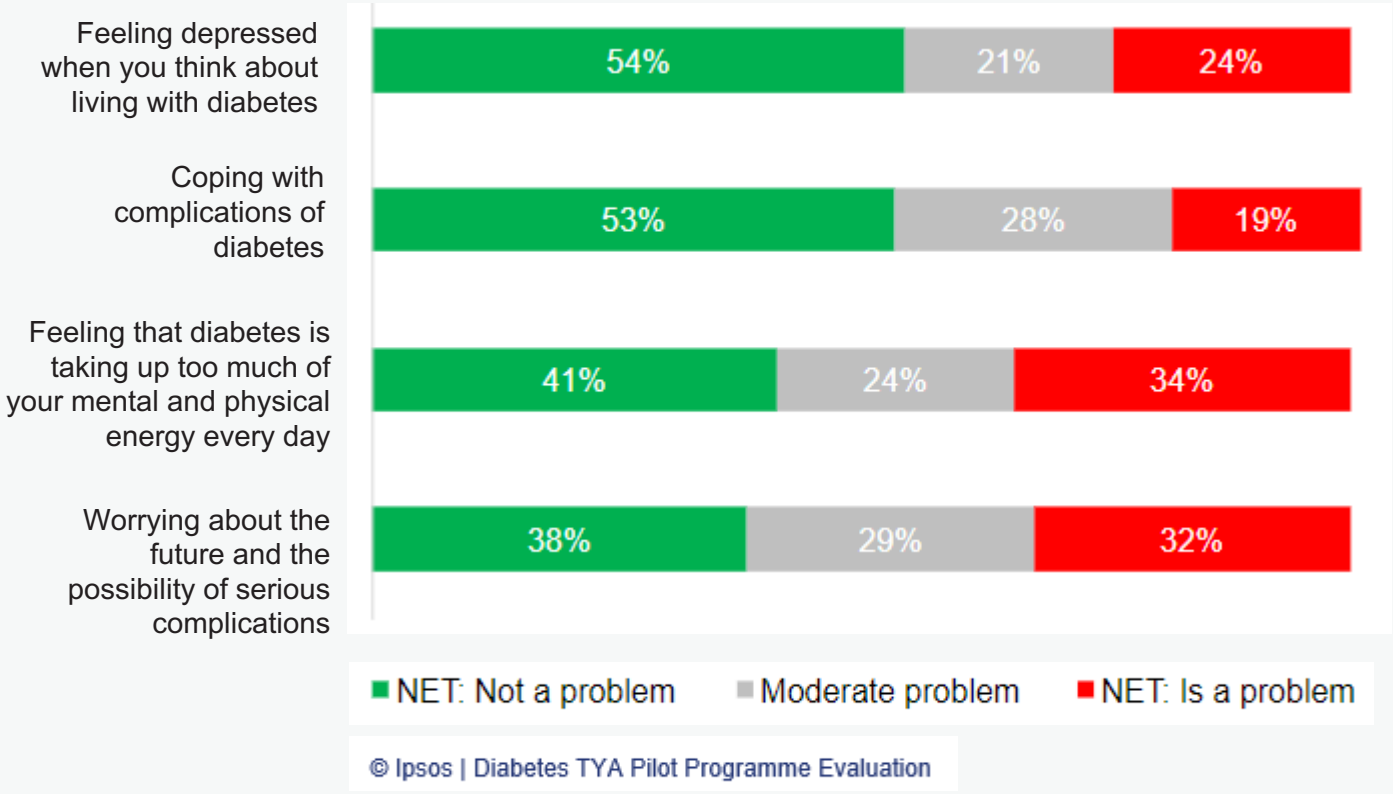
Mental health and wellbeing should be an **integral part** of a patient's review with their diabetes team



Mental Wellbeing – TYA Pilot baseline insights

Levels of diabetes-related distress

Q. Which of the following diabetes issues are currently a problem for you?



What could be done to improve services?

Embedding mental health and wellbeing support

Psychological support to manage diabetes-related distress (particularly for p**eople with new diagnoses**)

"Help with trying to manage mental health and diabetes as I've struggled pretty much from the moment I found out I had type 1 diabetes."

Holistic care/ general wellbeing

*"More advice around **how to manage my diabetes effectively around work**, as I am starting to work long night shifts and want to do them providing I can safely manage my diabetes and blood glucose levels"*

Avoiding stigma and shame

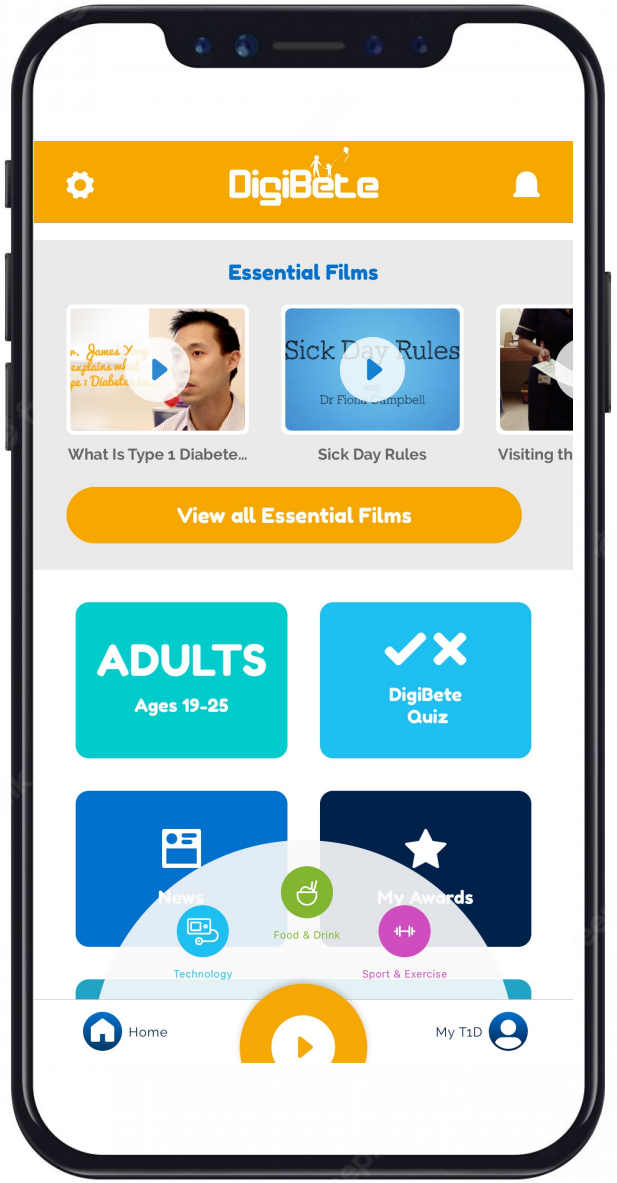
"I feel guilty for not doing well enough I try so hard"

NHS digital self-management services

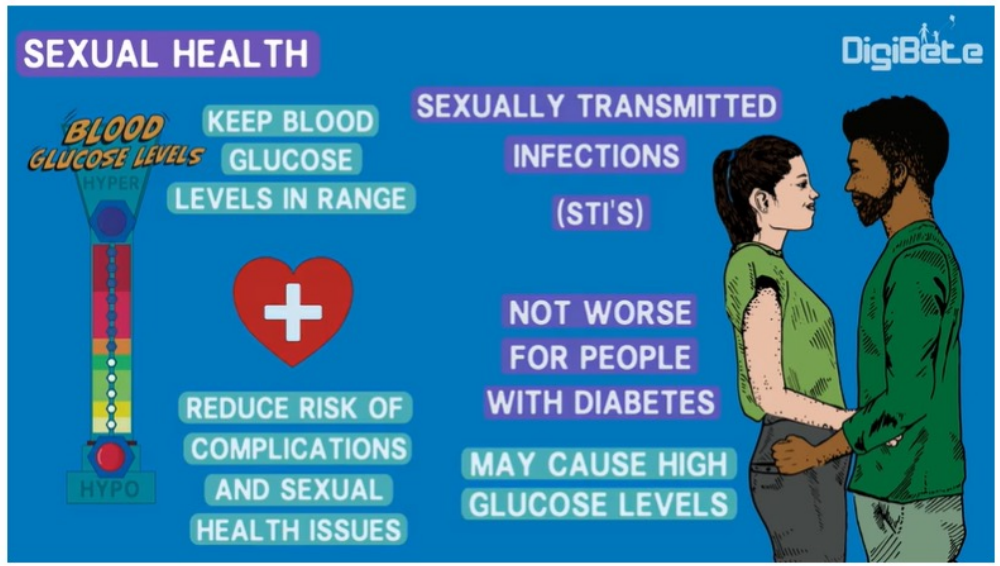
Verity Hawkes, NHS Diabetes Programme

DigiBete: Overview

- DigiBete is a platform, app and portal for children and young people living with type 1 diabetes and their families.
- It has been co-designed by parents, clinicians, and the type 1 community.
- It includes age-appropriate structured education, multi-lingual films and resources, and the app also includes clinic to patient communications.
- The app has had 83% patient uptake in England and is being used in 95% CYP Clinics
- Useful resources for patients are available direct from the webpage www.digibete.org/
- Access to the app needs a referral from a clinic. Clinics signed up to use DigiBete will have an access code to provide to their patients.



DigiBete Young Adult Resources 19-25yrs



MyType1 Diabetes: Overview

- MyType1 Diabetes includes tailored advice and educational resources created by NHS experts and in association with people with diabetes.
- It aims to support adult users to gain more understanding of type 1 diabetes and increase confidence in how to manage it.
- Web-based and optimised for use with multiple device types.
- Free to healthcare systems and to the participant. Self-referral is available online at www.mytype1diabetes.nhs.uk
- It has been used by over 9000 people to date.
- Massive Online Open Course running 28th of Feb – 5th March, to support all people to better understand their type 1 diabetes. For more information and to register please visit: understandingtype1.mydiabetes.com

Latest developments in technology

Dr Fulya Mehta - National Clinical Lead for Children and Young Adults

NICE Recommendations

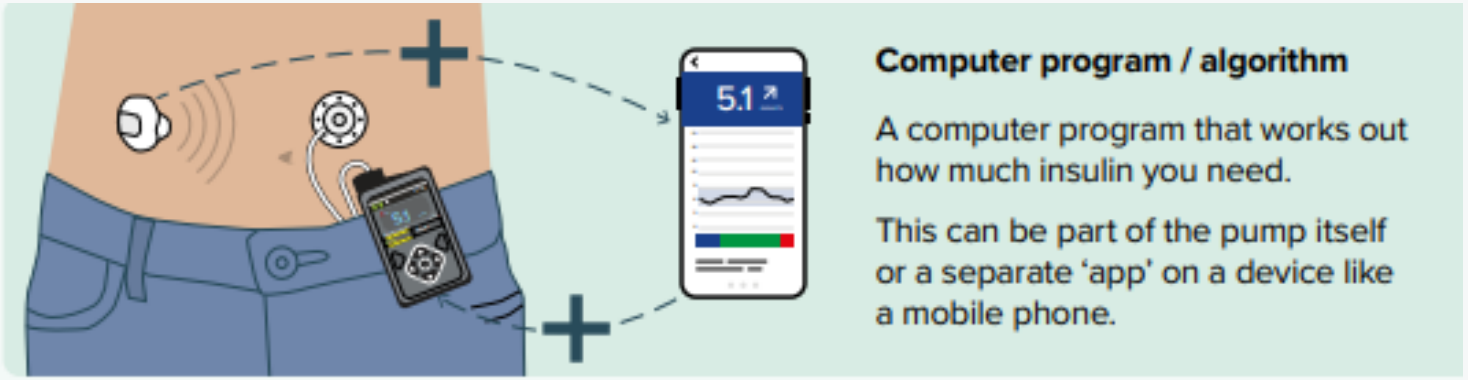
Continuous Glucose Monitoring (NG18 & NG17)

- All a **children and young people** with type 1 diabetes (0-18 years) should be offered real-time continuous glucose monitoring (rtCGM) alongside education to use it. Offer a choice of device, based on their individual preferences, needs, characteristics, and the functionality of the devices available.
- Offer **adults** with type 1 diabetes a choice of real-time continuous glucose monitoring (rtCGM) or intermittently scanned continuous glucose monitoring (isCGM), commonly referred to as 'flash', based on their individual preferences, needs, characteristics, and the functionality of the devices available

Continuous glucose monitors (CGM)

Hybrid Closed Loop Systems

- A hybrid closed loop system (HCL) is where a continuous glucose monitor (rtCGM) and an insulin pump ‘talk to each other’ through a computer program (algorithm).
- Some of a patient’s insulin doses are adjusted automatically in response to their glucose levels, as glucose is monitored all the time by the rtCGM.
- Patients’ will still need to tell the system when they eat.
- HCL systems can help prevent or minimise hyper and hypo situations.
- The algorithm will stop insulin delivery if it thinks a patient is going below target. This is usually set between 5.5 and 6.1mmol/l.

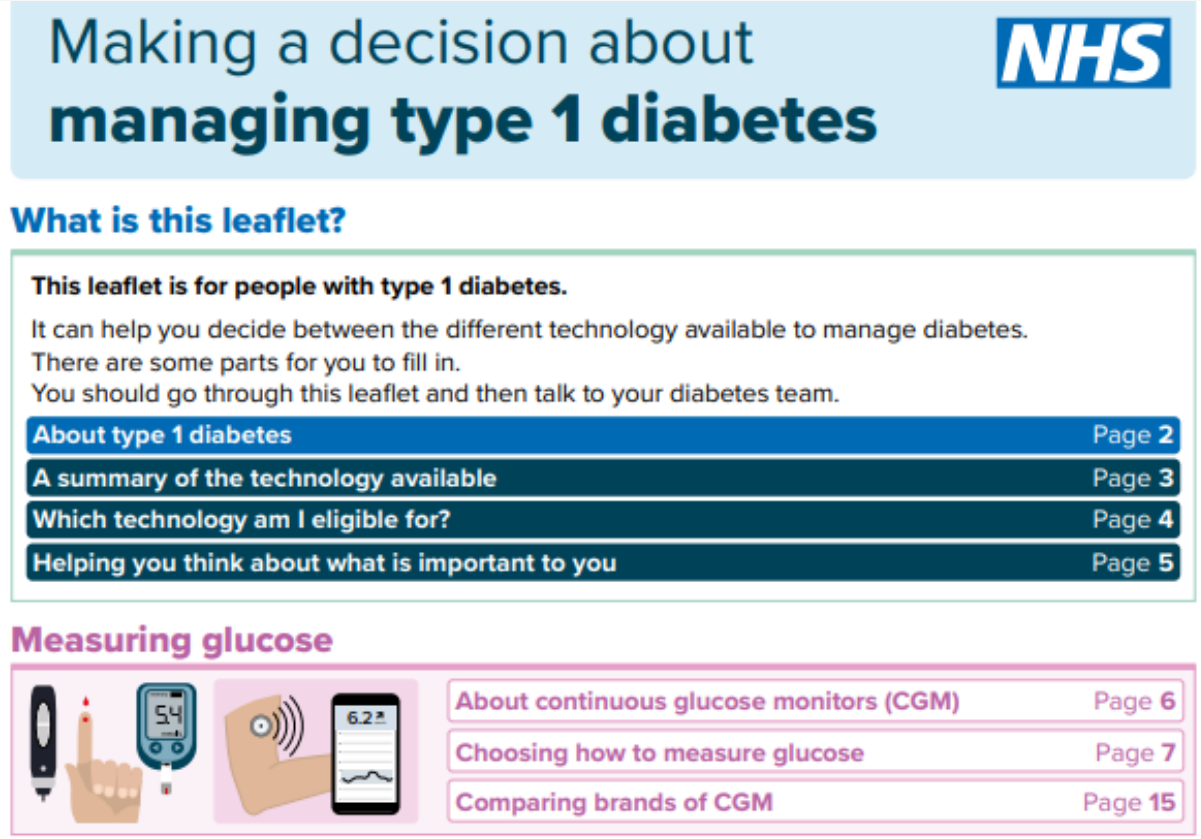


NICE Recommendations

Hybrid Closed Loop systems (TA943)

- Hybrid closed loop (HCL) systems are recommended as an option for managing blood glucose levels in type 1 diabetes for **children and young people (0-18 years)**.
- HCL systems are recommended as an option for managing blood glucose levels in type 1 diabetes for **adults (>18 years)** who have an HbA1c of 58 mmol/mol or more, or have disabling hypoglycaemia, despite best possible management with at least 1 of the following:
    - continuous subcutaneous insulin infusion (CSII) (an 'insulin pump')
    - real-time continuous glucose monitoring
    - intermittently scanned continuous glucose monitoring.
- HCL systems are recommended as an option for managing blood glucose levels in type 1 diabetes for women, trans men and non-binary people who are **pregnant or planning to become pregnant**
- HCL systems are only recommended if they are procured at a cost-effective price agreed by the companies and NHS England.

Decision Support Tool



Making a decision about
managing type 1 diabetes

NHS

What is this leaflet?

This leaflet is for people with type 1 diabetes.

It can help you decide between the different technology available to manage diabetes.
There are some parts for you to fill in.
You should go through this leaflet and then talk to your diabetes team.

Measuring glucose

Insulin and insulin pens

Insulin pumps

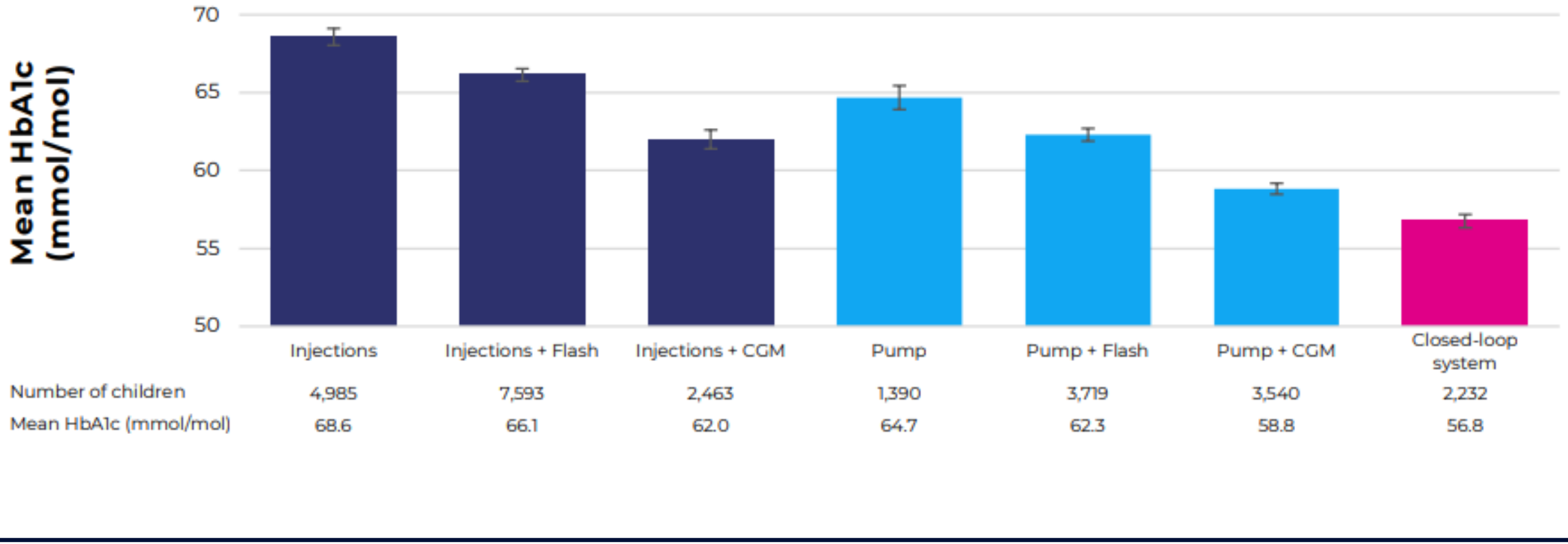
Hybrid closed loop systems

[NHS England » Decision support tool: making a decision about managing type 1 diabetes]

“This [HCL] gives me the confidence to remain active during the day and I rarely worry about my blood sugar overnight”

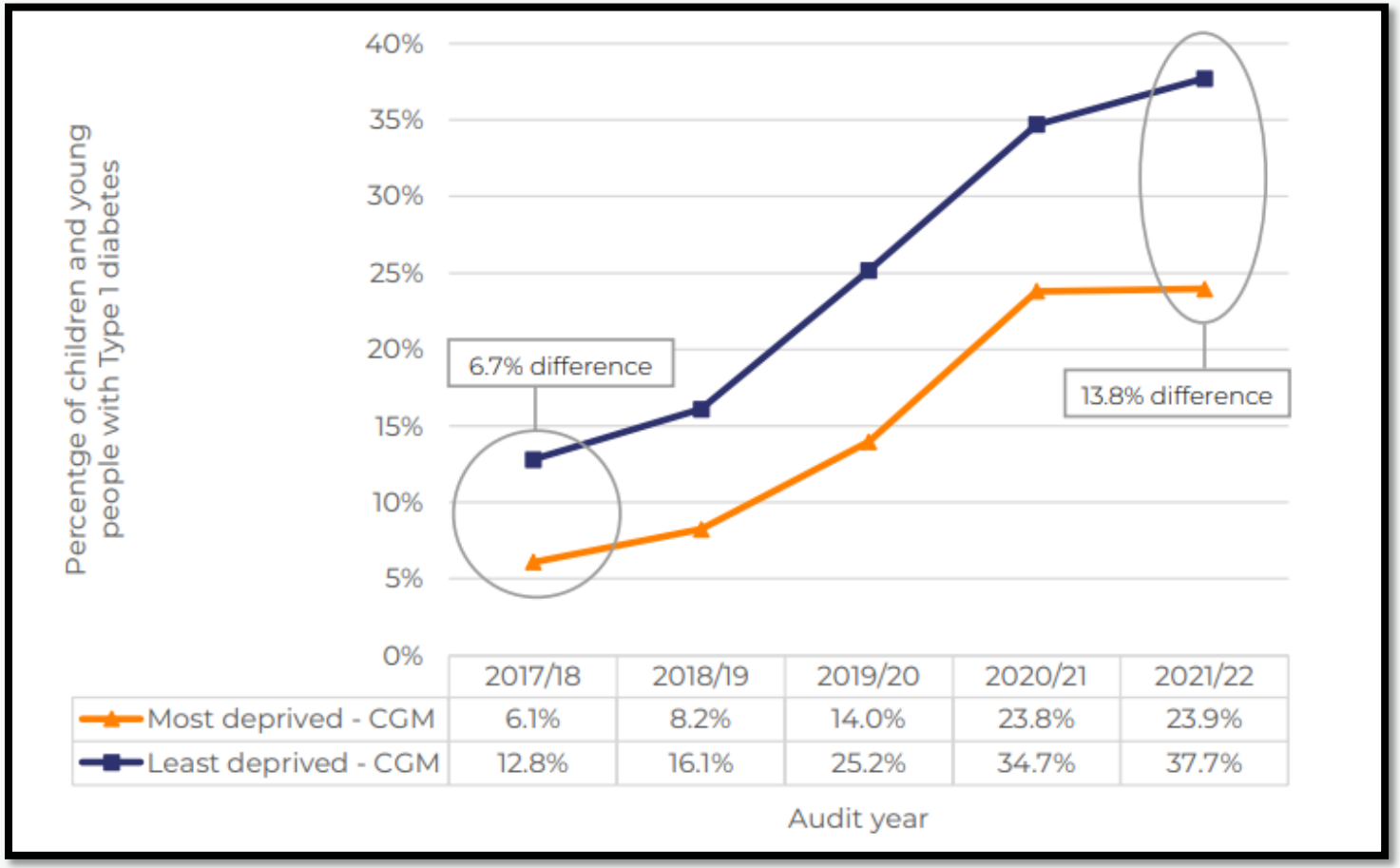
Katie L, aged 17, shares her experience of using a hybrid closed loop system (NPDA 2021/22)

Outcomes seen with technology



Mean HbA1c for CYP using different combinations of diabetes treatment technology, NPDA 2021/22

Persistent Inequalities



	2017/18	2018/19	2019/20	2020/21	2021/22
Most deprived - CGM	6.1%	8.2%	14.0%	23.8%	23.9%
Least deprived - CGM	12.8%	16.1%	25.2%	34.7%	37.7%

Percentage of children and young people with type 1 diabetes using a real time CGM by 'least and 'most deprived quintile, 2017/18 - 2021/22

NPDA, 2021/22

Improving Equity

- Improving the equity of diabetes technology usage is a key enabler of addressing inequalities in outcomes between groups of young people with Type 1 diabetes.
- A series of targeted projects were funded by NHS England in 2022/23 to help improve equity of uptake of rtCGM and insulin pumps by CYP and ran for 4, 6 or 12 months.
- National experts were drawn together to develop a ‘menu’ of interventions designed to have impact locally, this included:
    - Technology **awareness events** for CYA and families/carers
    - **Community outreach** (e.g. tailored satellite & evening/ weekend clinics to improve access to services)
    - **Staff training**/ CPD on diabetes technologies
    - Staff training on the **structural barriers to healthcare access** experienced by families on a low income
    - **Working with industry** to tailor training and support provided
    - Family Support Worker/ Youth Workers/ Social Worker roles
    - Patient and family/carer **peer support** networks
- Positive outcomes are already becoming apparent from these projects. There have been 1253 new technology starts across the completed projects so far, with >60% of new starts in CYP living in deprived areas or from ethnic minority backgrounds.
- We will be sharing further information on the outcomes of this work and case studies in coming months which will help spread learning and support opportunities to scale up activity to reduce inequalities.

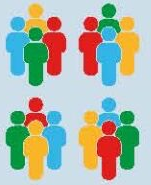
REDUCING HEALTHCARE INEQUALITIES FOR CHILDREN AND YOUNG PEOPLE

NHS

CORE20
The most deprived **20%** of the national population as identified by the Index of Multiple Deprivation

The **Core20PLUS5** approach is designed to support Integrated Care Systems to drive targeted action in healthcare inequalities improvement

PLUS
ICS-chosen population groups experiencing poorer-than-average health access, experience and/or outcomes, who may not be captured within the Core20 alone and would benefit from a tailored healthcare approach e.g. inclusion health groups



Target population

CORE20 PLUS 5

Key clinical areas of health inequalities

1. **ASTHMA**
   Address over reliance on reliever medications and decrease the number of asthma attacks

2. **DIABETES**
   Increase access to Real-time Continuous Glucose Monitors and insulin pumps in the most deprived quintiles and from ethnic minority backgrounds & increase proportion of children and young people with Type 2 diabetes receiving annual health checks

3. **EPILEPSY**
   Increase access to epilepsy specialist nurses and ensure access in the first year of care for those with a learning disability or autism

4. **ORAL HEALTH**
   Address the backlog for tooth extractions in hospital for under 10s

5. **MENTAL HEALTH**
   Improve access rates to children and young people's mental health services for 0-17 year olds, for certain ethnic groups, age, gender and deprivation

REDUCING HEALTHCARE INEQUALITIES FOR CHILDREN AND YOUNG PEOPLE

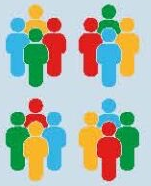
NHS

CORE20
The most deprived **20%** of the national population as identified by the Index of Multiple Deprivation

The **Core20PLUS5** approach is designed to support Integrated Care Systems to drive targeted action in healthcare inequalities improvement

Target population

PLUS
ICS-chosen population groups experiencing poorer-than-average health access, experience and/or outcomes, who may not be captured within the Core20 alone and would benefit from a tailored healthcare approach e.g. inclusion health groups



CORE20 PLUS 5

clinical areas of health inequalities

Diabetes:
Increase access to rtCGM and insulin pumps in the most deprived quintiles and from ethnic minority backgrounds

3

EPILEPSY
Increase access to epilepsy specialist nurses and ensure access in the first year of care for those with a learning disability or autism

4

ORAL HEALTH
Address the backlog for tooth extractions in hospital for under 10s

5

MENTAL HEALTH
Improve access rates to children and young people's mental health services for 0-17 year olds, for certain ethnic groups, age, gender and deprivation

Multi-lingual Technology Resources

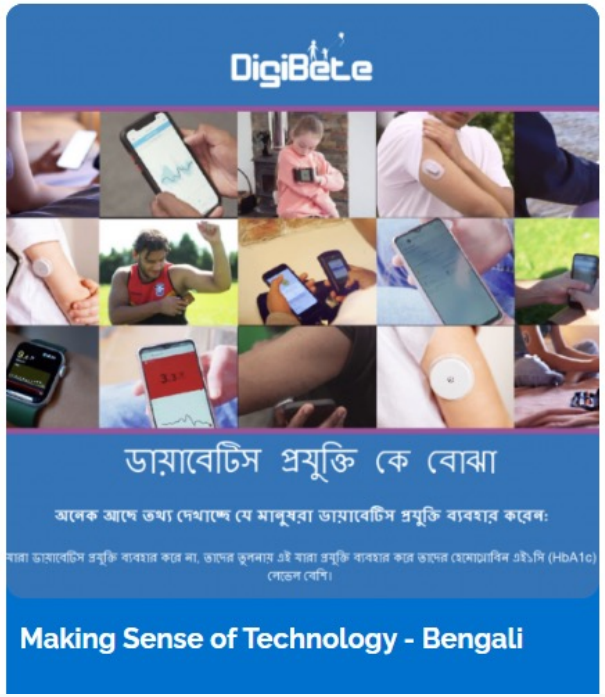
Welcome to our Multi-lingual Tech Guides page:

Here you will find our Making Sense of Technology workbook in different languages. More multilingual resources can be found using the language picker on the essentials page here or the technology resources page here.

If you have any feedback on these language resources then please contact us at hello@digibete.org

Making Sense of Technology - English

Making Sense of Technology - Arabic



Making Sense of Technology - Bengali

Making Sense of Technology - Chinese

Q & A

Candice Ward – CDEP Lead,
Cambridge Diabetes Education Programme

Next steps …

You will receive a certificate of attendance and a copy of the presentation via email in the next 1-2 weeks.

Please contact CDEP – info@cdep.org.uk – if you have any questions or need further support.

Thank You

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