Worcestershire Acute Hospitals NHS Trust

Operational Policy for the Children and Young People with Diabetes Multidisciplinary Team (MDT)

Worcestershire Acute Hospitals NHS Trust

Revised October 2020

This operational policy was agreed by the Worcestershire Paediatric Diabetes Team on 7th October 2020

Approved by – Paediatric Quality Improvement Meeting – 26th March 2021
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Contents

Introduction

The purpose of this document is to provide a comprehensive written guide of services offered to children and young people (CYP) with diabetes in Worcestershire. It also intends to clarify individual roles and responsibilities within the team and combines existing service delivery guidelines.

The service currently provides care to approximately 280 CYP up to 19 years of age within Worcestershire but also includes a small number of Warwickshire and other out of area CYP. The Paediatric Diabetes multidisciplinary team is spread across the County in the 3 localities of Redditch and Bromsgrove, Worcester and the Wyre Forest providing a local service in each area. It should be noted that Worcestershire is a mostly rural County and this needs to be taken into consideration in delivering the service.

Multi-disciplinary clinics take place at Worcester Royal Hospital, The Alexandra Hospital (Redditch) and Kidderminster Hospital sites. The Paediatric Diabetes Specialist Nurses provide a home visiting and school support service together with ongoing support by telephone, email, in clinic and other settings as appropriate. Dietitians offer telephone support and have their own clinics set up on each site where they see patients for additional appointments. There is also a need for the dietitians to conduct some home visits for difficult to reach or vulnerable families. Clinical psychology support is available at many clinics and some 1:1 patient or family work takes place at separate speciality appointments outside the consultant-led MDT clinic often at the hospital bases but sometimes at home or school. All admissions are to Riverbank (children's) Ward at Worcestershire Royal Hospital.

Changes to service due to COVID19

Due to COVID19 a number of changes to the service have been made including the following:

- All 20 minute MDT clinic appointments have been changed to 30 minute appointments to ensure adequate social distancing. Due to the reduction in total number of appointments, additional virtual clinics are being held.
- More virtual consultations are being offered by the PDSN's, dietitian and clinical psychologist.
- Insulin pump and CGM/Freestyle Libre device starts are taking place virtually.
- The Trustwide Management Group meetings are being held virtually every 2 months.
- The West Midland Paediatric Diabetes Network meetings are virtual, including specialist group meetings.
- During the lockdown we also provided additional virtual MDT clinic appointments and consultations as well as a drive thru HbA1c service.

Although many of these changes are currently temporary, some are likely to be incorporated into our normal service.

Scope of this document

This policy describes a current overview of the Paediatric Diabetes Service.

Definitions

CYP	Children and young people
PDSN	Paediatric Diabetes Specialist Nurse
MDT	Multidisciplinary team
HbA1c	Glycated haemoglobin (a marker of average blood glucose levels over the last 2-3 months)
CGM	Continuous glucose monitoring
FGM	Flash glucose monitoring
NICE	The National Institute for Health and Care Excellence
DKA	Diabetic ketoacidosis
Hypo	Hypoglycaemia (defined as a blood glucose level <4mmol/l in a type 1 diabetic)
DNA/WNB	Did not attend/Was not brought
EQA	External quality assessment
SOP	Standard operating procedure

Responsibility and Duties

This operational policy lays out the core principles and delivery of the service for the key members of the diabetes MDT. It also includes service delivery for medical/nursing staff that come into contact with CYP with diabetes for out-of-hours advice, inpatient management or the community nurses (Orchard Service).

Aims and Objectives of the CYPD Team

To provide consistent, high quality care to CYP with diabetes, their families and care providers. We hope to achieve this by:

- Making the care of CYP and their carers our main priority
- Reducing CYP's HbA1c across the whole county
- Providing a comprehensive structured education programme
- Performing and documenting all required care processes at the time of annual review
- Providing insulin pump therapy and CGM to CYP that satisfy NICE criteria
- Providing an effective transition service
- Having an active quality improvement programme
- Ensuring that policies, protocols and procedures for the hospital are up to date
- Satisfying the paediatric diabetes Best Practice Tariff criteria
- Submitting data to the National Paediatric Diabetes Audit
- Listening to PREM feedback and improving the quality of service provided
- Providing a range of social events for our CYP and their carers

Philosophy of Care

We will offer care, support and education to CYP and their carers to optimise quality of life and to enable the CYP to become independent in managing their own diabetes competently and safely by the time they reach adulthood by:

- Offering at least 4 HbA1c checks and 4 clinic appointments per year with a paediatric diabetes doctor, nurse and dietitian

- Offering annual screening for complications including blood tests for thyroid function and coeliac screen for all ages and a cholesterol blood test, foot examination, urine for microalbuminuria and retinopathy screen for over 12-year olds
- Offering psychological screening at least annually, and assessment and psychological support to CYP and their carers from team clinical psychologists as well as other MDT members, as required
- Being available for extra support, advice, troubleshooting and check-ups by e-mail, telephone and at follow-up appointments
- Offering home visits when required
- Offering an additional appointment with a dietitian once per year and as required
- Offering ongoing education tailored to the needs of the CYP and their care providers including structured education events, teaching in schools, at home visits and in clinics. Some of this will be included in social activities for the CYP and their carers
- Supporting the young person through transition and transfer to adult diabetes services

A mission statement of the service is displayed in each clinic (see Appendix 1).

Policy detail

Trust Wide Management Group (H1)

The Trust wide management group responsible for the co-ordination and care of CYP with diabetes is the Worcestershire Paediatric Diabetes Team at Worcestershire Acute Hospitals NHS Trust led by Dr James West (Consultant Paediatrician and Clinical Lead for Paediatric Diabetes).

The membership of this group includes:

Role	Team Member
Women's & Children's Directorate Manager	Jane Gordijn
Lead Paediatric Consultant for CYPD	Dr James West
Lead Paediatric Specialist Nurse for CYPD	Esther Anstey / Tracey Jones
Lead Paediatric Specialist Dietitian for CYPD	Dorota Amador Bueno
Lead Clinical Psychologist for CYPD	Dr Catherine Binney
Lead Consultant for care of adults with diabetes	Dr Irfan Babar
Trust Lead for point of care testing	Natasha Payne
Head of Children and Young People's Nursing	Amrat Mahal
Matron for Children's services	Dana Picken

The accountability of this group is to the Quality Improvement Group. Meetings are held every 2 months and all members of the Trust wide management group and CYP's diabetes team are invited. Other members are co-opted to attend when relevant. Minutes are documented electronically for governance purposes and action plans are discussed at the Children's Quality Improvement (governance) meeting. The Quality Improvement Group is accountable to the Women and Children's Directorate which in term is accountable to the Trust Board.

Fig 1: Governance structure overseeing Children's diabetes

Significant risks are added to the risk register and are discussed at both the Quality Improvement and the Women and Children's Divisional meetings. Clinical incidents (Datix's) are investigated and discussed at the Countywide meetings. Newly diagnosed CYP are discussed as well as those CYP admitted with DKA, hypo's and for restabilisation; DNA/WNB rates are reviewed according to age bands. In addition to these countywide meetings, twice a year there is a diabetes MDT away day or half day to discuss quality improvement strategies.

Terms of Reference are in Appendix 2.

Twenty-Four Hour Advice Service (H2)

The CYP's West Midlands Paediatric Diabetes Network has agreed the specifications for a 24-hour advice service, seven days a week (Appendix 3):

1) for telephone advice on diabetes management to patients/carers
2) for telephone advice to health care professionals (HCPs) on the management of CYP with diabetes admitted to hospital
3) for this local team's escalation policy to the tertiary centre at Birmingham Children's Hospital

1) <u>Telephone advice on diabetes management to patients/carers</u>

CYP and their carers can contact the PDSNs during normal working hours (9-5pm) Monday to Friday. All CYP and families have written information on the locality service and contact telephone numbers. There are many days when the PDSNs provide a later service to accommodate after school visits and group structured education and therefore are available for later calls. Out-of-hours there is a clear communication pathway for CYP to contact Riverbank Children's Ward, which has up-to-date guidelines to ensure appropriate, consistent advice for urgent and long-term insulin adjustment.

Guidelines to refer to:

- WAHT-PAE-039: Paediatric Diabetes Sick Day Management/hyperglycaemia and Ketosis in the Community
- WAHT-PAE-038: Nursing Protocol for Insulin Adjustment in the Community

Open access for patients to Riverbank Ward and advice from HCPs

All CYP have open access to Riverbank Ward for when emergency issues (potential or actual) arise after prior assessment by telephone call.

2) Telephone advice to HCPs on the management of CYP with diabetes admitted to hospital

If the on call Paediatric Middle grade requires advice or support, they should contact the on call non-diabetes specialist Paediatric Consultant. If further help is needed the on call non-diabetes specialist Paediatric Consultant can contact Dr West (Consultant Paediatrician and clinical lead for paediatric diabetes). Dr Ahmad (Paediatric Consultant with special interest in diabetes) covers Dr West's leave. A business case has been approved for the provision of local clinical cover out-of-hours by Dr West and the PDSN's.

Advice line and contact sheet are in Appendix 4.

3) Escalation policy for healthcare professions to gain additional advice 24/7

For more complex cases or management of severe DKA, advice can be sought from the Regional Endocrine on call service and/or KIDs service at Birmingham Children's Hospital based on the agreed Network statement. This advice is on a consultant to consultant basis.

Device Download Facilities (H3)

Out-patient services are based at Worcestershire Royal Hospital, Kidderminster General Hospital and the Alexandra Hospital, Redditch. At each out-patient clinic visit glucometers, insulin pumps and continuous glucose monitoring systems (including the Freestyle Libre device) are downloaded by the PDSN's so information is available to all members of the MDT whether seeing the patient separately or during a joint consultation. This is achieved by using the Medtronic Carelink, Accuchek (Expert meter), Diasend and Dexcom Clarity systems.

Patients are encouraged to regularly download at home using the appropriate software for their device; the MDT are able to review the information remotely or through email and give advice as required.

Point of Care Testing for HbA1c (H4)

On arrival to clinic CYP have their weight, height, and blood pressure measured and the clinic nurse takes a blood sample for point of care testing of IFCC HbA1c measurement. This is available in all clinic settings and the results are available for the consultation. The HbA1c is reported in both mmol/mol (IFCC) and % (DCCT) and is documented in the clinic notes and in the clinic letter (record of care) for CYP and their families. The result is also entered into the Twinkle.NET electronic database.

The point of care HbA1c Siemens DCA Vantage Analyzer machines are tested and calibrated every month. Three external quality assurance samples are distributed to each clinic every month (as detailed in laboratory procedure documentation) and are analysed as soon as possible upon receipt. Result forms are completed and the results are entered onto the UK NEQAS EQA website for which the clinic nurses have log in details. The results forms are posted back to Natasha Payne (Senior Biochemical Scientist) for storing. The biochemistry department accesses the results from the website and emails them to the named clinic nurses. Currently the UK NEQAS standards are complied with. Print outs can be provided as required. EQA for glucometers is covered in the Trusts' general SOP for glucose meters.

Siemens can be contacted if there are any concerns about the functionality of an HbA1c machine and they will organise a replacement machine if necessary.

Riverbank Children's Ward Training (H5)

Healthcare professionals on Riverbank Ward are required to complete the 'National Curriculum for the Training of Healthcare Professionals Who Care for Children and Young People with Diabetes Mellitus' E-Learning: Level 1 Basic Awareness'. In addition to this, the PDSN's deliver 2 half-day training sessions on alternate months. These sessions include teaching on diabetes care and competency sign-off. The training programme includes:

- What is diabetes and management of the newly diagnosed diabetic
- Safe use of insulin, which insulins are used and their actions, pumps vs injections
- Injection technique including
  - correct technique
  - same site same time of day
  - sites used/needle size
  - safety versus ordinary needles in learning demo
  - which insulin which site
- Blood glucose monitoring
- Normal blood glucose and ketone targets
- Management of hypos
- Ketone and glucose testing and when to test, management of DKA
- How to test – teach families
- Expert meter shown and given an idea of how used – ratios/corrections with brief demo
- Advice on appropriate meals and snacks post diagnosis and while in hospital
- Level 3 carbohydrate counting for all children and a reminder about the Carbs and Cals book
- Snacks under 15 g (5 - 10g for children <7 years) or low CHO snacks between each meal for patients on injections
- All snacks on pumps must be bolused for unless hypo or exercise related
- The care of children and young people with diabetes undergoing surgery
- Discharge home – check list
- TTO's:
  - sharps box
  - spare Echo pen device
  - who to contact for advice and support
  - consider Orchard service
  - information pack including blood glucose and food diaries
  - hypo treatment: brief resumé of below what BG a hypo is, common symptoms and basic treatment including glucose gel and protocol for the unconscious CYP
  - team information and where to find new patient packs and ward info folder

<u>Hand-outs</u>

- Locality service patient info sheets for each area
- Back page tick list re discharge from newly diagnosed guideline
- The Diabetes UK family info booklet plus the BD good injection booklet

<u>Link Nurses</u>

In addition to these sessions, there are 2 half day training sessions for the ward's diabetes link nurses.

Community

The Paediatric Diabetes Nurses hold annual training days for acute and community staff involved in diabetes and as well as undergraduate nursing students. They also do training sessions tailored to individual groups such as Orchard Service and Specialist School Nurses. In addition, the PDSN's take part in a joint Paediatric Specialist Nurse training day which health visitors and school nurses are invited to attend. Education sessions for school staff are also held twice a year.

Medical Trainees

Paediatric medical trainees receive training about Diabetes emergencies:

- Dr West delivers a diabetes update session at the paediatric departmental teaching on an annual basis.
- A training session on diabetes is held for all junior doctors in the department during their attachment.
- Dr West also takes part in paediatric GP study days (approximately alternate years).

Trainees are also encouraged to attend the diabetes MDT clinics to reinforce and build on existing knowledge.

The Riverbank Ward Manager keeps an electronic record of staff attendance at ward training sessions as well as hard copies of staff competencies. Esther Anstey and Tracey Jones (PDSN's) keep a record of the training programmes and the attendance of nurses and Dr West keeps a record for medical trainees.

Outpatients' Consultation Time (H6)

The MDT (no clinical psychologist present for afternoon clinics) meet 30 minutes before the first patient's appointment to discuss all patients on the clinic list. Each patient is discussed, and information shared including the plan from the last clinic appointment, an update on contacts since then, psychosocial factors, outstanding screening required and any other issues which may be relevant to the consultation.

Although each morning clinic appointment at Worcestershire Royal Hospital and Kidderminster General Hospital is scheduled for 20 minutes in duration, the CYP and their carers spend 20 minutes each with the PDSN, dietitian and consultant/associate specialist. Afternoon clinic appointments are scheduled for 30 minutes and the CYP and their carer see the PDSN, dietitian and consultant/associate specialist at the same time. There is sufficient time in both the morning and afternoon clinics for reviewing device downloads, interpretation of results and discussions to gain a clear picture of the current situation. A clinical psychologist is present for the morning clinics but also reviews the patient lists for the afternoon clinics with the rest of the MDT to see if they have (or the patient is likely to need) any ongoing input which they need to share. CYP and their carers attending the afternoon clinics are signposted to clinical psychology as required.

At the Alexandra Hospital, Redditch there is a MDT meeting before the clinic starts. Appointments are scheduled for 20 minutes but CYP and their carers can spend 20 minutes each with the PDSN, dietitian and consultant. There is also a nurse led young person's clinic where the consultant is present.

Across all 3 sites separate clinics are held for children under 13 years of age and for those young people aged 13 years and above so transition can be focussed on for the older CYP. CYP in these transition clinics are offered the chance to be seen on their own before a joint consultation with their carer.

CYPD MDT Measures

Leadership arrangements and responsibilities (M1)

Dr James West is the clinical lead for the children and young people's diabetes MDT and has 1 PA per week (included in PA's in table below) for being Lead clinician of the service.

The Lead Clinician's responsibilities include:

- Taking overall responsibility for and leading the clinical activity of the MDT, working to agreed guidelines, ensuring a high-quality integrated service which meets local, regional and national targets
- Ensuring Best Practice Tariff criteria are achieved
- Submitting data to the National Paediatric Diabetes Audit annually
- Overall responsibility for ensuring the MDT works towards meeting peer review quality measures
- Attending and contributing to the West Midlands Paediatric Diabetes Network (WMPDN) meetings or sending a representative
- Ensuring clinical management guidelines are produced, approved by the WMPDN and kept up to date
- Reviewing the audit programme and completing audit and performance reports required by the Trust and WMPDN
- Leading on service improvement which includes liaising with commissioners
- Coordinating the regular review of the MDT action log making sure the minutes are recorded and acted upon
- Leading countywide paediatric diabetes MDT meetings (along with meeting chair) and feeding back action plans to the Quality Improvement meeting
- Investigating Datix's related to paediatric diabetes and responding to patient safety incidents
- Liaising with the PDSN's and diabetes link nurses to ensure paediatric nursing competencies are up to date
- Delivering regular diabetes education sessions for junior doctors and an annual update for consultants
- Recognising and responding to issues of Safeguarding Children
- Attending Worcestershire Diabetes Network and Worcestershire Diabetes Interest Group meetings when able
- Overseeing the professional development of multidisciplinary team members
- Meeting a good standard of Continuing Professional Development
- Producing annual reports and work plans

Deputy lead Clinician
Dr Naeem Ahmad
Provides cover for Dr West at all times

Core Membership (M1)

Role	Name	Title	Start date in service	Qualification	Date	PA/WTE
Lead clinician for the CYPD MDT	Dr James West	Consultant Paediatrician	June 2015	Level 3 training diabetes SPIN module	2015	2.8
Doctors	Dr Naeem Ahmad	Consultant Paediatrician	May 2004	Certificate in diabetes, Surrey	2004	2.5
	Dr Chantal Solan	Associate Specialist	Jan 2013	Exempt		3.0
Nurses	Esther Anstey	PDSN	Aug 2002	BSc Hons Community Paediatrics Management of Childhood diabetes in home and community, Independent Nurse Prescriber.	1999	1.0
	Tracey Jones	PDSN	July 2012	BSc (Hons) in Children's Nursing Diploma in Type 1 diabetes in children, Warwick University, level 6	1999 2013	0.8
	Jane Francis	PDSN	July 2012	Diploma in Children's Nursing Paediatric Diabetes Course	1999 2006	0.8
	Lee-Ann Edwards	PDSN	May 2016	Diploma in Nursing Paediatric diabetes course level 6	 2018	0.6
	Becki Walling	PDSN	Jun 2020	BA (Hons) Nursing Management of Childhood Diabetes, Birmingham City University	2002 2015	1.0
Dietitians	Dorota Amador Bueno	Lead Paediatric Diabetes Dietitian	Aug 2012	BSc in Dietetics, University of Natal, South Africa MSc in Dietetics and Human Nutrition, University of Warsaw, Poland Certificate in Diabetes Care, University of Warwick Certificate in use of Insulin Pump Therapy, Royal Liverpool University	2000 2005 2004 2004	1.0

				Hospital		
Clinical psychologist	Dr Catherine Binney	Lead clinical psychologist	Sep 2012	BSc, University of Manchester D Clin Psych, University of Oxford Level one online course (National Curriculum for the Training of Health Care Professionals who Care for Children and Young People with Diabetes Mellitus).	1999 2004	0.36
	Vacancy					0.6
Administration support	Sarah Dent	Paediatric secretary, data entry clerk	Aug 2020			0.75

Cover for absence:

- The two Consultants and associate specialist in paediatrics with a special interest in diabetes liaise with each other and cross cover clinics during times of annual leave.
- The PDSN service has a system in place to cover absence which is clearly communicated to patients and staff by means of answer phone messages and out-of-office email replies.

Extended Team	Name	Job Title
Link for child safeguarding	Laura Phipps/Sam Dixon	Named Nurse for Safeguarding
Inpatient ward link nurse	Sharon Lownsbrough	Sister
	Emma Barton	Staff nurse
Podiatrist	Ann Bateman	Podiatrist
Diabetes clinician for adult services and responsible for transition	Dr Irfan Babar	Adult consultant diabetologist
Link nurses Orchard Service	Siobhan Nangle	Community children's nurse
	Nikki Beale	Community children's nurse
Clinic nurse and link nurse lead – WRH	Sarah Phillips	Staff nurse
Clinic nurse and link nurse lead – Alexandra Hospital	Sarah Weale	Sister
Clinic nurse and link nurse lead – KTC	Beverley Darbyshire	Staff nurse
Consultant secretarial support	Sarah Scotford	Paediatric secretary
	Gaynor Richardson	Paediatric secretary

Responsibilities of Core Nurse Members:

- Contribute to multidisciplinary team and patient assessment/care.
- Provide specialist educational and training support to patients, parents and schools, promoting holistic care.
- Provide link nurse responsibilities to their named patients, contributing towards high HbA1c meetings and informing team of specific problems.
- Liaising with key workers including schools on behalf of their patients.
- Contribute towards the efficient management of the team, completing templates and utilising new ideas and research as discussed by the team.
- Contribute towards audit.
- Acting as advice and an expert resource for other professionals.
- Maintain an up to date knowledge base and understanding all aspects of diabetes care and how it relates to dietetics and healthy living.

Responsibilities of Core Dietitian Members

- Contribute towards multidisciplinary discussions and patient assessment/care.
- Provide expert, evidence based, practical and culturally appropriate dietetic advice at diagnosis, including the education required to allow the CYP and their carers to self-manage diabetes at home.
- Lead on the education of the dietary management of diabetes, physical activity and carbohydrate counting for CYP, parents and carers as well as MDT members, other healthcare professionals, ward and clinic staff.
- Undertake assessments of nutritional status, growth and dietary intake and provide individualised nutritional advice to promote healthy growth and development and prevent development of nutritional deficiencies.
- Teach CYP and their carers how to adjust insulin doses according to blood glucose levels and carbohydrate intake and provide guidance on the nutritional management for CYP using insulin pump therapy.
- Interpret blood glucose monitoring results, including flash/continuous glucose monitoring, and provide appropriate advice to reduce hypo- and hyperglycaemia.
- Provide specific and individualised dietary advice on various conditions, including Coeliac Disease, Cystic Fibrosis, Type 2 diabetes, other types of diabetes and insulin resistance, weight and lipid management, gastro-intestinal problems, as well as restrictive or fussy eating and in specific nutritional deficiencies, food allergies or intolerances.
- Apply skills in behavioural change techniques and positive parenting skills training to help CYP to achieve individualised nutrition targets and implement principles of healthy eating and optimise blood glucose control.
- Educate CYP, families, other healthcare professionals, teachers and coaches, on exercise management including advise on carbohydrate intake and advances in insulin management.
- Provide advice on diet, carbohydrate management and insulin dose adjustment during illness and periods of fasting for religious reasons.
- Recognise signs and symptoms of emotional distress or behavioural difficulties that require a referral to the Clinical Psychologist or other mental health services.
- Work with the MDT to achieve the most appropriate care/action plans if there are safeguarding concerns about the child's welfare.
- Recognise and manage abnormal, dysfunctional, controlled eating behaviours and make appropriate referrals.
- Participate in the planning of transition from the CYP service to adult services.
- Coordinate additional dietetic appointments, keep records according to the departmental standards and liaise with the MDT to arrange suitable follow up.

- Produce and update nutritional information patient leaflets, carbohydrate counting aids and information on exercise management.
- Participate in strategic plans to improve services and contribute to the development and review of departmental guidelines and policies and attend the MDT and Network meetings and training days.
- Participate and contribute to service evaluation and audit in order to continue to improve dietetic service provision.
- Develop and evaluate age appropriate and theory based teaching packages for small and large groups of CYP and families, such as structured education workshops and the other events organised by the team.
- Advise schools on dietary management of diabetes, particularly in relation to school menus and contribute to school training programs.
- Maintain an up to date knowledge base and understanding of all aspects of paediatric dietary management and paediatric diabetes care and how it relates to dietetics, complication management and healthy living.

Responsibilities of Clinical Psychologists Core Member(s)

- Contribute towards multidisciplinary discussions and patient assessment/care.
- Provide specialist assessment of mental health and psychological wellbeing in CYP and their families and direct psychological interventions in relation to psychosocial aspects of living with diabetes.
- Signposting and referral on to local and regional mental health and social care services.
- Coordination of annual screening for psychological and emotional well-being in CYP and their families.
- Provision of consultation and advice to MDT members and other professionals from external agencies in relation to psychosocial adjustment.
- Teaching/training of MDT members in psychological principles/approaches to support members in their care of patients.
- Ongoing service development in line with relevant policies/guidance to enhance the overall psychological care provided to families.
- Development of information resources available to children and families in relation to psychological and emotional well-being.
- Participation in service evaluation and audit to further improve psychological care and incorporate patient-rated experience.
- Contribute to wider team patient activities e.g. structured education events.

Responsibilities of Data Clerk/Administrator

- Act as data administrator for the team.
- Support the team in ensuring accurate data is collected and validated by clinicians.
- Clinic proformas (relating to BPT and NPDA criteria): to go through clinic lists and highlight items on the patient proforma that need to be addressed at that clinic appointment and then enter the data into Twinkle.NET.
- Review clinic capacity and highlight available appointments.
- Print ‘Set up, Get up, Go’ leaflets ready for clinics.
- Format, photocopy and send newsletters and invitations for structured education events, the activity weekend, teen event, BBQ/tea and cake event and Xmas party.
- To enter patient contacts into Oasis.
- Arrange resources for structured education days e.g. handouts.
- Book rooms and organise calendar invites for meetings and take minutes.
- Send appointments using existing Bluespier templates.

- To undertake photocopying and document collation of patient information leaflets, questionnaires and education resources as required. To ensure there are enough psychology questionnaire packs for annual screenings.
- Liaise with admin who can use Iproc to order, track and distribute questionnaires as requested.
- Send Oasis pick list for Wednesday morning clinic to psychologists 1-2 days in advance.
- To type dictations/correspondence for the Clinical Nurse Specialists, Dietitians and Clinical Psychologists as required.

Ongoing Specialist Training (M1)

Initial training to qualify as a core member is listed in the core membership table above. The most recent Continuing Professional Development for those considered exempt will be itemised in the MDT's Annual Report.

All staff are encouraged to attend a training/conference at least once a year in their field of practice. At least 1 member (usually 2-3) of the MDT attends each West Midlands Paediatric Diabetes Network meeting which has an educational element. Dr West is also on the Steering Committee for the Network.

Clinical Guidelines (M3)

The team works within the NICE guidelines (2015) and ISPAD (2014)/BSPED (2015) in all aspects of diabetes management. The guidelines in use are detailed in the table below:

Guideline	Guideline Reference Number (if applicable)	Date last reviewed	Date agreed by/endorsed by CYPD Network
Care of children and young people newly diagnosed with diabetes, including that, for Type 1 diabetes, children and young people from diagnosis must be offered insulin therapy with multiple daily injections (MDI) and Level 3 carbohydrate counting.	WAHT-PAE-063	Mar 2019	Jun 2018
Care of children and young people with diabetes undergoing surgery.	WAHT-PAE-073	Mar 2019	Jun 2018
Care of children and young people with diabetic keto-acidosis (DKA).	WAHT-PAE-037	Feb 2020	Jun 2018
Care of children and young people with hypoglycaemia.	WAHT-PAE-083	Mar 2020	Jun 2018
Care of children and young people with an HbA1c greater than 69 mmol/mol (8.5 %).	WAHT-PAE-103	Mar 2019	Jun 2018

Sick day rules.	WAHT-PAE-039	Mar 2019	Jun 2018
For Type 1 diabetes, the option of continuous glucose monitoring (either on-going or intermittently) should be offered to patients who meet the NICE criteria.	WAHT- PAE-149	Mar 2019	Jun 2018
Failure to Attend for Children and Young People with Diabetes	WAHT-TP-045	Mar 2019	Jun 2018
Paediatric & Adolescent Diabetes Transitional Care	WAHT-TP-086	Mar 2019	Jun 2018
Continuous Glucose Monitoring Guideline for Children and Young People with Diabetes	WAHT-PAE-149	Jul 2019	
Insulin Pump Therapy Guideline for Children and Young People with Diabetes	WAHT-TP-045	May 2020	
	WAHT-TP-045		

Dr West is informed by the NICE and Key Documents Support Officer if a guideline or patient information leaflet is due to expire (all documents are reviewed every 2 years). The document will then be reviewed and updated as necessary before being submitted to the Quality Improvement Meeting for final approval. All clinical guidelines are available on the Children's page of the Trust's pathways on the Intranet.

Patient Pathways (M4)

Newly Diagnosed Diabetic Pathway

The West Midland Paediatric Diabetes Network referral pathway for newly diagnosed patients in primary care was circulated to the Chair of the Worcestershire Diabetes Network as well as the Quality Improvement Meeting for comments before onward distribution to the CCG's on the 28th March 2018. An updated version was sent to the CCG's on the 8th January 2020.

If a CYP has type 1 symptoms and is thought to have newly diagnosed T1DM they are referred to the on call paediatric doctor on bleep 676 either by their GP or the Emergency Department. If a newly diagnosed patient referred by their GP is felt to be in DKA or clinically unstable they are asked to attend the ED for stabilisation before transfer to Riverbank Ward (the ED are informed that the patient is attending and asked to contact bleep 676 when the patient arrives). If in DKA, the BSPED DKA guideline (WAHT-PAE-037) is followed.

Once on Riverbank Ward guideline 'WHAT-PAE-063: Guidance on Management of Children and Young People with Newly Diagnosed Type 1 Diabetes' is used and the structured education process begins. All CYP (including those between 17-18 years of age who choose to be admitted to an adult ward) are discussed with the Paediatric Diabetes Team (either consultant or PDSN) within 24 hours of diagnosis before they are reviewed by the Paediatric Diabetes MDT on the next working day. The GP is informed

of the newly diagnosed CYP via the electronic discharge summary by the end of the second working day post discharge.

Following discharge, the CYP and their carers receive a programme of structured education which includes daily (not including weekends) contact with the PDSN's and/or the dietitians. They also have support from the Orchard (Community) Nursing Team at weekends and Bank holidays.

DKA Pathway

All CYP with suspected DKA are referred to the paediatric doctor oncall on bleep 676. Patients referred by their GP or self-referrals of known diabetics are asked to attend the ED for stabilisation before transfer to Riverbank Ward. Patients are then managed in accordance with the 'WAHT-PAE-037 BSPED DKA guideline' using the 'WHAT-TP-045 BSPED Integrated care Pathway for the Management of Children and Young People with Diabetic Ketoacidosis'. It has been jointly agreed with the adult diabetes team that all CYP (including 16-18-year olds) are admitted to Riverbank Ward to ensure the BSPED DKA protocol is followed (although this patient group may initially be managed using the local adult guideline in ED if the ED team are more familiar with this). For known diabetics, overall self-management and precipitating causes are reviewed to try and prevent recurrence.

Hypoglycaemia Pathway

CYP and their carers are given clear guidance on how to manage hypoglycaemic episodes in accordance with 'WAHT-PAE-083 Paediatric Hypoglycaemia Guideline for Children with Type 1 Diabetes'. If a patient is conscious and able to tolerate oral fluids they should try self-treatment twice using rapid-acting glucose. If the CYP is uncooperative but conscious then a carer can try Glucogel. If these treatments aren't effective in raising the blood glucose level ≥4 mmol/l, or the child is unconscious or fitting and outside of hospital then the emergency services should be called. If in hospital, then the paediatric doctor on call on bleep 676 should be called. If IV access is available treatment with up to 5 ml/kg of 10% dextrose as a slow IV bolus is given. If no IV access is available glucagon can be given intramuscularly or subcutaneously into the thigh. The CYP is admitted to Riverbank Ward for ongoing monitoring and treatment. Referral to the diabetes team is made for review of treatment, advice and education.

Pathway	Pathway Reference Number (if applicable)	Date last reviewed	Date agreed by /endorsed by CYPD Network
Referral of the newly diagnosed patient (aimed at primary care and general paediatric services); including that a child or young person with a new diagnosis of diabetes is discussed with a senior member of the children and young people's diabetes team within 24 hours of presentation to hospital.	See appendix 5 as well as guideline: WAHT-PAE-063	Jun 2019	Jun 2018
That all new patients must be seen by a member of the specialist paediatric diabetes team on the next working day.	See appendix 5 as well as guideline: WAHT-PAE-	Jun 2019	Jun 2018

	063		
Management of complications of diabetes including DKA and hypoglycaemia.	See appendix 5 as well as guideline: WAHT-PAE-037 WHAT-PAE-083	Feb 2020 Mar 2020	Jun 2018

Patient Pathways in Appendix 5.

Primary Care Communication (M5)

GPs are informed about newly diagnosed diabetics by the electronic discharge summary (EDS) generated by the patient's admission. Clinical guideline WAHT-PAE-063 'Guidance on the management of children and young people with newly diagnosed type 1 diabetes' includes a checklist for completion by the paediatric doctors on the ward. One of the discharge items is 'patient should not be discharged before GP letter/EDS is complete'. Patients are discharged with the medication and equipment they need for the initial few weeks post diagnosis and the PDSN's send a newly diagnosed letter to the GP informing them of what needs to be included on repeat prescriptions.

Failure of same day referral of a newly diagnosed type 1 diabetic will be reported and investigated as a clinical incident. If there has been a delay in diagnosis or referral, this is fed back to the manager of the practice involved for discussion, reflection and shared learning at their practice meeting.

Letter Template to GP in Appendix 6.

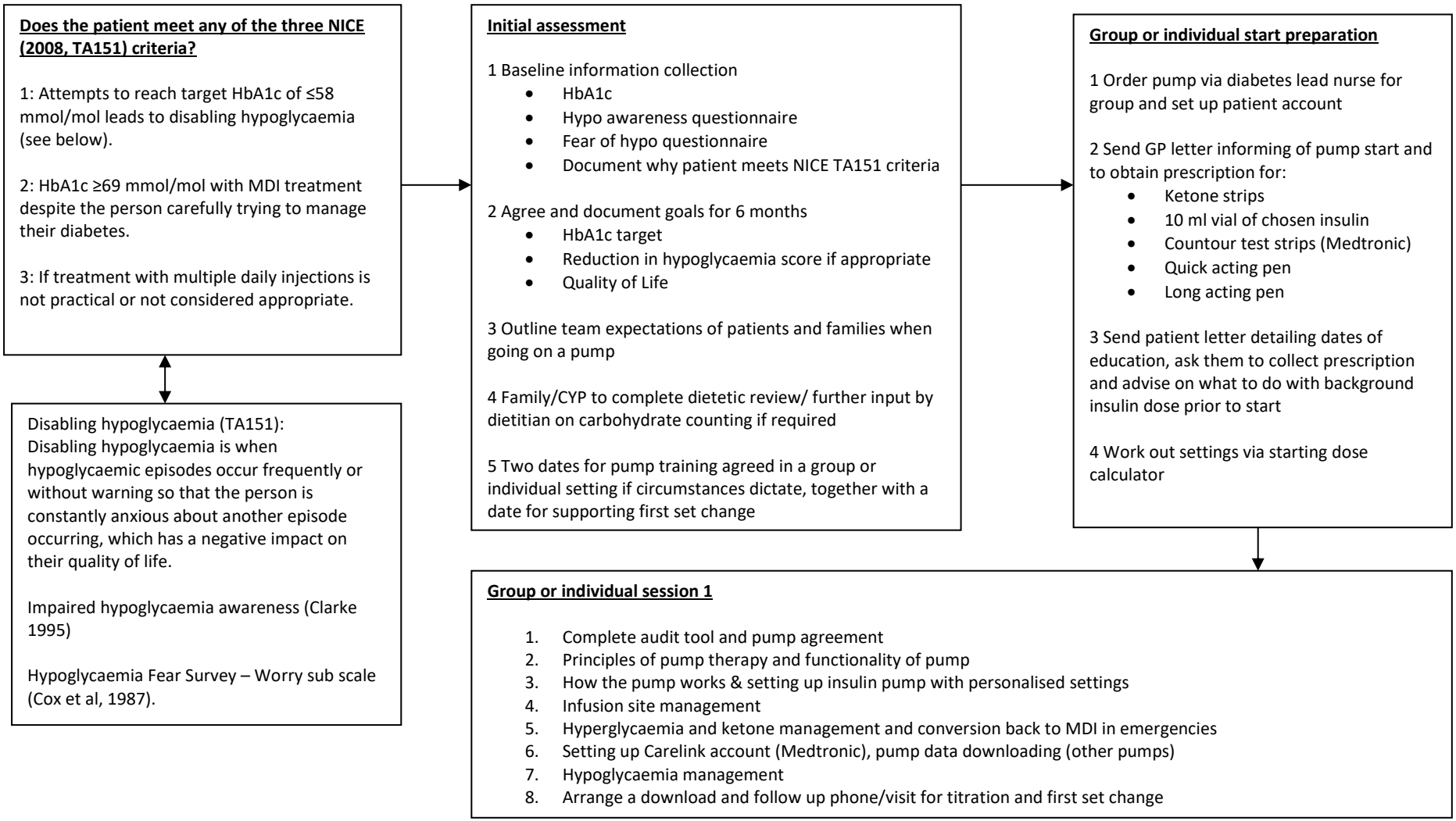
Patient Choice of Insulin Pump Therapy (M6)

Continuous subcutaneous insulin infusion (CSII) pump therapy is offered to all CYP across the service who fulfil the NICE Technical Assessment (TA151) criteria as an alternative to multiple daily injections. Currently we do not routinely start newly diagnosed CYP on insulin pump therapy.

See PAGE 21-22 for flow chart regarding patient journey from assessment to initiating insulin pump therapy and follow up

CYP on pump therapy attend the usual multidisciplinary clinics. They are encouraged to download their insulin pump and review their data prior to attending clinic however, facilities are available in all three clinics to download insulin pumps. CYP and their carers are encouraged to be in regular contact with the PDSN's by phone or email to assess pump downloads and optimise management in between clinic appointments.

Paediatric Diabetes Insulin Pump Pathway



Group or individual session (2 -4 weeks post start)

Download pump to assess progress and titrate doses

Education on:

- Advanced bolus options
- Travel and safety information
- Basic guide to exercise
- Arrange download and phone follow up
- How to assess and make changes at home by interpreting reports on data available
- How to manage alcohol on pump therapy
- Testing and modifying basal rates
- Testing and modifying carbohydrate ratios
- Arrange further download and follow up

→

3 month assessment

Download pump at clinic (or families do before if able)

Repeat baseline measurements and complete audit tool

- HbA1c
- Hypo awareness questionnaire

Have goals been met?

Yes continue with pump therapy

No consider:

1. Time extension to achieve goals
2. Pump holiday for 2 weeks and reassess
3. Return to injections

Continuous Glucose Monitoring (CGM) (M7)

In April 2019 an updated CGM policy was agreed with local commissioners. Ongoing real-time CGM with alarms is offered to all CYP that satisfy NICE criteria including those that have frequent, severe hypoglycaemic episodes, hypoglycaemia unawareness or an inability to recognise or communicate hypo symptoms. It is also considered for those <4 years of age who have persistent difficulties with blood glucose control. Flash glucose monitoring using the Freestyle Libre device is also offered to CYP who fulfil the national criteria. Please see guideline 'WAHT- PAE-149 Continuous Glucose Monitoring Guideline for Children and Young People with Diabetes' for further information. Group or individual structured education is delivered to CYP and their carers when commencing CGM or FGM. Information can be downloaded alongside the insulin pump both at home for email review and in the clinic setting.

In addition, professional CGM is carried out by the PDSN's on occasions for diagnostic/monitoring purposes.

Multidisciplinary Follow-Up Appointments (M8)

All CYP with diabetes across the 3 locality sites are offered a minimum of four multidisciplinary clinic appointments per year. At each appointment patients have their height and weight measured. They also have their HbA1c measured with results available in clinic to facilitate discussions on target blood glucose levels and HbA1c. CYP and their carers have the option of seeing the PDSN, dietitian and clinical psychologist (some clinics) but always see the consultant or associate specialist. Insulin adjustment, dietary and lifestyle advice, dependant on the CYP's stage of development, are also provided. Individualised objectives are agreed, and ongoing education is performed with the use of the Goals of Diabetes educational package and documentation. Clinic letters are written to the CYP and their carers (copied to GPs) and serve as their personal health record and their copy of personal goals discussed.

Patient non-attendance to clinic is monitored by the clinic receptionist and if the patient cancels 2 consecutive appointments a letter is sent reminding the family of the national recommendation of 4 MDT clinic appointments per year. If a patient DNA's 2 consecutive appointments, social factors are considered, and a letter is sent stating that the patient will be referred to social care if they do not attend their next appointment. Please see guideline 'WAHT-TP-045 Failure to Attend for Children and Young People with Diabetes'.

Data is collected during clinic and entered into the Twinkle.NET electronic database. Missing data is collected throughout the financial year.

HbA1C Measurement (M9)

All patients are offered a minimum of 4 MDT clinic appointments per year and at every clinic attendance patients are offered a HbA1c measurement. If a patient cancels or DNA's an MDT clinic appointment they are offered an additional opportunity to attend to have their HbA1c checked.

The HbA1c result is available in clinic to facilitate discussions on target blood glucose levels, HbA1c and to agree objectives. The results are recorded in the clinic notes, on the Twinkle.NET electronic database for monitoring and in the clinic letter to the CYP and their carer.

Dietetic Assessment (M10)

A paediatric diabetes dietitian attends MDT clinics across the county; cover for annual leave is provided by another paediatric dietitian with competencies in paediatric diabetes.

At diagnosis the dietitian undertakes an assessment of nutritional status and dietary intake for all CYP and coordinates appropriate follow up to facilitate education on dietary management of diabetes and physical activity to promote healthy growth and development. This includes carbohydrate counting and insulin dose adjustment to achieve optimal blood glucose levels. The dietitian reviews the CYP and carers' carbohydrate counting skills and carbohydrate intake and sets up the insulin to carbohydrate ratios based on blood glucose levels.

At MDT clinic appointments the dietitian conducts regular reviews of the CYP's nutritional status, growth and dietary intake. They also assess the CYP and their carers' understanding of CHO containing foods and different methods of estimating portion sizes and skills in insulin dose adjustment. The dietitian assesses the macro- and micro- nutrient intake and calculates carbohydrate requirements according to age, weight and activity levels. The dietitian reviews the changing carbohydrate intake and blood glucose levels and advises on insulin to carbohydrate ratios and correction factors. They also assess the management of physical activity and provide practical advice on appropriate carbohydrate intake and insulin dose adjustment for optimal blood glucose levels during and after physical activity.

In addition to the minimum of 4 MDT clinic appointments, where the CYP sees the dietitian, all patients are invited to make an additional appointment with the dietitian. Information about it is included at the bottom of all clinic letters. Additional appointments are encouraged for patients requiring further support with carbohydrate counting and those with specific dietary needs such as a gluten free diet, weight/lipid management, restrictive or fussy eating or patients who need advanced advice for sport management. The dietitian arranges additional dietetic appointments and telephone/virtual follow-ups and keeps a record of CYP and their carers who take up this additional dietary assessment and counselling. The dietitian participates in group education provided by the MDT.

Psychological Assessment (M11)

For detailed information on the referral pathway to clinical psychology please see the document:

- Worcestershire Paediatric Diabetes Team (WPDT) – Psychology Service Pathway Overview

A clinical psychologist is present for the morning clinics but also reviews the patient lists for the afternoon clinics with the rest of the MDT to see if they have (or the patient is likely to need) any ongoing input which they need to share. CYP and their carers attending the afternoon clinics are signposted to clinical psychology if it's felt to be needed and they can make additional appointments with the clinical psychologist by contacting them directly.

The clinical psychologist oversees the administration of annual screening psychology questionnaires in the MDT clinic. They analyse the results and determine whether input from a clinical psychologist is warranted. In addition to more formal screening, the clinical psychologist is in regular discussions with the rest of the MDT to ascertain if and when further, more targeted psychological assessment or intervention would be helpful to the CYP. Families are made aware form diagnosis that they can contact clinical psychology directly themselves at any stage.

Additional Contacts (M12)

All patients are offered a minimum of eight additional contacts annually but in reality most receive a lot more. These contacts are in addition to the MDT clinic visits and include telephone contacts, emails/texts, school visits, home visits, troubleshooting and a quarterly newsletter. The Trust's patient administration system (Oasis) is used to document and monitor these contacts.

Did Not Attend Policy (M13)

There is a policy for the CYPD MDT for the management of non-attenders. As mentioned above, patient non-attendance to clinic is monitored by the clinic receptionist and if the patient cancels 2 consecutive appointments a letter is sent reminding the family of the national recommendation of 4 MDT clinic appointments per year. If a patient DNA's 2 consecutive appointments, social factors are considered, and a letter is sent stating that the patient will be referred to social care if they do not attend their next appointment.

Dr West is responsible for the policy which was last revised in March 2019. It takes into account the Trustwide DNA/Safeguarding Policy and includes an assessment of any safeguarding concerns related to non-attendance, collaboration with other healthcare professionals and appropriate sharing of information (NB The Worcestershire Safeguarding Children's Board does not have a 'did not attend/was not brought policy'). DNA rates for different age bands across all clinics are discussed at the countywide meeting, action plans are developed and implemented. In addition, DNA/WNB rates are discussed annually at a West Midlands Paediatric Diabetes Network meeting. There is also a policy for CYP with high HbA1c's.

- WAHT-PAE-102: Failure to attend guideline
- WAHT-PAE-103: High HbA1c guideline

Support for Children in Education (M14)

PDSN's actively support and train school staff to deliver care and support to CYP with diabetes within nursery, school, academy and college settings. A guideline was written with the support of Worcestershire County Council to encourage good practice, clarify the roles of all parties and to ensure CYP with diabetes are supported to continue with their education. This has been available on the County Council's Children's Services Portal as well as within our own organisation since April 2018.

- WAHT-PAE-085: Supporting children in schools – A document shared on the Children's Services Portal by Worcestershire County Council

This guideline includes:

- arrangements for liaison with schools and colleges
- agreement of a school care plan for each child which is reviewed at least annually
- visits to the school or college by a PDSN to discuss the care of each newly diagnosed child
- training and assessment of competence of school and college staff by the CYP's diabetes team (including school day trips and residential trips)
- storage of medicines while in school or college, including the safe disposal of sharps
- responsibilities of school and college staff for supervising the delivery of/or administering insulin and the supervising of/or testing of blood glucose levels

- guidelines on care of children with diabetes while in school or college
- carbohydrate counting of meals
- management of physical activity
- guidelines on the management of diabetic emergencies

Following feedback, school staff are offered the opportunity to attend a training day twice a year (4 sessions - am/pm) on convenient dates. Staff are also asked to complete the Digibete and JDRF schools e-learning modules. After providing us with a copy of their certificate, the PDSN will go in to school and sign off their competencies for injections, pump boluses, BG monitoring, use of Flash GM and CGM. We aim to get children back to school safely as soon as possible after diagnosis by ensuring that there are a sufficient number of staff trained to support the child.

School care plans are routinely done by PDSN's at the time of need and are updated on a yearly basis. Copies of these are contained in the nursing notes and on Bluespier.

Screening of Children and Young People with Diabetes (M15)

CYP with diabetes are screened according to current NICE guidance.

In Type 1 disease, for:

- **Coeliac disease at diagnosis** – this test is included under the 'new diabetic profile' tab on the electronic pathology request and reporting system. Newly diagnosed patients are reviewed in clinic 6 weeks post diagnosis at which point it is checked that testing has occurred to ensure it is performed within 3 months of diagnosis. Following diagnosis patients are tested on an annual basis and this is monitored by the clinic nurses and entered into the Twinkle electronic database.
- **Thyroid disease at diagnosis and annually thereafter until transfer to adult services** - this test is included under the 'new diabetic profile' tab on the electronic pathology request and reporting system. Newly diagnosed patients are reviewed in clinic 6 weeks post diagnosis at which point it is checked that testing has occurred to ensure it is performed within 3 months of diagnosis. Patients are then tested on an annual basis and this is monitored by the clinic nurses and entered into Twinkle.
- **Retinopathy screening annually from the age of 12 years** – CYP are referred to their local retinopathy screening service at 12 years of age. Retinopathy screening results are entered into Twinkle for monitoring. If notification of a patient's screening result is not received the screening service and/or the patient are asked to clarify if screening has been performed. The screening service are asked to either send the patient's screening result or send them another appointment.
- **Moderately increased albuminuria (albumin: creatinine ratio [ACR] 3-30 mg/mmol; 'microalbuminuria') from the age of 12 years** – from the age of 12 years all CYP are asked to provide a random urine sample on an annual basis. This is monitored by the clinic nurses and entered into the Twinkle electronic database. If a patient has a high ACR, two more early morning urine samples are requested to confirm or exclude micro/macroalbuminuria.
- **Standard anthropometric data** – all patients have their height and weight measured at each clinic appointment. This data is entered into Twinkle for monitoring.
- **Blood pressure annually from the age of 12 years** – all CYP 12 years or older have their BP measured electronically on an annual basis. If this result appears abnormal, it is confirmed manually. If the readings are still high, the patient is asked to attend their GP for it to be

measured and if still high ambulatory BP monitoring is performed. The results are entered into Twinkle for monitoring purposes.

- **Dyslipidaemia annually from the age of 12 years** – a blood test for a lipid screen is performed by the clinic nurse annually. The result is entered into Twinkle for monitoring.
- **Foot assessment/examination** – all CYP 12 years or older have their feet examined to monitor for complications. This is entered into Twinkle for monitoring. Children under 12 years of age are offered foot care advice.
- **Formal assessment of psychological wellbeing** – this is performed with the use of specific CYP questionnaires to determine if further input from the clinical psychologist is needed and to guide access to psychological support. This complements regular and ongoing g psychological assessment by psychologists and the MDT.

In Type 2 disease, for:

- **Hypertension annually starting at diagnosis** – BP is measured at diagnosis and at least annually by the clinic nurse. The result is entered into Twinkle for monitoring.
- **Dyslipidaemia annually starting at diagnosis** – a blood test for a lipid screen is performed by the clinic nurse at diagnosis and annually thereafter. The result is entered into Twinkle for monitoring.
- **Retinopathy screening annually from the age of 12 years** – CYP are referred to their local retinopathy screening service at 12 years of age. Retinopathy screening results are entered into Twinkle for monitoring. If notification of a patient's screening result is not received the screening service and/or the patient are asked to clarify if screening has been performed. The screening service are asked to either send the patient's screening result or send them another appointment.
- **Moderately increased albuminuria (albumin: creatinine ratio [ACR] 3-30 mg/mmol; 'microalbuminuria') from diagnosis** – all CYP are asked to provide a random urine sample at diagnosis and annually thereafter. This is monitored by the clinic nurses and entered into the Twinkle electronic database. If a patient has a high ACR, two more early morning urine samples are requested to confirm or exclude micro/macroalbuminuria.
- **Formal assessment of psychological wellbeing** – this is performed with the use of specific CYP questionnaires to determine if further input from one of the clinical psychologists is needed and to guide access to psychological support. This complements regular and ongoing g psychological assessment by psychologists and the MDT.

Transition and Transfer Policy (M16)

A transition guideline is in place to formalise the transition process. Currently, the diabetic clinics are divided into those patients under 13 years of age and those 13 years old and above. This is so the MDT can focus on transition for the older age group. Prior to transfer the young person attends a joint clinic appointment with the paediatric and adult diabetes nurses. The PDSN will try and attend the patient's first appointment in the adult clinic if possible.

As well as documenting the patient journey there is also a pathway document which is held in the nursing records to record educational updates, assess if a young person is vulnerable and identify key workers in the paediatric and adult diabetes teams on transfer. The Goals of Diabetes programme of competencies is used to develop safe self-management of diabetes care prior to transfer. The decision to transfer a patient is based on the young person's physical development, emotional maturity, local circumstances and patient choice. Those with additional or complex needs have individualised

transition and transfer arrangements agreed. There are also leaflets on transition for the young people and their parents. A video on transition involving young adults describing their concerns and experiences has been produced and is on the Trust's website.

- WAHT-PAE-086: Transition

Young women attending our clinics who become pregnant are immediately referred to the adult diabetes team and obstetric/midwifery services for expert management of their pregnancy.

A transition working group has been formed consisting of members of the paediatric and adult diabetes MDT. This is to try and improve the transition and transfer process with the overall aim of introducing a young adult clinic whilst also maximising patient engagement and minimising the number of patients lost to follow-up. The lack of a young adult diabetes clinic is on adult medicine's risk register.

As mentioned in the DKA pathway section, it has been jointly agreed with the adult diabetes team that all 16-18-year olds are admitted to Riverbank Ward to ensure the BSPED DKA protocol is followed.

- WAHT-PAE-037: BSPED DKA guideline

Key Worker (M18)

Each CYP is allocated a key worker at diagnosis. This key worker is the first PDSN that the CYP meets from their locality. Because 2 PDSN's oversee the CYP in each locality, patients can contact the other PDSN when their keyworker is not available. The CYP and their carers are informed of this at diagnosis and it is documented in the nursing notes. This keyworker remains the same during transition and is the PDSN that attends the joint appointment with the adult DSN and the young adult's first adult clinic appointment.

Patient Information and Support (M19)

All families receive an A4 folder with information about diabetes (based on the Diabetes UK starter pack) on diagnosis. All leaflets are approved at the paediatric Quality Improvement (governance) meeting. Age/maturity appropriate written information on individual subjects and educational resources are provided as the CYP progresses through their educational journey.

These leaflets can also be used to top-up educational topics. Some information leaflets used are from the insulin company Lilly which have been designed and approved by the RCN special interest group in diabetes.

As per Trust policy all information is available in different formats (such as Braille or easy read) and languages by contacting Patient Services. CYP and their carers can also access patient information leaflets via the Trust's website.

There is also written information on how to make a complaint or a compliment.

Information	Local or Nationally produced	If included in other documents identify which	Date revised/ published
Brief description of the	**Local**		Jun 2020

condition and its impact			
Treatments available (pharmacological and non-pharmacological)	**Local and national**		Jun 2020
Management of high and low blood glucose crises	**Local and national** Also GlucaGen leaflet and instructions		Jun 2020
Management of diabetes during times of illness, including 'sick day rules'	**Local and national** – separate leaflets for MDI, IPT and BD insulin patients	Also, Lilly leaflet	Jun 2020
Nutritional advice	**Local** Initial nutritional advice Snacks Carbohydrate counting **Local** Healthy Eating Carbohydrate counting Insulin Dose Adjustment		Oct 2020 Apr 2017
Local arrangements for sharps disposal	**Local**		Jun 2020
Psychological well-being	**Local and national** A leaflet on the paediatric diabetes psychology service. A leaflet on Emotional wellbeing	Lilly leaflet on Emotional Wellbeing	Jan 2018
Disability living allowance advice	**Local**		Jun 2020
Travel advice	**Local and national**	Lilly leaflet	Jun 2020
Possible complications and how to prevent these (including vaccinations)	**Local**		Jun 2020
Information on local support groups on paediatric diabetes if available	**Local**	Out-of-hours info leaflet	Jun 2020
What to expect at annual review	**Local**		Jun 2020
Description of the steps in the transition process to adult care	**Local**		Jun 2020
The opportunity for peer support to young people during the transition process to adult care	**Local**		Jun 2020
Where to go for further information, including useful websites and books	**Local**		Jun 2020
Lifestyle advice, including	**Local and national**	Lilly leaflets	Jun 2020

physical activity, smoking cessation, use of alcohol and recreational drugs, sexual health and contraception, pre-conception care and driving (where applicable)			

Initial information provided at diagnosis:

- Paediatric diabetes service information (locality based) leaflet
  - Redditch
  - Worcester
  - Kidderminster
- What is diabetes?
- Healthy eating with diabetes - initial advice for young people with diabetes – includes simple hypo/exercise treatment
- Disposal of sharps
- How to look after my diabetes at school
- Insulin injections
- Hypo management – included in WAHT initial dietary leaflet, BD and Lilly leaflets
- Exercise – included in WAHT dietary leaflets and Lilly leaflets
- BD Growing up with diabetes or teenage version Living with Diabetes (includes hypo information)
- Blood glucose monitoring
- Receiving a good service from your paediatric diabetes team
- Paediatric diabetes psychology service
- Out of hours and other resources
- Pen User device leaflets
  - Novonordisk Novopen Echo
  - Novonordisk Novopen 5
  - Aventis Solostar/Flexpen

Deapp and the associated tools are also being implemented to help with education of the newly diagnosed diabetic and their carers. We will also use it for ongoing education of our CYP and during restabilisation when patients are admitted to Riverbank Ward.

Additional information given during the initial weeks following diagnosis:

- Second dietary advice leaflets - Healthy eating, Carbohydrate Counting, Insulin dose adjustment and Carbohydrate Counting Tables
- Adjusting insulin on a twice daily regimen
- Flu vaccine
- HbA1c
- Illness management
- Illness management on pump therapy
- Illness management on BD insulin
- Wearing identification
- What happens on clinic days
- Annual review
- Complications
- Disability living allowance

- Footcare
- Holidays
- Glycaemic index - dietitian to give if appropriate
- Sport and Exercise - dietitians or PDSN's to give own specific leaflet or use Gwent Healthcare booklet for the very sporty
- GlucaGen leaflet and instruction

Teenage leaflets and topics when appropriate:

- Diabetes and Careers
- Driving
- Exams and stress
- Smoking

Lilly Streetwise series:

- Safe drinking
- Drugs
- Sex and beyond
- Body piercing and tattooing
- Travelling
- Sick day rules
- Hyperglycaemia
- Hypoglycaemia
- Exercise
- Insulin pumps
- Emotional wellbeing
- Leaving home

Transition leaflet (locality based):

- Redditch
- Worcester
- Kidderminster

During transition young people and their carers are provided with the following information:

- Young Person's Information - What's the difference between the Paediatric and the Adult Diabetes Service?
- Parent Information - Transition to adult diabetes service: what's it all about?
- Parent Information - Encouraging independence in your son or daughter
- Young Person's Information - Negotiating independence
- Young Person's Information - Transition to adult diabetes service: what's it all about?

These leaflets have been shared and agreed with the adult diabetes team. Also, a video on transition involving young adults describing their concerns and experiences has been produced and is on the Trust's website.

Digibete has also been purchased as an extra learning resource for our CYP/their carers, enabling them to stay up to date by receiving National updates and allowing the diabetes team to communicate directly with our patient population. We also hope to use Digibete to send out our quarterly newsletter which includes updates from the team, 'top tips' for improving control, information from the Parents Support Group and it has upcoming events advertised. Other sources of support include:

- The Worcestershire Facebook group - parent led, all families have information on the West Midlands Paediatric Diabetes Network Facebook group for additional peer support.
- Parents Support Group - some parents, along with support from the MDT, run a parent support group and offer 3 or 4 meetings a year. Parents are encouraged to set the agenda and topics for discussion for these meetings.
- The West Midlands Paediatric Diabetes Network also run meetings (educational and support) for local families which we advertise on their behalf.

Funding permitted, extra-curricular activities take place to help improve the self-esteem of CYP, to encourage peer support as well as providing additional support to their parents. These also have an educational brief although in a more informal setting which is often beneficial in the learning process. This includes:

- An annual activity residential weekend for 8 to 13-year olds
- An annual teenage activity day for 11 to 17-year olds
- A Christmas party
- A family day and BBQ
- Diabetics rugby - every Tuesday evening during term time at The High Performance Centre, Sixways Stadium
- A monthly young person's support group for ages 11+

Individualised Objectives (M20)

Every child and young person has agreed individualised objectives, which are reviewed and updated regularly. These include:

- life-style goals which include explanations about the benefits and effects of exercise on blood glucose levels and about strategies for avoiding hypo- or hyperglycaemia during or after physical activity
- advice about smoking avoidance/cessation both for the CYP and their carers – this is monitored on Twinkle
- target blood glucose levels and how to achieve these through insulin adjustment
- therapeutic interventions (pharmacological and non-pharmacological)
- self-care
- individualised healthy meal planning for the child/young person and their family including carbohydrate counting and co-morbidities that effect dietary management
- education and education plan covering, as a minimum, school attended, medication details, what to do in an emergency whilst in school, giving/supervision of injections by school staff and arrangements for liaison with the school
- early warning signs of problems, especially high and low blood glucose levels, and what to do if these occur
- who to contact for advice and their contact details (emergency contact advice is included at the end of clinic letters)
- planned review date and how to access a review more quickly, if necessary – this information is included in the patient's clinic letter

During MDT clinic appointments the CYP is encouraged to develop their own individualised objectives based on the items listed above. They write these down on clinical goal setting worksheets to take home with them as a reminder. The objectives are reviewed at the next clinic appointment, if not before by the MDT.

Diabetes Self-Management Education (M21)

The aim of the Worcestershire Paediatric Diabetes team is to provide consistent high quality, age and maturity appropriate education from the time of diagnosis and throughout the diabetes journey of the CYP and family so that the individual can eventually manage their diabetes with confidence and fit it into their individual lives. The MDT ensures that each CYP has an individualised structured education programme that is updated on a continuous basis.

Structured education is commenced at diagnosis using a checklist proforma within the nursing notes documentation. This is consolidated with written information provided in an A4 folder for families called 'Living with Diabetes'. This folder can also act as the CYP's personal care record and families are encouraged to keep copies of subsequent clinic letters in this folder. Following discharge from Riverbank Ward, the PDSN'S have daily telephone contact (except at weekends) with the CYP and their carers for the first 2 weeks following diagnosis as well as delivering two face-to-face educational sessions to cover information on relevant topics given in the Living with Diabetes folder. This folder also contains information on the local Diabetes team and how and who to contact for advice. CYP and their carers also have two face-to-face meetings with a paediatric diabetes dietitian in the first fortnight following diagnosis. Carbohydrate awareness is taught with the aim of having CYP and/or their carers doing Level 3 carbohydrate counting within 2 weeks of diagnosis taking into consideration the individual learning abilities of families. As mentioned in 'Patient Information and Support', Deapp is being implemented to help with the structured educational process of the newly diagnosed diabetic.

All patients receive at least eight additional contacts annually e.g. telephone contacts, school visits, emails, troubleshooting advice, support etc and the PDSN's document these on an Excel spreadsheet.

Ongoing education and topics covered are documented using 'Goals of Diabetes'. This is an age banded, quality assured, educational and goal setting tool that identifies education given and assesses self-management in relation to the personal preferences, emotional wellbeing and age and maturity of the CYP. It is begun within 3 months of diagnosis and is held in the nursing notes but can be completed by any member of the team (who has had the appropriate training) at the multidisciplinary clinic or at any other contact such as during a home visit by the PDSN's. This is an especially useful tool for those young people who choose not to attend group education and it is reviewed annually.

There is a structured educational event held every year for all ages and treatment options. Dietetics offer educational events based on current need including carbohydrate counting and an update to the population with coeliac disease.

A group structured education programme is also offered for insulin pump starts. Pre-pump start there is a detailed appointment with the dietitian to ensure carbohydrate counting skills are up to date. The pump start session (for 2-8 patients at a time) consists of a full day when starting the insulin pump and one further 4-hour follow-up session. The aim of these sessions is for the CYP and their carers to get the most out of using their insulin pump, and to encourage self-management in the titration and alteration of doses where possible. For existing pump patients, an update event is offered every 12-18 months.

A structured education programme for CYP starting on continuous blood glucose monitoring/CGM augmented insulin pump therapy is also available, and training is provided on how to interpret and use the flash glucose monitoring Libre device.

		Date
Is the programme delivered by members of the CYPD MDT who have undertaken appropriate training in paediatric diabetes management and education?	Esther Anstey	N/A
Is there a structured, written curriculum?	Goals of Diabetes	Jul 2016
Is the programme adjusted to the age and developmental stage of the child/young person?	Yes, age bands include: 6-7 year olds 8-9 year olds 10-11 year olds 12-13 year olds 14-15 year olds 16-18 year olds	
Is the programme quality assured against the programme agreed across the Network?	Yes, nationally agreed programme	Jul 2016
Does the programme fulfil the requirements of NICE NG18 2015, NICE QS125 2016?	Yes	Jul 2016
Does the programme have a named core member of the CYPD MDT who is responsible for organising the diabetes self-management education programme on behalf of the CYPD MDT?	Esther Anstey	
Is the programme reviewed annually?	Yes, by Esther Anstey	

Record of Care (M22)

At diagnosis all CYP and their carers are provided with an information folder. They are encouraged to keep this as a hand-held record of care received and file clinic letters which are written to the CYP and their carers (with their GP copied in) as well as the goal setting worksheets they complete at clinic appointments.

Miscellaneous

Patient experience measures and audit participation

Patient Reported Experience Measures (PREM) (including Patient/Carer Experience of Transition and Transfer) - results are presented and discussed at CYPD MDT meetings with action plans agreed and implemented.

National Paediatric Diabetes Audit (NPDA) – individual unit reports are reviewed and presented to the CYPDN, Countywide diabetes team and Paediatric department for discussion and a programme for improvement is agreed.

Results of the above are fed back to CYP and their families.

Podiatry

Podiatry services are accessed via referral by the Consultant or PDSN.

Social Services Support

Social care is accessed via Worcestershire County Council's Family Front Door service. PDSNs actively attend safeguarding meetings, looked after child meetings and multiagency meetings.

Implementation

This policy is documenting current practice within the paediatric diabetes service and therefore is already being implemented.

Plan for implementation
Countywide paediatric meetings, Quality Improvement meeting, Diabetes Network meetings

Dissemination
To the Paediatric Diabetes team and associated services coming into contact with CYP with diabetes

Training and awareness
The training needs of the medical staff are identified in their annual appraisals and addressed as necessary with appropriate support for study leave.

The training needs of the PDSNs are also identified annually and they are supported to attend educational meetings (ACDC, Nottingham Paediatric Diabetes Conference, pump training, etc.)

All staff will attend mandatory training (listed in Analysis Appendix A of the Trusts Mandatory Training Policy) which may include occasional, additional safeguarding training.

Monitoring and compliance

NPDA
Data is submitted to the NPDA to assess performance, identify areas for improvement and benchmarking.

Paediatric diabetes BPT
Data is also submitted to the CCGs to demonstrate compliance with the BPT.

West Midlands Paediatric Diabetes Network audits
We also submit data to Network audits which have recently included a DKA audit and a transition audit.

Policy Review
The trust has a mechanism for automatic review of all guidelines - whereby the main author is reminded by email of the need to update a guideline that it due for review.

References

Please see the administration page for the Diabetes and Endocrinology treatment pathway for all references.

Supporting Documents

Supporting Documents 1: Equality Impact Assessment Tool
Supporting Documents 2: Financial Risk Assessment Tool

Supporting Document 1 - Equality Impact Assessment Tool

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

		Yes/No	Comments
1.	Does the policy/guidance affect one group less or more favourably than another on the basis of:		
	Race	No	
	Ethnic origins (including gypsies and travellers)	No	
	Nationality	No	
	Gender	No	
	Culture	No	
	Religion or belief	No	
	Sexual orientation including lesbian, gay and bisexual people	No	
	Age	No	
2.	Is there any evidence that some groups are affected differently?	No	
3.	If you have identified potential discrimination, are any exceptions valid, legal and/or justifiable?	N/A	
4.	Is the impact of the policy/guidance likely to be negative?	No	
5.	If so can the impact be avoided?	N/A	
6.	What alternatives are there to achieving the policy/guidance without the impact?	None	
7.	Can we reduce the impact by taking different action?	No	

If you have identified a potential discriminatory impact of this key document, please refer it to Assistant Manager of Human Resources, together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact Assistant Manager of Human Resources.

Supporting Document 2 – Financial Impact Assessment

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

	Title of document:	Yes/No
1.	Does the implementation of this document require any additional Capital resources	No
2.	Does the implementation of this document require additional revenue	No
3.	Does the implementation of this document require additional manpower	No
4.	Does the implementation of this document release any manpower costs through a change in practice	No
5.	Are there additional staff training costs associated with implementing this document which cannot be delivered through current training programmes or allocated training times for staff	No
	Other comments:	No

If the response to any of the above is yes, please complete a business case and which is signed by your Finance Manager and Directorate Manager for consideration by the Accountable Director before progressing to the relevant committee for approval

Appendices

Appendix 1 – Mission statement

Your Paediatric Diabetes Team

What you can expect from us: We will:

- *Offer at least 4 clinic appointments per year with a Paediatric diabetes doctor, nurse & dietitian and to check your Hba1c*
- *Offer annual screening for complications including: blood tests for thyroid function and coeliac screen for all ages and cholesterol blood test, foot exam, urine for microalbuminuria and retinopathy screen (over 12 years)*
- *Offer psychological support for the child / young person and family when required*
- *The team will be available for extra support, advice, troubleshooting and checkups by e-mail, telephone and in clinic*
- *Offer occasional home visits when needed*
- *Offer an additional appointment with a dietitian once per year and as required*
- *Offer ongoing education tailored to the needs of the child / young person and their care providers including structured education events, teaching in schools, home and clinics. Some of this will be included in social activities for the child / young person and their families to enjoy*
- *We will support the young person through the transition to adult Diabetes Services*

Our Aim:

To provide consistently high quality care to children & young people with diabetes, their families and care providers. We will offer support and education to enable the child / young person to become independent in managing their own diabetes by the time they reach adulthood.

What we expect from you as a parent/guardian or young person:

- *To attend your 4 clinic appointments per year and have available your blood glucose diary and meter for review*
- *Where possible, to download pumps in advance of clinic appointments to enable a more thorough review and in-between clinics for further support and guidance*
- *To be proactive in reviewing blood glucose levels and adjusting insulin and to request support and advice when needed*
- *To participate in offered education to enhance skills for managing diabetes*
- *To use your diabetes service to gain the knowledge and skills to manage your diabetes independently*

Appendix 2 - Paediatric Diabetes Countywide Meeting

Terms of Reference

1.0 Name of Group

Paediatric Diabetes Countywide Meeting

2.0 Terms of Reference

2.1 Agreed July 2020

3.0 Purpose of Group

3.1 To ensure the provision of high-quality care by the paediatric diabetes team. To be assured that the correct systems are in place within the service to deliver safe and effective care with as high a level of patient and family satisfaction as possible.

4.0 Membership

4.1 Consultant Paediatrician and Clinical Lead - Chair
Paediatric Diabetes Specialist Nurses
Consultant Paediatrician and Associate Specialist
Paediatric Dietitian
Clinical Psychologist
Paediatric Diabetes Administrator
Directorate Manager
Lead Consultant for Care of Adults with Diabetes
Trust Lead for point of care testing
Matron for Children's services
Named Nurse for Safeguarding
Secretarial Support

4.2 To be quorate the minimum of Chair or their deputy, one PDSN and one consultant need to be present.

5.0 Accountability

5.1 The paediatric diabetes team is accountable to the Women and Children's Directorate via the Quality Improvement Meeting.

6.0 Working Methods

6.1 The Paediatric Diabetes Countywide Meeting will review the following:

a. Children and young people's admissions related to DKA, hypoglycaemia, re-stabilisation, conditions unrelated to the management of diabetes and those with newly diagnosed diabetes.
b. Datix's (clinical incidents) and safeguarding issues.
c. Policies, protocols and procedures to ensure they are up to date.
d. Issues related to staffing within the team.
e. Ongoing quality improvement projects and action plans
f. Data of Young adults transferred to Adult diabetes care, their follow ups and admissions.
g. Training and educational policy for paediatric ward staff.
h. Compliance with service specification including Paediatric Diabetes BPT and the National Quality Improvement/Quality Assurance and National Peer Review Programmes.
i. PREM and National Audit results.
j. Information from the West Midlands Paediatric Diabetes Network meetings and WAHNHST governance meetings.

6.2 Meetings will be held every two months. Twice a year the meeting will be part of Paediatric Diabetes Away Days.

7.0 Sharing of Information

7.1 Agendas and minutes are approved by the Lead Paediatric Diabetes Consultant and the Lead PDSN and are sent out by email within a week of the meeting.

7.2 Agendas and minutes will be stored in a shared folder on the M:Drive for all parties to refer to.

7.3 The Lead Paediatric Diabetes Consultant will provide feedback to the Quality Improvement Meeting.

8.0 Review

8.1 Terms of Reference to be reviewed every two years.

Appendix 3 - West Midlands Paediatric Diabetes Network agreed 24-hour advice service specifications

Here is the agreed statement regarding BCH Diabetes Clinical Cover for local diabetes services operational policies to facilitate peer review standards:

- **All units must have local clinical cover for out of hours advice to non-diabetes specialist consultants for the care of diabetes, including support for insulin pump therapy issues and CGM.**

- **All non-diabetes specialists in the (local) Trust paediatric on call rota will be competent and have regular training in the management of diabetes emergencies including DKA, severe hypoglycaemia and managing diabetes during inter-current illnesses as well as care of the newly diagnosed with diabetes.**

- **Local guidelines for trouble shooting with CSII, CGM, DKA, hypoglycaemia and sick day rules and for the care of the well newly diagnosed are in place to support this.**

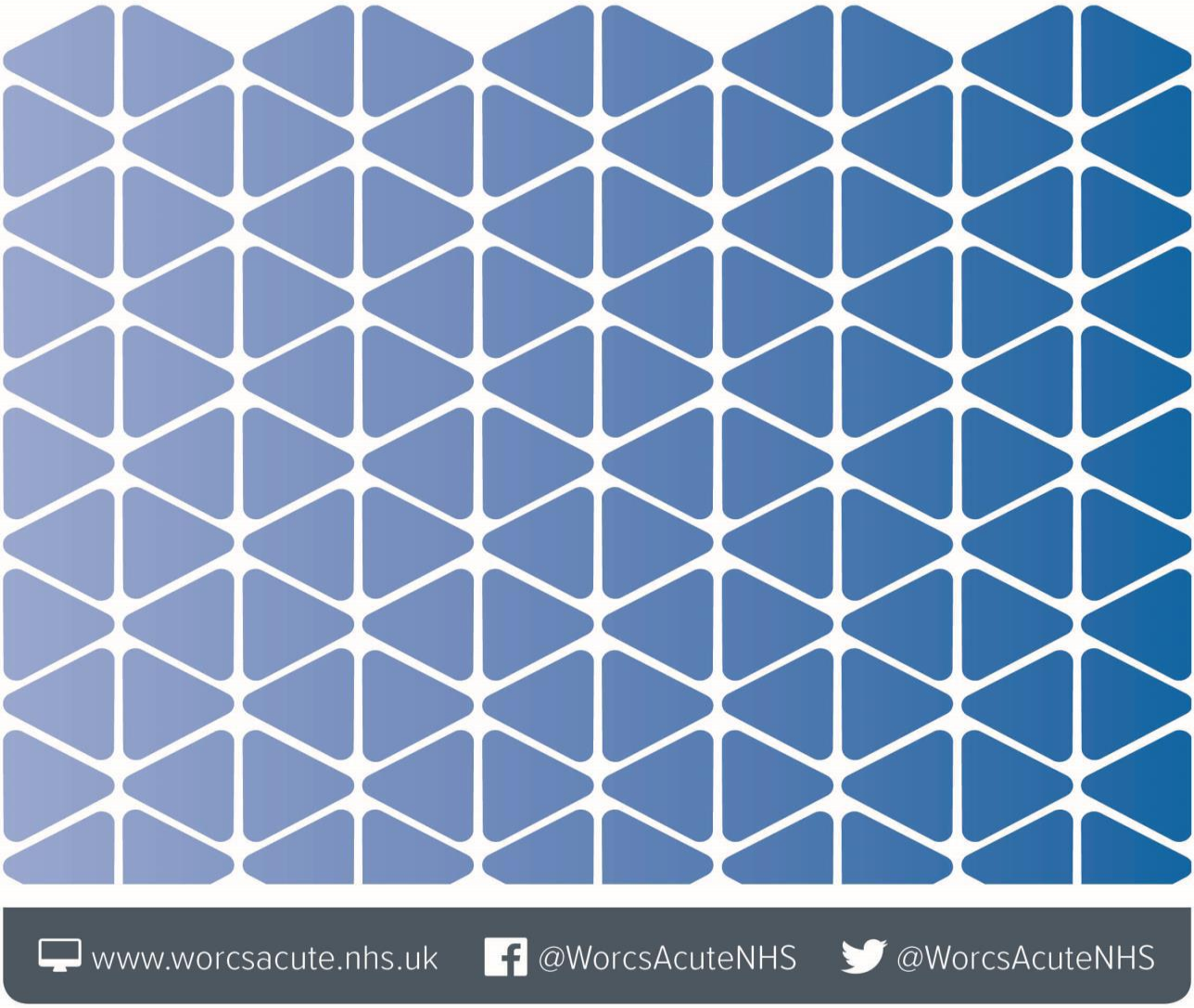
- **For patients with diabetes who are seriously unwell, in the unusual event of the local diabetes specialist being unavailable out of hours, and the local consultant paediatrician on call requiring medical advice, the Regional Endocrine on call service and / or KIDs service at Birmingham Children's hospital can be contacted for advice on a consultant to consultant basis.**

Appendix 4: Out-of-hours Advice Leaflet

NHS Worcestershire Acute Hospitals NHS Trust

PATIENT INFORMATION

Paediatric Diabetes – Out of Hours Emergency Contact and Other Information



During a normal working week (Monday – Friday 9am – 5pm) your usual diabetes nurse will be able to give advice should you experience any problems. Occasionally another Paediatric Diabetes Specialist Nurse (PDSN) in the County may be providing cover for your usual nurse. Contact numbers for the PDSN team are:

Esther Anstey/ Jane Francis – 07879 440181
Becki Walling – 07786 981146
Tracey Jones – 07436 037361
Lee-Ann Edwards - 07881 787239

Paediatric Ward - advice can also be obtained out of hours, weekends or bank holidays from **Riverbank Ward, Worcester Royal Hospital Tel 01905 760588. Ask to speak to the Registrar.**

Insulin Pumps

If you use an insulin pump chose the appropriate company below for advice:

Medtronic – 01923 205167
This is a 24hr helpline for technical problems with the pump or sensors (not for blood glucose or insulin dose related problems). You will only be charged for a local rate call even though the call goes to America.

Roche (Accu Chek) – 0800 731 2291
Advice can be obtained overnight and weekends or bank holidays, for problems with blood glucose levels, insulin doses and pump errors.

Omnipod- 0800 092 6787
24 hour advice can be obtained from a diabetes nurse.

Blood Glucose Meters

If you have a problem with your blood glucose meter please contact the relevant company below:

Ascensia (Contour) – 0835 600 6030 Monday – Friday 8.00am-20.00pm
Abbott (Freestyle/Insulinx/Libre) – 0800 612 3006 Monday – Friday 8.00am-5.30pm
Roche (Expert/Mobile) 0800 858 8072 Monday – Friday 8.00am-6.00pm

Other information resources

Diabetes UK and JDRF (Juvenile Diabetes Research Foundation) are leading national charities in the UK which do a great deal of work to help people with diabetes; supporting them and helping them to understand and manage their condition, they raise large amounts of money which goes towards research. They also have key educational areas for your child's age group on their web site. Ask a member of your Diabetes team for further details. If you join Diabetes UK, Balance magazine or a magazine related to your age (Tadpole times, On The Level) will be sent to you every few months, which contains information on Diabetes, latest news and recipes. JDRF also have a wide range of support material including Rufus the Bear for younger children.

Diabetes UK offer a free year's subscription if your child has Diabetes and JDRF offer a free kids pack with Rufus the Bear. Both organisations also provide additional support material for schools. If you want to meet other people living with diabetes, to share and learn from each

other in a relaxed and fun environment? Then Diabetes UK's events are for you. They have events for children, adults and families. They also offer a "My Life" section on their web site for age related information on diabetes.

All the blood glucose meter companies have useful helplines and web sites with additional support materials some particularly relating to children and young people.

Local Parents Group

There is a local parent support group which has about 3-4 meetings a year. They have a Facebook group to help support local families. You can contact the group by searching on **Facebook for "Worcestershire Juvenile Diabetes Group**". If you have difficulties accessing this or wish to be put on the mailing list, contact your Diabetes Nurse who will ensure you are invited to join the group.

West Midlands Paediatric Diabetes Network

This is a local organisation where all the professionals involved can meet and network the best ways forward to improve their services. There is also a Facebook group that lets parents connect to families in the West Midlands.

Search on **Facebook "West Midlands Paediatric Diabetes Network Parents Group"**

Useful websites

Diabetes UK www.diabetes.org.uk **JDRF** www.JDRF.org.uk

Abbott www.freestylediabetes.co.uk
AccuChek www.accu-chek.co.uk **Ascensia** www.diabetes.ascensia.co.uk

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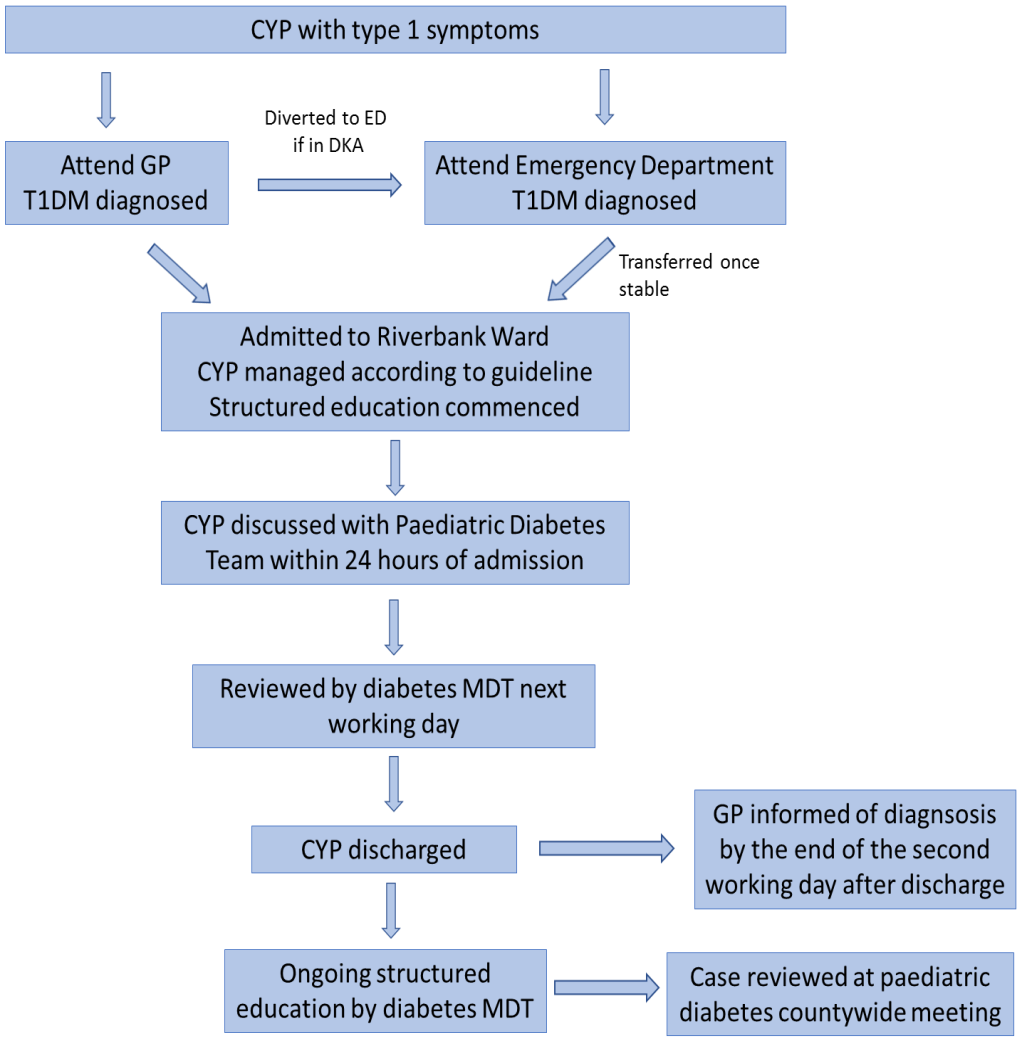
For teenagers www.teenagehealthfreak.org
For Parents and children www.Digibete.org
For sporty teenagers www.runsweet.com

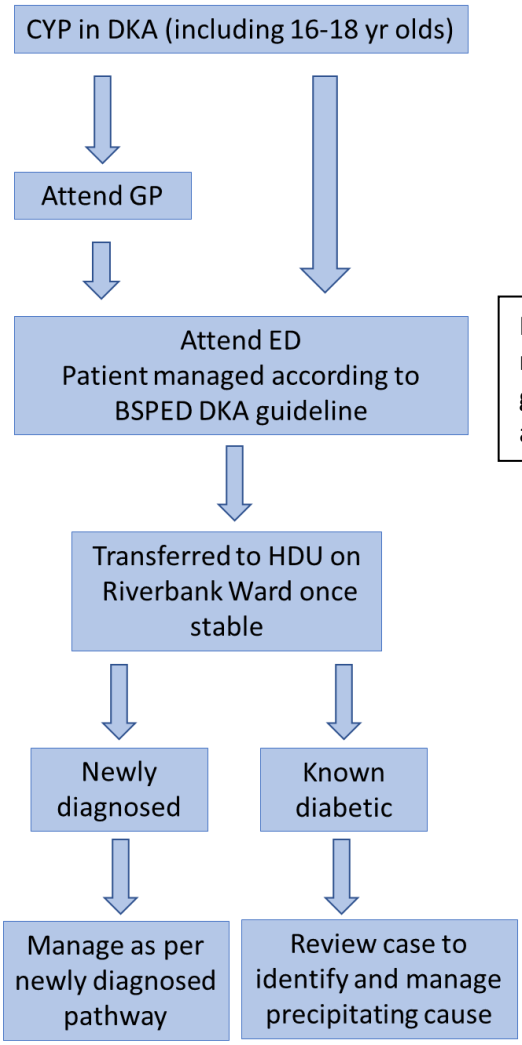
For ID www.medicalert.org.uk www.nextofkin.eu

Appendix 5 - Patient Pathways

Newly Diagnosed Pathway

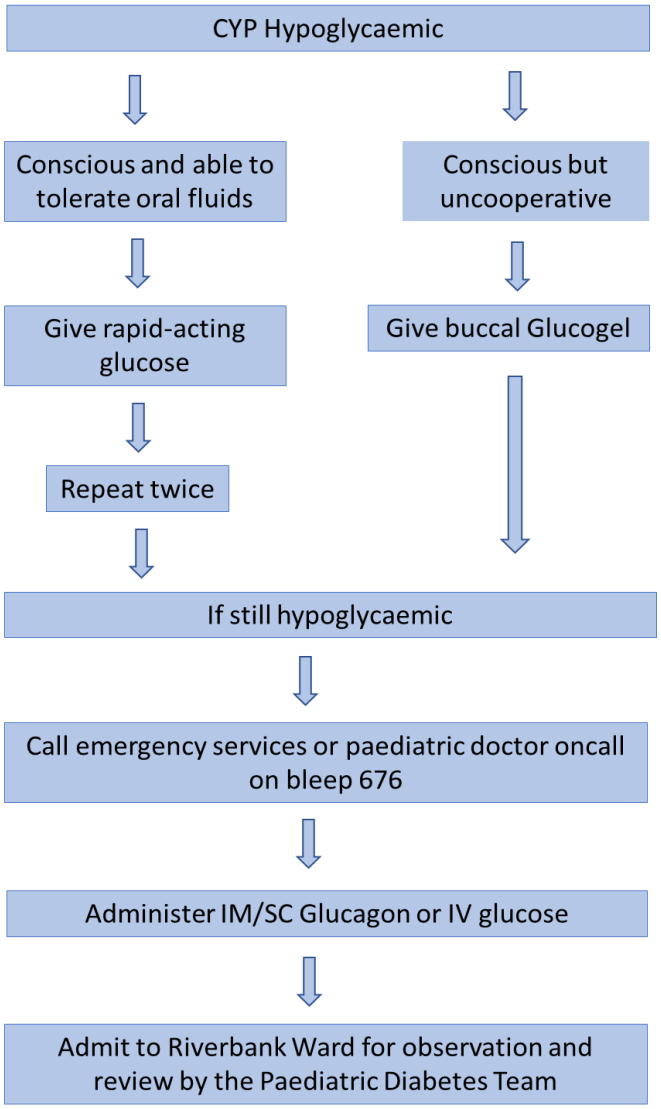


DKA Pathway



NB. 16-18 yr olds may initially be managed using the local adult guideline in ED if the ED team are more familiar with this

Hypoglycaemia Pathway



Appendix 6 – GP letter templates

Patient demographics

Patient name:
Hospital number:
NHS number:
Date of birth: Gender:
Patient address:

Worcestershire Acute Hospitals NHS Trust

GP practice
GP name:
GP practice details:
GP practice identifier:

Location: Worcestershire Royal Hospital

Paediatrics Medicine Discharge Summary

Admission details	
Admission method:	**Date of admission**:
Patient location: Worcestershire Royal Hospital	

Discharge details	
Discharging consultant:	**Date of discharge**: **Time of discharge**:
Ward: WRH River Bank Ward Paediatrics	**Discharging specialty / department**:
Discharge destination: Discharged home.	**Discharge address:**

Plan and requested actions	
Actions	**When**
No follow up tests for this admission.	
For review at outpatient department at Worcester Royal Hospital in	6 weeks.

Investigations and procedures requested
Investigations requested:

Diagnosis

Diagnosis	*Code*	*Date*	*Type*	*Status*
Juvenile Onset Diabetes Type 1	*E10.9*		*Primary*	*Confirmed*

Procedures		
Procedure	**Complications related to procedure?**	**Date**

Clinical summary
Management comprised of IV fluids, Initiation of insulin treatment. xxxxxxx is x years old and presented with ir thirst and some possible increased lethargy before bedtime, as well as a short duration of a headache. She ha polyuria. Urine Dipstix showed glycosuria and ketones. Her glucose on admission was 27.2 mmol/l with a norr 7.46, HC03 24.1. She was started on Novorapid 2.5units tds and Levemir 5 units nocte before bedtime. Xxxxxxx has been reviewed by Dr West, the PDSN and dietitian. The Orchard team will provide additional su discharge. MRSA screening not performed. The patient had no health care associated infection during this admission. Medication to take home and side effects discussed. Medicine last given on the ward: Novorapid at

Person completing record

Medical: Name & Grade: Date completed:
Nursing: Name & Grade: Date completed:

1

Patient demographics

Worcestershire NHS Acute Hospitals NHS Trust

Patient name:
Hospital number:
NHS number:
Date of birth: Gender:
Patient address:

Location: Worcestershire Royal Hospital

Paediatrics Medicine Discharge Summary

.
The venflon was removed. Resus training not applicable.
Please give insulin as prescribed and advised by doctors. If you are concerned please seek help through the appropriate ways e.g. diabetic nurse specialists (in hours), orchard community children's nurses or Riverbank Ward at Worcestershire Royal Hospital.

Investigations results:
No investigations to report.

Medications and Medical Devices

Prescribed by: **Ward pharmacy check:**
Pharmacy GP Advice:

Drugs on discharge:

Drug Name & Strength *Comments*	Form & Route	Dosage & Frequency	Qualifiers	Continue by GP or State Course	POD Qty	Ward Qty	Pharmacy Qty
INSULIN ASPART (Novorapid) 3mL CARTRIDGE *Pre meals*	S/C - Subcutaneous	2.5 units 3 times daily 8 hourly		Yes		TTO pack	Yes
INSULIN DETEMIR (Levemir) 3mL CARTRIDGE	S/C - Subcutaneous	5 units At night		Yes		TTO pack	Yes

Drug changes:

Medication	Started	Stopped	Dose Change	Reason for Change
INSULIN ASPART (Novorapid) 3mL CARTRIDGE	X			Pre meals
INSULIN DETEMIR (Levemir) 3mL CARTRIDGE	X			

Allergies and adverse reactions

There are no drug allergies or sensitivities

Assessment scales

Person completing record

Medical: Name & Grade: Date completed:
Nursing: Name & Grade: Date completed:

Patient demographics

Patient name:
Hospital number:
NHS number:
Date of birth: Gender:
Patient address:

Worcestershire NHS Acute Hospitals NHS Trust

Location: Worcestershire Royal Hospital

Paediatrics Medicine Discharge Summary

Information given	**Information and advice given**: Verbal information given to carer. Information leaflets given in Diabetic advice folder. Information leaflets given on Patient/ Carer satisfied with discharge arrangements.

Legal information	
Advance decisions about treatment:	

Distribution list		
Patient	GP	Copy of GP EDS given to parents and Community Paeds.

Person completing record

Medical: Name & Grade: Date completed:
Nursing: Name & Grade: Date completed:

3

Worcestershire NHS
Acute Hospitals NHS Trust

Kidderminster Treatment Centre
Bewdley Road
Kidderminster
DY11 6RJ
Lee-Ann Edwards/Tracey Jones
Paediatric Diabetes Specialist Nurses
Direct Line- 01562 826393

<Todays Date>

<GP: Address Label>

Hospital No: <Patient: Hospital Number>
NHS No: <Patient: NHS Number>

Name: <Patient: First Name> <Patient: Surname> D.O.B: <Patient: Date of Birth>
Address: <Patient: Address Line>

Dear <GP: Name>

Your above named patient has been diagnosed with Type 1 Diabetes. Together with the Paediatric Diabetes Team I will be providing regular support and guidance whilst the family are coming to terms with the diagnosis and learning about the care required.

The patient has been discharged using the following insulin and equipment. I would be grateful if you could ensure these items are put on repeat prescription.

1. Novopen 3 Demi
2. Novopen 4 insulin pen device
3. Luxura HD pen device
4. Glargine solostar disposable pen
5. Penfill 3ml cartridges of insulin
6. Penfill 3ml cartridges of insulin
7. Freestyle Optium Plus blood glucose Test Strips
8. Freestyle Optium B blood Ketone Test Strips
9. BD Microfine + Lancets 33g
10. Accu-chek FastClix lancets
11. BD Microfine + Needles 5 mm
12. BD Microfine + Needles 4 mm
13. Glucogel 1 box 3x25g tubes
14. BD Safeclip (needle clipping device)
15. GlucaGen Hypokit 1mg
16. Sharps Box 1L

Items in bold are required today

Parents are made aware that I provide support Monday to Friday basis except bank ho
and that out of hours they can access Ward 1 at the Alexandra Hospital direct should tl
advice or emergency care regarding Diabetes.

Please do not hesitate to contact me should you require any further information.

Yours sincerely

Tracey Jones
Lee-Ann Edwards
Paediatric Diabetes Specialist Nurse

Parents

Appendix 7 - Paediatric Diabetes Multidisciplinary Team (MDT) Home Visit Guideline

The PDSN's offer home visits to CYP and their carers particularly on diagnosis to help with adjustment to their diagnosis and aim to establish a good working relationship as well as offering a supportive and educational role. Home visits can be offered by all members of the multidisciplinary team (PDSN's, Dietitian, Psychologist) at any time when individual need is identified using the criteria below.

Home visits can be time consuming and are not always a cost effective use of team resources. This guidance is to offer a structured approach to whom and when home visits should be considered. It is however a guide only and home visits can be useful for specific needs and should be at the discretion of the MDT and health professional involved.

Where possible, families/young people should be encouraged to attend a clinic for health care appointments.

Safety of Staff and lone working

All staff who are home visiting should be aware of the **Lone Worker Policy WHAT CG 511** and know how to keep themselves safe. Newly diagnosed patients are assessed on the ward and staff will highlight any concerns to the team before discharge. A risk assessment in the home will be completed at the first visit and recorded on Bluespier. The multidisciplinary team should communicate to each other any on-going concerns surrounding visiting at home. All staff will keep a log in a diary/whiteboard at base of their intended visits and whereabouts and ensure colleagues and senior staff know where they are going.

MDT criteria for who may be considered for a home visit:

- Patients or their carers who have a disability, mental health issue or a medical condition that makes them less able to come to additional appointments.
- Patients from families where there are a number of siblings and child care is not available, making it difficult for the family to attend additional appointments.
- Patients from families who have no access to own transport and are unable to come for an additional appointment on public transport or in a taxi (this can be particularly difficult in rural areas).
- Families who are identified as experiencing financial hardship.
- Any vulnerable young person/family where a clinic visit does not help with engagement.
- Regular non-attendance at clinic – **See DNA guideline WHAT-PAE-102**.

School and nursery visits

- Patients living in boarding schools or other institutions may need to be considered for home visits to be able to provide education to a group of carers/catering company, if such a need is identified by the MDT.
- School or nursery visits by the dietitian should be performed in special circumstances if there is a need to address specific issues.
- It is routine for PDSN's to visit, educate and support medical needs in this environment.
- The psychologist or other member of the MDT may attend multi-agency meetings as necessary held in the school or other environment as required and occasionally may see a young person in school if a need is identified.

Appendix 8 - Clinical Outcome Targets and agreed Team advice to patients

1. **Blood glucose target ranges: all ages, all regimen**
    - Fasting BG level of 4-7 mmol/l on waking
    - Pre-meal and at other times of the day: 4-7 mmol/l
    - Pre-bed: 5-8 mmol/l
    - 2 hrs post-meal: <9 mmol/l, though be cautious with under 5's and review with a 4 hr post meal BG before changing ratio
    - Correcting down to: 6 mmol/l
    - Correct if BG >8 mmol/l
        - Need to look at insulin sensitivity and effect of smallest possible insulin dose e.g. in toddler 0.5 units could have a significant effect. Easier to do fine titration with a pump.
        - Bedtime correction: use 50% normal correction dose and correct to BG of 8 mmol/l.
    - At diagnosis: to have BG within normal range by 14 days
    - BG level of at least 5 mmol/l when driving

2. **HbA1c targets**
    - ≤48 mmol/mol (without significant hypoglycaemia) is ideal to minimise risk of long-term complications

3. **BG testing**
    - Aim for 6-8/day (minimum 5)
    - Pre-meal and pre-bed as minimum – all regimen (including on BD)
    - During night 2 x/month at 3 am
    - When unwell: 2 hourly
    - When thought to be hypo
    - Pre-exercise and post exercise (see exercise section below)

    Continuous glucose monitoring:
    - Offer real-time CGMS with alarms to those who have
        - Frequent severe hypoglycaemia or
        - Impaired hypoglycaemia awareness associated with adverse consequences (e.g. seizures, anxiety)
        - Inability to recognise or communicate symptoms of hypoglycaemia
        - Neonates/infants/children <4 years of age where there are persistent difficulties with blood glucose control
    - Consider real-time CGMS for
        - Those who undertake high levels of physical activity or recurrent severe hypoglycaemia following activity that cannot be resumed
        - Those who have comorbidities (anorexia nervosa) or treatments (corticosteroids) making blood glucose control difficult
        - Those who continue to have hyperglycaemia despite insulin adjustment and additional support

Eligibility criteria for continuation:
1-month assessment:

a. wearing CGM for more than 5 days per week and
b. family attendance at education session and 1-week follow-up session

3-month assessment:

a. wearing CGM for more than 5 days per week and
b. clinic attendance at least twice in the first 6 months and then at least 3 times a year thereafter
c. reduced number of SMBG tests
d. improved self-management evidenced by one or more of the following parameters and depending on the reason for commencement:
    i. Improved HbA1c (>5 mmol/mol if ≥ 58 mmol/mol pre-rtCGM)
    ii. Improved time in defined patient range
    iii. Reduced number of hypoglycaemic events or time in hypoglycaemia (<4 mmol/l)
    iv. Reduced time in hyperglycaemia (>14mmol/l)
    v. Improved hypoglycaemic awareness - necessitating an improvement from baseline (pre-rtCGM) in one or more of the following assessment tools: Clarke Hypoglycaemic Index, Gold Score or Hypoglycaemia Fear Questionnaire
    vi. Improvement in psycho-social well-being – necessitating an improvement from baseline in the PedsQL

Flash glucose monitoring

- Consider Flash Glucose Monitoring for
    - Monitoring >8 times a day
    - Diabetes associated with cystic fibrosis
    - Pregnancy (12 months total including post-delivery)
    - Inability to routinely self-monitor blood glucose due to disability requiring carer support for monitoring and insulin management
    - Occupational or psychosocial circumstances
    - Recurrent severe hypoglycaemia
    - Impaired awareness of hypoglycaemia
    - Avoidance of alternative specialist treatment e.g. insulin pump or rtCGM where appropriate

Eligibility for ongoing use of FGM (assessed initially at 4-6 months and 6-monthly thereafter):

a. wearing the sensor for more than 70% of the time and scanning at least 8 times a day
b. clinic attendance at least twice in the first 6 months and then at least 3 times a year thereafter
c. attendance at an annual education event (the initiation session counts for year 1)
d. improved self-management evidenced by one or more of the following parameters and depending on the reason for commencement:
    i. Reduced number of SMBG tests

ii. Improved HbA1c (>5 mmol/mol if ≥ 58 mmol/mol pre-FGM)
iii. Improved time in defined patient range
iv. Reduced number of hypoglycaemic events or time in hypoglycaemia (<4 mmol/l)
v. Reduced time in hyperglycaemia (>14 mmol/l)
vi. Improved hypoglycaemic awareness - necessitating an improvement from baseline (pre-FGM) in one or more of the following assessment tools: Clarke Hypoglycaemic Index, Gold Score or Hypoglycaemia Fear Questionnaire
vii. Improvement in psycho-social well-being – necessitating an improvement from baseline in the PedsQL

4. Ketones

- To check blood ketones if ill or hyperglycaemia (≥14mmol/l)

5. Diet principles

- Healthy eating principles and low GI diet
- Adequate fruit and vegetable intake, aim for 5 a day
- Intake of energy and essential nutrients to maintain ideal body weight, optimal growth, health and development
- CHO counting within the first few days of diagnosis
- Regular meals and the importance of breakfast
- Minimise snacking and encourage all snacks to be covered with insulin:
    - On MDI snacks up 10-15 g for some patients may not require insulin initially post diagnosis and for those with a low ICR (e.g. 1 unit for >15 g CHO)
    - On a pump aim to cover all snacks with insulin
    - Depending on BG levels additional CHO without insulin may be needed for physical activity
- Avoid sugary drinks; drink water or sugar-free cold drinks
- Use of low sugar alternatives and sweeteners in moderation
- 'Diabetic' products are not required
- Additional insulin dose adjustment may be required for high fat and high protein meals; on a pump may need an increase by 25% of the mealtime dose extended over 2.5 hours, on MDI may require a split injection.
- Nutritional advice on management of physical activity, exercise and competitive sports including adequate amounts of carbohydrate and suitable insulin dose adjustment

6. Insulin

- Before meals and snacks 15 grams or more if on MDI
- Multiple <10 gram snacks eaten within a short time, e.g. two hours, require insulin
- All snacks (any CHO amount) if on pump
- BD insulin – most will need a 10 gram snack mid-morning and afternoon
- Cover bedtime snack with usual ICR unless BG <5 mmol/l, in which case half usual dose
- Always give before food – 15 minutes for analogues

- In toddlers on pumps with erratic eating give 50% of expected pre-meal as the first component of a multiwave bolus. Cancel the extended portion if they do not complete the meal
- Toddlers on MDI – give pre-meal unless a very fussy eater. Avoid post meal insulin if possible and certainly pre-meal by school entry
- Recommend rotation of injection sites from day 1

7. Hypos

Definition: Mild – can recognise and self-treat
Mod/severe: needs third party help

- 2 mild symptomatic episodes per week acceptable
- > 2 mild/wk – look at insulin/food/exercise

Hypos management:

- Test
- Treat ideally with fluid Quick Acting (QA) CHO
  1 gram of glucose raises BG by 0.17 mmol/l in average adult
  5 g glucose < 30 Kg child
  10 g glucose 30-50 Kg child
  15 g glucose >50 Kg child
- Retest after 10-15 minutes
- If <4 mmol/l – repeat QA CHO and repeat until ≥4 mmol/l
- Advise 5-15 grams (depends on age/size of child) Long Acting (LA) CHO if no meal due in next half an hour (not for pump patients)
- Severe
  - MDI: reduce LA and QA insulin by 10-20% for 48 hrs
  - Stop pump until recovered from hypo then 80% TBR for 24-48 hrs
  - Avoid all hypoglycaemic episodes for next 3 weeks
- Look at hypo awareness (should be >3mmol/l)

8. Illness:

- Continue usual background insulin
- BG and ketones 2-4 hrly
- Encourage fluids ++ (sugary fluids if BG down but persistent ketones)
- Phone if vomiting/breathlessness/ketones persisting despite repeated treatment with QA insulin or worried

9. Exercise:

- Aim to keep BG around 6-8 mmol/l before, during and after exercise by having adequate amounts of CHO and/or adjusting insulin doses
- Test 15-30 minutes pre-exercise:
  - If <5.5 mmol/l – have 15-20 g CHO before exercise
  - If <8.0 mmol/l at the start of exercise, probably need a snack of 15 g of CHO, depending on the amount of active insulin, type and duration of exercise
- Consider:

  - For activity within 1-1.5 hours after insulin bolus, if duration is up to 30 min may need to reduce mealtime bolus by >25% and by >50% for activity with duration more than 30 min.
  - For activity more than 1.5 hours from the last insulin bolus give a full dose of mealtime insulin.
  - When BG is 4-8 mmol/l give 0.5 g/kg/hour CHO If activity is within 1.5 hours of the last insulin bolus and 1 g/kg/hour CHO if activity is more than 1.5 hours from the last insulin bolus.
  - When BG is 8-14 mmol/l, additional CHO is unlikely to be required for the activity.
- Check BG levels before and every 30 minutes.
  - If BG if >14 mmol/l, check for ketones. If ketones are <0.6 mmol/l consider half the usual correction and drink plenty of sugar free fluids to prevent dehydration. If ketones are >0.6 mmol/l, delay exercise, follow 'Sick Day Rules' and do not exercise until ketones go down
  - As a starting guide for every 30 min of activity, need to have 10-15 g CHO depending on the BG levels and intensity of exercise

- Post exercise:
  - Test BG immediately post exercise, then 1-2 hourly for a couple of hours and before bed (sometimes might need to test at 3 am if exercise was very intense or prolonged)
  - For exercise more than 30 minutes only give half of the usual correction dose. Reduce mealtime bolus by 25% if having a meal soon after the activity, if not eating for a longer time, have 10-20 g CHO snack without insulin.
  - Pump: for exercise longer than 30-60 min may need to put on a TBR about 1 hour before exercise and if prone to hypos, continue with the reduced TBR for a few hours after exercise. May also need to lower the basal rate by 20% between midnight and 3 am for any strenuous or prolonged exercise
- Intense and prolonged exercise might have hypoglycaemic effects for up to 24 hours, so have a snack with additional CHO and/or reduce insulin dose at the meal following exercise. If exercise is in the afternoon or evening and it is intense for longer than 1 hour, have additional CHO for supper
- Keep a record of BG levels before and after exercise and look for patterns to adjust CHO intake and insulin doses
- Ensure adequate hydration during and after exercise

10. Pumps

- Cannula change every 2-3 days
- BG check pre and 2 hours post meals for week prior to clinic or if control deteriorating
- Basal rate testing – 3 monthly in week leading up to clinic
- Use of multiwave function for high fat/low GI meals – adjust as per blood glucose results
- Standard bolus for sugary food and correction
- Check sites for lipoatrophy as well as lipohypertrophy

11. Screening/Annual review

- BP
  - Annually from 12 yrs
  - If >95th centile on 3 occasions = home BP monitoring or refer for ambulatory BP monitoring
- HbA1c every visit from 3 months from diagnosis
- Injection sites: offer review at every clinic visit
- Psychological wellbeing questionnaire annually to all families
- Coeliac
  - Screen at diagnosis then at least every 3 years until transfer to adult services
  - TTG (and IgA)

- Thyroid
  - TFT's and anti-thyroid antibodies (TPO) at diagnosis
  - TFT's annually
- Eyes
  - Examine at diagnosis (for cataracts)
  - Screen annually from 12 years: refer to retinal screening service at diagnosis
- Lipids
  - Commence screening following stabilisation after diagnosis from 12 years
  - ISPAD recommend check every 5 years if normal
  - Commence screening at 2 years if FHx of early CVD or hypercholesterolaemia
- Feet
  - Screen annually from 12 years
  - Initially ask re symptoms and give footcare advice
  - If symptoms – full neuro examination
- ACR

  NICE: annually from 12 years
  - Test an early morning urine sample
  - If EMU abnormal – repeat x 2
  - If 2/3 EMU abnormal: consider ACE inhibitor
  - Investigations for persistent microalbuminuria
    - Renal ultrasound
    - Autoantibody screen (including ANCA)
    - U&E, creatinine – calculated GFR
    - Phosphate, TMP, urate

12. Transition

- Start the process early from age 13 years
- See transition guideline
- Transfer to adult team around the 18th birthday

What do we say as a team?

At diagnosis:

Doctors/nurses:

- This is diabetes
- Find out about the family's experience/knowledge of diabetes
- Why do they think this has happened? Address concerns
- Explanation of normal physiology
- Normal insulin secretion
- Treatment of diabetes to mimic normal physiology
- Diabetes is important – need to prioritise learning about it
- Importance of good control from the first few weeks
- Treatment targets
- Address long term complications if raised
- Meeting with team psychologist soon after the diagnosis
- Practical aspects: testing and injections
- Hypoglycaemia: Mild initially. Discuss more severe hypos after first few days as BG readings settle
- Illness – address 2nd-3rd week or if arises PRN
- Work with dietitians week 2 to establish ICR

Dietitians:

- Regular meal plans, emphasize importance of breakfast
- No sugary drinks, drink water or sugar free cold drinks
- At least 5 portions of fruit and vegetables per day
- CHO at every meal, about 1/3 of the total portion, as per the 'Eatwell Plate'
- Explain and encourage low GI foods
- Healthy types and amounts of fats
- Appropriate snacks
- CHO counting from first week
- Work with PDSN's to adjust ICR

Team:

- Talk about highs and lows, not good and bad
- Explain the risk of complications:
    - From DCCT the intensive group had
        - 75% reduced risk of retinopathy
        - 50% reduced risk of renal disease
        - 60% reduced risk of neuropathy
    - From EDIC the intensive group had
        - ~50% reduced rick of CVD (MI/stroke)
- Metabolic memory: DCCT intensive group still benefiting after 18 years FU
- Tracking effect: Good control in first year leads to sustained improvement in control