Paediatric Endocrine Conditions and Suggested Types and Frequency of Clinical Reviews during and after the COVID-19 crises

The Covid-19 pandemic and accompanying national directives and lock downs led to a rapid implementation of virtual clinics across the country. Specialities such as diabetes and endocrinology which are primarily outpatient based had to adapt quickly to new ways of service delivery.

The preferred option continues to be carrying out face to face clinical reviews for children and young people, however in view of the on-going pandemic it is important to consider the convenience and benefits of virtual delivery of care in certain situations. If a virtual appointment is considered appropriate, it should ideally be alternated ensuring a face-to-face review at least annually.

This document was therefore created as a guide to support members to enable and optimise the care of children and young people with endocrine conditions. Please note that the suggested review timelines and types of appointment offered will depend on individual circumstances.

Codes

A	Admit or Assess urgently
CU	Clinic Urgent face to face (within 8 weeks)
CR	Clinic Routine
V	Virtual consultations-Primarily for follow up
D	Day Case investigations or review

Section 1: Summary of conditions requiring urgent clinic/hospital or day case admission

	Paediatric Endocrine Disorders	**Plan**	**Comments (New)**	**Comments (Follow up)**	**Link to guidance if available**
1	Precocious Puberty	CU		4-6 monthly review Consider virtual appointments -V	
2	Anterior pituitary hormone deficiencies: isolated or multiple hormone deficiencies	CU/ A	Neonates and infants: shared care with DGH/neonatal unit. Admission for resistant hypoglycaemia and DI	3-6 monthly (depending on age) Consider virtual if accurate growth data available-V	

			Others: Clinic face to face		
3	Hypothalamus Pituitary Axis Tumours: benign, malignant.	A	Liaise with neurosurgeons and oncologists	3-6 monthly (depending on age) Consider virtual if accurate growth data available- V	
4	Isolated Diabetes insipidus	A	Liaise with neurosurgeons and oncologists	4-6 monthly review Consider virtual if accurate growth data available- V	
5	Syndrome of inappropriate ADH secretion (SIADH)	A	Liaise with neurosurgeons and neurology	4-6 monthly review Consider virtual if accurate growth data available- V	
6	GH excess/ pituitary gigantism	CU/ D	Imaging and day case investigation	4-6 monthly review Consider virtual if accurate growth data available -V	
7	Prolactin excess: prolactinoma	CU	Imaging and baseline investigations	3-6 monthly review depending on compliance/severity Consider virtual if prolactin levels available-V	
8	Adrenocorticotrophin excess/Cushing disease	CU	Rare Admission for confirmation of diagnosis	3-6 monthly review Consider virtual if accurate growth data and baseline pituitary function available -V	
9	Primary congenital hypothyroidism	A/D	Same/next day review	Regular review with monitoring of thyroid function test	BTS guideline

10	Hyperthyroidism	A/D	Same/next day review	Regular review with monitoring of thyroid function test	
11	Hypocalcaemia	A/D	Same day/next day review depending on severity	Regular review with monitoring of bone profile	
12	Hypercalcaemia	A/D	Same day/next day review depending on severity	Regular review with monitoring of bone profile	
13	Generalised Arterial Calcification of Infancy	A	Refer to bone centre		
14	Hypophosphatasia: Perinatal and infantile	A	Refer to Nationally Commissioned Centres (Birmingham, Sheffield, Manchester)	As per Managed Access Agreement	
15	Osteogenesis imperfecta: neonatal presentation with moderate to severe	A	Refer to Nationally Commissioned OI Centres (Sheffield, Birmingham, GOSH, Bristol)		
16	Juvenile Idiopathic Osteoporosis	CU		3-6 monthly review Alternate virtual-V	
17	Adrenal crisis	A		3-6 monthly review Alternate virtual based on underlying diagnosis-V	
18	Disorders of Sex Development	CU/ A	Admission in case of crisis or urgent sex rearing issues MDT review with urology	Regular review based on diagnosis Consider virtual- V	? Consensus guidelines
19	Congenital Hyperinsulinism	A	Discuss with Nationally Commissioned Centres (GOSH,	Regular review based on severity Consider virtual -V	

			Manchester/Liverpool)		
20	Diabetes mellitus type 1	A		3 monthly MDT Ideally, not virtual. If virtual, download and HBA1c should be available	
21	Diabetes mellitus type 2	A/CU	Urgent clinic review if not admitted	3 monthly MDT Ideally, not virtual. If virtual, download (dependent on medication) and HBA1c should be available	
22	Diabetes: Drug induced, corticosteroids	A		3 monthly clinic or in patient review or joint clinic with referring speciality	
23	Neonatal Diabetes	A		3 monthly MDT Ideally, not virtual. If virtual, download (dependent on medication) and HBA1c should be available	

Section 2: Summary of paediatric endocrine conditions by system

A	**GROWTH - SHORT STATURE**				
		Plan	Comments (New)	Comments (Follow up)	Link to guidance if applicable
1	Evaluation of growth	CR		4-6 monthly follow up Consider virtual if accurate growth data available-V	
2	GH deficiency confirmed on diagnostic tests	CU		4-6 monthly follow up	

				Consider virtual if accurate growth data available-V	
3	Turner Syndrome	CU		4-6 monthly follow up Consider virtual if accurate growth data available-V	
4	Skeletal dysplasias	CR		Follow up based on underlying diagnosis Consider virtual-V	
5	Small for gestational age (SGA) with failure of catch-up growth	CR		4-6 monthly follow up Consider virtual if accurate growth data available-V	
6	Noonan syndrome, Silver Russell syndrome and other syndromes of growth	CR	CU/D- Silver Russell syndrome with hypoglycaemia	4-6 monthly follow up Consider virtual if accurate growth data available-V	

B	**GROWTH - TALL STATURE AND OVERGROWTH**				
		Plan	Comments (New)	Comments (Follow up)	Link to guidance if applicable
1	Tall stature:	CU/CR	CU: if concerns of precocious puberty	Follow up based on underlying diagnosis 4-6 monthly follow up Consider virtual if accurate growth data available-V	

2	Marfan syndrome	CR		4-6 monthly follow up Consider virtual if accurate growth data available-V	
3	Klinefelter syndrome	CR		4-6 monthly follow up Face to face for pubertal assessment Consider virtual if accurate growth data available-V	
4	Beckwith Wiedemann syndrome: growth, hypoglycemia, tumor risk, genetic investigations	CR	Assess if screening for tumors is ongoing	4-6 monthly follow up Consider virtual if accurate growth data available-V	
5	Syndromic overgrowth	CR		6 monthly follow up depending on diagnosis Consider virtual if accurate growth data available-V	

C	**PUBERTY**				
		Plan	Comments (New)	Comments (Follow up)	Link to guidance if applicable
1	Precocious puberty	CU	Urgent clinic if early menarche or clinical	Follow up will depend on underlying	

			suspicion of intracranial pathology.	cause, treatment 4-6 monthly	
2.	Premature thelarche	CU		Discharge or follow up 4-6 monthly	
3.	Delayed puberty	CU/CR	Urgent if underlying pathology suspected	Follow up 4-6 monthly	

D	**PITUITARY GLAND, HYPOTHALAMUS AND CENTRAL NERVOUS SYSTEM**				
		Plan	Comments (New)	Comments (Follow up)	Link to guidance if applicable
1	Anterior pituitary hormone deficiencies: isolated or multiple hormone deficiencies	CU/A	Neonates and infants: share care with DGH/neonatal unit. Admission for resistant hypoglycaemia and DI Others: Clinic face to face	Follow up 3-4 monthly. Virtual if growth data and blood investigations available-V	
2	HPAT: benign, malignant	A	Liaise with neurosurgeons and oncologists	Follow up 4-6 monthly. Virtual if growth data available-V. Joint clinic where possible	
3	GH excess/ pituitary gigantism	CU	Clinic followed by planned investigations and imaging	Follow up 4-6 monthly and virtual if accurate growth data are available-V.	
4	Prolactin excess: Prolactinoma	CU	Clinic followed by planned	Follow up based on	

			investigations and imaging	severity; virtual if blood results are available-V	
5	Adrenocorticotrophin excess/Cushing disease	CU/A	Clinic/admission for investigation and management of Cushing's.	Follow up based on aetiology; virtual if accurate growth data and blood results are available-V	
6	Diabetes insipidus	A	Water deprivation test and/or fluid intake-output charting	Follow up 4 monthly and can be virtual-V	
7	Syndrome of inappropriate ADH secretion (SIADH)	A	Co-existing with other pathologies	Follow up 4-6 monthly and can be virtual if blood results available-V	

E	**THYROID GLAND**				
		Plan	Comments (New)	Comments (Follow up)	Link to guidance if applicable
1	Primary congenital hypothyroidism	A	Urgent investigations and treatment	Follow up based on severity. Virtual if blood results are available-V	
2	Primary acquired hypothyroidism	CU/CR	W: letter to Referrer to start Levothyroxine		
3	Primary acquired hyperthyroidism	CU/A	Same/next day review. Shared care with DGH	Regular review with monitoring of thyroid function test	

4	Neonatal hyperthyroidism	CU/A	Share care with referrer. Commence treatment A: if symptomatic	Follow up based on severity and blood test results can be virtual. Also accurate growth data, then virtual -V	
6	Thyroid tumours: benign, malignant	CU	Share care with oncologist/ENT surgeon	Monitor 4-6 monthly based on clinical progress	

F	**PARATHYROID GLANDS, AND CALCIUM AND PHOSPHATE METABOLISM**		Comments (New)	Comments (Follow up)	Link to guidance if applicable
2	Hypocalcaemia: transient/ permanent	CU/A/D	Same day/next day review depending on severity	Regular review with monitoring of bone profile	
4	Hypercalcaemia	CU/A/D	Same day/next day review depending on severity	Regular review with monitoring of bone profile	
6	Rickets: Vitamin D and/or Ca deficiency	CU/CR	Shared care with referrer/advice to general paediatrics	General paediatrics	
7	Rickets: genetic defects (Vitamin D hydroxylation-deficiency, Hereditary	CU/A	A: Hereditary 1,25(OH)2 D-resistance	Monitor 4-6 monthly based on clinical progress	

	1,25(OH)2 D-resistance)				
8	X-linked hypophosphatemic rickets, Other familial hypophosphatemic rickets	CU		Monitor 4-6 monthly based on clinical progress	
9	Generalised Arterial Calcification of Infancy	A	Refer to bone centre		
10	Hypophosphatasia	CU/A	Refer to Nationally Commissioned Centres (Birmingham, Sheffield, Manchester)	As per Managed Access Agreement	
11	Osteogenesis imperfecta	A/CU/CR	A: Severe neonatal. Refer to nationally commissioned centres C: OI with new complications CR: Stable with history of fractures only. Request referrer to organise X-ray spine	Follow up based on severity	
12	Juvenile Idiopathic Osteoporosis	CR		3-6 monthly review Alternate virtual-V Follow up based on severity. Virtual if stable.	
13	Secondary osteoporosis: Steroid induced (Duchenne Muscular Dystrophy, management of	CU/CR		3-6 monthly review Alternate virtual-V	

	malignancies), Rheumatoid disorders and other inflammatory condition of bone				
14	Osteopetrosis	A/CU	A: Liaise with BMT for admission or joint review C: milder variant	Follow up based on severity.	
15	Skeletal Dysplasia	CR		Follow up based on underlying diagnosis Consider virtual-V	
16	Unexplained fractures in safeguarding cases	CU/A	Share care with DGH/referrer	Based on outcome.	

G	**ADRENAL GLANDS**				
		Plan	Comments (New)	Comments (Follow up)	Link to guidance if applicable
1	Hypocortisolism	CU/A	Share care with referrer.	4-6 monthly. Virtual if accurate growth data available-V	
3	New diagnosis Congenital Adrenal Hyperplasia (CAH) or Adrenal Hypoplasia	CU/A	Admission in case of crisis or urgent sex rearing issues MDT review with urology	4-6 monthly. Virtual if accurate growth data available-V	
4	CAH existing patients	CR		4-6 monthly. Virtual if accurate growth data and blood investigations available-V.	

6	Premature adrenarche	CU/CR	CU: urgent if strong suspicion of adrenal tumours or late onset CAH	4-6 monthly- some units may opt to discharge.	

H	**Disorders of Sex Development**				
		Plan	Comments (New)	Comments (Follow up)	Link to guidance if applicable
1	DSD	D/A	Admission in case of crisis or urgent sex rearing issues MDT review with urology	4-6 monthly. Virtual if accurate growth data available-V	

I	**DISORDERS OF GONADS - TESTES AND MALE REPRODUCTIVE TRACT**			
	Comments (New)		Plan	Comments (Follow up)
1	Maldescended testes: unilateral, bilateral, retractile	C/W	Share care with referrer and urology	Based on aetiology. If endocrine problems 4-6 monthly can be virtual if accurate growth data available
2	Micropenis: Neonate	CU/W	Share care with referrer and request investigations. Ensure adrenal function stable	Based on aetiology. If endocrine problems 4-6 monthly can be virtual if accurate growth data available
3	Micropenis: Older children	CR/W	Share care with referrer and request investigations.	Based on aetiology. If endocrine problems 4-6 monthly, can be virtual if accurate growth data available
4	Enlarged penis	CU?/W	Share care with referrer and	Based on aetiology. If endocrine problems 4-6

			request investigations	monthly can be virtual if accurate growth data available
5	Hypospadias: isolated	CR/W	Share care with urology	Based on aetiology. If endocrine problems 4-6 monthly can be virtual if accurate growth data available

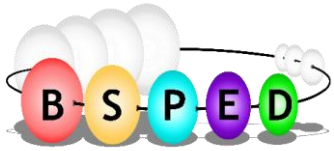
J	**DISORDERS OF GONADS - OVARIES AND FEMALE REPRODUCTIVE TRACT**			
	Comments (New)		Plan	Comments (Follow up)
7	Primary ovarian failure: congenital, acquired	CU/CR		4-6 months. Follow up can be virtual if blood investigations available
8	Polycystic ovary syndrome	CR		4-6 monthly. Follow up can be virtual if blood investigations available.
9	Ovarian tumours • germ cell (germinoma/dysgerminoma, teratoma) • mesenchymal (granulosa cell) • adrenal rest tumour associated with congenital adrenal hyperplasia	CU/A	A; Under oncologist and gynaecologist.	Follow up based on endocrine involvement.
10	Menstrual problems: amenorrhoea; disorders of menstrual frequency, duration and flow; dysmenorrhoea; premenstrual syndrome	CR		Follow up based on aetiology. Consider virtual appointments.
11	Non-menstrual vaginal bleeding-prepubertal	CU		Follow up based on aetiology. 4-6 monthly. Consider virtual appointments.

K	GLUCOSE AND LIPID METABOLISM - DIABETES MELLITUS			
		Plan	Comments (New)	Comments (Follow up)
1	Impaired glucose tolerance	CR		?Follow up 3 monthly as per national recommendation.
2	Diabetes mellitus type 1: immune mediated, idiopathic	A	As above	
3	Ketoacidosis	A	As above	
4	Exocrine pancreas disorders: cystic fibrosis, pancreatitis, pancreatectomy	CU/A	CU: If stable	Follow up as for diabetes, 3 monthly MDT
5	Diabetes mellitus type 2	A/CU	As above	
6	Drug induced: corticosteroids	A	As above	
7	Neonatal Diabetes	A	As above	
8	Genetic defects of beta cell function: Maturity onset diabetes of youth (MODY)	CU		Follow up as diabetes, 3 monthly MDT
9	Genetic defects in insulin action: insulin resistance, Donohue syndrome	CU/A	Nationally commissioned Center Cambridge	Joint clinics, 3-6 monthly. Virtual if accurate growth data and blood investigations available.

L	GLUCOSE AND LIPID METABOLISM - HYPOGLYCAEMIA			
		Plan	Comments (New)	Comments (Follow up)
1	Non-diabetic hypoglycaemia: ketotic vs nonketotic; differential diagnosis and management (medical and surgical)	CU/A	A: if severe and history suggestive of hyperinsulinism	Follow up based on aetiology
2	Transient neonatal hypoglycaemia • infant of mother with diabetes • perinatal asphyxia • neonatal hemolytic disease • intrauterine growth retardation	CU/A	Share care with neonatal team. Discuss with nationally commissioned centre	3 monthly, Virtual if possible.

3	Congenital hyperinsulinism: causes, investigations, diagnosis, immediate management, definitive management	A	Discuss with Nationally Commissioned Centres (GOSH, Manchester/Liverpool)	Frequency based on severity. 3-4 monthly. Can be virtual if accurate growth data available.
4	Hypoglycaemia associated with hormone deficiency: GH deficiency or resistance, cortisol deficiency	A		Follow up based on aetiology and 4-6 monthly. Virtual if growth data is available.
M	**SALT AND WATER REGULATION**			
		Plan	Comments (New)	Comments(Follow up)
1	Polydipsia and polyuria: primary polydipsia, central vs nephrogenic diabetes insipidus	CU/A	Liaise with neurosurgeons and oncologists as needed	Follow up based on aetiology and 4-6 monthly. Virtual if growth data and blood investigations available.
2	Hyponatraemia: • sodium deficiency or loss: adrenal insufficiency, cerebral salt wasting • excessive free water gain: water intoxication, SIADH	CU/A	Management in conjunction with DGH initially where possible, with subsequent clinic appointment (eg Addison's)	Follow up based on aetiology and 4-6 monthly. Virtual if growth data and blood investigations available.

N	**WEIGHT DISORDERS**			
		Plan	Comments	
1	Obesity	CR		3-6 monthly dependent on local commissioning arrangements
2	Complications of obesity	CR	If pre-diabetic or known metabolic comorbidities noted. If T2D – then to have monitoring as per diabetes service	4-6 monthly. Option for joint clinics.



General recommendation: ideally it may be reasonable for a virtual appointment to be followed by a face to face review