

An Integrated Career and Competency Framework for Children and Young People's Endocrine Nurse Specialists

CLINICAL PROFESSIONAL RESOURCE





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This publication is due for review in October 2023. To provide feedback on its contents or on your experience of using the publication, please email publications.feedback@rcn.org.uk

Publication

This updated RCN practice framework is an evidence-based consensus document.

Description

The overall aim and objective of this framework is to help guide endocrine nurse specialists with decisions and inform appropriate care of a child or young person and their family.

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Introduction

Competence can be defined as: “The state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one’s professional responsibilities” (Roach, 2002, p54).

According to the Health and Safety Executive (HSE, 2015) competence in health is the combination of training, attitude and physical ability to perform a task safely.

The changing context

The fields of nursing are highly specialised, and subject to dramatic change as innovations and new techniques are adopted. The RCN Children and Young People’s (CYP) Endocrine community believes that professional advice and support are required for nurses developing their roles in a dynamic and rapidly advancing field.

The competency framework has been developed in this context, as well as taking into account other professional and political factors such as:

- Agenda for Change
- the need for leadership in specialist nursing
- the need for the development of UK-wide standards in paediatric endocrine nursing
- the first NHS Mandate (DH, 2012) and its equivalent in Scotland, Wales and Northern Ireland, revised England 2017-18 and 2018-19
- the increased focus on work-based and lifelong learning plus supervision
- increasing patient and user expectations
- the inconsistency of provision and access to paediatric endocrine nursing education in the UK
- the need for professional accreditation of skills and knowledge in practice
- the national service frameworks and service modernisation
- *The Future Nurse: A Discussion Paper* (RCN, 2004)
- the NHS Knowledge and Skills Framework (DH, 2004-2019).

Agenda for Change

Agenda for Change (AfC) was implemented in the NHS, across the UK, in December 2004. It was the biggest overhaul of NHS-wide pay, terms and conditions in more than 50 years. It applies to all NHS organisations and therefore sets a UK framework for pay, terms and conditions of employment.

AfC and the NHS Knowledge and Skills Framework (NHS KSF) means that all staff will have clear and consistent development objectives; can develop in such a way that they can apply the knowledge and skills appropriate to their level of responsibility; and are helped to identify and develop knowledge and skills that will support their career progression.

Under AfC, jobs are evaluated using a bespoke NHS job evaluation scheme. This gives each job a ‘weighting’ that then determines where each job slots into the pay bands. Common job profiles are applicable across the UK. Each pay band has a number of pay points. Staff below the maximum point can expect to progress to the next point each year.

There are two points on each pay band called gateways where staff knowledge and skills are assessed using the knowledge and skills framework. Pay progression at the gateways is linked to the demonstration of applied knowledge and skills to support continuing professional development. The presumption in the NHS KSF is that staff will pass through these gateways unless there are reasons as to why they shouldn’t.

For more comprehensive information on AfC please refer to www.rcn.org.uk/agendaforchange. This site is your guide to the ins and outs of the pay, terms and conditions for the NHS. It will help you to understand AfC, how it was developed and how you can make the most of the system, particularly the NHS KSF.

1. Children and young people's endocrinology

Children's endocrinology – children's hormones – covers a wide range of illnesses and disorders, varying from minor disorders to severe life-threatening conditions. The most common disorder seen in a children's endocrine clinic is short stature. The National Institute for Health and Care Excellence estimates that the prevalence of growth hormone deficiency is estimated to be between one in 3,500 and one in 4,000 children (NICE, 2010). Congenital hypothyroidism has an even higher incidence and every newborn baby in the UK is now tested for it (Raine et al., 2011). It is therefore clear that the need for specialist children's endocrine services is paramount, and it is suggested that these patients would benefit from the care provided by specialist children's endocrine nurses.

Most children or young people can maintain a normal, healthy lifestyle with the assistance of hormone replacement. However, this can only be gained through accessing specialist children's endocrinology services, where the position of a nurse specialist is paramount. Links from primary, secondary and perhaps tertiary care can be formed, as well as links with schools and multidisciplinary agencies. Conditions can be congenital or acquired, and can sometimes be lifelong, necessitating seamless links into adult endocrine services. The NICE guideline Transition from children's to adult services for young people using health or social care services aims to help young people have a better experience of transition with a named worker who can coordinate and support their transition care (NICE, 2016).

The children and young people's endocrine nurse specialist role

The intricate detail of the role and what is expected is reflected in the specific competency framework in section 5. The children's endocrine nurse specialist should be working towards the aims in the mission statement for the RCN CYP Endocrine community:

“To offer support, advice and expertise to nurses and professionals working with children, young

people and their families with an endocrine disorder.”

Through this, optimum nursing care should be delivered. In essence, the children's endocrine nurse specialist should:

- promote excellent practice in the assessment, diagnosis, treatment and transition of children and young people and their families with an endocrine disorder
- be the first point of contact and principle keyworker/advocate for children and young people and their families with an endocrine disorder
- act as principle liaison for the GP, health visitor, school nurse, and other members of the multidisciplinary team to ensure a smooth provision of optimum care
- support and counsel the child/young person and their family by providing teaching, ongoing support (by nurse-led clinics, telephone, text message and email, according to local hospital policy), access to specialist support networks, and referral to other professionals when necessary
- provide education and training to other disciplines in the community where necessary. For example, providing training in the administration of emergency IM hydrocortisone to school nurses and teachers
- practise as key member of the local multidisciplinary team, leading in the development of key policies, protocols and standards, through research and audits.

Qualifications

The children's endocrine nurse specialist should be a nurse with a children's nursing qualification and registered as such on the Nursing and Midwifery Council (NMC) register, with additional paediatric endocrine theoretical and practical knowledge. It is envisaged that the children's endocrine nurse specialist acting in the expert role should be practising at master's degree level, with the view to working towards such a qualification.

Support and development

Establishing local and national links is paramount to functioning effectively as a children's endocrine nurse specialist. Links should be made with the local paediatric multidisciplinary team, and also adult endocrine services, to initiate effective transition services. It is important that endocrine nurse specialists work in partnership with children, young people and their families, in order that good clinical decisions may be made and together they are able to decide on the best care from a fully informed position.

Effort should be made to join the RCN CYP Endocrine Community, and also the British Society for Paediatric Endocrinology and Diabetes (BSPED) nurses group. Annual meetings are an effective way of networking and forming valuable professional relationships. Additional nurse meetings are run by the different pharmaceutical companies, offering opportunities to share clinical expertise, research and practice. Such meetings and conferences are essential in benchmarking and appreciating other roles. Links can also be formed with the European Society Paediatric Endocrine Nurses EPSEN and American Paediatric Endocrine Nursing Society (PENS), if UK children's endocrine nurse specialists have the opportunity to travel to their meetings.

2. Purpose and scope of the framework

This competency framework was developed by the RCN CYP Endocrine Community to enhance the clinical care that children and young people with an endocrine disorder receive. There are only approximately 80 children's endocrine nurses in the UK, and it is imperative that specific competencies are outlined. To achieve the appropriate care, nurses must be deemed to function at an optimal level, and "assessing competence in clinical practice is of paramount importance" (Gibbon and Luker, 1995; NMC, 2015). By formulating a competency framework from which a children's nurse specialist can work, it is envisaged that their development as a professional practitioner can be enhanced.

3. How to use the framework

The framework focuses on knowledge, skills and interventions that are heightened in, or specific to, nurses working in children's endocrine nursing. Although the intention is for this framework to have a stand-alone function, it should be used in conjunction with other frameworks that focus on core skills and competencies for all qualified nurses. In addition the specific frameworks developed by specialist nurses can be used to support and enhance their nursing practice.

Benefits of the framework

The competency framework provides benefits for nurses, their employers, patients and the public.

Nurses benefit because it helps them to:

- deliver consistently high standards of care
- identify their level of practice and plan a career in a more structured way
- pinpoint their personal education and development needs
- realise their potential more effectively
- seize opportunities to influence the direction of nursing.

Employers benefit because it provides:

- a model to ensure consistently high standards of care
- clearer insight into the expertise and competence of staff, for example, in the assessment of risk management
- assistance in organisational planning.

Patients and the public benefit because it makes it possible to deliver:

- consistently high standards of patient care
- increased effectiveness of service provision
- improved access and choice for care provision.

Using the framework

Rather than practice being strictly questioned, it should be used as a tool to plan clinical aims

and objectives. It can also be used for a personal development plan, and used by mentors and managers in the performance appraisal process. This needs to be used with reference to local and national guidelines, incorporating the NHS KSF and National Occupational Standards.

It should be used for:

- assessing clinical competence at differing levels
- developing personal goals and objectives
- performance appraisal
- supporting job descriptions and pay reviews/negotiations by detailing targets in accordance with local and national guidelines and policies.

However, it must be recognised that a nurse specialist working in the field of children and young people's endocrinology undertakes a vast role. Not every nurse specialist has the same job description, and therefore not every competency is relevant to each practitioner. For example, not every endocrine nurse specialist undertakes dynamic endocrine function testing.

Therefore, it must be made clear which competencies are relevant when this framework is used as an organisational tool. The document is a starting point, and practitioners using the framework need to ensure that they keep up to date with changes in legislation, policy and practice that can impact on their role, in line with the NMC Code (NMC, 2015).

Overview and sources

The primary sources for this document are as follows: *RCN Competencies: A Competency Framework and Guidance for Developing Paediatric Epilepsy Nurse Specialist Services* (RCN, 2005); *Paediatric Diabetes: RCN Guidance for Newly Appointed Nurse Specialists* (RCN, 2013); *Benner novice to expert model according to the Dreyfus Model of Skill Acquisition* (Benner, 2005); and *Key Elements of the Career Framework* (Skills for Health, 2006; 2010).

The principle concept to focus on is that the "Dreyfus definition of competence is based on how people approach their work, not on whether they should be judged as qualified to do so"

(Eraut, 1994). Links to the NHS KSF have also been explored, by concentrating on the 'novice' (competent nurse but novice in specialty), 'competent' (experienced nurse) and 'expert' (senior practitioner). These are drawn up against the levels 5 to 7. A full list of references, further reading and useful websites are included at the end of this document.

4. Specialist competencies

The children's and young people's endocrine nurse specialist competency framework is presented in the tables in section five. The children's endocrine nurse specialist should be working at an 'expert' level (levels 3/4 in NHS KSF guidelines) within children's nursing. The levels of competence, which had previously been based on Benner's novice to expert continuum, have been translated into *RCN Competencies: Integrated core career and competence framework for registered nurses* (RCN, 2009). The levels in this framework refer to competent, experienced and senior or expert practitioner. They align to levels 5, 6 and 7 of the *Career framework for health* (Skills for Health, 2006). These levels refer to a lifelong learning continuum and do not directly correlate with the AfC pay bands.

Progression through the levels will obviously be different for each nurse, depending on context, level of skill, performance appraisal, and individual objectives. However, it is envisaged that movement towards becoming an experienced practitioner (level 6) should occur after being in post for approximately 18 months to two years. Dependent on the patient population, workload, and individual needs, the children's endocrine nurse specialist should be achieving 'expert' (level 7) status after approximately five years in post. It should be stressed that nurses should always be working to advance their practice. Even in the early 1990s, the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (now the NMC) 1992 *Code of Conduct* clearly described how all nurses, midwives and health visitors must endeavour always to achieve, maintain and develop knowledge, skills and competence (Lillyman, 1998), and this is echoed in the new, updated version (NMC, 2015).

Formulating the differing competencies was a challenge because there are so many cross-overs in skills and abilities and differing role needs. Levels 5, 6 and 7 of the key elements of the career framework are used as previously described. They range from practitioner, senior/specialist practitioner and advanced practitioner.

Care of children and young people with growth and endocrine disorders

The competencies in section 5 outline four stages of care requirements:

- during the period where the diagnosis is not yet confirmed
- once the diagnosis is confirmed
- endocrine testing
- transition to adult services.

Nursing considerations and understanding children and young people with growth and endocrine disorders

- factors influencing growth and puberty
- auxology
- assessment of skeletal maturity
- physiology and pathology.

The following competencies have been researched by the RCN CYP Endocrine Community, and are included in *Core competencies for nursing children and young people* (RCN, 2012). Therefore, focus within this framework is directed solely at paediatric endocrine practice only. The framework addresses the following areas for children's endocrine nurse specialists:

- relationships with children and young people with endocrine disorders and their families
- personal planning and organisation
- working in different health and social environments
- accountability
- teaching and sharing knowledge
- research and audit
- relationships with professionals
- professional and personal development.

Practical applications

This framework has a multi-faceted purpose. It is a personal tool to form individual goals and objectives to advance nursing practice continually – both personally and professionally. It can also be used as a management tool. In this way, the RCN framework can be used against national NHS frameworks in the performance appraisal process. This will ensure that children's endocrine nurse specialists are banded in AfC fairly and equally throughout the UK, while operating within their scope of professional practice. Such continual practice is echoed by Eraut (1988):

“Part of a professional's capacity involves being able to:

- develop or transform one's own practice over time, to
- create new knowledge through one's own practice, as
- well as learning from others” (Eraut, 1998).

It is stressed that this method for enhancing nurses' clinical, practical and professional skills is the way forward in advancing and enhancing specialist nursing practice. It has been described that “the competence-based approach to education has been heralded as an objective assessment method, facilitating distinctions in levels of competence when a variety of sources of evidence are used to support judgements concerning performance” (Percival et al., 1994; cited by Gibson and Soanes, 2000).

Next steps

The RCN CYP Endocrine community welcomes constructive feedback on the framework, both nationally and internationally, in the hope that further developments and ideas can be incorporated into future versions.

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Visit www.rcn.org.uk/communities to find out more about the work of the RCN CYP: Specialist Care Forum and the RCN CYP Endocrine community.

5. The competencies

Care of children and young people with growth and endocrine disorders

During the period in which the diagnosis is not yet confirmed						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
5	Provide support by listening and providing contact details for the endocrine team along with simple factual information about test procedures.	Core 1 level 3	Keep clear documentation of issues raised by the child/young person and family; relevant information and contact details are given.	<ul style="list-style-type: none"> Knows how to access relevant information; including the test/ investigation procedures and contact details for the endocrine team. 	Actively listens.	Skills for Health competences: CS19, CS22.
6	Respond confidently to emotional responses.		The child/young person and their family are supported effectively. Patient records clearly document the support provided.	<ul style="list-style-type: none"> Shows awareness of the emotional responses likely to be experienced by the child/young person and family during the period of investigation. 	Calm. Reassuring. Sensitive.	Skills for Health competences: CS1.
	Provide more detailed information and support - individually tailored to the needs of the child/young person and family.		Clear documentation of the issues raised and correct information is given to the child/young person and family.	<ul style="list-style-type: none"> Knows common endocrine investigations. Information and support is made available for children/young people and their families in relation to specific endocrine conditions and investigations. 	Understanding.	Skills for Health competences: CS20, CS30.
7	Develop an ongoing relationship with the child/young person and family.	Core 1 level 4	Records clearly demonstrate an auditable trail of contact and support provided, relevant to the child/young person's needs.	<ul style="list-style-type: none"> Understands cultural and social diversity issues applicable to the child/young person and their family. 	Confident social skills. Empathetic.	Skills for Health competences: CS19, CS22.
	Empower the child/young person and family to be actively involved in managing their condition and making decisions about treatment.	HWB4 level 4	Records clearly demonstrate child/young person and their family being actively involved in decision making regarding their plan of care.	<ul style="list-style-type: none"> Enables behaviours to promote individual development and independence. 	Enabling. Empowering.	Skills for Health competences: CS9, CS22, CS30.
	Refer to other agencies when appropriate, such as CAMHS* support groups.	HWB6 level 4	Accurate completion of referral documentation and clear records kept of other agency involvement.	<ul style="list-style-type: none"> Identifies relevant agencies and referral pathways to key agencies and support groups. 		Laming report - Climbié.

Care of children and young people with growth and endocrine disorders

Once the diagnosis is confirmed						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
5	Identify any need for further information or support.	Core 2 level 3 HWB4 level 2	Complete a clear and comprehensive assessment of child/young person's needs and the needs of their families.	<ul style="list-style-type: none"> Understands normal patterns of growth and puberty, and nonpathological factors that may influence normal growth patterns (such as the child's nutritional state, underlying chronic disease and parental stature). Knows the information and support available and how to access and refer patients to it. 	Seek support, advice and guidance.	NMC Code of Conduct. Skills for Health competences: CS2, CS3, CS20.
	Provide written information on condition and details of support groups where available, such as CAF support groups.	Core 1 level 3 HWB4 level 3	Patient documentation clearly shows that the child/young person and family have been provided with information relevant to their need, age and level of understanding.	<ul style="list-style-type: none"> Knows the relevant agencies, information available and support groups, and how to access and use these channels. Understands common endocrine conditions and how to appraise information as to whether it is correct and/or beneficial to the child/young person and their family. 		Skills for Health competences: CS22; CS30, GEN62.
	Liaise with outside agencies as needed.	HWB2 level 3 HWB6 level 3	Patient documentation shows clear evidence of liaison with relevant agencies such as the child/young person's school, GP, health visitor, local community or paediatrician.	<ul style="list-style-type: none"> Builds good relationships with all agencies, professionals, and relevant contacts for the individual child/young person in their care. Knows how to contact relevant agencies/professionals and involve them in the care plan. 		Skills for Health competences: CS1.
6	Discuss information about the condition or treatment in more detail.	Core 1 level 3	Patient documentation clearly records the extent of the information given. All documented information accurate, complete and applicable to the patient's condition, situation, age and understanding.	<ul style="list-style-type: none"> Knows relevant anatomy and physiology and common endocrine conditions such as isolated growth hormone deficiency; Turner syndrome; thyroid disorders and adrenal insufficiency; PSM; CDGP; DI and craniopharyngioma; CAH; MPH; Prader Willi Syndrome; small for gestational age. Is aware of treatments available and the genetic implications of some of these disorders. Identifies content of information available and its applicability to the child/young person's needs and the needs of their family/carers. 	Alert to child/family's information need.	RCN Information Sharing Competences. Skills for Health Competences: CS20, CS30.
	Give advice on management of intercurrent illness for children/young people with cortisol insufficiency.		Patient documentation is clear and shows correct advice given to the child/young person, their family/carers in relation to the management of intercurrent illness for a child/young person with cortisol insufficiency.	Manages intercurrent illness for a child/young person with cortisol insufficiency.	Counselling.	Skills for Health competences: CS30.

Once the diagnosis is confirmed (continued)						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
6	Where choices of treatment need to be made (such as growth hormone device), consider the needs and resources available to the family prior to providing objective information/advice.	HWB2 level 3 HWB6 level 3	Patient documentation is clear and shows consideration of treatment options available and the accurate advice given to the child/young person/their family.	<ul style="list-style-type: none"> Knows treatment choices available and applicable to the child/young person's condition. Is aware of the financial implications of high cost treatments. 	Sensitive.	Skills for Health competences: CS5, CS6, CS7, CS8, CS9, CS20, CS22, CS30.
	Plan and implement treatment with growth hormones.	HWB7 level 3	Maintains clear documentation of an accurate plan of care and implementation as per the care plan.	<ul style="list-style-type: none"> Understands use of growth hormones, side effects and potential complications. Manages the care of children/young people being treated with growth hormones. 	Organised.	Skills for Health competences: CS13, CS14.
	Monitor straightforward treatments such as growth hormones.		Clear records of monitoring, evaluating and reassessing the child/young person's needs are kept in relation to the treatment. Action is undertaken as necessary, such as discontinuing growth hormone if there is a poor response.	<ul style="list-style-type: none"> Knows dosages and side effects of commonly prescribed endocrine drugs. 		
	Assess problems that may arise with compliance and take steps to address these.		Patient documentation details the actual and potential issues in relation to compliance with treatment regimens and the advice/support provided.	<ul style="list-style-type: none"> Knows possible issues regarding compliance and solutions to overcome these. 	Understanding.	Skills for Health competences: CS15.
7	See child/young person and/or family independently in nurse-led clinic.	HWB6 level 4	Organisational policies are adhered to, and appropriate assessment processes are carried out that are applicable to the child/young person's condition.	<ul style="list-style-type: none"> Knows relevant anatomy and physiology; how to undertake pubertal and physical assessment and local organisational policies/procedures. Knows relevant agencies and maintains confidentiality. 	Sensitive. Counselling.	
	Discuss complex conditions and treatment regimens.		Discussions with the MDT are held. Clear discussions are undertaken with the child/young person using language appropriate to their age and level of understanding. Clear records are kept of the condition and treatment regimens discussed.	Has indepth knowledge of complex conditions and treatment regimens, such as MPHD; endocrine late effects in survivors of childhood cancer; congenital adrenal hyperplasia; disorders of sexual development; diabetes insipidus and craniopharyngioma; Prader Willi Syndrome; bone and calcium disorders.		Skills for Health competences: CS9.

Once the diagnosis is confirmed (continued)						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
7	Takes into account educational, social and cultural needs of the family when planning education or support.		Patient records clearly demonstrate the education support required, agreed, provided and clarified with the child/young person and their family.	<ul style="list-style-type: none"> Identifies and utilises educational and social support mechanisms available. Is aware of the potential benefits/difficulties of support groups. 		
	Is able to assess critically written information/websites prior to recommending them to the child/young person and family.	IK2 level 3	Patient records clearly demonstrate that the child/young person and their family have been directed to appropriate sources of information and advice.	<ul style="list-style-type: none"> Uses critical appraisal skills to assess available information/websites in terms of content and suitability for the child/young person and their families. Understands child development and what constitutes age appropriate material. Knows how to identify gaps in the literature available. 		Skills for Health competences: GEN32, HI11..
	Develops written information for families and other health care professionals where need identified.	Core 1 level 4	Written information is applicable to the needs of the family/health care professional and supplements existing resources.	<ul style="list-style-type: none"> Contributes to relevant local policies and protocols. Understands child development and what constitutes age appropriate material. Knows how to identify gaps in the literature available. 	Sensitive.	Skills for Health competences: CS20, GEN62.
	Prescribe safely and cost effectively.	HWB7 level 4	Patient records clearly identify the appropriate prescription for the child/young person's clinical needs.	<ul style="list-style-type: none"> Considers side effects and contraindications of medications used in clinical practice. 	Sensitive.	Completion of a recognised independent prescriber course and accreditation as an independent prescriber. Skills for Health competences: CM_A7, CS15.

Endocrine testing							
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors	
5	Assist the senior nurse or medical practitioner in carrying out tests.	HWB6 level 3	Support provided is applicable to the tests required.	<ul style="list-style-type: none"> Knows protocols for endocrine function tests, including normal ranges and their role. Understands responsibilities in relation to assisting tests and investigations. 	Observant.		
6	Be able to explain the rationale behind protocols for endocrine function tests.	HWB6 level 3	An accurate explanation of the protocols is given to the child/young person, their families, and relevant health care professionals.	<ul style="list-style-type: none"> Knows relevant anatomy and physiology, the normal functioning of the endocrine system, and common endocrine function tests. 	Understanding.		
	Have an understanding of limitations of tests.			<ul style="list-style-type: none"> Understands the rationale behind the protocols for endocrine function tests, such as differing protocols/assays/indicators. 			
	Safely and competently carry out shorter tests with minimal supervision.			Preparation, implementation, and completion of the test are undertaken in accordance with agreed protocol, and the child/young person and family are supported effectively throughout.			<ul style="list-style-type: none"> Knows what shorter tests are available, why and how they are carried out, such as LHRH, TRH, short synacthen, and HCG stimulation tests.
	Safely and competently carry out complex tests with supervision from a senior nurse or experienced medical practitioner.						<ul style="list-style-type: none"> Knows what complex tests are available, why and how they are carried out, such as insulin tolerance test, glucagon and clonidine for growth hormone stimulation.
	Be able to identify results outside normal limits and liaise with medical personnel.	IK2 level 2	Prompt reporting is provided to the relevant member of the MDT. Patient records clearly show an accurate interpretation of results, and the actions taken.	<ul style="list-style-type: none"> Identifies normal results and values applicable to the child/young person's age and gender. 			

Endocrine testing continued						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
7	Develop and update evidence-based protocols for endocrine function tests.	IK2 level 3	Protocols clearly reference appropriate and timely research. Clear review dates are included in the protocols.	<ul style="list-style-type: none"> Knows how to critically appraise available research to inform the evidence base used to develop the protocols. 	Organised. Critically analytical.	Skills for Health competences: CHS170.
	Provide advice on all aspects of endocrine tests at local and regional level.		Records are kept of all advice given, including when and to whom. Advice provided is clear, accurate and within own local sphere of influence.			
	Carry out endocrine tests adhering to organisational policies and procedures.	HWB6 level 4	Keep clear documentation of endocrine tests undertaken.	<ul style="list-style-type: none"> Knows relevant local protocols, referral pathways and their own limitations. 	Observant.	
	Initiate new tests where indicated and appropriate using standard operational procedures.				Empathetic with children and families.	
	Accept direct referrals from other consultants as agreed by local protocols.				Clear documentation is kept of referrals received.	
	Supervise nursing and medical practitioners undertaking tests.	Evidence of supervision is provided to demonstrate continuing professional development.				
	Interpret results and act appropriately as indicated.	IK2 level 3 HWB6 level 4	Discussions are held with the MDT of the need for further tests or to initiate/change treatment regimens.	<ul style="list-style-type: none"> Knows the normal values of endocrine biochemistry, treatment regimens and desired outcomes. 	Skills for Health competences: CS14. NICE guidelines for growth hormone treatment in children. Day 5 heel prick: newborn blood spot screening.	

Transition to adult services						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
5	Demonstrate understanding of the changing needs of adolescents and young adults.	HWB6 level 3	Clear identification of needs is shown in patient documentation. Transition clinics are attended where available.	<ul style="list-style-type: none"> Understands the changing needs of adolescents and young adults. 	Empathetic. Understanding.	RCN guidance on transition. DH guidance on transition. ESPE transition guidance.
	Identify the key people within adult endocrine services.		Records clearly show where advice and support has been sought from the adult endocrine services.	<ul style="list-style-type: none"> Knows who the key people in the adult endocrine services are and how to access them. 	Liaises and networks.	
6	Demonstrate understanding of how endocrine conditions change during adolescence	HWB7 level 3	The management of endocrine conditions is clearly explained in ways relevant to the target audience, for example using simple terms to the young person and their family.	<ul style="list-style-type: none"> Knows relevant anatomy and physiology and growth and development trends. Manages endocrine conditions related to growth and development. 	Understanding.	Skills for Health competences: CS23.
	Develop a working relationship with the adult endocrine team.		Core 1 level 3	Effective working relationships are built with all members of the MDT. Records show clear evidence of seeking advice and support from the adult endocrine team in order to support service development.	<ul style="list-style-type: none"> Knows the roles and responsibilities of members from the MDT. 	
7	Demonstrate the ability to manage endocrine conditions during the transition phase.	HWB7 level 4	Patient records clearly demonstrate appropriate management of the young person's endocrine condition.	<ul style="list-style-type: none"> Knows the needs and requirements of the child/young person during the transition phase. 	Liaises. Empathetic.	Skills for Health competences: CHS170.
	Take a lead in educating young people about their ongoing health needs and how these will change over time.	HWB1 level 3	Appropriate educational materials is provided and use according to the young person's needs.	<ul style="list-style-type: none"> Uses educational strategies to engage young people in the management of their health and wellbeing. 	Empowering.	Skills for Health competences: CS11, CS12, CS20, CS30.
	Encourage the young person to become more responsible for their own health and more involved in consultations with the MDT.	HWB4 level 4	Patient records clearly show the young person has been involved in the discussion with the MDT.	<ul style="list-style-type: none"> Uses enabling and empowering strategies to encourage independence and the development of self management of the patient's condition. Is aware of treatment regimes and assessment strategies to determine management of endocrine disorders. 		NICE guidelines in adult growth hormone deficiency. Skills for Health competences: CS22 CS15.

Transition to adult services continued						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
7	Initiate contact with adult endocrine nurses at start of transition process.	Core 5 level 3	Patient records show the involvement of the adult endocrine nurses at the start of the transition process.	<ul style="list-style-type: none"> Knows how to identify the transition phase. Uses appropriate adult endocrine team contact details. 	Liaises. Team worker. Negotiates.	Trust and local guidelines and policies. Skills for Health competences: CS23 M&L A3.
	Identify the gaps in service provision and work closely with paediatric and adult colleagues to address these.		Service improvement and development plans demonstrate stakeholder engagement across organisational boundaries.	<ul style="list-style-type: none"> Knows how to analyse service provision to identify gaps. Knows how to engage colleagues and stakeholders across the adult and paediatric endocrine services. 		
	Work closely with appropriate commissioning departments to establish appropriate services.			<ul style="list-style-type: none"> Knows how to identify and engage key stakeholders external to the endocrine service. 		

Nursing considerations and understanding children and young people with growth and endocrine disorders:

Factors influencing growth and puberty						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
5	Demonstrate understanding of normal patterns of growth and puberty.	HWB2 level 3	Patient assessment records clearly identify all required measurements have been undertaken correctly and show the development of an appropriate plan of nursing care as a result. Patient records clearly identify all issues identified and reported to the MDT.	<ul style="list-style-type: none"> Knows normal patterns of growth in the developing child. Knows normal childhood milestones. Knows non-pathological factors that may influence growth. 		
	Demonstrate understanding of non-pathological factors that may influence this including: <ol style="list-style-type: none"> the child/young person's nutritional state underlying chronic disease parental stature. 					
6	Be able to explain common endocrine conditions.	Core 2 level 3	Knowledge is clearly articulated and shared in a manner appropriate to the target audience.	<ul style="list-style-type: none"> Knows relevant anatomy and physiology; endocrine-related pathology and common endocrine conditions such as isolated growth hormone deficiency; Turner syndrome; thyroid disorders; disorders of puberty and adrenal failure. 	Understanding.	Skills for Health competences: CS5, CS6.
	Understand the genetic implications of some of these disorders.					
	Understand the investigations of short and tall stature, metabolic syndrome and obesity.	Core 3 level 3	A clear, documented plan of nursing care is developed that identifies risk factors.			
7	Demonstrate expertise in managing more complex endocrine conditions.	Core 2 level 4 HWB6 level 4 HWB7 level 4	Knowledge is clearly articulated and shared in a manner appropriate to the target audience. Records clearly document the contributions made to the care plan for patients with complex endocrine conditions.	<ul style="list-style-type: none"> Knows of MPHD; endocrine late effects in survivors of childhood cancer; congenital adrenal hyperplasia (CAH); disorders of sexual development (DSD); diabetes insipidus (DI); Prader Willi Syndrome; and familial endocrine neoplasia syndromes. 	Applies critical thinking skills.	

Auxology						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
5	Demonstrate understanding of techniques for measuring children.	HWB6 level 3	Height, length, sitting height, head circumference and weight of children is reliably and accurately measured. These measurements are accurately plotted on appropriate centile charts. Calculations of BMI, BSA, height velocity and mid-parental height are accurately taken.	<ul style="list-style-type: none"> Uses techniques for measuring children, including centile charts and decimal ages. 	Attention to detail.	Skills for Health competences: CHS19.
6	Enable other health care workers to measure children accurately using recognised tools.	Core 2 level 3	Health care workers are individually taught techniques for measuring children. Centile charts and normal growth patterns are explained.	<ul style="list-style-type: none"> As for level 5. 	Facilitates learning in others.	Skills for Health competences: LLUK_L4 LLUK_L7.
	Be able to describe Tanner system for pubertal staging		The Tanner system is described in a manner appropriate to the target audience.	<ul style="list-style-type: none"> Knows relevant anatomy and physiology, and the Tanner system for pubertal staging. 		
7	Teach pre- and post-graduate health care professionals correct techniques for measuring children.	Core 2 level 4	Lesson plans and associated documentation clearly demonstrate the correct techniques taught and the teaching and assessment methods used.	<ul style="list-style-type: none"> Uses all techniques required to measure children's growth. Undertakes teaching and assessment activity. 	Organised.	Skills for Health competences: LLUK_L4 LLUK_L7.
	Accurately interpret growth patterns such as familial short stature, constitutional delay of growth and puberty.	HWB6 level 4	Growth patterns are accurately interpreted, assessed and clearly documented in patient records.	<ul style="list-style-type: none"> Knows normal growth patterns and signs of growth patterns relevant to endocrine conditions, such as familial short stature, constitutional delay of growth and puberty. Interprets growth charts. 	Sensitive. Empathetic.	Skills for Health competences: CS4, CS7, CS13.
	Accurately assess pubertal development according to local guidelines.			<ul style="list-style-type: none"> Knows normal pubertal development. Uses and applies pubertal development tools. 		

Assessment of skeletal maturity						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
5	Demonstrate an understanding of techniques for assessing skeletal maturity using the TW3 (2001) method.	HWB2 level 3	Skeletal maturity is reliably and accurately assessed with guidance from a senior nurse or medical practitioner.	<ul style="list-style-type: none"> Uses the TW3 (2001) method, 13 bones or 20 bones, score. 	Attention to detail.	Appropriate new standards for assessment.
6	As an independent practitioner reliably and accurately assess skeletal maturity.	HWB2 level 3	<p>Skeletal maturity of children and young adults is reliably and accurately assessed.</p> <p>Findings are accurate and clearly documented.</p>	<ul style="list-style-type: none"> Knows other forms of skeletal assessment eg the Greulich and Pyle (1959) system. 		
7	Teach junior nurses and doctors the techniques of assessing skeletal maturity using the TW3 (2001) method.	Core 2 level 3 G1 level 3	Records of training given are kept.	<ul style="list-style-type: none"> As for level 6. Knows how to teach others. 	Facilitates learning in others.	Skills for Health competences: LLUK_L4 LLUK_L7.

Physiology and pathology						
Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes and behaviour	Contextual factors
5	Demonstrate understanding of: the endocrine system; glands and hormones involved; stimulation, suppression and feedback mechanisms.	HWB5 level 3	An accurate plan of nursing care is developed to meet the child/young person's needs. The care required is clearly and accurately explained to a senior team member.	<ul style="list-style-type: none"> Knows relevant anatomy and physiology. Understands the endocrine system, glands and hormones involved. Uses stimulation, suppression and feedback mechanisms and understands how this relates to normal growth and development. 		Skills for Health competences: CS5.
6	Teach (one-to-one or small groups) the basic anatomy and physiology of the endocrine system, hormone regulation and feedback mechanisms.	Core 2 level 3	Knowledge of the endocrine system is clearly and correctly articulated and shared in a manner appropriate to the target audience, eg, junior doctors training programmes or staff inductions.	<ul style="list-style-type: none"> Identifies learning and development strategies. Understands teaching methods. Knows basic anatomy and physiology of the endocrine system, hormone regulation and feedback mechanisms. 		Skills for Health competences: LLUK_L10 LLUK_L11 LLUK_L13.
	<ul style="list-style-type: none"> Knows physiology and pathology of common disorders such as IGHD, Turner syndrome, thyroid disorders and disorders of puberty. 			Understanding.		
7	Teach at local and regional/national level on paediatric endocrine care.	G1 level 4	Endocrine care and its related anatomy and physiology (A&P) is incorporated in teaching at an appropriate level for the audience.	<ul style="list-style-type: none"> Has indepth knowledge of A&P including developments of biology and genetics, and how this relates to complex endocrine disorders. 	Networks. Facilitates learning in others. Liaises.	Poster presentations at conferences. Lecturing. Skills for Health competences: LLUK_L4 LLUK_L7 CM_F1.

6 Legislation, policy and practice

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8 Resources and contacts

Royal College of Nursing
www.rcn.org.uk www.rcn.org.uk/agendaforchange

RCN Children's and Young People's Endocrine Community
www.rcn.org.uk/get-involved/forums/children-and-young-people-specialist-care-forum/communities/cyp-endocrine-nurses

Nursing and Midwifery Council
www.nmc-uk.org

British Society for Paediatric Endocrinology and Diabetes
www.bsped.org.uk

The Society of Endocrinology
www.endocrinology.org

European Society of Paediatric Endocrinology
www.eurospe.org

Pituitary Foundation
www.pituitary.org.uk

Child Growth Foundation
www.heightmatters.org.uk

Turner Syndrome Support Society
www.tss.org.uk

Association for multiple endocrine neoplasia disorders
www.amend.org.uk

Disorders of sexual development
www.dsdteens.org

Klinefleters Syndrome Association
www.ksa-uk.net

Addison's disease
www.addison.org.uk

Congenital adrenal hyperplasia
www.livingwithcah.com

Prader-Willi Syndrome Association (UK)
<http://pwsa.co.uk>

British Thyroid Association
www.british-thyroid-association.org

Congenital Hyperinsulinism
<https://congenitalhi.org>

Contact a Family
www.cafamily.org.uk

Skills for Health
www.skillsforhealth.org.uk

Endocrine courses

Paediatric Endocrine Module, Level 7: South Bank University

General courses of relevance/interest

- Teaching and assessing in clinical practice
- Counselling
- Independent and Supplementary prescribing for nurses
- Advanced assessment of the presenting child
- Care of adolescents
- BSc modules
- MSc modules
- PhD/Doctorate of Health Care.

Glossary

A&P	Anatomy and physiology	RUS	Radius ulna score
BMI	Body mass index	TRH	Thyrotrophic releasing hormone
BSA	Body surface area	TW3	Tanner Whitehouse Three
BSPED	British Society of Paediatric Endocrinology and Diabetes		
CAMHS	Child and Adolescent Mental Health Services		
CAF	Contact a Family		
CAH	Congenital adrenal hyperplasia		
CCG	Clinical commissioning group		
CDGP	Constitutional delay of growth and puberty		
CHI	Congenital hyperinsulinism		
DI	Diabetes insipidus		
DSD	Disorders of Sexual Development		
EPSEN	European Society Paediatric Endocrine Nurses		
GP	General Practitioner		
HCG	Human chorionic gonadotrophin		
IGHD	Idiopathic growth hormone deficiency		
IM	Intra-muscular		
KSF	Knowledge and skills framework		
LHRH	Luteinizing hormone releasing hormone		
MDT	Multidisciplinary team		
MPHD	Multiple pituitary hormone deficiency		
NICE	National Institute for Health and Care Excellence		
NMC	Nursing and Midwifery Council		
PENS	Pediatric Endocrine Nurses Society (US)		
PSM	Premature sexual maturation		
PWS	Prader Willi Syndrome		
RCN	Royal College of Nursing		

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