



**London
South Bank
University**



The Endocrine Nurse career progression: The UK experience with endocrine nurse competencies, courses and further tertiary education

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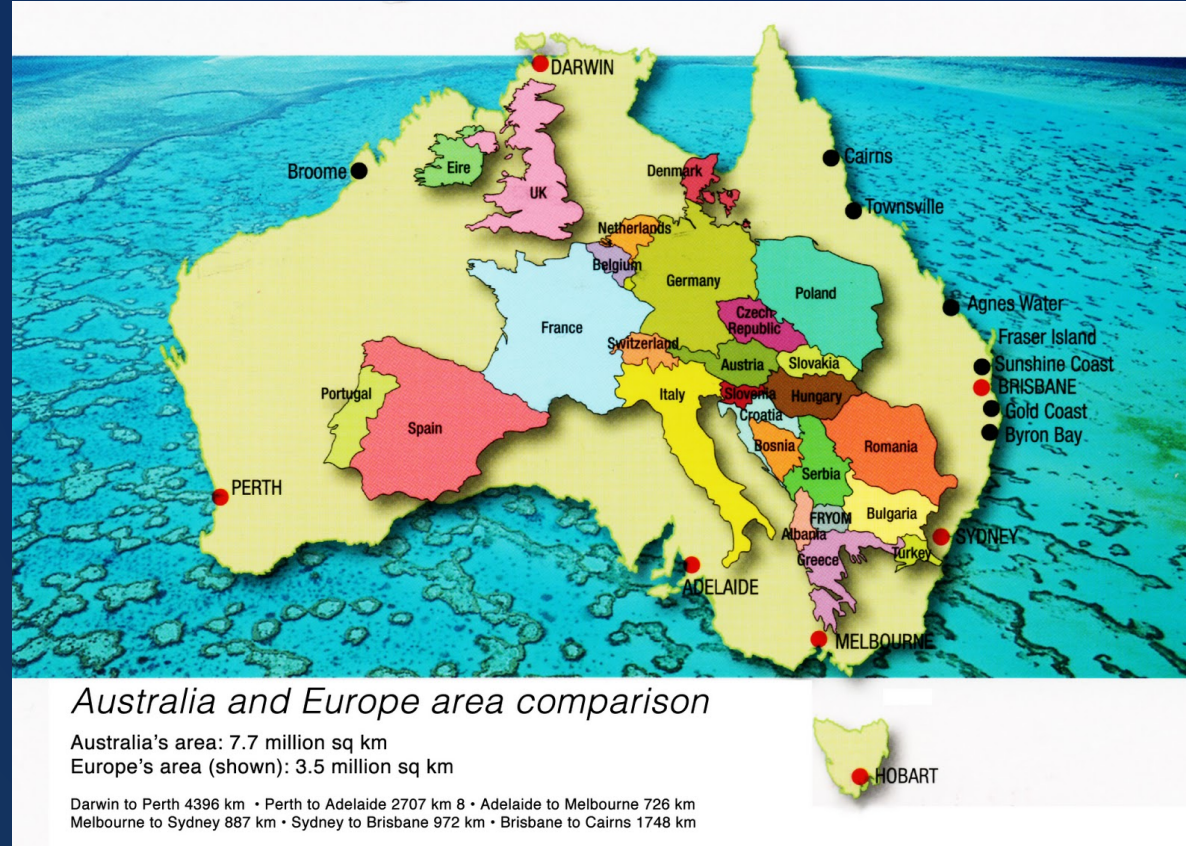
Introduction

- History of Nursing in the UK
- Nursing Today
 - Autonomy and Advanced Practice
- Roles for Endocrine nurses
- Competency frameworks
- Further tertiary education
 - Endocrine Nurses education
 - MSc Advanced Nurse Practitioner
- The way forward

Background

Senior Lecturer in Children's Nursing in London UK

Clinical Nurse Specialist in Paediatric Endocrinology – 16 years



Background

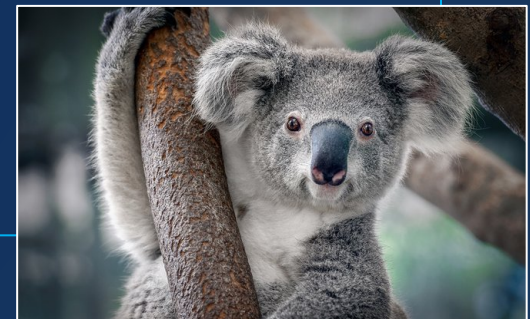
United Kingdom

- 65.5 million
- London
 - 8.2 million



Australia

- 24.13 million
- Adelaide
 - 1.2 million
- Melbourne
 - 4.2 million
- Sydney
 - 4.6 million



Nursing numbers

United Kingdom

- 690,773 (2017)
- 95 Nurses to 1 person

Australia

- 360,000 (2015)
- 67 Nurses to 1 person

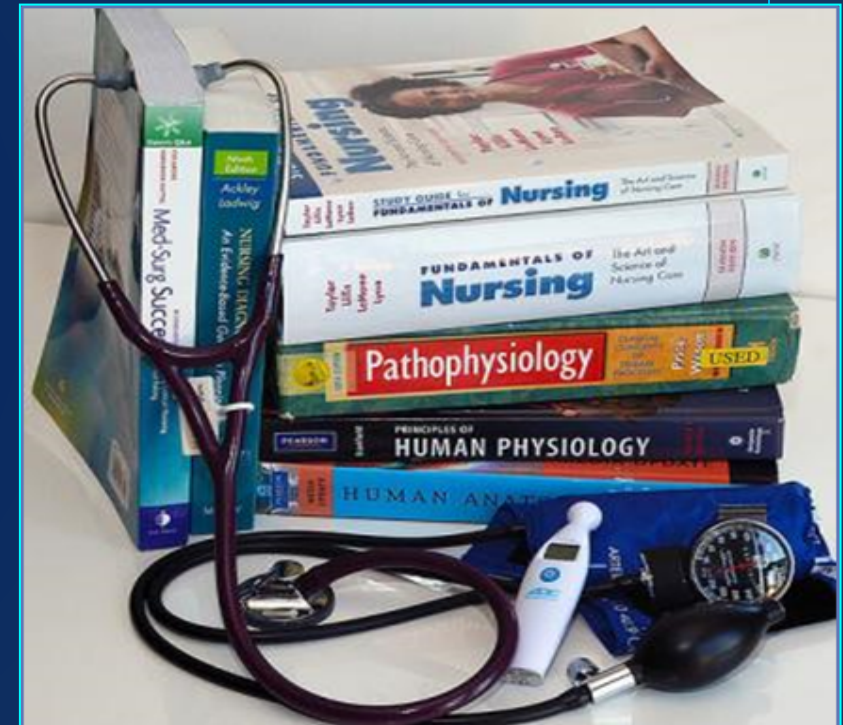


History of nursing in the UK


- First school of nursing established in 1860
- 1940s
 - State Enrolled Nurse (SEN)
 - 2 years training
 - State Registered Nurse (SRN)
 - Registered General Nurse (RGN)
 - Launch of National Health Service (NHS)
- 1960s
 - First degree in Nursing

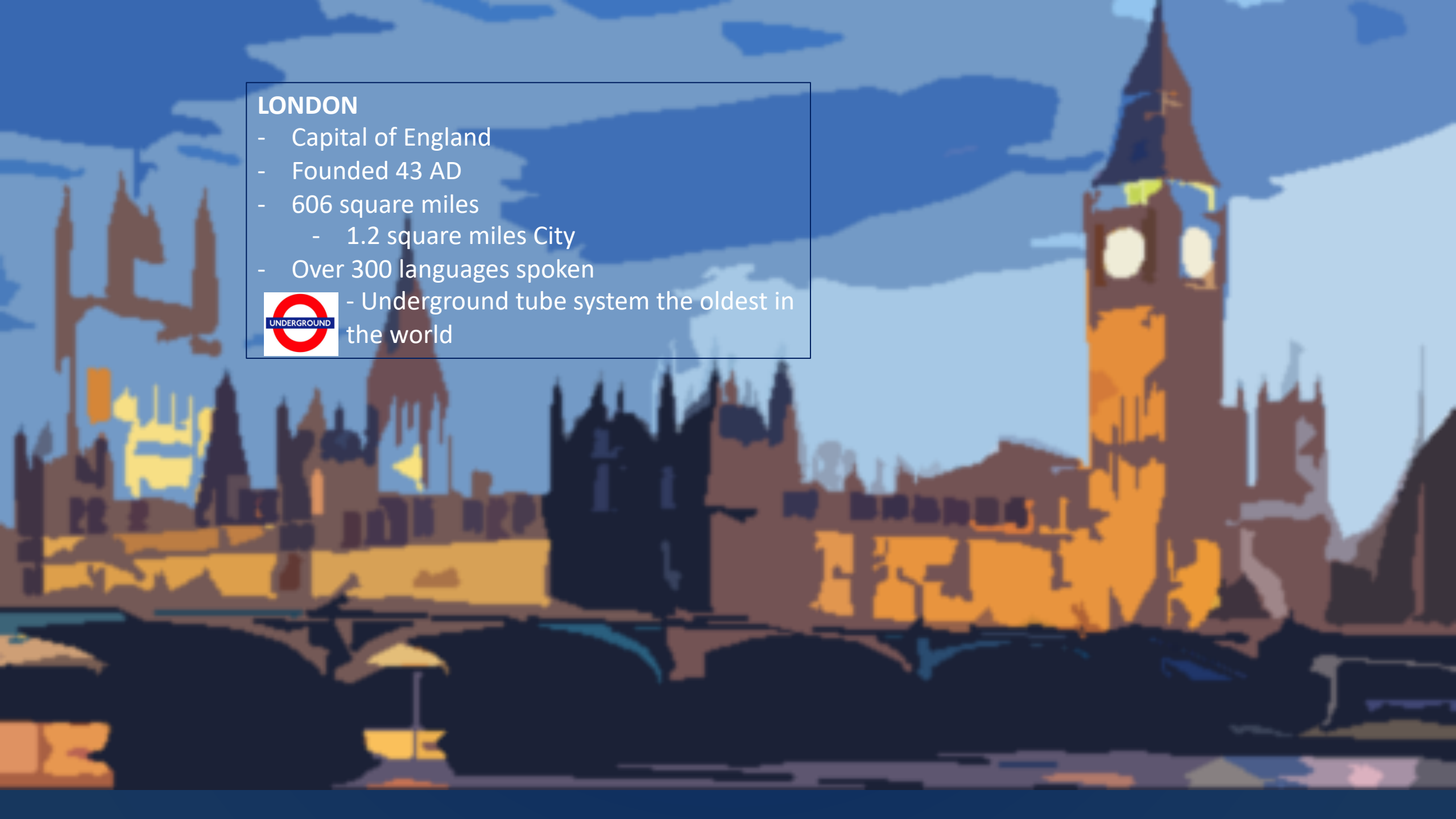
History of nursing in the UK

- 1990s
 - Diploma 3 year training
 - Post graduate education introduced
- 2000s
 - All graduate profession
 - Training university based
 - MSc level education
 - Doctorate/PhD



LONDON

- Capital of England
- Founded 43 AD
- 606 square miles
 - 1.2 square miles City
- Over 300 languages spoken
-  - Underground tube system the oldest in the world



The British National Health System

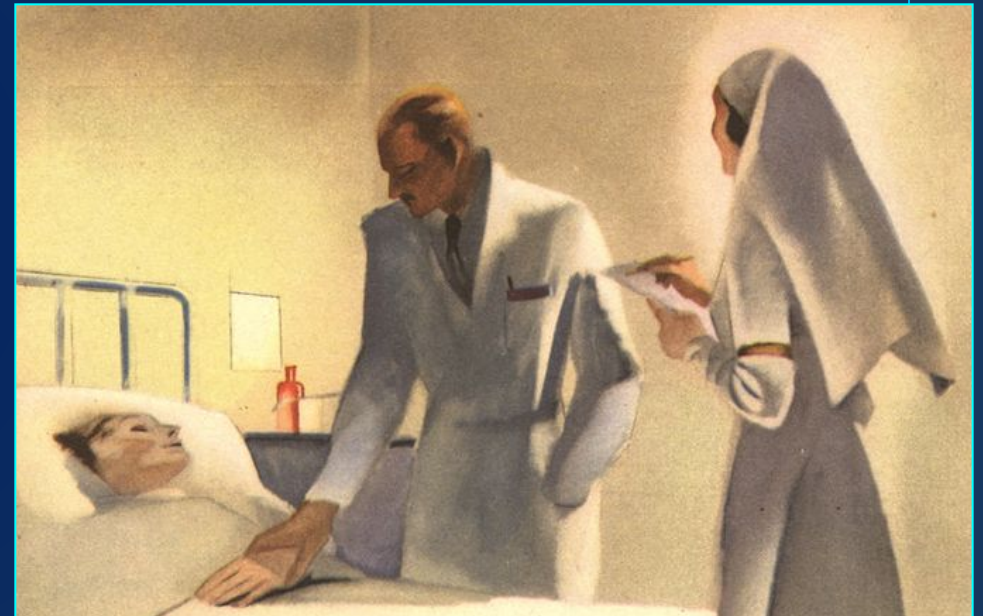
- Formed in 1948 to provide **FREE** healthcare for all
 - Antenatal, maternity, postnatal, immunisations, child health, screening, ER
- **Primary healthcare**
 - General Practitioners, Practice Nurses, Health Visitors, School Nurses
 - Day to day healthcare
- **Secondary healthcare**
 - Provided by medical specialists – ‘hospital care’
 - Referrals made by the patient’s GP
- **Tertiary healthcare**
 - More highly specialised healthcare
 - Referral made by a secondary healthcare professional

Nursing stereotypes



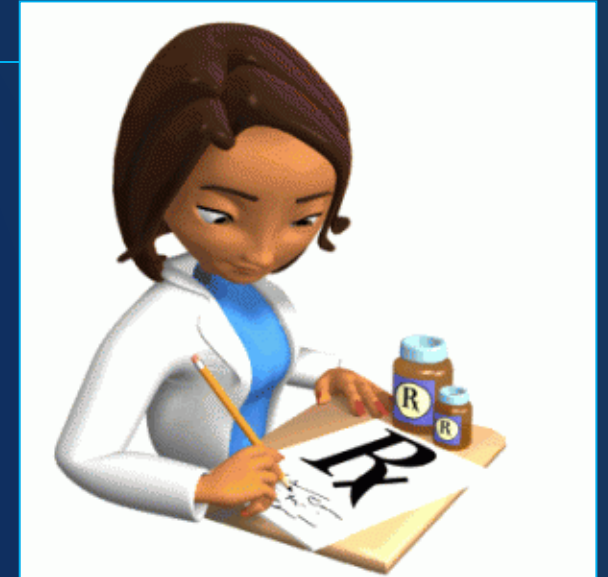
Nursing stereotypes

- Doctor's Handmaidens
 - Do nurses actually work *for* doctors
 - Training and education
 - Recruitment
 - Management structure
 - Co-workers
 - Daily care of patients
 - Liaison between patients and doctors
 - Autonomous profession



Autonomy → Advanced practice

- Clinical nurse specialists
- Advanced nurse practitioners
 - Advancing roles
 - Expanding skills
- Nurse Consultant
 - 50% clinical, 50% research / service development/ education



How to become....

- **Clinical Nurse Specialist**

- Usually a few years experience
- Now job descriptions say should have a MSc

- **Advanced Nurse Practitioner**

- University courses at MSc level
- RCN guidelines

- **Nurse Consultant**

- Usually Doctoral level

- Very different roles / names compared to the USA

- NONE of them are regulated by the UK Nursing Midwifery Council (NMC)



What are these roles?

- Patient education
- Patient / parent / family support
- Hands on nursing care
- Dynamic function tests
- Liaising with community teams / GP
- Liaising with pharmaceutical industry
- Teaching
- Research

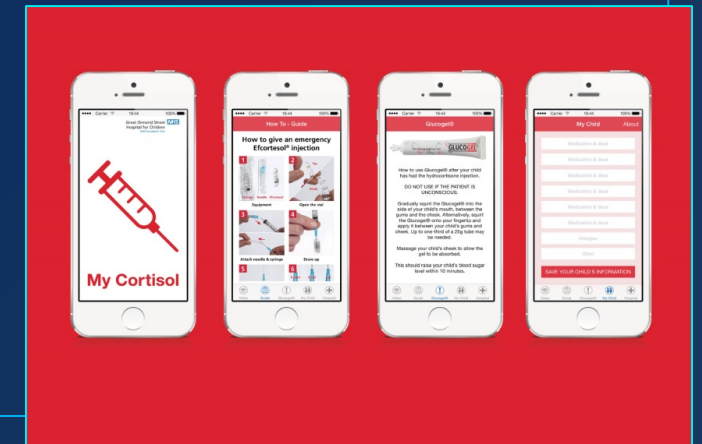


Clinical Nurse Specialist roles



Clinical Nurse Specialist roles

- Clinical Expert
 - Clinical knowledge
 - How can your knowledge and skills within endocrinology be enhanced
 - ? Further training / development
- Education
 - Sub-role as Educator
 - Patients, families, staff
 - Evaluate and develop educational programmes
 - Build teaching packages for patient education



Clinical Nurse Specialist roles

- Consultant
 - Leading on case management
 - Becoming more involved in external forums
 - Society committees
 - Patient support groups
 - Advisory boards
- Research
 - Identifying gaps within your clinical service which could use research / audit
 - Explore shortfalls / Positive aspects
 - Patient questionnaires
 - Participation in clinical research



Clinical Nurse Specialist roles

- Patient advocate
 - Identify patient support groups not already utilised by your team
 - Develop and strengthen links
 - Enhance existing relationships
 - Develop own patient literature
- Collaborator
 - Enhance collaboration within the MDT and interdisciplinary teams
 - Ensure common purpose
 - Working with other endocrine nurses
 - Pharmaceutical companies

CNS as Change Agent

- Success of CNSs

- Depends on their ability to develop their own support system

- Generate own job satisfaction

- Motivation

- Increased high output

- Negotiation

- = Change!
- Occurs at a slow pace
- ? Cost

- Need evidence for need for change

- » ? Shortfalls in existing service

- » ? Decreased patient satisfaction

(Llahana, 2005)



Advancing CNS roles

- Using Change Agent concept
 - Back up what you do
 - Use this evidence to change practice
 - Utilise frameworks to provide the evidence
 - Explore educational pathways
 - See how nursing care can be advanced



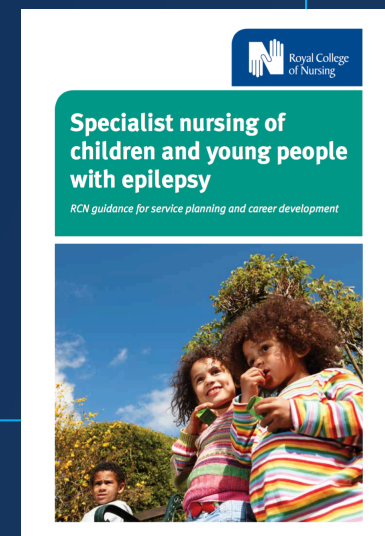
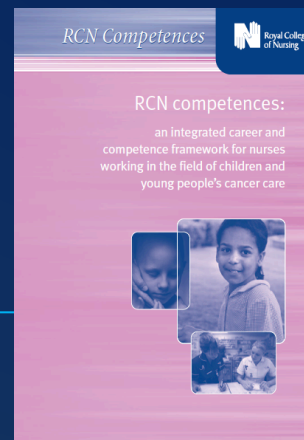
Competency Frameworks

- Re-structure of NHS in 2004 '*Agenda for Change*'
 - A set of national job profiles were agreed to assist in the process of matching posts to pay bands
 - Designed to evaluate the job rather than the person in it
- Group of paediatric endocrine nurses
 - Formed to justify their roles
 - Not money makers
 - Mostly outpatient based



Why?

- There had been many drivers that had influenced nurses to take on advanced roles that had traditionally been the domain of doctors
- Competency and career frameworks have been initiated successfully in other specialities but one had not been established within paediatric endocrinology



Competencies:

an integrated career and
competency framework for paediatric
endocrine nurse specialists



Guidelines for practice

- Focus on knowledge, skills and interventions specific to endocrine nurses
- References local and national guidelines
- Adheres to Benner's (1982) 'Novice to Expert' concept
 - Competent practitioner (5)
 - Experienced practitioner (6)
 - Expert practitioner (7)

Benefit to three groups

– Nurses

- Delivers high standards of care
- Identifies practice level
 - Plan career in a structured way
- Pinpoint personal educational needs
- Realise potential
- *Seize opportunities to influence the direction of nursing*

– Employers

- A model for high care standards
- Clearer insight into staff competence
- Assistance in organisational planning

– Patients

- Provide high standards of care



Competencies

- During period where diagnosis is not yet reached
- Once diagnosis is confirmed
- Endocrine testing
- Transition
- Factors influencing growth
- Auxology
- Assessment of skeletal maturity
- Physiology and pathology



Endocrine testing

Level	Competence	KSF	Performance criteria	Knowledge and understanding	Attitudes & 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 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 & 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.				<ul style="list-style-type: none"> Knows relevant anatomy and physiology. Has in-depth knowledge of all aspects of endocrine tests, and potential adverse reactions.
	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.	IK2 level 3 HWB6 level 4	Evidence of supervision is provided to demonstrate continuing professional development.	<ul style="list-style-type: none"> Has in-depth knowledge of all aspects of endocrine tests. 			Skills for Health competences: CS4.
	Interpret results and act appropriately as indicated.						
						Skills for Health competences: CS14. NICE guidelines for growth hormone treatment in children. Day 5 heel prick: newborn blood spot screening.	

Drawbacks?

- Lots of disagreement
- Took a LONG time
- Had to adhere to the RCN format
- Nurses thought they had to achieve everything within the framework
 - Had to make clear only use the competencies that are relevant

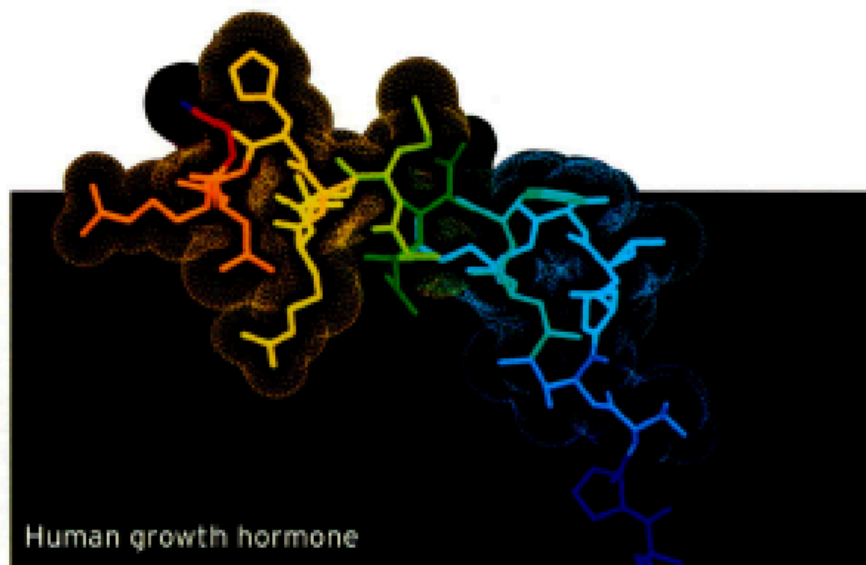
Competencies for paediatric endocrine nursing

The quality of services for children and young people with endocrine disorders is enhanced by specialist nurses.

Kate Davies and colleagues explain

Paediatric endocrinology covers various illnesses and disorders related to children's hormones, ranging from minor disorders to more life-threatening conditions. The most common disorder is short stature, particularly growth hormone deficiency, but the specialty also covers other conditions such as congenital hypothyroidism, early and delayed puberty, adrenal disorders, salt and water balance conditions, calcium and bone disorders, and also obesity (Raine *et al* 2006). With the assistance of hormone replacement and expert care, most children with an endocrine disorder can maintain a normal, healthy lifestyle.

Access to specialist nurses with specific knowledge and skills in managing children and young people with endocrine disorders is essential. To support the development of these nursing roles, a competency framework has been constructed by a group of paediatric endocrine nurses from across the UK (RCN 2008). Specific roles



This section includes care:

- When a diagnosis is not yet made.
- After the diagnosis is confirmed, including liaising with outside agencies, such as relevant pharmaceutical companies for growth hormone.
- During endocrine testing.
- During transition, where understanding of the needs of adolescents and young

endocrine nurse in career progression, and enhance service delivery plans.

This is the first competency framework developed for paediatric endocrine nurses; it is being launched at the annual meeting of the British Society of Paediatric Endocrinology and Diabetes in November 2008. Once in use, the framework will need

Implementing the Royal College of Nursing Competency Framework for Paediatric Endocrine Nurse Specialists

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Background

There have been many drivers that have influenced nurses to take on advanced roles that have traditionally been the domain of doctors. Competency and career frameworks have been initiated successfully in other specialities but one has not been established within paediatric endocrinology

Aim

To establish an integrated career and competency framework for paediatric endocrine nurse specialists

Outline of Framework

Descriptions of specific competencies, KSF indicators, performance criteria, nursing knowledge and understanding, attitudes and behaviours, and contextual factors are described in detail, within the two following sections:

Care of children and young people with growth and endocrine disorders

- During period where diagnosis is not yet reached
- Once diagnosis is confirmed
- Endocrine testing
- Transition

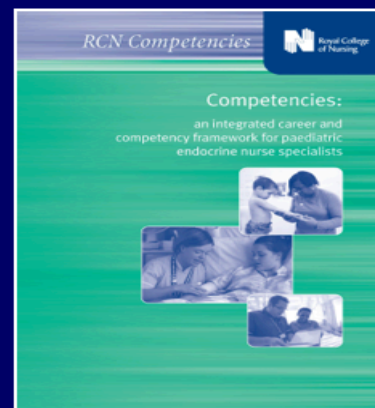
Nursing considerations and understanding children and young people with growth and endocrine disorders

- Factors influencing growth
- Auxology
- Assessment of skeletal maturity
- Physiology and pathology

Methods

In 2006, a working group of nine nurses and one consultant was formed to ensure optimum clinical nursing care is delivered to children and young people with endocrine disorders, with specific detailed competencies being achieved at varying levels of nursing expertise. Levels of competencies are linked in with The Department of Health's NHS Knowledge Skills Framework (KSF) and The Skills for Health competencies. Three levels of nursing expertise are put forward, in line with Benner's (2005) Novice to Expert continuum:

- **Competent**
- **Experienced**
- **Senior / Expert Practitioners**



Benefits of the framework are multifaceted:

For Nurses

- Helps to deliver consistently high standards of care
- Identifies the levels of practice and plan a career in a more structured way
- Pinpoints personal education and development needs
- Realises potential more effectively

For Employers

- Provides a model to ensure high standards of care
- Helps in the establishment of new posts with regards to organisational planning
- Can be utilised in the appraisal process to form the basis of personal development plans
- Provides a clearer insight into staff expertise and competence

For Patients and the Public

- Makes it possible to deliver high standards of care
- Increases effectiveness of service provision
- Improves access and choice for care provision

Conclusion

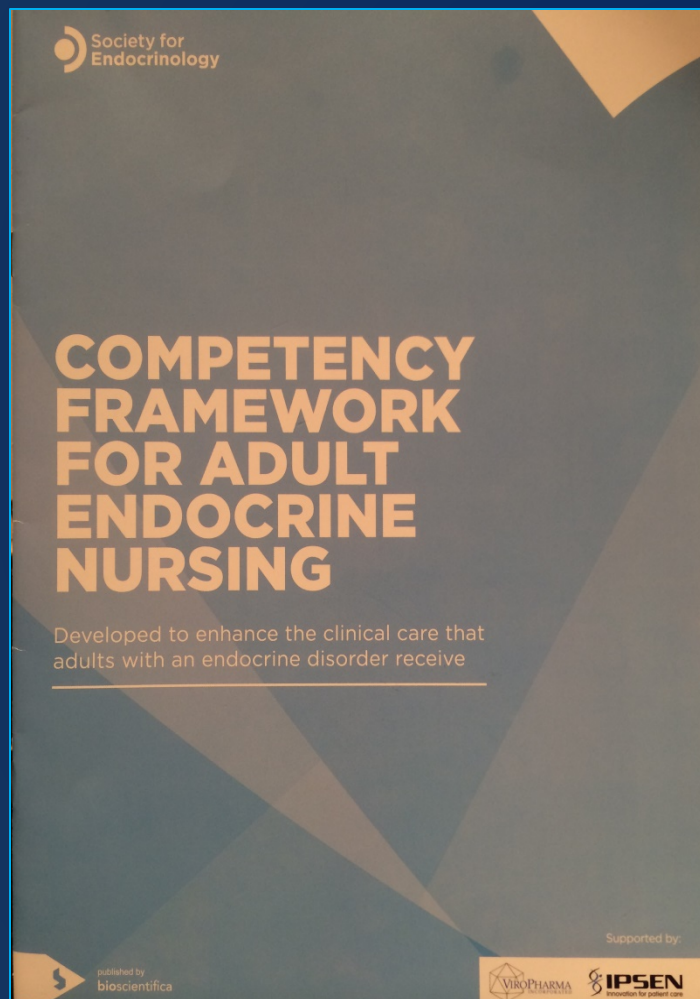
It is important that the whole multidisciplinary team is aware of differing levels of nursing competence, and it is visualised that this framework will be utilised within the different realms of the organisational planning of the paediatric endocrine service, as well as achieving clinical competence

Acknowledgements

We would like to thank the following pharmaceutical companies for their generous support:

Ferring Pharmaceuticals Ltd, Ipsen Ltd, MerckSerono Ltd, Novo Nordisk Ltd, Pfizer Ltd and Sandoz Ltd

Adult Endocrinology – 2013



- Acromegaly
- Cushing's Syndrome
- Endocrine dynamic function tests
- Growth hormone deficiency
- Hypogonadism
- Hypopituitarism
- Steroid replacement therapy
- Thyroid disease
- Transition
- Benign adrenal tumours
- Hypo and hyperparathyroidism
- Osteoporosis
- PCOS

Adult Endocrinology 2015

Competency Framework Open Access	V Kieffer et al.	Society for Endocrinology competency framework	1-17	4:W1
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**Society for Endocrinology
Competency Framework for Adult
Endocrine Nursing: 2nd edition**

**Veronica Kieffer, Kate Davies¹, Christine Gibson², Morag Middleton³,
Jean Munday⁴, Shashana Shalet⁵, Lisa Shepherd⁶ and Phillip Yeoh⁷**

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⁷The London Clinic, London, UK

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- New competencies added
 - Benign adrenal tumours, hypo- and
 - Hyperparathyroidism
 - Osteoporosis
 - Polycystic ovary syndrome

Acromegaly

Competency 1 Acromegaly.


Competent	Proficient	Expert
	As competent plus	As competent and proficient plus
<ul style="list-style-type: none"> Understands the pathophysiology of acromegaly including signs, symptoms and diagnosis and is able to explain this to the patient Has knowledge and understanding of investigations required according to national evidence-based guidelines^a Has awareness and knowledge of local GH and IGF1 reference ranges Knows local and national policies, protocols and shared care guidelines Knows appropriate investigations and treatment modalities and is able to explain these to the patient^a Acknowledges the role of patient support services and is able to guide the patient on how they may be accessed Acknowledges psychological aspects of the condition Supports the patient and family by listening to their concerns, offering access to further support as needed Accurately documents and communicates with members of the wider team 	<ul style="list-style-type: none"> Recognises abnormal test results and escalates appropriately^{a,b,c} Provides disease-specific education to the patient regarding the long-term effects of the diagnosis and management Initiates medical therapies including self-injection techniques and monitors appropriately; advises patient of the potential side effects and when to seek advice Incorporates research and evidence-based practice into clinical service Adheres to local and national policies, protocols and shared care guidelines Provides teaching and support to colleagues within the primary care setting Has knowledge of current clinical trials and referral pathways Recognises condition-specific psychological issues and provides support to patient and family Acts as a role model for junior staff 	<ul style="list-style-type: none"> Uses biochemical evidence to design and implement clinical pathways, including prescribing as appropriate^{a,b,c} Is able to assess the effectiveness of treatment Initiates additional necessary biochemical and radiological investigations^a Assesses cost implications and effectiveness of treatment options, including ability to facilitate access to funding Develops advanced practice through leadership and consultancy Identifies service shortfalls and develops strategies to address them Takes responsibility for integration of national and local policies Supports, teaches and assesses junior staff

^aEndocrine dynamic function testing competency.

^bSteroid replacement therapy for disorders of the pituitary and adrenal glands competency.

^cHypopituitarism competency.

Moving up the levels

- **Competent**
 - Nurses new to endocrinology should have reached a competent level within six months
- 
- **Expert**
 - Some years of experience in the speciality
 - Working autonomously
 - Independent Nurse Prescriber
 - Should hold, or be working towards, a Masters degree

Courses for Adult Endocrine Nurses

- Nationally run annual updates
 - Pharmaceutical companies
- Certificate in Endocrine Nursing
 - Society of Endocrinology
- University MSc module (20 credits at Level 7)
 - Oxford Brookes University

Tertiary Education

Work based learning module in Endocrine Nursing – OBU

- A reflective portfolio
 - Reflective work utilizing Reflective models, and engagement with the Framework
 - Three attendances at the Society of Endocrinology Endocrine Nurse Update
 - Oral / poster communication at national / international meeting where the nurse is the first author
 - One attendance at the Society of Endocrinology British Endocrine Society conference
- Reflective essay (2500 words)
 - Addressing each of the competencies
 - Identify key areas of learning and development, and
 - Areas of nursing research, service development and practice development
 - Nurse led clinic
 - Patient information sheet
 - Developing outreach services

Courses for Paediatric Endocrine Nurses

- Auxology course – St Bartholomew's and The Royal London Hospitals
 - Growth measurement
 - Bone age reading
 - Growth clinic
- BSc Module – [Keele University](#)
- BSc / MSc module – [London South Bank University](#)
(20 credits at Level 6 / 7)



Assessment - 1

- Competency based booklet
 - Practice based assessment
 - Specific skills
 - Ward
 - Community
 - Based on RCN competency framework (2013)



Principles of Care for the Child and Young Person in Endocrinology
Competency 1

The student is required to demonstrate competence by: **Reflecting on a patient they have cared for and demonstrating their ability to....**

Performance Criteria:

1. Assess the impact/potential impact of diagnosis on the child or young person and family.
2. Articulate knowledge of the specific endocrine disorder of this patient.
3. Effectively assess the Child or Young Person and family's needs, and implement appropriate action/care.
4. Identify the wider multi-disciplinary team involved in the child or young person and families care. Show an understanding of their own professions role in this treatment journey

Level Indicators:

Advanced Beginner	Competent Practitioner	<u>Proficient Practitioner</u>
With supervision, the student can effectively and safely care for a child / young person and their family, assessing, planning, prioritising and evaluating care. The student has begun to develop the ability to articulate the evidence base underpinning their care.	The student can effectively and safely care for a child / young person and their family, assessing, planning prioritising and evaluating care. The student demonstrates the ability to identify changes or abnormalities in the child's / young person's condition and <u>is able to</u> seek appropriate advice and support from the inter-professional team. The student <u>is able to</u> articulate the research and evidence based findings which underpin their care. The student demonstrates an adequate understanding of the principles of hormone replacement and rationale for treatment.	The student can effectively and safely care for a child / young person and their family, assessing, planning prioritising and evaluating care. The student <u>is able to</u> anticipate potential complications and can plan ahead using knowledge and previous experience to respond efficiently to rapidly changing situations, in order to provide intuitive, adaptable and skilled care. Leadership skills are demonstrated through the co-ordination of care with members of the inter-professional team. The student's practice is underpinned by research and evidence based findings and they <u>are able to</u> critically evaluate care delivery. The student demonstrates a comprehensive understanding of the principles of hormone replacement & rationale for treatment
1 2 3	4 5 6	7 8 9

Principles of Care for the Child and Young Person in Endocrinology
Competency 2

The student is required to demonstrate competence by: **Reflecting on the same patient as in competency 1 and demonstrate the ability to...**

Performance Criteria:

1. Identify any immediate endocrine emergencies this patient may be at risk of, and the appropriate management. This can include: adrenal insufficiency, hypo/hyper glycaemia or hypo/hyponatraemia.
2. Identify the appropriate management of the specific endocrine treatment, detailing which modalities this will incorporate and the rationale for this.
3. Show knowledge of the most common side effects this patient is at risk of and their role in managing these.

Level Indicators:

Advanced Beginner	Competent Practitioner	<u>Proficient Practitioner</u>
With supervision, the student can effectively and safely care for a child/young person and their family, assessing, planning, prioritising and evaluating care. The student has begun to develop the ability to articulate the evidence base underpinning their care.	The student can effectively and safely care for a child/young person and their family, assessing, planning prioritising and evaluating care. The student demonstrates the ability to identify changes or abnormalities in the child's/young person's condition and <u>is able to</u> seek appropriate advice and support from the inter-professional team. The student <u>is able to</u> articulate the research and evidence based findings which underpin their care.	The student can effectively and safely care for a child/young person and their family, assessing, planning prioritising and evaluating care. The student <u>is able to</u> anticipate potential complications and can plan ahead using knowledge and previous experience to respond efficiently to rapidly changing situations, in order to provide intuitive, adaptable and skilled care. Leadership skills are demonstrated through the co-ordination of care with members of the inter-professional team. The student's practice is underpinned by research and evidence based findings and they <u>are able to</u> critically evaluate care delivery.
1 2 3	4 5 6	7 8 9

Assessment - 2

- Formative assessment
 - Group work (in pairs)
 - Given scenario
 - Endocrine condition
 - Medical management
 - Pharmacological intervention
 - Nursing care
 - Feedback and present to the group 4 weeks later



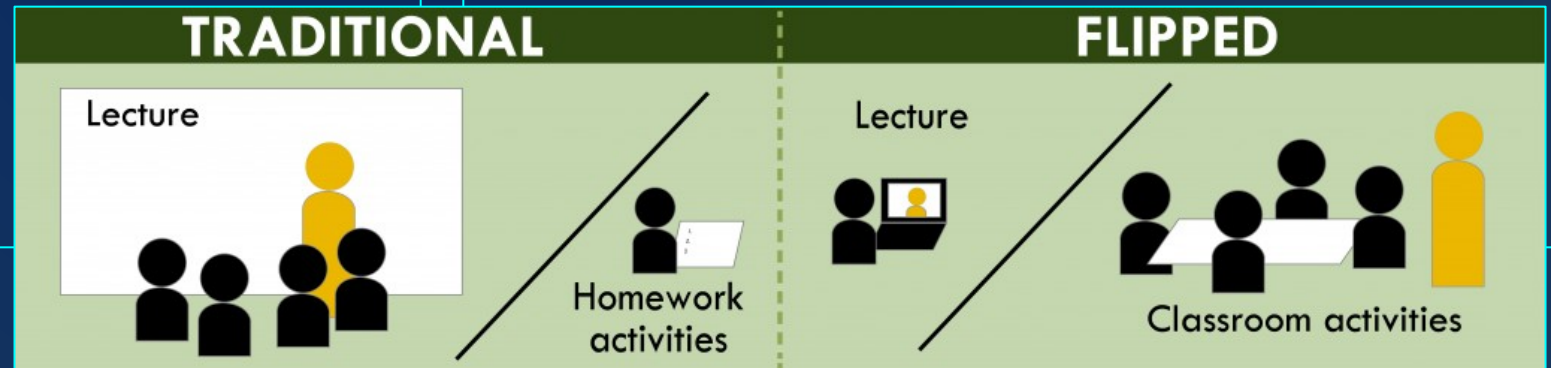
Which GH device would you feel is best for the child in your scenario?

Problem based learning and the flipped classroom

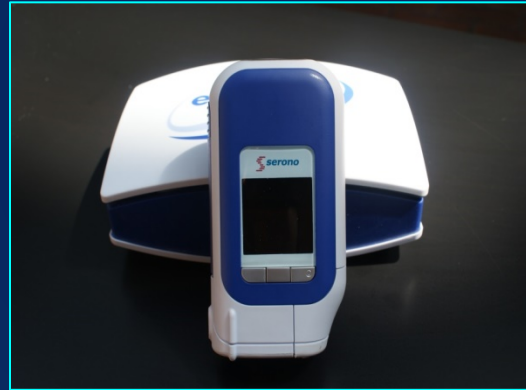
- Problem based learning
 - Can be used to solve patients' problems
 - Problem solving then discussed by the students
 - Apply their prior knowledge and experiences from similar problems to the one in question



- Flipped classroom
 - Instructional content is delivered outside the classroom
 - Online
 - Actual time in class is dedicated to problem solving activities
 - Discussion – group feedback



GH devices



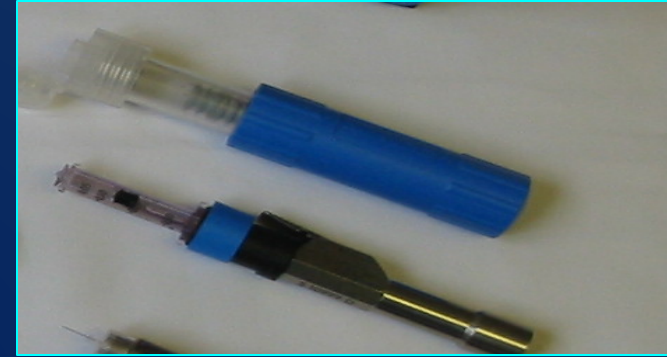
Introducing the NEW
HumatroPen™

- Precision Dosing
- Flexibility to dose in small units
- Available in 3 colour coded pens

HumatroPen™	HumatroPen™	HumatroPen™
6 mg	12 mg	24 mg



Needle free devices



Different growth hormone delivery devices

- **Pfizer**
 - Genotropin – Pen, GoQuick, Miniquick
- **NovoNordisk**
 - Norditropin Simplexx – Pen, PenMate, Nordiflex, Nordiflex PenMate
- **Merck Serono**
 - Saizen – Easypod, Coolclick
- **Ipsen**
 - Nutropin Aq – Pen
- **Eli Lilly**
 - Humatrope – Pen
- **Sandoz**
 - Omnitrope – SurePal Pen
- **Ferring**
 - Zomacton – Zomajet Vision X

UK Licenses for growth hormone

- Growth Hormone Deficiency
- Adult GHD
- Turner Syndrome
- Small for Gestational Age
- Prader Willi Syndrome
- Chronic Renal Insufficiency
- SHOX deficiency



GH licenses held in the UK

Company	GHD	TS	SGA	PWS	CRI	SHOX	AGHD
Lilly <i>Humatrope</i>	✓	✓	✓	X	✓	✓	X
Ferring <i>Zomacton</i>	✓	✓	X	X	X	X	X
Ipsen <i>NutropinAq</i>	✓	✓	X	X	✓	X	✓
Novo – Nordisk <i>Norditropin Simplexx</i>	✓	✓	✓	X	✓	X	✓
Pfizer <i>Genotropin</i>	✓	✓	✓	✓	✓	X	✓
Sandoz <i>Omnitrope</i>	✓	✓	✓	✓	✓	X	✓
Merck – Serono <i>Saizen</i>	✓	✓	✓	X	✓	X	X

Sample scenarios

- **Small for Gestational Age**

- Jamie is 5 years old and is in Year 1 at school, and is the smallest in his class. Dad works full time and is usually home around 6pm, and Mum helps out at the school at lunchtime, and knows that Jamie hardly touches his lunch, which is a concern as he doesn't eat much at dinner time either. Jamie remembers his pre-school vaccinations and reacted very badly to having the injections. Dad is very concerned on how they are all going to manage with injections every day, as they all hate needles. He is to start on 0.3 mg daily.

- **Growth Hormone Deficiency**

- Robert, 3 weeks. Has been diagnosed with Septo-Optic Dysplasia. Currently on hydrocortisone, thyroxine and desmopressin. Due to be discharged home from hospital and needs to commence growth hormone 0.1mg daily. First baby, Mum is 19 and Dad 20. Currently living with her parents whilst they try to find their own accommodation. They are both struggling with the diagnosis and Robert's blindness.

Knowing our patients

- What is the CNS role in patient choice of growth hormone product?
 - Relationships with families
 - In depth knowledge about the condition
 - In depth knowledge regarding the product



Patient choice – what are the issues?

- Ease of use
- Needle free
- Colour
- Quietness
- Size
- Needle guard
- 'Feel'
- Automatic needle insertion
- Reduced time holding device against the skin post injection

Wickramasuriya, 2005

How well do we know our patients?

- Need to understand parental perceptions and beliefs concerning illness and treatment
- Discussions of the patients' view of the disease and their expectations of the treatment
 - Shown to increase concordance

Spoudeas, 2014; Van Dongen, 2012; Cutfield, 2011; Haverkamp, 2008; Kapoor, 2008

But how does this work in practice?

- Children with learning difficulties
 - Septo Optic Dysplasia
 - Need for quick injection → **Zomajet**
 - Visual problems → **Easypod, digital pen devices**
- Teenagers
 - Something small, discreet, disposable → **Miniquick**
- Girls with Turner syndrome
 - Manual dexterity issues → **Easypod, Zomajet**
 - Larger doses needed → **Easypod, Humatropen (20,24mg)**
- Travelling families / children with more than one home
 - Think about non-refrigeration → **Easypod, Miniquick, Norditropin**

- SGA
 - Reduced s/c fat →
 - Want more control over administering the injection
 - No autoinjectors
 - Smallest needle, small vial sizes (4mg, 5mg, 5.3mg)
- Control taken away → **Easypod**
- Post oncology patients → **Zomajet**
- Fear of needles
 - Needle free → **Zomajet**
 - Needle covers / hidden needle → **Easypod, Nutropin Aq, Genotropin pen and Miniquick, Nordipenmate, SurePal**

Emerging themes

- Nurses clinical judgement and prior knowledge of the patient and family's needs
 - Big factor to consider when implementing patient choice for growth hormone delivery devices
- Patient choice of growth hormone delivery device
 - Used to be widely practiced throughout the UK
 - Reducing products in the choice discussion
 - Cost



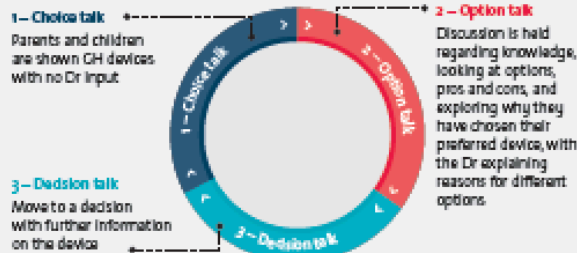
BACKGROUND

There are a variety of growth hormone delivery devices (GHDD) available to children requiring growth hormone (GH) therapy. Many paediatric endocrine nurses can offer patients and their families a choice of the products that are available, which can sometimes be overwhelming. However, factors such as licensed clinical indications have to be considered, as well as cost.

Patient choice for growth hormone devices is well documented in the literature, with regards to compliance (Ahmed et al. 2008, Gau & Takasawa 2017, Kapoor et al. 2008, van Dongen & Kaptain 2012, Wickramasuriya et al. 2006), with onus on the parents and children making the final choice for the delivery of growth hormone.

However, research has shown (Aggar & George 2015) that involving the health care professional (HCP) within the decision making process can have an influence on the desired GHDD, although the HCP referred to was the prescribing Doctor. The proposed model (Elwyn et al. 2012) is seen below.

SHARED DECISION MAKING MODEL



AIMS

The purpose of this project was to explore whether other factors suggested by paediatric endocrine nurses should be considered when exploring choice of GHDD within the shared decision making model.

METHODS

Participating nurses (N=6) attended an interactive and detailed training session on all of the GHDD currently available within the UK. Subsequently, each nurse was given a box of marketing materials for each GHDD, including training materials, patient information literature and DVDs. The nurses were given five case study scenarios on different conditions. The scenarios reflected the five licensed indications for GH in children in the UK. The patients were fictional but were representative of the typical complex patient that paediatric endocrine nurses see within the clinic environment. Nurses were advised to work in pairs. In their pairs, the nurses were asked to feed back on their choice of GHDD, detailing why they had chosen that specific device, utilising a problem based learning approach. Themes were extrapolated using thematic analysis.

CASE STUDY SCENARIOS

TURNER'S SYNDROME

Jade is 7 and lives at home with both parents. Mum has learning difficulties and Dad is partially sighted. They are known to social services and receive support. Jade is on the autistic spectrum and has challenging behaviour. She has recently been diagnosed with Turner syndrome. She is to start GH at a dose of 0.5mg daily.

SHOX DEFICIENCY

Neelam is 14 and has recently been diagnosed with SHOX deficiency. She lives with her parents and two younger brothers in a two bedroom flat. Neelam speaks good English and has to translate for her parents at hospital appointments. Neelam is very small for her age – only 160cm and keen to start treatment. She is glib.

GROWTH HORMONE DEFICIENCY

Joseph is 6 and the second of four children (youngest sibling is 3 months old). He lives with both parents but Dad works long hours and is often not around at bedtime. Joseph is adamant he will not have injections. His Mum is struggling with the new baby and doesn't have any support from Dad with regard to GH treatment as Dad is on the and onble for adult MVA height and doesn't see being small as an issue. The Consultant at the local hospital wants him to start on 0.5mg daily.

PRADER WILLI SYNDROME

Bonnie is 2 years old and lives at home with her Mother, two older siblings and two dogs. Bonnie stays overnight with her Dad for one night every other weekend. Bonnie has been diagnosed with PWS and has been advised to start GH. She weighs 20kg. She has only recently begun walking and prefers to bottom shuffle.

SMALL FOR GESTATIONAL AGE

Arthur is 4 and starting school soon. He has always been small and had failure to thrive in his first year – he remains a picky eater. Mum and Dad are concerned that he looks about 2 and worried he will be picked on at school. They both work full time and have a lot of support from both sets of Grandparents – Arthur frequently goes to stay with his grandparents if Mum and Dad are travelling with work. Arthur has recently had his pre-school vaccinations and reacted very badly to having the injections. Mum is very concerned about how Arthur is going to manage having GH every day. He is to start on 0.5mg daily.

RESULTS

Nurses had a variety of devices to choose from (N=1); three groups had chosen different devices (N=3) apart from two groups had chosen the same device. Influencing themes that emerged included: knowledge of patients learning difficulties, social and housing implications, child's body composition, child friendly device design, and ease of use. Cost was also discussed, but was not the deciding factor for a final decision.

RESULTS – THEMES

Theme	Influencing factors	Aspect of GH device
Child	<ul style="list-style-type: none"> - Fear of needles - Learning disability - Body composition - SGA ↓ body fat - PWS ↑ body fat 	<ul style="list-style-type: none"> - Ease of use - Needle length - Small needle - Hidden needle
Parent	<ul style="list-style-type: none"> - Learning disability - Partially sighted - Language barrier 	<ul style="list-style-type: none"> - Available speech - No recalculation - Simple cartridge replacement - Pre set dose - Adherence monitoring - Translated instructions
Social and housing	<ul style="list-style-type: none"> - Parents work full time - Grandparents main carers - Living in different home - April family 	<ul style="list-style-type: none"> - No need to refrigerate - Ease of use - No recalculation - Pre set dose

GROWTH HORMONE DELIVERY DEVICES



CONCLUSIONS

Themes that emerged from the study demonstrate that the nurses' clinical judgement and prior knowledge of the patient's needs is an intrinsic factor to consider when implementing patient choice in GHDD.

CLINICAL IMPLICATIONS

Further research needs to be conducted on a larger scale to examine nurses' thoughts and opinions on the different GHDDs available, and the need to remain conscious of underlying issues which may not be obvious or apparent to the child and family. From this, a reduced number of choice of devices can therefore be demonstrated to children and their families, thereby giving the nurse more time to focus on the most appropriate devices. Implementation of the shared decision making model utilising paediatric endocrine nurses, and not necessarily the prescribing doctor, is suggested to be used within the GHDD choice process.

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THANKS

to the students on the 2017 Intake of the CPD module 'Principles of care for children and young people in endocrinology'

FOR FURTHER INFORMATION

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Assessment - 3

- Summative assessment
- 20 minute case study presentation
 - Module lead
 - Clinical expert
 - Examiner
- Patient of student's choice
 - Demonstrating emphasis
 - Knowledge of endocrine condition
 - Pharmacological knowledge
 - Nursing care
 - Nursing intervention
 - Reflection



Variety of case studies

January 2017 group

- Hyperthyroidism
- SGA
- Congenital Hypopituitarism
- Congenital Hyperinsulinism x 2
- Precocious Puberty
- CAH (late presenting)
- Craniopharyngioma
- Hypothalamic Hamartoma

January 2018 group

- Graves disease
- Congenital Hyperinsulinism x2
- Prader Willi Syndrome
- GHD
- Precocious Puberty
- DSD x2
- Congenital Hypothyroidism
- Diabetes Insipidus
- Septo Optic Dysplasia

Formative v Summative

- Formative
 - Informal assessment partway through the module
 - Does not count towards the final mark
- Summative
 - Final assessment of what has been learned in the module
 - Final mark

*Formative assessment can be said to serve as assessment **for** learning, whereas summative is assessment **of** learning (Duers and Brown 2009)*

On completion..

- BSc in children's nursing
 - Old style training
- Pg Diploma in children's nursing
 - Already have a degree
- MSc in children's nursing
 - Clinical Nurse Specialist
 - 'Expert' Benner level

- Leading case study
 - Invited to speak at BSPED

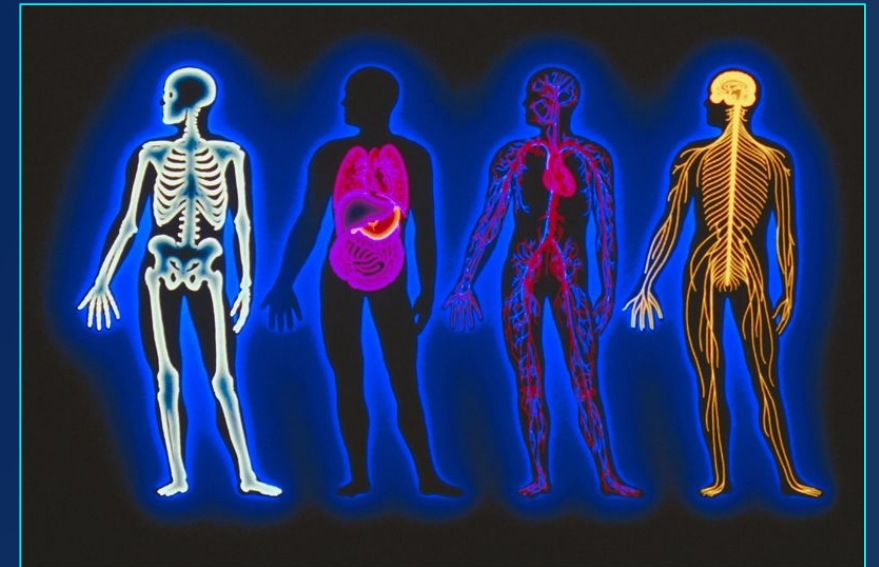


MSc Advanced Nurse Practitioner



Advanced assessment

- History taking
- Examination of the infant, child and adolescent
- Physical assessment techniques
 - Inspection, palpation, percussion and auscultation
- Principles of anatomy, physiology and pathology
 - Respiratory and CXR interpretation
 - Cardiac
 - Neurological
 - Abdominal
 - Neonatal
 - Head, Eyes, Ear, Nose and Throat
 - Pain
 - Mental health
 - MSK
 - Assessment of Growth and Puberty



Diagnostic approach

- History
- Physical examination
 - Auxology
 - Height, weight, BMI, height velocity
 - Parental heights
 - Birth weight
 - Gestational age
- Exclusion of any dysmorphic features
- Pubertal examination
- Full systematic examination
- General investigations
- Endocrine investigations



Taking a history

- Birth history, weight, length, gestation
- Heights of parents, grandparents and siblings
- Parental consanguinity?
- Origin of short stature, nutrition, psychological disturbance
- Appetite, gastrointestinal symptoms, stool frequency, stool features, abdominal pain, mouth ulcers
- Hypoglycaemia, chronic infections
- Respiratory symptoms, urological symptoms
- Motor, intellectual development milestones, school performance, learning difficulties
- Headache, visual disturbances

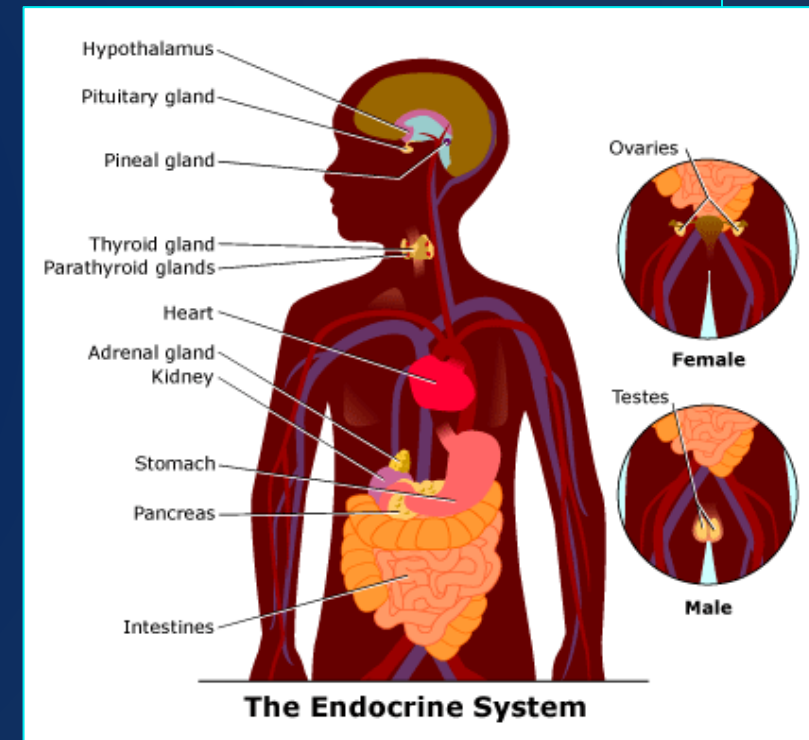
Take home messages

- Look at the whole child during physical assessment
- Growth disorders / short stature
 - Clinical sign in many paediatric disorders
- Accurate auxology
 - Red book / clinical notes
 - Effective height screening virtually non existent
 - National child measurement programme UK – Reception / Year 6
 - Finland – 20 height measurements from post birth – 12 years
- Some children with pathological disorders
 - May not have been referred for investigations into growth
- Earlier diagnosis is optimal
 - Can then potentially identify underlying disease
- REMEMBER
 - Subtle features can be important!



Applied Clinical Physiology

- Brain development
- Management of raised ICP
- **Endocrine physiology**
- Paediatric oncology
- The immune system
- Embryology
- Respiratory physiology
- The liver and metabolism
- Haematology
- Maturation of the renal system
- Physiology of the GI system



Non medical prescribing – Paediatric from June 2018

- Practical aspects of prescribing
 - Clinical portfolio
 - Practice log hours (75)
 - Reflection (650 words) on Domains:
 - The Consultation
 - Prescribing effectively
 - Prescribing in context
 - 72 competencies to achieve
 - Clinical management plan
 - Prescription
- Prescribing in clinical practice
 - Clinical conditions
 - History taking and differentials
 - Written case study (3500 words)
 - OSCE
 - History taking and differential diagnosis

- Pharmacology and applied therapeutics
 - Pharmacological management of common conditions in all body systems
 - Written exam
 - Drug calculation exam
 - OSCE
 - Omeprazole, paracetamol, salbutamol, Vitamin D, hydrocortisone cream, amoxicillin



Managing the Complex Presenting Child

- Principles of A&P
- Physical examination
- Models of problem solving
- Clinical decision making
- Indications for referral / how to refer
- Pharmacological management
- Appropriate documentation of findings
- Managing clinical uncertainty and complexity

- Blood gases
- Interpreting X-rays, Ultrasounds
- Complex paediatric presentations
 - Cardiology
 - Respiratory
 - Neurology
 - Endocrinology
 - DSD
 - DKA
 - Adrenal crisis



The way forward...



- More autonomous roles for endocrine nurses
 - Clinical Nurse Specialist
 - Advanced Nurse Practitioner
 - Nurse Consultant
- Expert practice
- Professional leadership
- Education and training
- Clinical practice
- Service development
 - 50% clinical
 - 50% research / service development / education

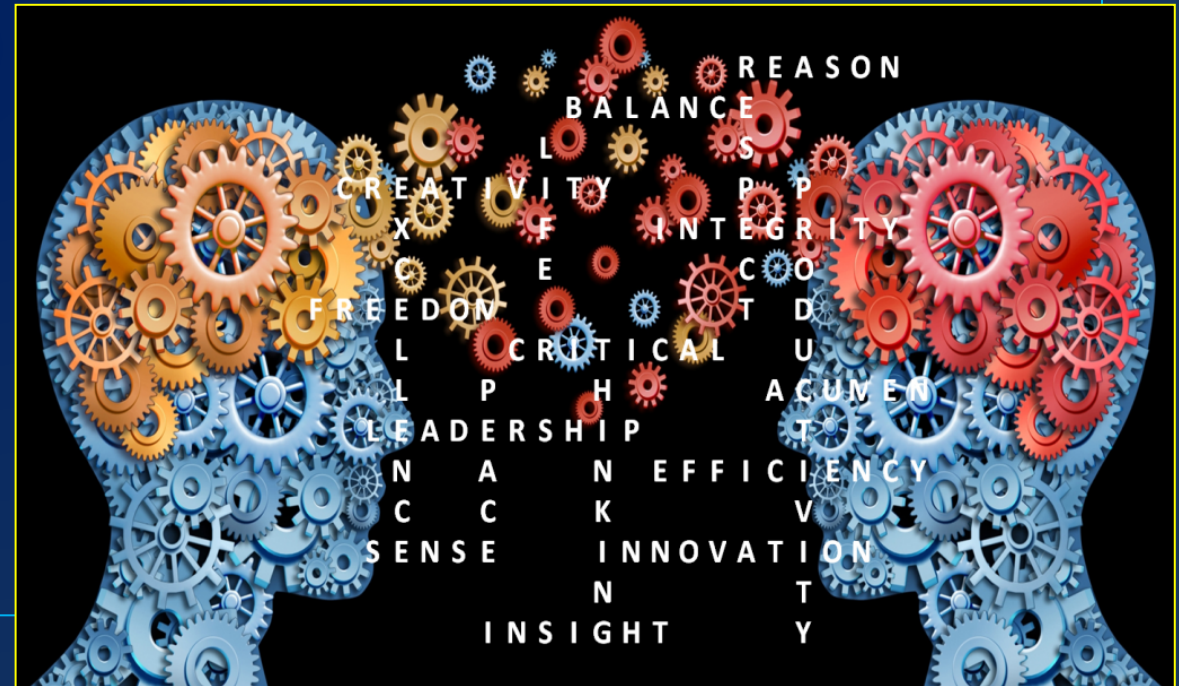
McSherry et al, 2005

- Nurse Led Clinics
 - To support intermediate care after the acute phase of disease and/or diagnosis
 - Integrate patient into the care pathway
 - Deliver holistic care
 - Person centered and evidence based
 - Promote self care and enhance patient autonomy and concordance
 - Decreases patients' waiting times
 - Including the nurse-led clinic
 - GH prescribing process
 - Increases consultants' time for more complex patients
 - Build stronger relationships with patients and their families
 - Enhances patient satisfaction



Conclusion

- Insight into the varied role of the Endocrine Nurse
- Advancing endocrine nursing roles
 - Competency frameworks
 - Education
 - Tertiary education
 - Advanced Nurse Practitioner
 - Nurse Consultant
- Discussion..



Further reading

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