





NEUROENDOCRINE CANCER NURSE COMPETENCY FRAMEWORK



This Framework is dedicated to all past, current and future members of the Neuroendocrine Cancer Community

RCN accreditation

The Neuroendocrine Cancer Nurse Competency Framework first received RCN Accreditation in May 2021 - since then it has undergone re-formatting and successful re-accreditation process.



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Working Group Biographies How to use this framework Assessment form template	4 6 7 9
Neuroendocrine Cancer Nurse Competencies: 1. Neuroendocrine Cancer Overview 2. Carcinoid Syndrome and disease related considerations	10 12
Site Specific Competencies: 3a. Lung 3b. Gastric 3c. Colorectal 3d. Appendix 3e. Small Bowel 3f. Duodenum 3g. Pancreas 3h. Adrenal (Adrenocortical Carcinoma and Pheochromocytoma) 3i. Thyroid (Medullary Thyroid Carcinoma) 3j. Skin (Merkel Cell Carcinoma)	15 18 21 23 25 27 29 32 34 36
References Further Reading and Resources	38 39
Appendices Appendix 1 : Reflective Practice Form Template Appendix 2 : Competency Feedback Form Notes Page	40 41 43



Introduction - Neuroendocrine Cancer: a nurse competency framework

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Abstract:

The Neuroendocrine Cancer Nurse competency framework was developed by a working group of neuroendocrine cancer nurse specialists to enhance the clinical care that adults with a neuroendocrine cancer receive. By preparing a competency framework from which an adult nurses can work, from those who may not see many people with Neuroendocrine Cancer to those who have taken on a specialist nurse role for this group of cancer patients, it is envisaged that their development as professional practitioners can be enhanced. It introduces new competencies that cover the many and varied types and sites of Neuroendocrine Cancer - for nurses to utilise those applicable to their particular sphere of practice.

The authors welcome constructive feedback, acknowledging the importance of dynamic evaluation and revision of the framework.

Keywords: nursing; neuroendocrine cancer; competency framework

Introduction

According to Fukada (1) 'Nursing competency includes core abilities that are required for fulfilling one's role as a nurse'. It has also been 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' (2).

Adult neuroendocrine cancer nursing is a highly specialised field where expertise in both knowledge and appropriate skills can make a significant contribution - 'especially in the promotion and maintenance of high standards of practice, education for the patient' and the application of safe evidence-based knowledge and skills 'the patient requires when diagnosed with a rare disease' (3).

Whilst considered rare, 'Neuroendocrine Cancer' has seen an exponential growth in incidence, in the UK, over the last two decades - from approximately 2 : 100,000 in 2001 to 8.7 : 100,000 in 2015 (4). However, the heterogeneity in primary site and disease behaviour, alongside variation in symptoms, can lead to wide variation in where and how patients may initially present and be investigated, before reaching a definitive diagnosis and appropriate specialist care (5).

There is an identified gap in nurse education regarding neuroendocrine cancers - they are not currently part of the oncology curriculum, nor are they completely covered within endocrinology, gastroenterology, respiratory/cardio-thoracic or other formal resources. Studies have found that the presence of a specialist nurse has the potential to support a more positive patient experience (6,7,8,9). Yet, research suggests that many nurses, even those within the Neuroendocrine Cancer field, do not have the confidence to help and support those diagnosed with it (10,11). While confidence is not a substitute for competency, it is an important characteristic of the healthcare workforce, in professional development and delivery of care (12).

In 2018, a working party of experienced neuroendocrine cancer specialist nurses confirmed the unmet need in awareness and availability of specialised education in neuroendocrine cancers amongst the nursing community. They agreed a consensus statement on a specialist competency framework to address this need, raise awareness, raise confidence, skills and knowledge to promote and enhance appropriate care for those diagnosed and living with Neuroendocrine Cancer.

This Neuroendocrine Cancer Nurse Competency (NCNC) framework builds on core nursing competencies, from entry level to the speciality (competent practitioner), progressing through to the skills and knowledge required at Advanced Practitioner level (expert practitioner). It recognises the continuous learning process inherent in professional nursing practice.

These competencies are not an exhaustive list of knowledge areas and all skills required to treat and care for those diagnosed with Neuroendocrine Cancer: recognising that that knowledge in this rare and less common groups of cancers is constantly evolving.

From primary through to tertiary/specialist care and from general awareness to an in-depth understanding of neuroendocrine cancers, studies have highlighted the many areas nurses may encounter neuroendocrine cancer patients - the most common being oncology, endocrinology and surgery - but also include nuclear medicine, gastroenterology, lung and internal (general) medicine (10,11). Therefore nurses, and their clinical managers, will need to select the specific competencies and level that is appropriate to their role. In addition, it is recognised that some nurses may be caring for patients in situations not covered in this document.

The NCNC framework contains 3 levels of practice and an indicative timeframe within which a UK nurse may reasonably attain the level of knowledge and skills indicated; this should be interpreted cautiously because the rate at which nurses will gain experience will depend on the degree of clinical activity in their centre, the roles that nurses are allowed to undertake in the UK vs. other countries the nurse may have come from and the transferability of skills from previous roles:

- competent, in practice for over 6 months (level 1)
- proficient, in practice for 18-24 months (level 2)
- expert, in practice for a minimum of 3 years (level 3).

Each level of practice includes indicators that provide a standard against which nurses can measure their personal practice - including a reflective practice record. Where possible, evidence sources supporting the indicators is referenced - these include guidelines, publications and other resources, as well as pointers to disease-specific and/or related education and training opportunities.

By preparing a competency framework from which an adult nurses can work, it is envisaged that their development as professional practitioners can be enhanced. The NCNC framework introduces competencies, not available elsewhere, that cover the many and varied types and sites of Neuroendocrine Cancer - for nurses to utilise those applicable to their particular sphere of practice.

Feedback

The authors welcome constructive feedback, acknowledging the importance of dynamic evaluation and revision of the framework - to reflect the evolution and ongoing change within Neuroendocrine Cancer care and learning needs of those providing that care.

We would be grateful if users of this framework would email feedback comments or complete and return the feedback form (Appendix 2) - to allow for evaluation - anticipating that further developments will be incorporated into future versions.

Please post or email feedback form / comments to:

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How to use the Neuroendocrine Cancer Nurse Competency Framework

This framework offers a starting point to define expectations of skills and performance in Neuroendocrine Cancer nursing, but should be applied flexibly depending on the context of the job: the individual's development needs, levels and aspirations, and the organisation's requirements, ethos and values.

The heterogeneity in primary site and disease behaviour, alongside heterogeneity in symptoms, can lead to wide variation in where and how those with a Neuroendocrine Cancer may initially present and be investigated, before reaching a definitive diagnosis and appropriate specialist care (5). Once diagnosed and reviewed by a Neuroendocrine Cancer specialist MDT, treatment and follow-up may occur in a variety of healthcare settings, depending on mode of care recommended and patient choice.

The scope of practice, therefore, depends on a number of factors, which may differ between settings and the requirements for the role(s) held. While this framework provides comprehensive guidance for nurses working with Neuroendocrine Cancer patients, it should be used flexibly and within the context of meeting practice and revalidation requirements.

Self-assessment and the development of a learning plan can help inform the optimal utilisation of this framework. It is recommended that realistic developmental goals are set at each one-to-one meeting and reviewed in a timely manner. At each meeting, there should be an agreement on which specific competencies have been achieved or maintained and which need to be progressed before the next meeting. It may be decided that some competencies are not applicable to the care environment in which the individual is working. It is not envisaged that all nurses working in primary and secondary care will need to meet all of the competencies: this framework has been developed to allow nurses to select relevant competencies to their role and scope of practise. Those not appropriate, can be marked 'N/A' and dated.

This framework is dynamic and therefore can follow the practitioner through role and care setting changes - previously marked 'N/A' competencies can be 're-activated' as appropriate, and learning development plan reviewed and updated accordingly.

Within each competency there are a number of key areas for assessment:

- awareness and understanding of disease : anatomy & physiology, presentation, diagnostics, treatment options and associated care through and beyond this trajectory
- holistic assessment of bio-psychosocial needs: impact physically, mentally and socially from diagnosis, through treatment, surveillance and, where appropriate, recurrence/progression and end-of-life care.
- knowledge and understanding policies, pathways and guidelines includes related incidence and prevalence of disease, alongside good practice guidance.

Nurses using the framework will need to produce evidence for each competency, or part thereof, in order to demonstrate that they have achieved the competence at the identified or desired level. Evidence can take many forms and may include:

- · direct observation of practice
- · case-based discussion
- simulation
- reflective report
- · question and answer
- anonymised clinical case notes
- · feedback from colleagues and/or patients
- accredited CPD activity /certification
- · nationally recognised courses

This evidence will also help with NMC revalidation in meeting requirements for this process.

Assessment

Assessment Form

Within each Trust or care setting different layouts of competency assessment forms may be used.

The form provided within this framework, is not prescriptive, but illustrative and can be adapted for use.

More than one form may be required to complete a full and/or ongoing assessment for each competency or area within it.

A reflective practice template is also included - this can be found in Appendix 1

Assessor

The practice supervisor/assessor should have undergone specific training in supervision and assessment of others and have demonstrable experience and expertise in the practice setting and a disease-related speciality - for example, endocrinology, oncology, site-specific surgery - if not Neuroendocrine Cancer specific.

It is recognised that given the relative rarity of Neuroendocrine Cancers, there may be insufficient nurses, within a particular care setting, that have achieved the 'expert' level competencies to supervise the development of 'competent' and 'proficient' level nurses.

A practical approach should be applied and senior nurses should be allowed to supervise others appropriate to their current role

Networking within the specialist field is encouraged to support competency development and achievement, for both assessor and assessee.

Resources for networking: peer support and 'expert' level Neuroendocrine Cancer nurses:

- ENETs accredited Centres of Excellence for Neuroendocrine Cancer in the UK,
- The Nurse Forum and Education Committee within UKINETs
- Healthcare Professionals information and support at Neuroendocrine Cancer UK.



Assessment Form

Competency	
Objective	
Evidence	
Level of achievement	
Discussion	
New +/- ongoing learning objectives	
Any additional comments / plans	
Appraiser signature and date	
Appraisee signature and date	
External verification signature and date (if required)	

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the Endocrine and Neuroendocrine systems including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Neuroendocrine Cancers including common presenting signs and symptoms signs and likely sites of metastatic spread
- · the common presentations of hormonal symptoms and syndromes associated with Neuroendocrine Cancers
- the common diagnostic investigations and their role in identifying Neuroendocrine Cancers biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Neuroendocrine Cancers the role of surgery and non-surgical approaches and where these may combine for both primary and metastatic disease.
- the potential increased risk of nutritional compromise due to Neuroendocrine Cancers and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation care
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Neuroendocrine Cancer diagnosis for patients and their quality of life acknowledging the
 psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Neuroendocrine Cancer, in terms of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Neuroendocrine Cancers

- Utilises correct and appropriate terminology and taxonomy / classification of Neuroendocrine Cancers
- Demonstrates an awareness of the incidence and prevalence of Neuroendocrine Cancers

 Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment – and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status

Recognise the different hormone excess symptoms / syndromes that may affect patients - identifies and can implement appropriate care strategies to treat and manage these.

- · Identify & rationalise appropriate investigations/diagnostic tests
- · Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- · Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side-effects, longer-term consequences and when to seek advice.

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and biopsychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family.
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Expert: APC 8+: Masters level and above

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- Proactive engagement in continuous professional development
- Active participant in / chair of MDT: leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability to build business case, grant proposals and treatment funding applications.

Demonstrates an awareness and basic understanding of:

- the anatomy, physiology and normal functioning of the Endocrine and Neuroendocrine systems including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Neuroendocrine Cancers including common presenting signs and symptoms signs and likely sites of metastatic spread
- the common presentations of hormonal symptoms and syndromes associated with Neuroendocrine Cancers the common diagnostic investigations and their role in identifying Neuroendocrine Cancers - biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Neuroendocrine Cancers the role of surgery and non-surgical approaches and where these may combine for both primary and metastatic disease
- the potential increased risk of nutritional compromise due to Neuroendocrine Cancers and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation care
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Neuroendocrine Cancer diagnosis for patients and their quality of life acknowledging the
 psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Neuroendocrine Cancer, in terms of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Neuroendocrine Cancers

- Utilises correct and appropriate terminology and taxonomy / classification of Neuroendocrine Cancers
- Demonstrates an awareness of the incidence and prevalence of Neuroendocrine Cancers

 Undertake a structured and appropriate history, including clinical, symptom, nutritional & psychosocial assessment – and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status

Recognise the different hormone excess symptoms/syndromes that may affect patients - identifies and can implement appropriate care strategies to treat and manage these.

- · Identify & rationalise appropriate investigations/diagnostic tests
- · Recognise abnormal test results and instigate remedial steps

Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being

- · Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side-effects, longer-term consequences and when to seek advice.

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family.
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Expert: APC 8+: Masters level and above

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- Proactive engagement in continuous professional development
- Active participant in / chair of MDT: leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability to build business case, grant proposals and treatment funding applications.

Site-specific competencies

The following pages contain competencies related to site-specific Neuroendocrine Cancer eg Lung primary.

You do not have to complete all competencies - or indeed all levels : choose those most applicable to your area and level of practice.

You may use your own form - or print off and use the template provided on page 9.

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the Respiratory system including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers of the Lungs
- the anatomy and physiology of Neuroendocrine Cancers of the LUNGS including common presenting signs and symptoms signs, grading and behaviours and likely sites of metastatic spread
- · indications for genetic testing : understanding the difference between sporadic and inherited disease
- the common presentations of hormonal symptoms and syndromes associated with Neuroendocrine Cancers of the Lungs, e.g. Cushings and Carcinoid syndromes
- the common diagnostic investigations and their role in identifying Neuroendocrine Cancers of the Lungs biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Neuroendocrine Cancers of the Lungs the role of surgery and non-surgical approaches and where these may combine for both primary and metastatic disease.
- the potential increased risk of nutritional compromise due to Neuroendocrine Cancers of the Lungs and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Neuroendocrine Cancer of the Lungs diagnosis for patients and their quality of life acknowledging the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Neuroendocrine Cancer of the Lungs, in terms of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Neuroendocrine Cancers of the Lungs

- Utilises correct and appropriate terminology and taxonomy / classification of Neuroendocrine Cancers of the Lungs
- Demonstrates an awareness of the incidence and prevalence of Neuroendocrine Cancers of the Lungs

- Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status
- Awareness of guidance regarding genetic testing and understands the relationship of genetics and genomics to health, prevention, screening and treatment.
- Able to gather family history, identify hereditary risk, and make appropriate referrals for genetic consultation and testing in collaboration with medical team

Recognise the functional and potential hormone excess symptoms/ syndromes that may affect patients -identifies and can implement appropriate care strategies to treat and manage these.

- Identify & rationalise appropriate investigations/diagnostic tests including physiotherapy assessment and interventions
- · Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side-effects, longer-term consequences and when to seek advice.

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis
- Pre-operative assessment and counselling regarding possible functional alterations e.g.lung capacity and function following surgery
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary tea
- · Understand and explain rationale for ongoing monitoring including modality
- Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

16

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- Proactive engagement in continuous professional development
- · Active participant in / chair of MDT : leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- · Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/feedback and pathway analysis.
- · Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability to build business case, grant proposals and treatment funding applications.

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the STOMACH including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Gastric Neuroendocrine Cancers including common presenting signs and symptoms signs, grading and behaviours and likely sites of metastatic spread
- · the common presentations of hormonal symptoms and syndromes associated with Gastric Neuroendocrine Cancers
- the common diagnostic investigations and their role in identifying Gastric Neuroendocrine Cancers biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Gastric Neuroendocrine Cancers the role of surgery and non-surgical approaches and where these may combine for both primary and metastatic disease
- · the potential increased risk of nutritional compromise due to Gastric Neuroendocrine Cancers and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation care
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Gastric Neuroendocrine Cancer diagnosis for patients and their quality of life acknowledging
 the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Gastric Neuroendocrine Cancer, in terms of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Gastric Neuroendocrine Cancers

- Utilises correct and appropriate terminology and taxonomy / classification of Gastric Neuroendocrine Cancers
- Demonstrates an awareness of the incidence and prevalence of Gastric Neuroendocrine Cancers

 Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment – and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status

Recognise the functional and potential hormone excess symptoms/ syndromes that may affect patients -identifies and can implement appropriate care strategies to treat and manage these.

- · Identify & rationalise appropriate investigations/diagnostic tests including SLT for swallowing concerns
- · Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- · Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side effects, longer-term consequences and when to seek advice.

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis
- Pre-operative assessment and counselling regarding possible functional alterations e.g. Dumping Syndrome following gastrectomy
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family.
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- Proactive engagement in continuous professional development
- · Active participant in / chair of MDT : leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- · Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability to build business case, grant proposals and treatment funding applications

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the Colon, Rectum and Anus including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of COLORECTAL Neuroendocrine Cancers
- the anatomy and physiology of Colorectal Neuroendocrine Cancers including common presenting signs and symptoms signs, grading and behaviours and likely sites of metastatic spread
- the common presentations of hormonal symptoms and syndromes associated with Colorectal Neuroendocrine Cancers
- the common diagnostic investigations and their role in identifying Colorectal Neuroendocrine Cancers biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Colorectal Neuroendocrine Cancers the role of surgery and non-surgical approaches and where these may combine for both primary and metastatic disease.
- · the potential increased risk of nutritional compromise due to Colorectal Neuroendocrine Cancers and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation care
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions an importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Colorectal Neuroendocrine Cancer diagnosis for patients and their quality of life acknowledging the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Colorectal Neuroendocrine Cancer, in terms
 of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Colorectal Neuroendocrine Cancers

- Utilises correct and appropriate terminology and taxonomy / classification of Colorectal Neuroendocrine Cancers
- Demonstrates an awareness of the incidence and prevalence of Colorectal Neuroendocrine Cancers

 Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment – and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status

Recognise the functional and potential hormone excess symptoms/ syndromes that may affect patients -identifies and can implement appropriate care strategies to treat and manage these.

- Identify & rationalise appropriate investigations/diagnostic tests
- Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side effects, longer-term consequences and when to seek advice.

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis
- Pre-operative assessment and counselling regarding possible functional alterations e.g. stoma care and output management
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family.
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Expert : APC 8+ : Masters level and above

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- Proactive engagement in continuous professional development
- Active participant in / chair of MDT: leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- · Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability to build business case, grant proposals and treatment funding applications

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the APPENDIX including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Appendiceal Neuroendocrine Cancers including common presenting signs and symptoms signs, grading and behaviours and possible sites of metastatic spread.
- the difference between Appendiceal Neuroendocrine Cancers and Goblet Cell / other adenocarcinomas
- the uncommon presentations of hormonal symptoms and syndromes associated with Appendiceal Neuroendocrine Cancers
- the diagnostic investigations and their role in identifying Appendiceal Neuroendocrine Cancers biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Appendiceal Neuroendocrine Cancers the role of surgery and non-surgical approaches and where these may combine
- · the potential role for further intervention following primary treatment pending histological assessment
- the role, where required, of ongoing surveillance and prehab/ rehabilitation care
- the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Appendiceal Neuroendocrine Cancer diagnosis for patients and their quality of life acknowledging the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Appendiceal Neuroendocrine Cancer, in terms of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Appendiceal Neuroendocrine Cancers

- Utilises correct and appropriate terminology and taxonomy / classification of Appendiceal Neuroendocrine Cancers
- Demonstrates an awareness of the incidence and prevalence of Appendical Neuroendocrine Cancers

 Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment – and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Treatment and follow up informed by evidence-based guidelines and clinical assessment including histological and staging findings.
- Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis
- Pre-operative assessment and counselling regarding possible implications of further surgical intervention e.g. right hemicolectomy and, for women, possibility of oophorectomy
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Recognise the rare potential hormone excess symptoms/ syndromes that may affect those with Appendiceal Neuroendocrine Cancer -identifies and can implement appropriate care strategies to treat and manage these.

- · Identify & rationalise appropriate investigations/diagnostic tests
- · Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side-effects, longer-term consequences and when to seek advice

Provision of symptom management advice and biopsychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Expert: APC 8+: Masters level and above

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- · Proactive engagement in continuous professional development
- Active participant in / chair of MDT: leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- · Engagement with horizon scanning for future developments and their Implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- · Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability
 to build business case, grant proposals and treatment funding applications.

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the SMALL BOWEL AND MESENTERY including common or preexisting conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Small Bowel Neuroendocrine Cancers including common presenting signs and symptoms signs, grading and behaviours and likely sites of metastatic spread
- the common presentations of hormonal symptoms and syndromes associated with Small Bowel Neuroendocrine Cancers
- the common diagnostic investigations and their role in identifying Small Bowel Neuroendocrine Cancers biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Small Bowel Neuroendocrine Cancers the role of surgery and non-surgical approaches and where these may combine for both primary and metastatic disease.
- the potential increased risk of nutritional compromise due to Small Bowel Neuroendocrine Cancers and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation care the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options :

- Recognising the impact of Small Bowel Neuroendocrine Cancer diagnosis for patients and their quality of life acknowledging the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Small Bowel Neuroendocrine Cancer, in terms of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Small Bowel Neuroendocrine Cancers

- · Utilises correct and appropriate terminology and taxonomy / classification of Small Bowel Neuroendocrine Cancers
- Demonstrates an awareness of the incidence and prevalence of Small Bowel Neuroendocrine Cancers

 Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment – and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status

Recognise the functional and potential hormone excess symptoms/ syndromes that may affect patients -identifies and can implement appropriate care strategies to treat and manage these.

- Identify & rationalise appropriate investigations/diagnostic tests
- · Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side-effects, longer-term consequences and when to seek advice.

Provision of appropriate pre and post treatment advice - responding to concerns and alerts • Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis

- · Pre-operative assessment and counselling regarding possible functional alterations e.g. short bowel syndrome
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family.
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Expert: APC 8+: Masters level and above

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- Proactive engagement in continuous professional development
- · Active participant in / chair of MDT : leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability
 to build business case, grant proposals and treatment funding applications.

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the DUODENUM including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Duodenal Neuroendocrine Cancers including common presenting signs and symptoms signs, grading and behaviours and likely sites of metastatic spread
- the common presentations of hormonal symptoms and syndromes associated with Duodenal Neuroendocrine Cancers
- the common diagnostic investigations and their role in identifying Duodenal Neuroendocrine Cancers biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Duodenal Neuroendocrine Cancers the role of surgery and non-surgical approaches and where these may combine - for both primary and metastatic disease
- the potential increased risk of nutritional compromise due to Duodenal Neuroendocrine Cancers and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation care
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Duodenal Neuroendocrine Cancer diagnosis for patients and their quality of life acknowledging the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Duodenal Neuroendocrine Cancer, in terms
 of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Duodenal Neuroendocrine Cancers

- Utilises correct and appropriate terminology and taxonomy / classification of Duodenal Neuroendocrine Cancers
- Demonstrates an awareness of the incidence and prevalence of Duodenal Neuroendocrine Cancers

 Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment – and baseline physical exam -analysing severity and potential impact on other body systems and overall health - including nutritional status

Recognise the different symptoms/syndromes that may affect patients -identifies and can implement appropriate care strategies to treat and manage these

- Identify & rationalise appropriate investigations/diagnostic tests able to differentiate between functioning and nonfunctional Duodenal Neuroendocrine Cancers and discuss/ initiate appropriate interventions
- · Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- · Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side effects, longer-term consequences and when to seek advice
- Pre-treatment assessment and counselling regarding potential effects and consequences e.g. Dumping syndrome post surgery

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis and risk of paraneoplastic and cancer related oncological emergencies
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Expert: APC 8+: Masters level and above

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate:
 including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- Proactive engagement in continuous professional development
- Active participant in / chair of MDT : leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- · Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- · Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability 28 to build business case, grant proposals and treatment funding applications.

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the PANCREAS including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers e.g. diabetes
- the anatomy and physiology of both functioning and nonfunctioning Pancreatic Neuroendocrine Cancers including common presenting signs and symptoms signs, grading and behaviours and likely sites of metastatic spread
- · indications for genetic testing: understanding the difference between sporadic and inherited disease
- the common presentations of hormonal symptoms and syndromes associated with Pancreatic Neuroendocrine Cancers
- related Endocrine Nurse Competencies: e.g. Society for Endocrinology Competency Framework for Adult Endocrine Nursing: 2nd edition (2015) Competency 4
- the common diagnostic investigations and their role in identifying Pancreatic Neuroendocrine Cancers biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Neuroendocrine Cancers the role of surgery and non-surgical approaches and where these may combine - for both primary and metastatic disease
- the potential increased risk of nutritional compromise due to Neuroendocrine Cancers and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Pancreatic Neuroendocrine Cancer diagnosis for patients and their quality of life acknowledging the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Pancreatic Neuroendocrine Cancer, in terms of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Pancreatic Neuroendocrine Cancers

- Utilises correct and appropriate terminology and taxonomy / classification of Pancreatic Neuroendocrine Cancers
- Demonstrates an awareness of the incidence and prevalence of Pancreatic Neuroendocrine Cancers

- Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status
- Awareness of guidance regarding genetic testing and understands the relationship of genetics and genomics to health, prevention, screening and treatment.
- Able to gather family history, identify hereditary risk, and make appropriate referrals for genetic consultation and testing in collaboration with medical team

Recognise the functional and potentially different hormone excess related symptoms/ syndromes that may affect patients - identifies and can implement appropriate care strategies to treat and manage these.

- Identify & rationalise appropriate investigations/diagnostic tests
- Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- Understands the role of SSA's and other targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side-effects, longer-term consequences and when to seek advice.
- Pre-treatment assessment and counselling regarding potential effects and consequences e.g. Pancreatic Enzyme Insufficiency

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to Neuroendocrine specific conditions eg Carcinoid Crisis risk and appropriate prophylaxis and risk of paraneoplastic and cancer related oncological emergencies
- · Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, genetics, dietetics, and other disciplines/agencies

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- Proactive engagement in continuous professional development
- · Active participant in / chair of MDT : leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/feedback and pathway analysis.
- · Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability to build business case, grant proposals and treatment funding applications.

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the ADRENAL GLANDS including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Adrenal based Neuroendocrine and Endocrine Cancers (Cortex and Medulla) including common presenting signs and symptoms signs, grading and behaviours and likely sites of metastatic spread (Adrenocortical Carcinoma OR Pheochromocytomas)
- the common presentations of hormonal symptoms and syndromes associated with Adrenal-based Neuroendocrine and Endocrine Cancers
- the common diagnostic investigations and their role in identifying Adrenal-based Neuroendocrine and Endocrine Cancers
 biochemical, endoscopic and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- related Endocrine Nurse Competencies: e.g. Society for Endocrinology Competency Framework for Adult Endocrine Nursing: 2nd edition (2015) Competency 2, 4 and 11
- · indications for genetic testing: understanding the difference between sporadic and inherited disease
- the treatment modalities used for Adrenal-based Neuroendocrine and Endocrine Cancers the role of surgery and nonsurgical approaches and where these may combine - for both primary and metastatic disease
- · the potential increased risk of nutritional compromise
- the role of ongoing surveillance and prehab/rehabilitation
- the risks of recurrence and/or progression & lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Adrenal-based Neuroendocrine and Endocrine Cancer diagnosis for patients and their quality
 of life acknowledging the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Adrenal-based Neuroendocrine and Endocrine Cancer, in terms of specialist referral, treatment accessibility and long-term surveillance
- · Offering access to further support as needed
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Adrenal-based Neuroendocrine and Endocrine Cancers

- Utilises correct and appropriate terminology and taxonomy / classification of Adrenal-based Neuroendocrine and Endocrine Cancers
- · Demonstrates an awareness of the incidence and prevalence of Adrenal-based Neuroendocrine and Endocrine Cancers

NB You may see Pheochromocytoma abbreviated to or referred to as belonging to a group called Pheo-para (or PPGL) : which includes PHEOCHROMOCYTOMA and PARAGANGLIOMA

Paraganglioma a type of neuroendocrine tumour that forms near certain blood vessels and nerves outside of the adrenal glands but has similar behaviour to Pheochromocytoma

Demonstrates knowledge of Adrenal-based Neuroendocrine and Endocrine Cancers and competency in ability to

- Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status
- Awareness of guidance regarding genetic testing and understands the relationship of genetics and genomics to health, prevention, screening and treatment. Able to gather family history, identify hereditary risk, and make appropriate referrals for genetic consultation and testing - in collaboration with medical team

Recognise the different hormone excess symptoms/syndromes that may affect patients - identifies and can implement appropriate care strategies to treat and manage these

- Identify & rationalise appropriate investigations/diagnostic tests
- Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- Understands the role of targeted therapies to address excess hormone symptoms and tumour control •
- Initiate medical therapies and monitor appropriately; advises patient of the potential side-effects, longer-term consequences and when to seek advice.

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to Adrenal-based Neuroendocrine and Endocrine specific conditions eg
 Emergency management of acute adrenal insufficiency (adrenal crisis) in adult patients and pre-operative blockade in
 functional Pheochromocytoma and risk of paraneoplastic and cancer related oncological emergencies
- · Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, genetics, dietetics, and other disciplines/agencies

Expert: APC 8+: Masters level and above

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- · Proactive engagement in continuous professional development
- Active participant in / chair of MDT : leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability to build business case, grant proposals and treatment funding applications.

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the THYROID GLAND including common or pre-existing conditions and how these may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Neuroendocrine Cancer of the Thyroid (Medullary Thyroid Carcinoma {MTC}) including common presenting signs and symptoms signs, grading and behaviours and likely sites of metastatic spread
- · the common presentations of hormonal symptoms and syndromes associated with MTC
- the common diagnostic investigations and their role in identifying Neuroendocrine Cancers biochemical, endoscopic and radiological work-up and detailed case history
- related Endocrine Nurse Competencies: e.g. Society for Endocrinology Competency Framework for Adult Endocrine Nursing: 2nd edition (2015) Competency 4 and 12
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- · indications for genetic testing : understanding the difference between sporadic and inherited disease
- the treatment modalities used for MTC the role of surgery and nonsurgical approaches and where these may combine for both primary and metastatic disease
- the potential increased risk of nutritional compromise due to Neuroendocrine Cancers and/or their treatments
- the role of ongoing surveillance and prehab/rehabilitation
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options :

- Recognising the impact of diagnosis for patients and their quality of life acknowledging the psychosocial and physical
 aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of MTC in terms of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dietician, support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for MTC

- Utilises correct and appropriate terminology and taxonomy / classification of Neuroendocrine Cancer of the Thyroid Gland (MTC)
- Demonstrates an awareness of the incidence and prevalence of Neuroendocrine Cancer of the Thyroid Gland

- Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status
- Awareness of guidance regarding genetic testing and understands the relationship of genetics and genomics to health, prevention, screening and treatment. Able to gather family history, identify hereditary risk, and make appropriate referrals for genetic consultation and testing - in collaboration with medical team

Recognise the different hormone excess symptoms/syndromes that may affect patients - identifies and can implement appropriate care strategies to treat and manage these

- · Identify & rationalise appropriate investigations/diagnostic tests
- Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- Understands the role of targeted therapies to address excess hormone symptoms and tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side effects, longer-term consequences and when to seek advice.

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to MTC and risk of paraneoplastic and cancer related oncological emergencies
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Expert : APC 8+ : Masters level and above

Demonstrates a comprehensive, expert knowledge & proficiency

- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
- Integrates advanced knowledge of the disease process from diagnosis to treatment and aftercare, in formulating and evaluating a comprehensive coordinated plan of care with agreed identified outcome indicators
- Develops autonomous advanced practice integrating nursing and delegated medical interventions as appropriate: including nurse-led clinics and nurse prescribing advising, prescribing and/or requesting therapeutic interventions
- Educates others using an advanced expert knowledge base and clinical experience in managing highly complex patient care concerns
- · Proactive engagement in continuous professional development
- · Active participant in / chair of MDT : leading discussion on complex patients and their management.

- Acts as a resource for Neuroendocrine Cancer at local and regional level education and research role through teaching and/or publication
- Identifies service development opportunities and devises strategies to explore/implement them promoting a culture of quality care
- Engagement with horizon scanning for future developments and their implications for practice and care delivery
- Proactive engagement with audits and research, including, where applicable, local and national treatment appraisals, patient experience surveys/ feedback and pathway analysis.
- Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability
 to build business case, grant proposals and treatment funding applications.

Demonstrates an awareness and basic understanding of

- the anatomy, physiology and normal functioning of the SKIN including common or pre-existing conditions and how these
 may affect or influence the diagnosis and treatment of Neuroendocrine Cancers
- the anatomy and physiology of Neuroendocrine Cancer of the Skin (Merkel Cell Carcinoma {MCC}) including common presenting signs and symptoms signs, and likely sites of metastatic spread
- · the common risk factors and presenting symptoms associated with Neuroendocrine Cancer of the skin
- the common diagnostic investigations and their role in identifying Neuroendocrine Cancer of the Skin biochemical, and radiological work-up and detailed case history
- the role of Nuclear Medicine in both diagnostic and therapeutic interventions for Neuroendocrine Cancers
- the treatment modalities used for Neuroendocrine Cancer of the Skin the role of surgery and non-surgical approaches including immunotherapy and where these may combine for both primary and metastatic disease
- · the potential increased risk of nutritional compromise due to Neuroendocrine Cancers and/or their treatments
- · the role of ongoing surveillance and prehab/rehabilitation care
- · the risks of recurrence and/or progression
- lifetime risk of other malignancies and health conditions and importance of national screening programmes in maintaining general health

Can holistically assess an individual and their health related concerns - Is able to explain to patients in simple terms including signs and symptoms, investigations and possible treatment options:

- Recognising the impact of Neuroendocrine Cancer of the Skin diagnosis for patients and their quality of life acknowledging the psychosocial and physical aspects of living with rare and potentially life-limiting malignancy
- Demonstrating an awareness and basic understanding of the implications of Neuroendocrine Cancer, of the Skin in terms
 of specialist referral, treatment accessibility and long-term surveillance
- Offering access to further support as needed e.g. dieticians support groups, psychological support, socio-economic services
- · Accurately documenting and communicating with members of the multidisciplinary team

Demonstrates knowledge and understanding of the national and international guidelines, local policies and agreed pathways for Neuroendocrine Cancer of the Skin

- Utilises correct and appropriate terminology and taxonomy / classification of Neuroendocrine Cancer of the Skin
- Demonstrates an awareness of the incidence and prevalence of Neuroendocrine Cancer of the Skin

 Undertake a structured and appropriate history: including clinical, symptom, nutritional & psychosocial assessment – and baseline physical exam - analysing severity and potential impact on other body systems and overall health - including nutritional status

Recognise the symptoms and potential syndromes that may affect patients -identifies and can implement appropriate care strategies to treat and manage these

- · Identify & rationalise appropriate investigations/diagnostic tests
- · Recognise abnormal test results and instigate remedial steps
- Provide disease specific education to the patient including the longer-term consequences of disease, treatments and surveillance on bio-psychosocial well-being
- · Understands the role of targeted therapies and immunotherapy to address tumour control
- Initiate medical therapies and monitor appropriately; advises patient of the potential side-effects, longer-term consequences and when to seek advice
- Assess risk of paraneoplastic and cancer related oncological emergencies in advanced/ metastatic disease

Provision of appropriate pre and post treatment advice - responding to concerns and alerts

- Instigate appropriate safeguards for care related to MCC and treatment
- Discuss the need for further tests, or initiation of changes to treatments /plan of care with the multidisciplinary team
- · Understand and explain rationale for ongoing monitoring including modality
- · Demonstrate knowledge of clinical trials, criteria and appropriate referral pathways
- · Awareness of treatment access routes NHS, Managed Access, Private care and other

Provision of symptom management advice and bio-psychosocial support - short & long-term - in both early and metastatic disease

- Assess and recognise psychosocial concerns: providing support, sign-posting and/or referral as appropriate for patient & family
- Identify the need for and instigate additional clinical and professional support, such as referral for expert opinion, counselling, dietetics, and other disciplines/agencies

Expert: APC 8+: Masters level and above

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- Undertakes a comprehensive holistic assessment using evidence-based frameworks including advanced history taking and prescribing
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- · Takes responsibility for integration of, and contribution to, national and local policies
- Assesses cost implications and effectiveness of service provision including ability to facilitate access to funding ability to build business case, grant proposals and treatment funding applications.

REFERENCES

- 1 Fukada. (2018) Nursing Competency: Definition, Structure and Development. Yonago Acta Med.; 61(1): 1–7.
- 2 Roach. (1992) In The Human Act of Caring: A Blueprint for the Health Profession, revised edition. Ottawa, Canada: Canadian Hospital Association Press.
- 3 Bouvier. (2003) Nurse developments in neuroendocrine tumour management. Endocr Relat Cancer 10(4):487-8
- 4 Genus et al. (2019) Impact of neuroendocrine morphology on cancer outcomes and stage at diagnosis: a UK nationwide cohort study 2013–2015. Br J Cancer 121, 966–972
- 5 Basuroy et al. Delays and routes to diagnosis of neuroendocrine tumours. BMC Cancer 18, 1122 (2018).
- 6 NHS England. National Cancer Patient Experience Survey 2013. https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2013-national-cancer-patient-experience-survey/2013-national-cancer-patient-experience-survey-programme-national-report/file (Accessed August 2020).
- 7 NHS England. National Cancer Patient Experience Survey 2014. https://www.quality-health.co.uk/resources/surveys/national-cancer-experience-survey/2014-national-cancer-patiente-experience-survey/2014-national-cancer-patiente-experience-survey-national-reports/688-2013-national-cancer-patiente-experience-survey-national-report-pdf/file (Accessed August 2020).
- 8 NHS England. National Cancer Patient Experience Survey 2017. http://www.ncpes.co.uk/reports/2017-reports/national-reports-2/3579-cpes-2017-national-report/file (Accessed August 2020).
- 9 Leyden et al. (2020) Unmet needs in the international neuroendocrine tumor (NET) community: Assessment of major gaps from the perspective of patients, patient advocates and NET health care professionals. Int J Cancer; 146 (5): 1316–1323.
- 10 Davies et al. (2017) Pilot electronic survey to assess education needs for Nurses in NETs throughout Europe. Neuroendocrinology 105 (suppl 1)
- 11 Davies et al. (2018) Current educational strategies used by nurses caring for NET patients: Electronic survey across 25 countries. Neuroendocrinology 106

Further Reading and Resources

- European Neuroendocrine Tumour Society (ENET) Guidelines https://www.enets.org/enets_guidelines.html
- ESMO Guidelines : https://www.esmo.org/guidelines?hit=ehp
- Kieffer et al. (2015) Society for Endocrinology Competency Framework for Adult Endocrine Nursing : 2nd edition Endocrine Connections: 4, W1–W17
- ESE Guidelines : https://www.ese-hormones.org/publications/guidelines/
- Owens and Keller. (2018) Exploring workforce confidence and patient experiences: A quantitative analysis. Patient Experience Journal: Volume 5, Issue 1, pp. 97-105
- Macmillan Competency Framework for Nurses
- NMC Code of conduct: https://www.nmc.org.uk/standards/code/
- NMC Standards for competence for registered nurses https://www.nmc.org.uk/globalassets/sitedocuments/standards/nmc-standards-for-competence-for-registered-nurses.pdf
- RCN Advanced Level Nursing Practice: Introduction
- RCN Principles of Nursing Practice: https://www.rcn.org.uk/professional-development/principles-of-nursing-practice
- RCN Advanced level Nursing Practice Section 2: Advanced level nursing competencies (PDF)
- RCN Career and Education Framework for Cancer Nursing
- UK and Ireland Neuroendocrine Tumour Society (UKINET) Bitesize Guidance: https://www.ukinets.org/net-clinics-clinical-practice/

NEUROENDOCRINE CANCER UK: www.neuroendocrinecancer.org.uk

NCUK Academy: https://ncukacademy.org.uk/

AMEND (Association for Multiple Endocrine Neoplasia Disorders): https://www.amend.org.uk

ACC Support UK (Adrenocorticol Carcinoma): https://accsupport.org.uk

INCA (International Neuroendocrine Cancer Alliance): https://incalliance.org

UKINETs (UK & Ireland Neuroendocrine Tumour Society): https://www.ukinets.org

ENETs (European Neuroendocrine Tumour Society): https://www.enets.org

SfE (Society for Endocrinology): https://www.endocrinology.org

ECE/ESE (European Society of Endocrinology): https://www.ese-hormones.org

NMC (Nursing & Midwifery Council): https://www.nmc.org.uk

RCN (Royal College of Nursing): https://www.rcn.org.uk

UKONS (UK Oncology Nursing Society): https://www.ukons.org

UKAOS (UK Acute Oncology Society): https://www.ukacuteoncology.co.uk/

ESMO (European Society for Medical Oncology): https://www.esmo.org

BNMS (British Nuclear Medicine Society): https://www.bnms.org.uk/

RCGP e-learning (modules on Neuroendocrine Cancer): https://elearning.rcgp.org.uk/course/info.php?id=472 (accessed September 2022)



REFLECTIVE PRACTICE FORM

Reflective Practice What was the nature of the activity / event / experience? e.g. practice-related, education
What did you learn from this activity / event / experience?
Has this activity / event / experience impacted on your practice?
Yes / No
Even if your answer above was no - how has this activity/ event /experience impacted on your practice ? e.g. reconfirmed existing knowledge/skills /level of practice or added / improved / expanded existing knowledge/skills /level of practice
If you would like to use this account for revalidation - please also record how this activity / event / experience is relevant to the NMC Code e.g. Prioritise people - Practice effectively - etc
Name:
Signature:
Date:

COMPETENCIES FEEDBACK FORM

You can complete the feedback form anonymously: you do not have to provide any personal identification details. By completing it, however, you are giving permission, to NCUK, to use any answers to help disseminate, evaluate and further develop the framework.

Any information provided will only be used by the NCUK for the purposes stated – we will never give or share your personal information to or with other organisations to use for their own purposes.

You are free to change your mind at any time

Should you wish to withdraw your consent please let us know by emailing your decision to: nikie@nc-uk.org

Name (Optional)	
Are you the assessor or assessee?	
What is your area of practice ?	
Which of the site specific competencies did you use - if not all please list	
How easy or difficult did you find the framework to use?	
How relevant to your area of practice were the competencies you chose to use?	
Were you able to identify and track clear learning objectives through using the framework?	
What was most relevant / helpful ?	
What would you add or change to the framework?	

Overall comments / feedback	
Please provide name and email/contact details* IF you: consent to future contact, consent to future involvement in framework review, would like information on any further educational resources/ opportunities related to Neuroendocrine Cancer	Name : Email / contact details :
I consent to future contact - please add me to your HCP (healthcare professional) mailing list Please only answer Yes if you agree	Yes / No
I would like to be part of ongoing framework review Please only answer Yes if you agree	Yes / No
I would like information on any further educational resources and/or opportunities related to Neuroendocrine Cancer Please only answer Yes if you agree	Yes / No
Date	

THANK YOU!

Your feedback is vital to the ongoing use and development of this framework.

As stated, any information provided will only be used by NCUK – and only for the purposes stated.

NCUK will never give or share your personal information to or with other organisations to use for their own purposes.

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Should you wish to withdraw your consent please let us know by emailing your decision to: nikie@nc-uk.org

NOTES PAGE:





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www www.ncukacademy.org.uk

Neuroendocrine Cancer UK (NCUK) exists to address the unmet needs voiced by the Neuroendocrine Cancer community, to support patients and their loved ones with the biopsychosocial burden of living with a Neuroendocrine Cancer.



The NCUK Academy is independent and free-to-access at any time. It was designed for nurses (and allied healthcare professionals) working across a range of healthcare settings, to provide a free online resource on Neuroendocrine Cancer – what it is, how it may present and how it is diagnosed, treated and managed.

Developed by our specialist nurse, AHP and expert patient faculty, CPD accredited and endorsed by UKINETs, the Academy includes a combination of evidence-based, resources, clinical practitioner and patient video presentations and is divided into 4 key inter-related E-learning components:

Part 1: An introduction and overview of Neuroendocrine Cancer

Part 2: Site Specific Neuroendocrine Cancers

Part 3: Related Syndromes

Part 4: Holistic Care Considerations

The Academy is a competency-based modular programme that aims to promote awareness and encourage a deeper understanding of Neuroendocrine Cancers – enhancing knowledge, problem-solving and the critical thinking skills of those completing it.