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NATIONAL OPTIMAL PATHWAY FOR NEUROENDOCRINE CANCER (Neuroendocrine Tumours NETs):

Point of Suspicion to First Definitive Treatment in Adults (aged 16 and over)

Date of Issue: January 2022
Date of Review: January 2024
Owner: Neuroendocrine Tumour Tertiary service

Background

The **Single (Suspected) Cancer Pathway (SCP)** programme is to improve access to timely and effective diagnostic tests and treatments, ensure patients are supported through the pathway and allow improvement of upstream factors that will improve earlier detection of cancer.

The SCP is a Welsh Government target for diagnosing cancer and starting treatment more quickly. The performance target for the SCP is that:

At least 75% of patients start their first definitive treatment (FDT) within 62 days of the point of suspicion (POS).

The NHS Wales National Optimal Pathways (NOPs) have been developed to support the SCP programme of work. The Wales Cancer Network (WCN) has worked with health professionals, third sector organisations, and the Welsh Government to develop these cancer specific NOPs. The pathways are owned and reviewed by the relevant Cancer Site Group (CSG). They describe good practice diagnostic and treatment pathways for site specific cancers to support a shortened time to diagnosis.

Aim

The NOPs aim to:

- standardise care, reduce unwarranted variation and drive improvement
- increase quality across each of the cancer pathways
- support the service to meet the SCP cancer waiting time of 62 days for patients presenting with a suspicion of cancer,
- improve cancer patient experience,
- improve cancer patient outcomes throughout Wales to that comparable with the best outcomes in Europe
- reduce the percentage of patients diagnosed having presented as an emergency

The NOPs are designed to support the following services:

- Cancer service providers and their commissioners
 - Outlining the basic structure of an effective and efficient cancer pathway
 - Detailing each stage of the pathway, including communication with patients
 - Consistency across pathways, assisting with standardised data collection and evaluation
 - Enable demand and capacity planning, making the case for expansion of workforce, facilities and equipment
- Primary and non-specialist secondary care teams
 - Providing clarity and consistency around the referral process into secondary care
 - Improve detection rates

General principles

Some general principles have been applied when developing the NOPs. These include the following:

- Patients diagnosed with cancer should start their treatment within 62 days of POS
- The diagnostic (and staging) pathway should be completed within 28 days from POS¹
- First definitive treatment should be commenced within 21 days from date of decision to treat (DTT). The DTT is the date that the consultation between the patient and the clinician took place and a Planned Cancer Treatment was agreed. The definition for FDT and other reported waiting time definitions are incorporated in the Welsh Government's Guidelines for Managing Patients on the Suspected Cancer Pathway (see reference below)

¹ The diagnostic and staging pathway for tertiary services is currently being reviewed and may be 38 days for some tertiary services to allow for the complexity of the pathway

- Patients should be managed with the aim of starting treatment at the earliest clinically appropriate time rather than against any performance measure. All patients should wait the shortest possible time for diagnosis and treatment.
- The pathways are an expression of good practice based on the best available evidence for each respective cancer tumour site. Typically, the authoritative source will be NICE or professional guidelines which are referenced below. Where this is absent, clinical consensus among the appropriate clinical community has been channelled through the CSGs
- Straight to test (STT) is encouraged and has been incorporated into the NOPs where clear referral criteria has been specified in NICE guidance. STT allows primary care to refer for diagnostic procedure (instead of outpatients' appointment) as the first episode of care enabling patients to be appointed to a diagnostic investigation within 2 weeks of referral
- Direct access to diagnostic tests should be applied and have been incorporated in the NOPs where appropriate (e.g. where recommended as part of NICE NG-12 Guidelines). This enables GPs to use direct access for specific diagnostic tests including endoscopy, ultrasound, MRI and X-ray where cancer is suspected. The GP retains responsibility for the person's care, including following up and acting on the results in this circumstance.
- Proactive safety netting in primary care is necessary for early diagnosis of cancer. This is a process where people at low risk (but not no risk) of having cancer are actively monitored in primary care to see if the risk of cancer changes. It involves a 'diagnostic strategy' or 'consultation technique' to ensure timely re-appraisal
- Patients should receive consistent information and support, tailored to meet their needs. The NOPs are heavily influenced by the person centred care strategy outlined at appendix one.

Neuroendocrine Tumour Pathway

Neuroendocrine Tumours are heterogeneous in terms of primary site of tumour, and behaviour according to grade, and therefore it is extremely difficult to define a pathway for each one. However, early histopathology review and confirmation can often be crucial in determining pathways and can significantly change management, particular when distinguishing common well differentiated neuroendocrine tumours (NETs) from the rare aggressive neuroendocrine carcinomas (NECs).

After discussion with the NET team or within the NET MDT, a decision will be made as to whether the patient is seen a NET gastroenterology, oncology or endocrinology clinic centrally or whether care will continue in a referring local health board with advice. Generally, completely resected NETs will have follow up and surveillance in the referring local health board with certain cases in the central gastroenterology-led NET clinic in Cardiff or Liverpool. Due to their heterogeneity, other specialist commissioned services and pathways may be required depending on the case e.g. hepatobiliary surgery for liver metastases, pancreatic surgery, advanced endoscopy, cardiothoracic surgery.

Gallium68 DOTA-PET imaging is the nuclear medicine imaging modality of choice for well differentiated NETs, currently available in London for patients in Wales (or Liverpool/Manchester for North Wales). A local octreotide (or Tektrotyd) scan can be useful as an alternative and a discussion with the NET team is advised if this is considered prior to referral. Nuclear medicine imaging is generally not required in gastric, appendiceal, rectal NETs or high grade NETs or NECs. Peptide Receptor Radionuclide Therapy (PRRT or radioligand therapy) is currently provided for patients in Liverpool (North Wales) and Royal Free Hospital, London (South Wales) but this is not a first line therapy. Chromogranin A is the general NET blood marker for most NETs but fasting gut hormones will be required for NETs of the pancreas/duodenum/stomach or unknown primary. 24-hour urinary 5HIAA is usually reserved for mid-gut and bronchopulmonary NETs at diagnosis, but may occasionally be required for other sites with suspected carcinoid syndrome.

Gastric NETs require ascertainment of Type (different to Grade) with Type I and II being indolent and Type III more aggressive. This does require background gastric biopsies which may require a repeat OGD. After central review, a plan for endoscopic surveillance in the local health board may be advised or a plan for

endoscopic/surgical resection according to local health board pathways. However, central GI-NET review may be required.

Rectal NETs are picked up incidentally but do require appropriate staging, often managed through endoscopic resection unless metastatic (rare). Surveillance may be undertaken in the local health board with advice but central GI-NET review may be required. Duodenal NETs may be managed similarly but may require input from the pancreatic surgical team (part of the NET MDT).

Advanced or metastatic Jejunoileal (midgut) and pancreatic NETs are managed by gastroenterology-led NET teams for somatostatin analogue therapy or when requiring chemotherapy or oral systemic therapy e.g. Sunitinib, Everolimus, from oncology centres in South West, South East and North Wales. All cases should be discussed in the NET MDT and some completely resected cases will require central review.

Rare functional pancreatic or duodenal NETs such as glucagonomas, insulinomas, ACTH-secreting NETs, paragangliomas, and patients with rare endocrine genetic syndromes, e.g. MEN1, will require input from the endocrine NET team.

All Bronchopulmonary NET cases are welcomed to be discussed at the NET MDT, especially those that are inoperable, locally advanced or metastatic. Ongoing work is being carried out to make the lung NET pathways more efficient

Bronchopulmonary and Thymic NETs are managed through existing lung cancer pathways with input from the NET MDT and for typical/atypical lung NETs (carcinoids), somatostatin analogue therapy will be provided by the central gastroenterology NET team.

NETs or NECs arising from other uncommon sites e.g. head and neck, gynaecology, skull base, will have advice from the central NET MDT but will require ongoing care from local health board or central services for those anatomical sites.

Due to the complex nature of this cancer, early contact with the MDT lead and nurse specialists is welcomed, in order to provide timely guidance.

Management of patients with NETs should adhere to European NET Society (ENETS) guidelines.

For children and young patients, the treatment plan should be made and delivered by the paediatric oncology MDT and the NETS MDT should be informed of the plan.

For teenagers and young adults (TYA), the TYA MDT should be informed of the diagnosis and treatment plan in order to identify psychosocial needs / palliative care / symptom control and work collaboratively with 3rd sector organisations to deliver the support.

Further guidance and references

Direct to test

[Quality statement 1: Direct access to diagnostic tests | Suspected cancer | Quality standards | NICE 2900089 - Direct access to diagnostic tests for cancer Final \(publishing.service.gov.uk\)](#)

Neuroendocrine tumours

<https://collaborative.nhs.wales/networks/wales-cancer-network/clinical-hub/cancer-site-groups/neuroendocrine-cancers/>

European NETS society guidelines

[Guidelines - enets.org](https://www.enets.org/)

UK & Ireland NET society clinical practice

<https://www.ukinets.org/net-clinics-clinical-practice/>

Neuroendocrine Cancer UK patient website

<https://www.neuroendocrinecancer.org.uk/>

Recognition and referral

[Overview](#) | [Suspected cancer: recognition and referral](#) | [Guidance](#) | [NICE](#)

[Cancer Risk Assessment Tool \(RAT\)](#)

[Q Cancer Risk Assessment Tool](#)

Safety netting

Royal College of General Practitioners

<https://www.rcgp.org.uk/~media/44975652AC794FCEBDD1C59EA0EB32A7.ashx>

[safety_netting_table_march_2020.pdf \(cancerresearchuk.org\)](#)

SCP waiting time data standards

Welsh Government (2020) Guidelines for Managing Patients on the Suspected Cancer Pathway; version 2; December 2020; https://gov.wales/sites/default/files/publications/2021-01/guidelines-for-managing-patients-on-the-suspected-cancer-pathway_1.pdf

Straight to test

Delivering Cancer Waiting Times: A Good Practice Guide; [delivering-cancer-wait-times.pdf \(england.nhs.uk\)](#)

Wales CPD Module for GPs and Secondary Care

[Neuroendocrine Tumours CPD](#) | [Online CPD Course \(studyprn.com\)](#)

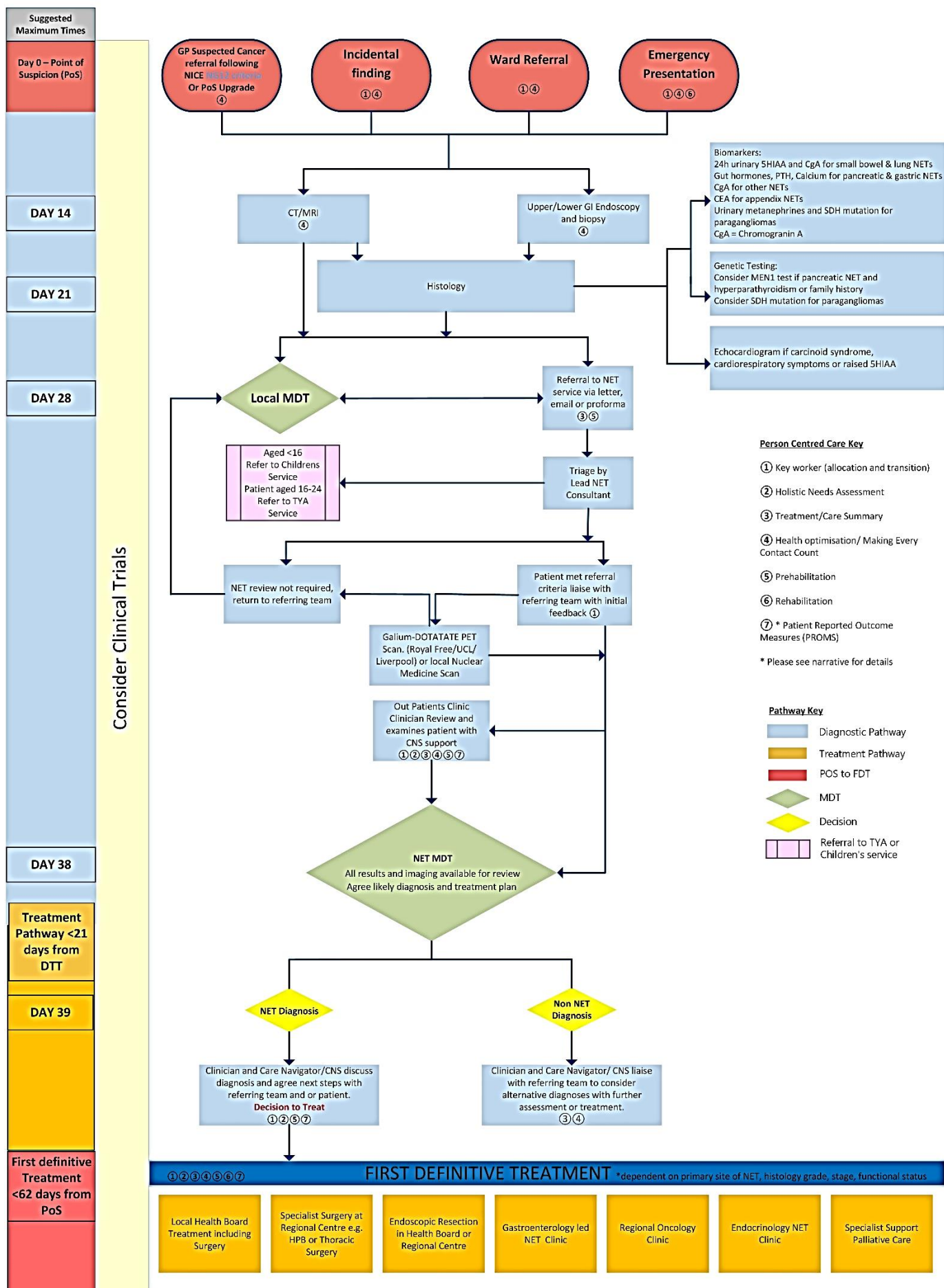
Pathway development and approval

The pathway development was led by Dr Mohid Khan, Consultant Gastroenterologist, Cardiff and Vale UHB and NET Clinical Lead for Wales with Catherine Powell and Kathryn Cook Neuroendocrine Tumour CNS's, Cardiff and Vale UHB.

Approved by:

The Wales Cancer Network Board

National Optimal Cancer Pathway for suspected and confirmed Neuroendocrine Cancer (incorporating or including Neuroendocrine Tumours NETs): Point of Suspicion (PoS) to First Definitive Treatment (FDT)



Appendix one - PERSON CENTRED CARE

Key Worker	<p>QS 14: Patients are made aware of who to contact, how to contact them and when to make contact about their ongoing healthcare needs. National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</p> <p>A cancer key worker is “a person who, with the patient’s consent and agreement, takes a key role in coordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice”.</p> <ol style="list-style-type: none"> 1. All cancer patients must have an allocated key worker 2. Allocation / Review of key worker to take place at key time points including: <ol style="list-style-type: none"> a. Around the time of diagnosis <i>*please note: allocation of key worker may occur earlier than time of diagnosis, if there is a very high level of suspicion of cancer e.g. evidence obtained via pathology, radiology, endoscopy.</i> b. Commencement of treatment 3. When not under active management by the cancer MDT, the Key worker would be a member of the primary care team. This involvement is critical as many patients living with cancer also live with 2 or more other chronic conditions. <p>Key workers for cancer patients (Welsh Health Circular /2014/001) GOV.WALES Welsh Government. Cancer Delivery Plan for Wales 2016-2020.</p>
Holistic Needs Assessment and Associated Care Plan	<p>QS 4: Patients have opportunities to discuss their health beliefs, concerns and preferences to inform their individualised care.</p> <p>QS 10: Patients have their physical and psychological needs regularly assessed and addressed, including nutrition, hydration, pain relief, personal hygiene and anxiety. National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</p> <p>Assessment and discussion of patients’ needs for physical, psychological, social, spiritual and financial support should be undertaken at key points including:</p> <ul style="list-style-type: none"> • Around diagnosis <i>*please note: undertaking a Holistic Needs Assessment may occur earlier than time of diagnosis, if there is a very high level of suspicion of cancer e.g. evidence obtained via pathology, radiology, endoscopy; and it is supported by professional judgement.</i> • At commencement, during, and at the end of treatment; <p>National Institute for Clinical Excellence (NICE, 2004) CSG4 Improving Supportive & Palliative care for adults with cancer</p> <p>Ideally Holistic Needs Assessments should be undertaken electronically. The Macmillan eHNA is one tool which is both valid and reliable. Snowden A & Fleming M (2015) Validation of the electronic HNA.</p>
Health Optimisation / MECC	<p>QS 9: Patients experience care that is tailored to their needs and personal preferences, taking into account their circumstances, their ability to access services and their coexisting conditions. National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services</p> <p>Health Optimisation refers to a proactive approach to supporting people who present to NHS services with concurrent comorbid health conditions (e.g. anaemia, diabetes), or health risk behaviours (e.g. smoking, physical inactivity). Welsh Government (2018) A Healthier Wales. Welsh Government (2015) Wellbeing of Future Generations Act.</p>

	<p>Making Every Contact Count (MECC), is a behaviour change approach that helps health and social care professionals to help people to improve their health and wellbeing through prevention and early intervention. Public Health Wales Strategic Plan 2018-2021</p> <p><i>Lifestyle advice / resources are available from Making Every Contact Count (MECC)</i></p> <p><i>*Please note: Whilst addressing concurrent comorbidities and health risk behaviours is the responsibility of all health and social care professionals, at every contact throughout the pathway; earliest possible intervention may impact on cancer treatment choices / outcomes (especially in respect to tobacco smoking). National Institute for Clinical Excellence (NICE, 2018) NG92 NICE Guideline Stop Smoking Interventions and services.</i></p>
Prehabilitation	<p>Patients should have the opportunity to take part in evidence-based education and rehabilitative activities, including self-management programmes, <i>where available</i>, that promote their ability to manage their own health if appropriate.</p> <p>National Institute for Health & Care Excellence (NICE, 2012) CG138 Clinical Guideline: Patient Experience in adult NHS services Welsh Government (2018) A Healthier Wales. Welsh Government (2015) Wellbeing of Future Generations Act.</p>
Rehabilitation	<p>All patients will have their needs for rehabilitation services assessed, with referral to an appropriate level of rehabilitative support, throughout the patient pathway.</p> <p><i>*Please note: not all patients will require specialist cancer rehabilitation services. Referral into non-cancer rehabilitation, self-management, and fitness services may be suitable to meet some patients' needs.</i></p> <p>National Standards for Rehabilitation of Adult Cancer Patients (2010) GOV WALES National Institute for Health and Care Excellence (NICE) CSG4 (2004) resources for improving supportive and palliative care for adults with cancer.</p>
Patient Reported Outcome Measures (PROMs) / Patient Reported Experience Measures (PREMs)	<p>Patient Reported Outcome Measures (PROMs) are questionnaires that patients are asked to complete through the pathway to assess the impact on health and wellbeing. EORTC.GINET21 is a validated tool for NETs. Symptom PROMs are also used routinely in NETs e.g. GSRs.</p> <p><i>Some</i> of the Cancer Site Groups (CSGs) have been working with the International Collaboration for Health Outcome Measurement (ICHOM), Value Based Healthcare Team, National PROMS, PREMS, & Effectiveness Programme (NPP&EP) and other partners, to pilot tools and data capture methods, which will inform a consistent approach to PROMS & PREMS for cancer. Welsh Government. Cancer Delivery Plan for Wales 2016-2020.</p> <p><i>*Please note: there are outstanding questions relating to tool selection, data capture intervals, data capture methods and data analysis / reporting which may prevent the implementation of PROMS & PREMS across all pathways at this time. PROMS & PREMS have been included in the pathways, in recognition of this work, and will be updated pending further advice from the CSGs.</i></p> <p>Patient Reported Experience Measures (PREMs) are questionnaires that patients are asked to complete at any time during their pathway to help professionals to understand their experience of NHS services. This information is crucial to understanding the value of healthcare as perceived by patients. Welsh Government (2018/19). Chief Medical Officer Annual Report.</p> <p><i>*Please Note: Whilst it is good practice to collect PREMS throughout the pathway, there is no current standard for cancer PREMS in Wales; further advice regarding this will be sought via the CSGs in due course.</i></p>

