Nurse-Led Follow up for Patients diagnosed with Neuroendocrine tumours (NETS) requiring hospital follow-up.	University Hospitals of Leicester NHS NHS Trust Trust Ref C14/2021

Introduction

The purpose of the Nurse-Led Neuroendocrine tumour (NET) clinic is to provide patients with a safe guideline-based service to monitor, treat and support them with their tumour.
The nurse led service will be either via clinic attendance at the Oncology/Surgical out-patients department and / or via a nurse led virtual telephone surveillance clinic.
The nurse led virtual clinic will enable patients to be monitored remotely rather than attending the Oncology/Surgical out-patients department, thus reducing waiting times and cost for the patients. There are benefits to the service by reducing patient follow-up and attendance at Oncology/Surgical Out-patients and providing a more cost-effective service overall.
This document outlines the arrangements for the management of patients with identified neuroendocrine disease as well as the management of their symptoms and surveillance ensuring that any disease recurrence or progression is identified early.

Scope

This document applies to the Nurse Specialist responsible for the care of NET patients within the University Hospitals of Leicester NHS Trust.

Guideline Standards and Procedures

Recommendations, Standards and Procedural Statements

A neuroendocrine tumour is defined as the presence of a rare tumour that develops in cells of the neuroendocrine system. Although they develop from the same types of cells, they develop in different organs in the body – see appendix 1.
This clinic will be dealing with mainly tumours found in the gut or pancreas, also known as gastroenteropancreatic neuroendocrine tumours (GEP NETs for short), approximately 10% of people with Nets with be affected by Carcinoid syndrome. These symptoms have a major impact on their quality of life and can be controlled by the administration of Somatostatin analogue (SSA) injections every 3-4 weeks.
NETs can also be defined as functioning neuroendocrine tumours (F-NETs) or non - functioning neuroendocrine tumours (NF-NETs) as well as being malignant or benign.
NETs are uncommon, they make up 2% of all cancers worldwide at any time. Ratio of occurrence is equal between men and women and average age at diagnosis is 50-60 years.
Benign neuroendocrine tumours tend to be slow growing and are low or intermediate grade.
Neuroendocrine carcinomas tend to be faster growing and higher grade.

Aims of the Service

The aim of the NET CNS service is to:

- Improve patient education.
- Enable patients to develop a better understanding of their condition.
- Improve adherence with medication.
- Enable early identification of disease progression.
- Reduce the development of complications.
- Support the patient with their physical, emotional and social symptoms/ use of holistic needs assessment/E-HNA
- More appropriate use of medical staff and reduced clinic waits.
- Reduce medical workload as patients are only seen by doctors when unwell.
- Expedite medical review of new patients.
- Improve access to services.
- Provide a nurse led service to facilitate prompt and effective treatment.
- Provide early treatment of an exacerbation and reduce the number of hospital admissions.

- Ensure safe administration of therapeutic agents.
- Administration of biologic medication when Homecare/primary care team are unable to administer/prescribe.
- Monitoring of patient during and after treatments.
- Counselling on the commencement of medication.
- On going review by nurse specialist to monitor for side effects.
- Joint co-ordination of radio targeted therapy by nuclear medicine team and NET nurse specialist.

CNS Role in the NET nurse-led clinics (in Oncology and Surgery)

The CNS role within the clinic will include;

- Assessing how the patient's condition has been since their last appointment – have things improved?
- Monitoring symptoms and side effects –see appendix 2 p8
- The organisation of routine blood tests and other screening programmes – see appendix 2 p8
- Supervision of safe administration and monitoring of Somastatin Analogue injections (SSA)
- The provision of information and support and health promotional materials.
- Quick easy contact by telephone helpline to any patients experiencing problems, highlighting need for review.
- The identification of patients experiencing poor response and relapse and appropriate referral to the Dietitian and Consultant NET Specialists.
- Early identification of Carcinoid heart disease
- For surgical patients only, identifying early signs of disease recurrence

Profile of NET Virtual Telephone Clinic

These clinics are virtual clinics and take place twice a week for 2 sessions on Wednesday morning (DJM NET) and Wednesday afternoon (SD NET) They run concurrently with either the NET Consultant HPB Surgeon or NET Consultant Oncology, in their clinic to ensure medical supervision for advice/review of cases is available. In the absence of one of the NET Consultants, the medical supervision role can be delegated to a suitably qualified medical NET Consultant.

The clinic has 4 x 30-minute slots – allowing for assessment of symptoms, holistic needs assessment and care planning

Appointments are scheduled by the allocated clinic co-ordinator, who also prepares the medical notes for the clinic. The Clinic codes are DJM NET (Surgery) AND SD NET (Oncology)

Prior to referral to the NET CNS virtual telephone clinic all diagnostic tests such as Computed Tomography (CT), Octreotide scan, bloods, NET MDT discussion must be complete, reported and results documented in the patient's medical/oncology notes or available via ICRIS, ILAB, ICE and Somerset. If there are outstanding investigations or results pending for the patient, a further appointment will be made for the patient to attend the Consultant's clinic so that results can be medically reviewed and communicated to the patient.

The Oncologist/Surgeon will have reviewed the patient with the Nurse Specialist first in the Oncology/Surgical clinic before any patient is reviewed by the nurse specialist in the follow-up clinic, or in the virtual telephone clinic, and a copy of the clinic letter must be in the Oncology/medical notes or copy of letter sent to the CNS.

The patient must have been informed and educated about their NET and the rationale for ongoing monitoring and the patient will have verbally consented to nurse led monitoring and will have received the UHL 'Your Local Cancer Services' UHL 'Neuroendocrine tumours and the treatments available to you' UHL' The NET MDT and you' and information provided by Neuroendocrine Cancer UK. This will be clearly documented in the patient's Oncology/medical notes with a dictated letter to the GP (using Dictate 3) and copied to the patient.

Profile of NET SSA Out-Patients clinic

The clinic is for NET patients attending and receiving somatostatin analogue injections (SSA). This takes place for 1 session on Monday morning. It is run concurrently with the Oncology Consultant clinic to ensure medical supervision for advice/review of cases is available.

The clinic has 1 x 45-minute slot – allowing for review, injection, holistic needs assessment and care planning.

The patient will at their initial appointment meet both their Consultant and NET CNS together. If a subsequent clinic appointment for the SSA injection is needed, the patient will be reviewed by the NET CNS only. (Where possible the patient will receive the injection at their initial appointment)

Subsequent injections will be referred out to the Healthcare at home team for medication delivery – see appendix 5 p11**.** Administration of the injection to be done by the patient or relative (training available by the Homecare team) or their local GP practice or in certain circumstances, the NET CNS will refer to the homezone nurse for administration or self-administration teaching.
Otherwise, the profile is the same as for the telephone clinic above. The patient will have received information about UHL 'Your Local Cancer Services' UHL 'Neuroendocrine tumours and the treatments available to you' UHL' The NET MDT and you' and information provided by Neuroendocrine Cancer UK.
The patient will also receive the injection information as provided by the pharmaceutical company.

Inclusion of Patients for Nurse-led NET Out–Patients clinic and NET virtual telephone clinic

Any patient the NET Consultant Oncologist has assessed as suitable to enter the Nurse led injection and screening programme can be referred to the service.

Exclusions to monitoring in Nurse Led Out-patient Clinic

The following patients will not be seen in the nurse clinic:

- Any patient being referred for surgical opinion
- Any patient undergoing chemotherapy
- When the Consultant states that the patient should not be reviewed in the nurse clinic, as patient due for consultant review.
- Any patient with known complex problems such as diabetes and dementia.
- Any patient who has declined to be seen in the nurse-led clinic.

Exclusions to monitoring in Nurse Led Virtual Telephone Clinic

It is envisaged that most patients with NET having SSA out in the community (with Homecare) will be monitored in the virtual clinic, however some patients will not be suitable for virtual monitoring for example-

- when the consultant states patient should not be reviewed in nurse led clinic
- when the patient is not suitable for Homecare prescription service.
- the patient is unable to communicate verbally by telephone
- when it is the patient's choice not to be monitored in the Nurse led service.

Patients not monitored in Nurse Led virtual clinic can be followed up in either the Nurse Led out-patient list on Wednesdays or maintained in the Oncologist Consultant clinic.

Process for Virtual Clinic

Oncology/medical Notes will be prepared for the morning clinic by the Oncology/Surgical clinic Co-ordinator
The patient will have been instructed to have blood tests (see appendix 2) in the community 1-2 weeks prior to their appointment.
Standard blood sampling-

Full blood Count – to assess for anaemia
Urea, Creatinine, e-GFR – to assess for deterioration in renal function
CRP- can indicate infection/inflammation
Bone Profile – to look for hypercalcaemia
Liver function – to check bilirubin, patency of Bile ducts, presence of gall stones
Chromogranin A and B – high levels can indicate tumour activity
NT pro BNP – to assess for heart failure, used to assess for carcinoid heart disease. If raised, echocardiogram to be requested. Results to be discussed with consultant and a decision to be made as to whether a Cardiac opinion is needed.

Urine sampling-

5 Hiaa 24-hour urine collection may be monitored intermittently – certainly on the first visit to clinic for a baseline recording and to identify carcinoid syndrome.
The CNS collates results, documents in the patient's Oncology/surgical notes.
If patient results are stable and no new symptoms are reported the CNS will schedule the patient's next appointment and dictate a letter on Dictate 3 to the GP of which the patient will receive a copy.
Patients will be telephoned so they know the results of their blood tests.
If the patient has reported symptoms or shows a deterioration in their blood results the CNS will contact the patient by telephone, after discussion with their NET Consultant.

Due to the nature of the clinic specified times for telephone calls are not given. The CNS rings the patient and asks re specific symptoms.

- flushing or increased flushing
- Abdominal pain
- unexplained weight loss
- diarrhoea/constipation
- difficulty breathing
- irregular heartbeat
- new unexplained symptoms
- offer of Holistic Needs Assessment, particularly if there has been a shift in the patient's physical, social or psychological well-being.
- Care plan

The CNS documents the conversation in the Oncology/medical notes and on the electronic cancer register, Somerset. If the patient is not available on telephone to discuss results the CNS will not leave messages on answer machines, or send texts, in case of breach of confidentiality.
The CNS dictates a letter on Dictate 3 to the GP and patient to include:
- specific problems identified by the conversation with the patient
- any issues relating to the blood results
- follow up schedule for patient
- any requested actions for GP.
- any action resulting from the holistic needs assessment.

The blood/urine forms for the patient's next appointment will be written by the CNS and forwarded to the patient after the clinic with follow-up details.
Any bloods requested by the CNS in clinic will be followed by the CNS.
If blood sampling has not been performed, the CNS will send a reminder letter and reschedule appointment for 4-6 weeks. This will be repeated 2 times in total after which the case will be discussed with the medical supervisor and either scheduled for a medical appointment in clinic (High Intermediate/High risk groups) or discharged to GP (Low/Low/Intermediate Risk groups).
The virtual clinic will be cancelled when the CNS has planned leave or if there is no medical supervision available for the clinic slot. In the absence of the NET Oncologist/Surgical Consultant, the Consultant can delegate the responsibility of medical supervisor to another suitably qualified medical practitioner in the Oncology/Surgical team.

Imaging frequency:

<u>For surgical NET patients post operatively with resected disease:</u>
Octreotide/ Gallium scan 3 months after surgery
CT scan every 6 months during first year with chromogranin A+B blood tests
After this, annual CT of Chest, abdomen and pelvis with Crgs A&B
If patient has surgery involving liver resection – MRI liver required every 6 months for first year, then annually.

<u>For oncology patients on SSA:</u>
Three monthly follow-ups for first year with routine bloods, then review every 6 months if stable with Crgs A&B, NT pro BNP and routine bloods.
CT of Chest, abdomen and pelvis every 6 months for first year.
MRI liver required with CT scan if liver metastases involved:
If stable, annually, after discussion with NET Oncologist.

<u>For Oncology patients on surveillance only:</u>
CT of Chest, abdomen and pelvis, MRI liver (if liver involvement)
Crgs A&B, NT pro BNP and routine bloods every 6 months.
If stable, annually, only after discussion with NET Oncologist

Triggers for discussion with Consultant/Medical Supervisor

Abnormal scan results

Abnormal blood results – lowing haemoglobin, increasing liver function, raising chromagranin levels,
New symptoms-
Pain if new or progressive pain
Increasing diarrhoea
Increasing nausea, vomiting
Progressive flushing
Unexplained and sudden weight loss with no intention or reason.

Unrelated symptoms CNS should suggest patient should self-refer to GP and alert GP of symptom in letter.

Suspected Recurrence/Progression of Neuroendocrine tumour.
Any patients with suggestion of recurrence being identified will be reviewed by the NET Consultant Surgeon and referred to the NET MDT.
Patients with suggestion of progression will be identified and will be reviewed urgently by the NET Oncology Consultant and referred to the NET MDT.
Results of blood tests and symptoms will be discussed by the CNS with the patient and an explanation of reason for urgent transfer to the Consultant Oncologist clinic will be given.
A summary letter will be sent to patients GP with a copy being sent to the patient.
Discharge of patients from the NET virtual clinic
Currently all monitoring of NET patients remains within UHL.
Patients offered UHL Macmillan recovery package
These patients will be discussed with the supervising consultant who will review the Oncology/medical notes and results and will discharge the patient back to the GP/Community if appropriate.

Education and Training

It is the responsibility of the nurse to ensure they regularly update their knowledge and skills in line with continuing professional development.
The nurse specialist needs to be an active member of the UKI Neuroendocrine Society and be aware of current neuroendocrine treatments and research.
Monitoring and Audit Criteria
Regular and systematic audit of the nurse led services must be undertaken to ensure patient safety and to ensure adherence to guidelines and to ensure the CNS maintains skills and knowledge.
The CNS will audit the clinic every third year, reviewing a sample of 20 notes and including a patient experience survey. Results would be evaluated and presented to the Neuroendocrine MDT business meeting.
Legal Liability Guideline Statement
The University Hospital of Leicester NHS Trust as an employer will assume vicarious responsibility for the nurse providing that
-the CNS has undergone adequate preparation for the development of this practice
-The nurse has followed the provision of this policy and the UHL Standard operating procedures, work programme and Clinical Guidelines for the management of neuroendocrine tumours.
Supporting Documents and Key References
The nurse led service will work within local UHL and national –UKI NETS guidelines and be supported by multidisciplinary clinical meetings held fortnightly.
Essential national guidelines and documents that the nurse specialist must be familiar with;
ENETS Consensus Guidelines Update for Gastroduodenal Neuroendocrine Neoplasms.
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ENETS Consensus Guidelines Update for the Management of Patients with Functional Pancreatic Neuroendocrine Tumors and Non-Functional Pancreatic Neuroendocrine Tumors. **Falconi M, Eriksson B, Kaltsas G, Bartsch DK, Capdevila J, Caplin M,et al.** 2, 2016, Neuroendocrinology. , Vol. 103, pp. 153 - 171.

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UK and Ireland Neuroendocrine Tumour Society
European Neuroendocrine Tumor Society

Key Words

NET – neuroendocrine tumour
CRG – Chromogranin A+B the blood tumour marker used for detecting the activity of neuroendocrine tumour.
5Hiaa – the 5-hydroxyindoleacetic acid 24hr urine collection done to measure activity of tumour.
SSA - Somastatin Analogue injections given to treat some neuroendocrine tumours

CONTACT AND REVIEW DETAILS	
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Details of Changes made during review: Following 2019 NET CNS guidelines covering Oncology NET FU clinic, these include surgical NET FU clinics.	

Appendix 1
Background – from the Royal Free 'Advanced Practice protocols – January 2013'

Neuroendocrine tumours (NETs) comprise of 2% of all malignant tumours within the gastroenteropancreatic system (which comprises of the pancreas, stomach, large and small bowel, rectum and appendix) (Caplin et al 1998). Carcinoid tumours develop from neuroendocrine (enterochromaffin) cells and are the most frequently occurring NET (Ramage et al 2005). They have an incidence of 2.5-5 per 100.00 (Modlin et al 2008). Carcinoid tumours occur commonly in the midgut region (jejunum, ileum, right colon and appendix). These tumours tend to be slow growing, and most patients are diagnosed when the disease has spread to the liver. Surgery is the only curative therapy however, once metastasis has occurred surgical cure is often not possible (Wilander 1989). The aim of care therefore turns to prolonging and improving the quality of life. The 5-year survival for all types of carcinoid tumours is 67.2% (Modlin et al 2003).

The secretory nature of neuroendocrine tumours and the hormones that are released by these cells can cause symptoms such as flushing and diarrhoea in carcinoid tumours to hypoglycaemia and fainting in pancreatic insulinomas (Caplin et al 1998). The link between peptides (including serotonin) and endocrine cells in the gut led to further understanding of carcinoid in 1940's and 50's(Rapport et al 1948, Lembreck 1953, Pearse 1955). Once NETs have metastasized to the liver a proportion of these cancers (known as functioning tumours) hyper-secrete certain hormones that are released into the circulation and cause symptoms as opposed to NETs that do not release hormones causing symptoms being "non-functioning" (Modlin et al 2008, Rubin et al 1999, Oberg et al 2004). These symptoms include flushing, diarrhoea, pain, rash and heart disease, collectively known as carcinoid syndrome (Ramage et al 2005). Serotonin can also affect heart valves causing fibrotic deposits, leading to carcinoid heart disease most commonly affecting the tricuspid valve. Carcinoid tumours can also cause reduced protein synthesis and hypoalbuminaemia which in turn can lead to pellagra (skin rash, glossitis, stomatitis and confusion) (Caplin et al 2006).
Goblet cell carcinoids display features of NETs and adenocarcinomas which originate from the appendix. These tumours behave in a more aggressive form and are treated as adenocarcinomas.
Functioning pancreatic NETs have distinct symptoms related to the peptide released by the tumour. Symptoms for insulinoma patients include hypoglycaemic attacks, palpitations, sweating, anxiety, dizziness and irritability due to excess insulin. VIPoma patients have a raised VIP levels which can lead to Verner-Morrison syndrome. This incorportates the key symptoms of watery diarrhoea (diffuse, continues even when fasting), hypokalaemia and achlohydria. Symptoms of Glucagonoma include NME (Necrolytic migratory erythema), weight loss, diabetes, inflammation of cheeks and lips, anaemia in 50% of patients and vulvovaginitis in women.
Phaeochromocytomas are tumours of the adrenal glands with one in ten cases found outside the adrenals (paragangliomas). Most phase occur within the adrenal medulla and increase the release of catecholamines. This can lead to a range of symptoms including headache, dizziness, pallor, sweating, palpitations, panic attacks, weight loss , anxiety and high blood pressure.
Non-functioning tumours symptoms relate to the tumour bulk and positioning and may include jaundice, abdominal pain, weight loss, steatorrhoea, bleeding or tiredness.

The development of Neuroendocrine Tumour Nurse Specialist service is to facilitate an improvement in the quality of life individuals with NETs. Due to the rare nature of neuroendocrine Tumours there are no specific documents for this but similar specialist papers are relevant. The British Society of Gastroenterology (BSG) strategy document (2006) states 'the IBD specialist nurses plays an important and integral role, particularly at primary / secondary care interface, in education, telephone access, monitoring and patient support.'

Appendix 2 - History of Symptoms

The CNS will take a history of clinical symptoms that will be recorded in the patient's notes.

This will include;
- Bowel actions frequency
  - Urgency / soiling / incontinence
  - Consistency
  - Bleeding
- Flushing (pattern and associated symptoms), Pain, palpitations, rash
- Appetite, weight change, dietary restrictions, dizziness, headaches, irritability, BP, Pulse
- Peripheral oedema
- Significant past medical history – eg MEN 1
- Social history
  - smoking
  - work / family
  - support network
- Drug history – any current medications, any allergies
- Family history particularly any Cancers

Previous Investigations

Note of most recent biopsy/surgery, CT scanning, nuclear medicine imaging and biochemical markers should be highlighted.

Routine Investigations

All patients receiving three, six or twelve monthly review will routine blood tests which must include; Full blood count, liver, renal and bone profiles.

NT pro BNP

Chromogranin A and B levels will be checked on a 6 to 12 monthly basis.

All new referrals will have a Fasting Gut Hormone profile and 24 hour urine as appropriate.

Any abnormalities will be discussed with a consultant NET Specialist. Any resulting nutritional supplements will be recommended to the general practitioner.

Other routine investigations available to the nurse specialist will include CT Chest, abdo and pelvis with dual phase liver, MRI liver and plain abdominal and chest xray (once the CNS has successfully completed the radiology requesting for nurses training).

Octreotide/ gallium and PET scans will require requesting from the Consultant Oncologist/Surgeon.

Commencement and monitoring of patients receiving somatostatin analogues

Patients planned for this will be treated as per department agreed guidelines

Acute Investigations

All patients with acute symptoms should be considered for baseline blood tests Hb, renal, liver and bone profiles, clotting screen, CRP as a minimum and stool and blood cultures as appropriate.

Plain abdominal and chest x-ray will be the only acute investigations available.

Any other investigations must be agreed by a consultant NET Specialist/ Oncologist.

Xray ordering will be carried out under Trust policy (see appendix) and be IRMER compliant.

Nurse Prescribing

Independent nurse prescribing may be used in the clinic setting after agreement from the non-medical lead for independent prescribing, specialist pharmacist and lead clinician as per Trust policy and on CNS completing the Non Medical prescribers course.

Information and Support

All patients will be given a direct line telephone contact number and secure email address to use to contact the CNS, if they have concerns or questions between appointments.

Written information regarding neuroendocrine tumour management and local patient support with be given as required.

Appendix 3 – Administration of Somatostatin analogues

Rationale and Indication for use:

Long acting preparations Sandostatin LAR and Lanreotide Autogel are used for symptom control and anti-tumour effects for NET patients (PROMID, CLARINET).

Symptom management research mainly examines the use of somatostatin analogues (Ramage et al 2005). Ramage et al showed that 70-90 percent of NETs display somatostatin receptors (Ramage et al 2013). Somatostatin analogues (Octreotide) inhibit the release of various hormones in the gut, pancreas and pituitary. Drugs such as Octreotide, Somatostatin LAR and Lanreotide Autogel (slow release formulae) are used to help relieve symptoms.

Possible Side Effects Medication:

Site of injection:
Pain, tingling and redness
Sometimes:
Weight loss, nausea, stomach pain and bloating, wind, steatorrhoea, changes in sugar levels.
Gallstones.
Rarely:
Anaphylaxis, a slow pulse rate, hair loss, allergic skin reactions, giddiness, restlessness, jaundice.

Long acting Somatostatin analogues (SSA)

- Patients attend the joint Consultant and nurse clinic for their first dose.
- Baseline observations: Height, Weight
- Lanreotide Autogel is a gel injection given by deep subcutaneous injection into the buttock. The injections are alternated between the buttocks each time.
- The patient also has the option for this medication for self-injection and partner injection, and this should be discussed with the patient.

Following doses are given via the nurse clinic every 4 weeks for injection 2 and 3. Subsequently the patient will be referred out to Homecare.

Dosages:

60-120mgs Lanreotide Autogel 3-4 weekly.

Possible Side Effects Medication:

Site of injection:
Local injection site reactions – usually mild and of short duration. They include local pain and, rarely, swelling and rash.
Sometimes:
gastrointestinal side effects, including anorexia, nausea, vomiting, abdominal pain, bloating, flatulence, loose stools, diarrhoea and steatorrhoea.
Rarely:
Acute pancreatitis after first dose; gastrointestinal side effects may resemble acute intestinal obstruction.

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Appendix 4: Healthcare at home

UHL patients receiving Lanreotide injections are referred out to the Homecare team, with the patient's permission.

This scheme covers the delivery of the drug to patients as well as nurse **training** so that patients can self-administer or train partners/carers to administer.

Presently there are 2 groups of patients:

1. Patients who get drug delivered and will self-administer or train partners/carers to administer after training
2. Patients who are unable to self-administer and need home administration, company nurse will administer.
3. Patients who get drug delivered but cannot self-administer-these patients get the GP practice nurse to administer as previously arranged.

New patients have first injection supplied by TrustMed at Leicester Royal Infirmary and administered in the Oncology Clinic after which they are referred with their signed consent, to 'Healthcare at home'.

The Oncologist and NET CNS discuss with the patient in the Oncology outpatient clinic, regarding the transfer of their medication delivery over to the 'Healthcare at home' team, including the offer of self-administration training.

When a patient consents to the 'healthcare at home' service :

- an initial 'Patient Information Record Form (PIRF)' is completed, discussed and signed by the patient and filed in the patient's Oncology notes.
- the patient is given the written information ,' Your medication home delivery service' and contact details
- a registration form is completed by the Consultant or NET Nurse Specialist in clinic.
- the Homecare prescription is completed by the Consultant Oncologist in clinic.

At the end of the clinic session, the registration and prescription forms are handed to the Oncology Pharmacy team.