# Model of neuroendocrine cancer care

## (Gastroenteropancreatic NETs)

**Version: 1.0**

**March 2022**

**Produced by the Gippsland Regional Integrated Cancer Service in collaboration with Peter MacCallum Cancer Centre and Neuroendocrine Cancer Australia**

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**Statement of acknowledgement**
We acknowledge the Traditional Owners of Country throughout Australia and their continuing connection to the land, sea and community. We pay our respects to them and their cultures and to Elders past and present.

Gippsland Regional Integrated Cancer Service is supported by the Victorian State Government

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## 1.0 Background

Neuroendocrine tumours (NET) can arise from neuroendocrine cells anywhere in the body. Most commonly, NET arise in the GI tract (upper and lower) or pancreas (referred to as pancreatic islet cell tumours). Pancreatic islet cell tumours include insulinomas, VIPomas, gastrinomas, somatosatinomas, glucagonomas (Peter MacCallum Cancer Centre, 2016)**.** These tumour types (in the pancreas and GIT) can also be referred to as gastroenteropancreatic neuroendocrine tumours (GEP-NETs) (National Cancer Institute, 2021).

Individualised, specialist cancer care is particularly important for this group of patients (Neuroendocrine Cancer Australia, 2021). In Victoria, the Peter MacCallum Cancer Centre is the centre of excellence for the management of NETs, having well established multidisciplinary teams in place. Nonetheless, for patients who live in rural locations, the impact of travelling to receive care should always be acknowledged.

## 2.0 Aims and objectives

This model aims to provide a patient-centred framework for delivery of care to patients diagnosed with GEP-NETs, which minimises the travel implications while still delivering access to disease experts.

The objectives are:

- To provide clinicians managing NETs in Gippsland with a guide to deliver shared-care in partnership with PMCC
- To ensure patients with NETs receive high quality coordinated care equal to that of metropolitan patients
- To optimise use of hospital resources, by providing care in the community, where possible

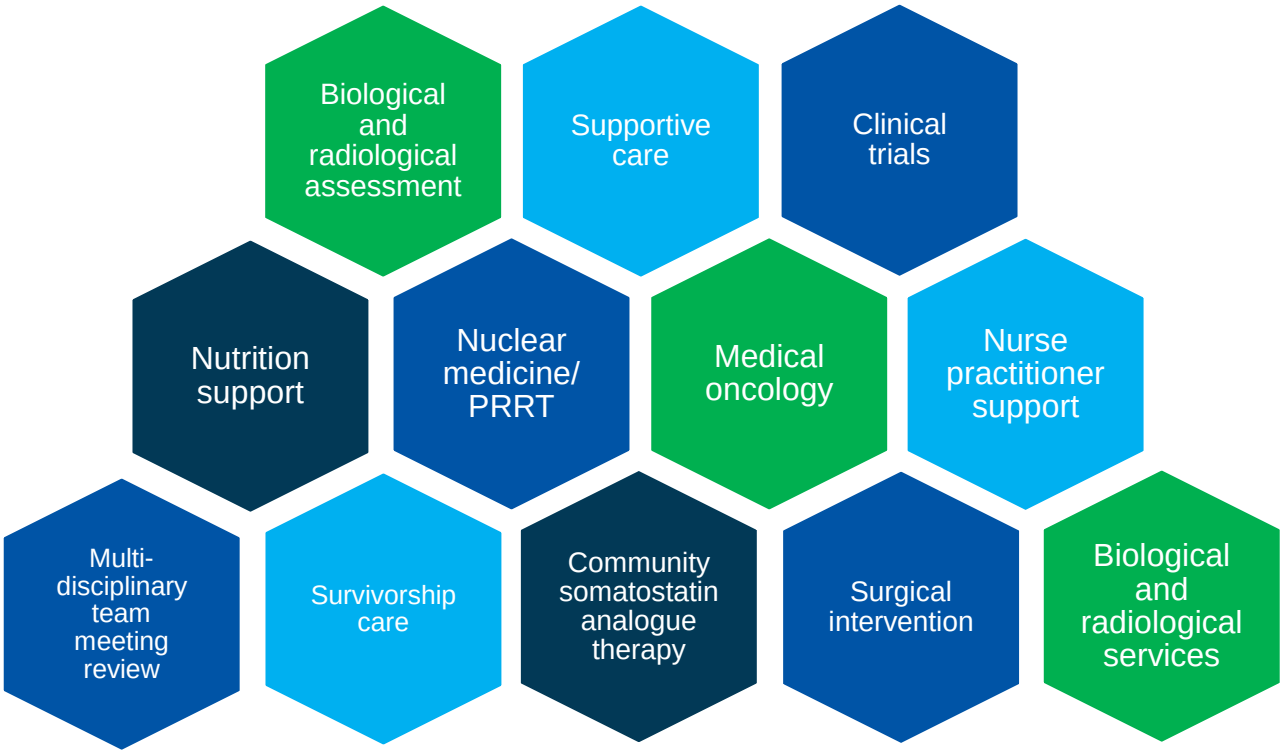
## 3.0 Components of optimal care for NET patients

Patients with a NET diagnosis have complex and varied needs. The components of care depicted in the graphic below form part of optimal care, though not all components are necessary for all patients.

The care required is dependent on the point of diagnosis (pre-surgery or post-surgery), resectability of disease, suitability for PRRT (peptide receptor radionuclide therapy) and tumour stage and grade. Guidance for clinical management and surveillance dependent on these factors is available in Appendix 2.

Patients may require different components at different stages of their journey, and NET patients are unlikely to have a linear transition between health care providers or health services.

The ideal timeframes for the delivery of care (e.g. optimal timeframe to initiate treatment) are detailed in Appendix 3.
This document will detail how each of these components can be delivered for Gippsland patients.



## 4.0 Biological assessment

Coordination of biological assessment remains the responsibility of the managing Gippsland based clinician.

Biological assessment can occur at the private pathology provider of the patient's choice.

Where possible, consistent use of a single provider should be encouraged, to enable an accurate comparison of results between tests.

Results from biological investigations must be included in all PMCC MDM referrals.

## 5.0 Radiological assessment, nuclear medicine and PRRT

Coordination of radiological assessment and referral to a nuclear medicine physician (where appropriate) remains the responsibility of the managing Gippsland clinician.

Radiological assessment has 2 components; functional imaging and anatomical imaging. In most cases, both assessments are required at the time of diagnosis to confirm staging and management plan, for surveillance purposes and when therapeutic interventions are indicated.

Gippsland GEP-NET patients cared for through the shared-care model will have access to the i-MED Network radiological and nuclear medicine services, located at LRH.

i-MED at LRH can currently provide Positron Emission Tomography (PET Scan with FDG, dotatate and PSMA), ultrasonography, Computed Tomography (CT scan), Magnetic Resonance Imaging (MRI Scan) and echocardiogram.

Where possible, consistent use of a single provider should be encouraged, to enable an accurate comparison of results between sequential scans.

Where scans have been performed in Gippsland, results will be attached/referred to in all PMCC MDM referrals.

Where appropriate, Peptide Receptor Radionuclide Therapy (PRRT) is available at PMCC. Suitability for PRRT is determined through the MDM referral system. Further information about when to consider PRRT is available in Appendix 2.

## 6.0 Surgical management

Surgical management may be required as part of the management of GEP-NETs.

All patients will ideally be discussed at the relevant multidisciplinary meeting prior to surgery (if possible). The MDM team will refer the patient to a specialist surgical team with relevant experience (may be based in Gippsland or a metropolitan health service). This applies for resection of the primary tumour and any identified distant metastases.

## 7.0 Medical oncology

In Gippsland, the medical oncologist (in collaboration with local nurse practitioners) coordinates NET patient care. While the patient journey may begin with surgical treatment, medical oncologists will provide ongoing care.

The medical oncologist is responsible for:

- Provision of clinical care and patient surveillance
- Prescription of somatostatin analogues (SSA) therapy (where appropriate)
- Referral to PMCC MDMs
- Referral to multidisciplinary team members, including supportive care clinicians (e.g. nuclear medicine physician, allied health practitioners)
- Referral to Community SSA programs (more info below)

Through mutual agreement, PMCC will provide access to specialist medical oncologist advice (including in person Gippsland clinic attendance on an annual basis).

Care coordination will remain the responsibility of the home health service. Medical oncologists involved in the shared care of patients with PMCC are encouraged to utilise the Parkville Connect interface to view information about care provided at PMCC.

Instructions for sign up to Parkville Connect are available here and in Appendix 4

## 8.0 Nurse practitioner support

The nurse practitioners will work alongside the medical oncologists under a 'shared-care model' one day per month at Latrobe Regional Hospital, with the capacity to increase this in keeping with the patient population needs locally. A medical oncologist will always be available to support the nurse practitioner in person at Gippsland Cancer Care Centre on the day of the NET Clinic.

The medical oncologist and nurse practitioner will see each patient alternatively either face-to-face or via telehealth. The method of review will depend on the patients progress and current health, with a preference for unwell patients being seen face-to-face. The nurse practitioner also has the opportunity to review the NET patients in the dedicated nurse practitioner clinics which run each Friday and every alternative Wednesday.

The nurse practitioner will:

- liaise with the PMCC regarding patient care and follow-up
- request patients be reviewed within the PMCC NET MDMs and follow up care recommendations with the medical oncologist. The outcomes and recommendations of each NET multidisciplinary meeting will be discussed between the nurse practitioner and the medical oncologist on the dedicated NET clinic day
- coordinate SSA therapy in the community
- ensure care occurs in line with current clinical guidelines

NB: The nurse practitioner will not request PET scans (out of scope of practice). This will remain the role of the medical oncologist

## 9.0 Community SSA therapy

Both Ipsen and Novartis (pharmaceutical companies that have SSA products registered for use in Australia) offer community-based support programs for patients prescribed SSA therapy. For Gippsland patients, an LRH based nurse practitioner will lead the assessment of suitability for a program. Administration in the hospital setting should only be used if no community-based option is suitable for the patient.

The Ipsen program is called "Assist Beyond". Ipsen can offer:

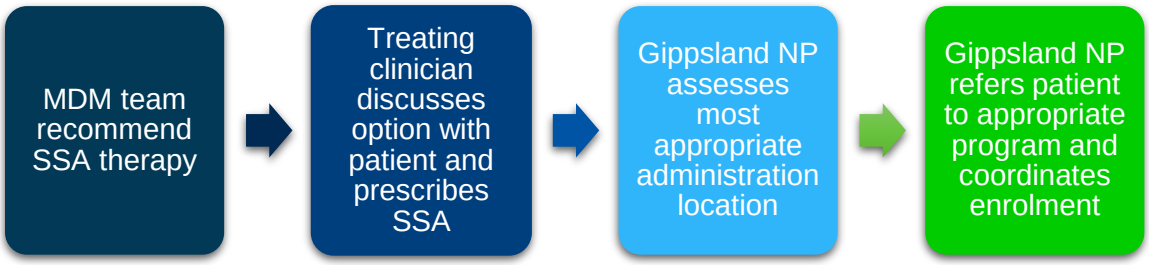
- In home training of patients and carers to facilitate independent medicine administration
- Training for a patient's nominated practitioner in general practice (e.g. GP or clinic nurse) to administer the medicine

- Patient education materials
- Patient SMS reminders for scripts and appointments
- Nurse support via phone

The Novartis program is called “E Shine”. Through this program Novartis offer:

- Training for a patient’s nominated practitioner in general practice (e.g. GP or clinic nurse) to administer the medicine
- Delivering the medicine to the patient at home
- Administration of the medicine by a nurse in the patient’s home
- Patient education

Novartis are not currently offering this service in the Gippsland region (at the time of document publication)




## 10.0 Multidisciplinary care

It is well established that the provision of multidisciplinary cancer care positively impacts patient outcomes. This is especially true of patients with NETs. Every effort should be made to provide patients access to speciality multi-disciplinary teams. In Victoria, the Peter MacCallum Cancer Centre (PMCC) is recognised as the centre of excellence for the management of NETs.

For regionally based patients, accessing specialist care can be more difficult. Reasons for this include:

- Issues related to distance and transport
- Workforce variations
- Socioeconomic status
- Infrastructure differences (Department of Health and Human Services, 2020)

Innovative methods of multidisciplinary care delivery can ensure regionally located patients have access to the same standard of care as their metropolitan counterparts.

This framework aims to facilitate equitable care through co-delivery using a “provider alliance model” between Gippsland and PMCC.

Patients with a new or suspected diagnosis should be referred to the appropriate PMCC multidisciplinary meeting.

## *10.1 Referrals to multidisciplinary meetings*

All NET cancer cases should be discussed at the NET multidisciplinary meeting at PMCC. The MDM team's role is to:

- Confirm diagnosis
- Assist with staging
- Provide follow up and management recommendations (noting that management can be initiated by the Gippsland clinician where clinically appropriate)

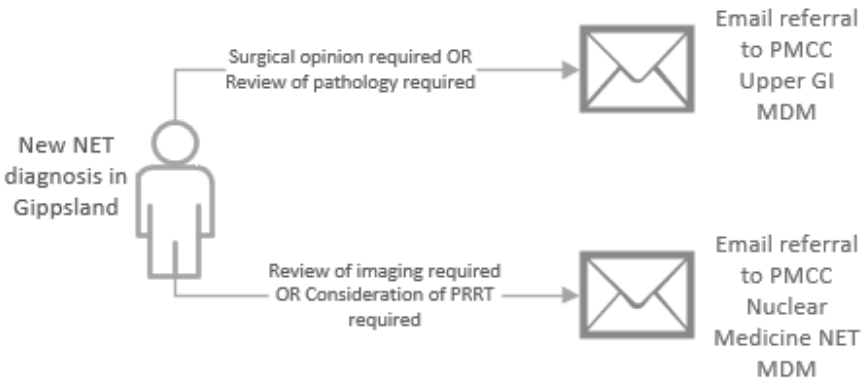
PMCC hosts two relevant meetings:

- PMCC Upper GI MDM (for pathology review or surgical opinion)
    - 12:30pm every Wednesday
    - Referral cut off time: Midday Monday
- PMCC Nuclear Medicine NET MDM (review of imaging or consideration for PRRT, including routine review of surveillance scans)
    - 8am every Monday
    - Referral cut off time: Midday Thursday

Gippsland patients should be referred using the Peter Mac Referral Form. Referring clinicians should ensure that (where clinically appropriate):

- A copy of recent scans is attached or referenced in the referral (including where and when they occurred)
- A copy of histology (for the first referral made or if there has been a recent biopsy)
- A copy of recent haematology, biochemistry, chromogranin A and any other relevant blood results
- A copy of echocardiogram reports
- A copy of recent correspondence
- A clinical question for the MDM team to consider
- An accompanying referral to a PMCC clinician post-MDM
- An accompanying referral to the nutrition team at PMCC (if required)

All referrals must be emailed to referrals@petermac.org or urgentreferrals@petermac.org. A copy of the referral documents should be saved in Genie (Gippsland health service).




## *10.2 Referrals to PMCC clinicians*

All referrals (to MDMs or individual PMCC clinicians) must be emailed to referrals@petermac.org or urgentreferrals@petermac.org

Referrals must not be sent directly to clinicians, though clinicians can be cc'd.

### *10.3 MDM recommendations*

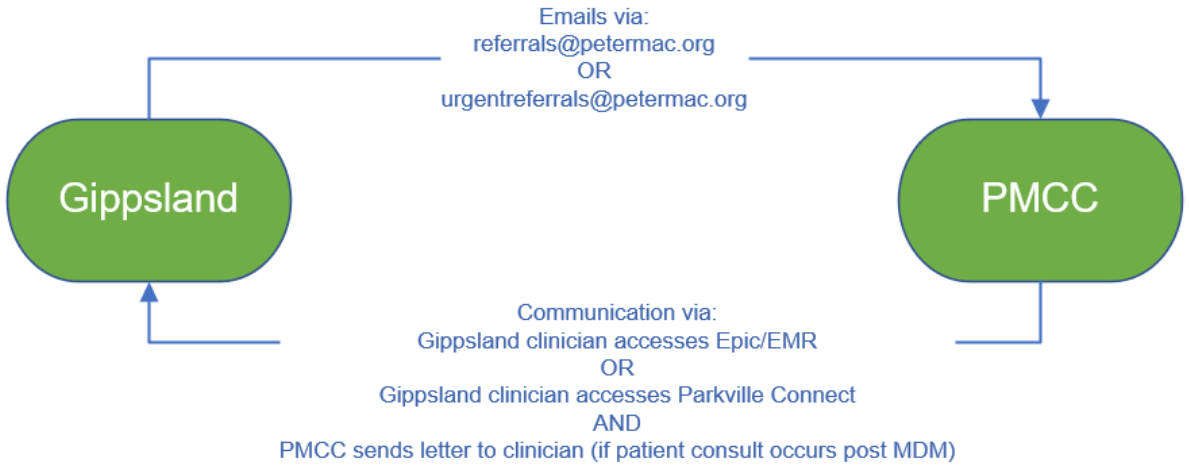
All recommendations from MDMs at PMCC, consultation notes from PMCC, all laboratory or imaging investigations results performed at PMCC will be available in the Epic EMR system to clinicians with access via honorary appointment or Parkville Connect.

Clinicians involved in patient care may additionally, where appropriate, receive correspondence from PMCC clinicians regarding MDM discussions and subsequent consultations. In some instances it may be appropriate to cc nurseconsultantupperGI@petermac.org into correspondence to ensure seamless patient care.

### *10.4 Storage of correspondence*

Gippsland:
All correspondence received via email must be uploaded to Genie by the Senior Administration Officer (Cancer Services) or their delegate.

PMCC:
All correspondence received via email must be uploaded and stored in Epic.




## 11.0 Supportive care and nutrition support

### *11.1 Nutrition support*

Specialist nutrition consultations are available at PMCC for patients being under the shared-care model.

A nutrition consult is appropriate for patients whom:

- Have loss of weight/malnutrition (MST >3)

- Uncontrolled diarrhoea
- Report changing their diet in response to NET symptoms

Referral to a PMCC dietician must be made via the PMCC EMR, Epic. Referrals must be made by a PMCC involved in the patient's care.

Additionally, printed diet related resources are available via Neuroendocrine Cancer Australia:
- Diet information booklet
- Food and symptom diary

### *11.2 Support through Neuroendocrine Cancer Australia (NECA)*

Neuroendocrine Cancer Australia (NECA) is the only not for profit medical charity in Australia supporting patients with neuroendocrine tumours. NECA provides the following services:

**Support:**
- Specialist telehealth NET nurse hotline – 1300 CURE NETS (1300 287 363) Monday – Friday 9.00am-5.00pm, for information about symptom management, referral pathways and general support enquiries
- Moderated private Facebook groups, available to patients and families wanting to connect with other families with NETs
- National face to face patient support groups in each state, as well as a National monthly zoom meeting.
- Peer support via phone, which connects patients with trained Peer Support Volunteers who have experienced NETs through Cancer Connect

Useful link: Patient Support - NeuroEndocrine Cancer Australia

**Information and resources:**
- Patient friendly multi-media resources – videos, booklets, fact sheets, toilet & medical cards to assist in knowledge about NETs and treatments

Useful link: Patient Support - NeuroEndocrine Cancer Australia

**Healthcare education:**
- Accredited through the Royal Australian College of General Practitioners (RACGP) and the Australian College of Nurses (ACN), NECA provides free online learning modules to assist in the improving personalise care of NET patients outside of their specialist centres.
- National delivery of in-services and training to hospitals (nurses, registrars, allied health, specialists) about NETs, treatment delivery and symptom management. Delivered virtually or in-person.

Useful link: Neuroendocrine Tumour Education Course - NeuroEndocrine Cancer Australia

## 12.0 Research and clinical trials

Clinical trials will be considered and recruited to via the PMCC MDMs.

Current clinical trials can be identified by clinicians via the:
- NeuroEndocrine Cancer Australia page
- Cancer Clinical Trials page

## 13.0 Survivorship

Neuroendocrine Cancer Australia in collaboration with the Australian Cancer Survivorship Centre has developed a "Treatment & Wellness Care Plan for people with neuroendocrine tumours" (NeuroEndocrine Cancer Australia, 2021). The document is intended to assist patients and families keep track of all aspects of their care and follow up.

Patients may ask clinicians for assistance to complete or understand this plan. The plan may also be used to communicate care needs to between clinicians, including the patient GP.

## References

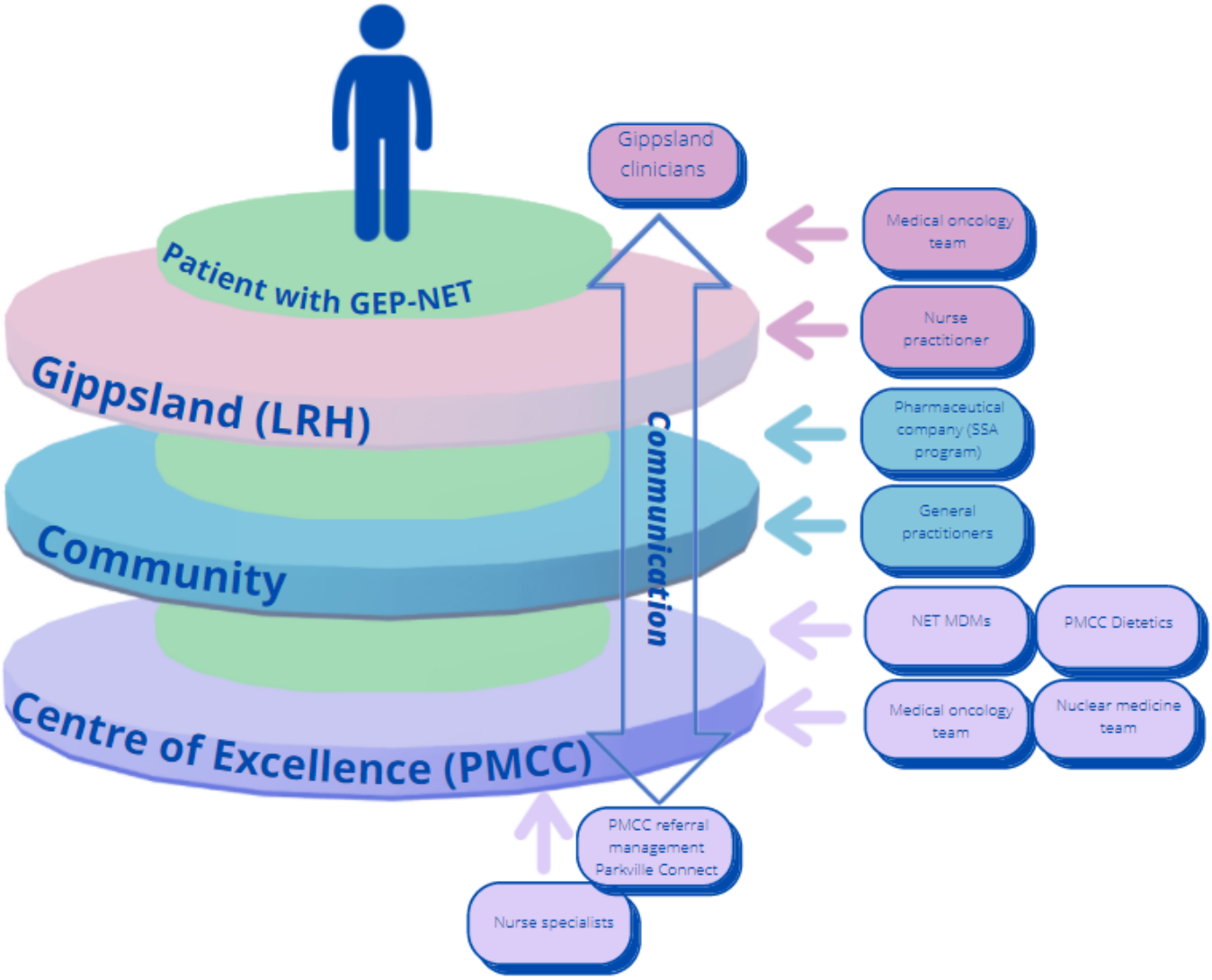

Department of Health and Human Services. (2020). *Victorian Cancer Plan.* Melbourne: State of Victoria.

National Cancer Institute. (2021, July). *GEP-NET*. Retrieved from National Cancer Institute: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/gep-net

NeuroEndocrine Cancer Australia. (2021, August). *Treatment & Wellness Care Plan*. Retrieved from NeuroEndocrine Cancer Australia: https://neuroendocrine.org.au/treatment-wellness-care-plan/

Peter MacCallum Cancer Centre. (2016). *Medical Oncology Unit Standard Treatment Guidelines - Gastrointestinal Cancer.* Melbourne: Peter MacCallum Cancer Centre.

## Appendix 1 – Model of care



# Appendix 2

## Guidance for diagnosis, disease management and surveillance

### Diagnosis:

Patients with GEP-NETs will fit into one of three diagnostic groups:

Group A: Diagnosed after surgery
Group B: Suspected before surgery (on imaging)
Group C: Diagnosed before surgery (on histology)

Initial work up for all diagnostic patient groups should include:

- Clinical assessment
- Biochemical assessment (FBE, U&E, LFT, CMP, chromogranin A, and relevant hormonal screens
- Radiological assessment (CT, MRI, PET/CT – Ga68-DOTATATE +/- FDG, echocardiogram for patients with functional midgut NET)

### Disease management and surveillance:

The below table provide basic information about the assessments and frequency of follow up required to achieve good patient care, noting that exceptions to the below will exist.

Note that:

- Clinical assessment of patients in Gippsland will ideally occur with a medical oncologist and nurse practitioners who has completed the PMCC NET clinical preceptorship.
- All PET scans, including GATATE PET scans can be delivered in Gippsland. Specialist input relating to these scans can be sought via the PMCC MDMs
- Somatostatin analogues (SSA) – refers to medicines which mimic the action of somatostatin, including octreotide and lanreotide

### Overview of appropriate actions by NET stage and grade

| Group | Action | Timing | Location | Duration |
|---|---|---|---|---|
| Resected Stage 1-4 NET Grade 1 | Clinical assessment | Every 3 to 6 months | Gippsland | Surveillance for minimum 5 years |
| | Radiological assessment | Every 6 to 12 months | Gippsland | |
| | MDM review | At Initial diagnosis and then when significant clinical change detected | PMCC | |
| Resected Stage 1-4 NET Grade 2 | Clinical assessment | Every 3 months | Gippsland | Surveillance for minimum 5 years |
| | Radiological assessment | Every 6 months | Gippsland | |
| | MDM review | At Initial diagnosis and then When significant clinical change detected OR once every 3 years (whichever occurs first) | PMCC | |
| Resected Stage 1-4 NEC Grade 3 | Clinical assessment | Every 3 months | Gippsland | Surveillance for |
| | Radiological assessment | Every 3 months (for first 12 months) then every 6 months | Gippsland | |

| Group | Action | Timing | Location | Duration |
|---|---|---|---|---|
| | MDM review | At Initial diagnosis then When significant clinical change detected OR annually (whichever occurs first) | PMCC | minimum 5 years |
| | Adjuvant chemotherapy | When indicated as per MDM | Gippsland | |
| Unresected Stage 1-4 NET Grade 1 | Clinical assessment | Every 3 months | Gippsland | Surveillance for minimum 5 years (likely lifelong) |
| | Radiological assessment | Every 12 months | Gippsland | |
| | MDM review | At Initial diagnosis and then when significant clinical change detected OR once every 3 years (whichever occurs first) | PMCC | |
| | SSA | Consider disease volume and growth rate, and the patient's wishes | Gippsland | |
| | Surgical resection (primary or metastatic disease) | As per MDM recommendation. Palliative debulking may be considered Surgery site/location subject to local expertise and resources. | To be determined based on patient's needs | |
| | PRRT | Refer to MDM for consideration/appropriateness | PMCC | |
| Unresected Stage 1-4 NET Grade 2 | Clinical assessment | Every 3 months | Gippsland | Surveillance for minimum 5 years (likely lifelong) |
| | Radiological assessment | Every 6 to 12 months | Gippsland | |
| | MDM review | At Initial diagnosis then When significant clinical change detected OR once every 2 years (whichever occurs first) | PMCC | |
| | Surgical resection (primary or metastatic disease) | As per MDM recommendation. Palliative debulking may be considered Surgery site/location subject to local expertise and resources. | To be determined based on patient's needs | |
| | SSA or molecular targeted agents (MTAs) or chemotherapy | May be considered based on Ki67 and disease volume | | |
| | PRRT | Refer to MDM for consideration/appropriateness | PMCC | |
| Unresected Stage 1-4 NET Grade 3 | Chemotherapy | Commence as soon as possible. May be started prior to MDM discussion for high grade NEN (e.g. Ki67>55%) or significant symptom burden | Gippsland | Surveillance for minimum 4 years (likely lifelong) |
| | Radiological assessment | Following chemotherapy and every 3 months | Gippsland | |

| Group | Action | Timing | Location | Duration |
|---|---|---|---|---|
| | MDM review | At Initial diagnosis then Post-chemo for consideration of surgical intervention OR at least once every 12 months | PMCC | |
| | Clinical assessment | Every 3 months | Gippsland | |
| | Surgical resection (primary or metastatic disease) | As per MDM recommendation. Palliative debulking may be considered | To be determined based on patient's needs | |
| | PRRT | Refer to MDM for consideration/appropriateness | PMCC | |
| On progression post curative resection/post first line therapy/surveillance | MDM review | At time of progression AND at least once a year thereafter (every 3 months if on chemotherapy or MTA) | PMCC | |
| | SSA/MTAs/ PRRT/chemotherapy | May be required even if not previously required | Gippsland* | |
| | Clinical assessment | Every 3 months | Gippsland | |
| | Radiological assessment | Every 3 to 6 months | Gippsland | |

*SSA therapy will be led by the LRH based nurse practitioner. Where Novartis and Ipsen community programs can be utilised, administration should occur in the community (self-administered, carer administered or GP/nurse administered).

## Appendix 3

Optimal timeframes for care delivery:

| Time in patient journey | Care Point | Timeframe |
|---|---|---|
| Diagnosis | Appointment with medical oncologist in Gippsland | Should take place within 4 weeks of initial referral |
| Diagnosis and treatment planning | Referral to PMCC MDM | All newly diagnosed patients should be discussed in a multidisciplinary meeting before beginning treatment. Referral should happen within a week of the initial appointment with a medical oncologist. Time to discussion at multidisciplinary meeting will be dependent on the availability of relevant results, but should be within 4 weeks of diagnosis |
| Treatment | Treatment | The time from initial referral to treatment should be no more than 4 weeks, except in the case of high-grade disease where a rapid initiation of discussion or treatment is indicated |

## Appendix 4

Parkville Connect

# Sign up instructions

The initial sign-up process involves two steps:

### Step 1

Identify one or more staff to be the site administrator for your practice or health service. This can be a clerical or clinical staff member. A single business (not personal) email address must be used by the person(s) nominated to be the site administrator.

### Step 2

The nominated site administrator must ensure that details for all interested healthcare providers at the practice or health service are up-to-date on the National Health Services Directory (NHSD), including provider and professional registration numbers. Hospitals may be registered on the NHSD.

You will receive a confirmation email from the NHSD when records have been updated. If these details are not up-to-date in the NHSD, your registration with Parkville Connect will be significantly delayed.

Please note: it may take 4-6 weeks for the NHSD to update health service and provider records.

You can check if your practice, health service or healthcare providers are already registered on the NHSD by emailing nhsd@healthdirect.org.au.

Alternatively, visit Health Direct's NHSD page here: https://about.healthdirect.gov.au/contact-the-nhsd.

If your listing is not up to date with the NHSD we may be unable to proceed with your application.

### Additional Information

It is preferable that the site administrator sign up all interested users at the same time. You can add and remove users at any time after the initial sign up process has been completed.

The Parkville Connect administrator will post user IDs and passwords, addressed to individual users, to the site administrator to distribute.

Ensure your health service is accredited and has an Information Technology Terms of Use and Privacy Policy.

A user manual is available once you log into Parkville Connect.

If you have any queries regarding the sign up process or would like to provide feedback, please email support@parkvilleconnect.org.au.