

NEUROENDOCRINE TUMOURS (NETs) FACT SHEET

What are NETs?

NETs are relatively rare neoplasms typically arising from sites in the GI tract and pancreas, and are therefore often termed GEP-NETs (but can also originate from the lungs or liver).^{1,2} Historically, the term NETs encompasses a biologically diverse group of tumours; the umbrella term NEN (neuroendocrine neoplasm) is now preferred, with NETs referring to a subset of well-differentiated NENs with Ki-67 usually <55% and NEC (neuroendocrine carcinoma) being reserved for poorly differentiation tumours of Grade 3 and typically Ki-67 >55%.²

NETs are rare, with an excess of 200 patients **diagnosed with NETs in Ireland each year**.³ Because patients with NETs are infrequently encountered by healthcare professionals, and may also present with non-specific symptoms resulting from bowel obstruction (e.g., diarrhoea, fatigue, changes in bowel habit) and carcinoid syndrome (flushing and wheezing), **misdiagnosis is common** and patients can face long diagnostic delays.^{2,4,5}

Many patients with NETs are diagnosed at a late stage with consequent poor outcomes; earlier diagnosis is key to improving outcomes.⁴ Among GEP-NETs, symptom presentation varies by tumour location, but some common warning signs can be present.⁶

Consider NETs if you see:^{2,6}



Persistent symptoms, e.g., diarrhoea or abdominal pain



Features suggesting **bowel obstruction**



A patient aged >50 years at symptom onset



Weight loss >4.5 kg



Wheezing



Facial flushing

What to do if you suspect NETs in your patient²

Take a thorough history, including symptom duration, pattern and any family history of endocrine tumours.



Refer promptly to a specialist NET centre or one of the satellite centres in Ireland for further tests. If a NET is strongly suspected based on symptoms or identified on radiological investigations—**do not wait for diagnostic certainty.**

Diagnosis

May involve investigations such as:²

- Endoscopy
- Endoscopic ultrasound
- Biomarker testing (chromogranin A, 5-hydroxyindoleacetic acid, N-terminal pro-B-type natriuretic peptide)
- Imaging (computerised tomography, magnetic resonance imaging, functional imaging)
- Biopsy

Classification

Characterisation of a NET involves establishing a tumour's grade, stage, primary site and secretory status and often requires further specialist investigations.²

The Ipsen Hub has more content which can support you and your patients with NETs, including podcasts and patient support materials.

The 2020 Survey of Challenges in Access to Diagnostics and Treatment (SCAN) survey of patients with NETs in Ireland (N=119) revealed challenges in the diagnostic journey:^{1,4}

~5 years

Mean time to correct NET diagnosis

9%

of patients received their diagnosis in a **medical centre specialised in NETs**

50%

of patients received their diagnosis at a hospital **without a NET specialist**

~1/3

of patients with NETs were **initially misdiagnosed**

41%

of patients had **Stage IV NETs** at diagnosis

This non-promotional material has been commissioned by Ipsen and is intended for Irish healthcare professionals only.

¹A survey was conducted in Ireland from September–November 2019, comprising 119 patients with a NET or their carers.⁴

GEP-NET=gastroenteropancreatic neuroendocrine tumour; GI=gastrointestinal; NEC=neuroendocrine carcinoma; NEN=neuroendocrine neoplasm; NETs=neuroendocrine tumours; SCAN=Survey of Challenges in Access to Diagnostics and Treatment.

¹. Dasari A, et al. JAMA Oncol. 2017;3(10):1335–1342; ². Khan MS, Pritchard DM. Frontline Gastroenterol. 2022;13(1):50–56; ³. Irish Health Pro. Neuroendocrine tumours: The unusual suspect. Available from: <https://www.irishhealthpro.com/content/articles/show/name/neuroendocrine-tumours-the-unusual-suspect> [Last accessed: July 2026]; ⁴. Bouvier CV, et al. Endocr Abst. 2020;72:P1; ⁵. Eads JR, et al. Pancreas. 2020;49(9):1123–1130; ⁶. Basuroy R, et al. BMC Cancer. 2018;18(1):1122.

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