

## **Neuroendocrine Tumours (NETs)** <sup>[1]</sup>

Neuroendocrine tumours (NETs) are rare, slow growing types of cancer that develop from neuroendocrine cells which are located throughout the body. NETs can arise in many different areas of the body, including the digestive system (stomach and intestines), pancreas and lungs. The digestive system is the most common primary site of occurrence.<sup>1</sup>

As they are slow growing and often induce minor symptoms, many people can be unaware that they have them. For these reasons NETs may take several years to diagnose. It is not unusual for NETs to be found incidentally during tests or treatments for other conditions, such as irritable bowel syndrome, peptic ulcer disease, gastritis, gallstones or Crohn's disease.<sup>2</sup>

Some NETs are called 'functioning tumours' because they produce extra hormones which are released into the bloodstream and can cause symptoms such as flushing and diarrhoea. NETs that do not produce extra hormones are called 'non-functioning tumours' and are not associated with these types of symptoms.<sup>3,4</sup>

In 2015 the incident rate for NETs in England was recorded at 9 per 100,000 persons<sup>5</sup> and over 4000 new NETs patients are being diagnosed each year.<sup>6</sup> The incidence and prevalence is steadily rising both in the US and UK and this is owed due to earlier diagnosis and increasing awareness.<sup>7</sup>

At Novartis we are committed to improving the lives of patients with NETs. We have a strong heritage in research and innovation in NETs and work closely with patient advocacy groups and healthcare professionals to ensure quality of care and equality for all. Some of our work includes:

- Supporting the creation and development of NETs services in the UK. We have a dedicated team committed to developing innovative tools and solutions to improve patient care and help the NHS to meet The NHS Long Term Plan.
  - Working in collaboration with doctors, nurses and NHS managers to drive improvements in care through innovative, tailor-made solutions such as a homecare programme that allows patients to receive their medicines at home.
  - Partnering with the NHS to facilitate a number of solutions to improve ways of working and ultimately patient outcomes
  - Working in collaboration with the NHS on Joint Working projects\* (JWPs) to improve outcomes for patients with NETs:
    - NHS Lothian NET Service Development
    - University Hospital Coventry & Warwickshire NET Service development
    - University of Hospitals Leicester NET Service development
    - The Christie NHS Foundation Trust NETs service development
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## References

1. Vinik AI, Woltering EA, Warner RR, et al. NANETS consensus guidelines for the diagnosis of neuroendocrine tumour. *Pancreas* 2010;39:713-34
2. Net Patient Foundation, Your guide to Neuroendocrine, 2014, p3
3. Modlin Im, et al. *Lancet Oncol.* 2008 ;9(1) :61-72
4. Oberg KE. *Ann Oncol* 2010 ;21(Suppl 7) : vii72-vii80
5. [www.netpatientfoundation.org/wp-content/uploads/Incidence-and-Prevalence-of-Neuroendocrine-Tumours.pdf](http://www.netpatientfoundation.org/wp-content/uploads/Incidence-and-Prevalence-of-Neuroendocrine-Tumours.pdf) [2] (Accessed August 2019)
6. Incidence and survival in neuroendocrine tumours and neuroendocrine carcinomas (NETs/NECs) in England, 2013-2014 [ebook] Public Health England. Available at: <http://Incidence> [3] and survival in neuroendocrine tumours and neuroendocrine carcinomas (NETs/NECs) in England, 2013-2014 [Accessed 24 Jun. 2017]
7. Dasari, A., Shen, C., Halperin, D., Zhao, B., Zhou, S., Xu, Y., Shih, T. and Yao, J. (2017). Trends in the Incidence, Prevalence, and Survival Outcomes in Patients With Neuroendocrine Tumours in the United States

\*When a pharmaceutical company works in partnership with the NHS, this is normally known as 'joint working', where both the company and the NHS contribute financially, provide skills, knowledge and other resources.

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**Source URL:** <https://www.novartis.co.uk/neuroendocrine-tumours-nets>

## Links

[1] <https://www.novartis.co.uk/neuroendocrine-tumours-nets>

[2] <http://www.netpatientfoundation.org/wp-content/uploads/Incidence-and-Prevalence-of-Neuroendocrine-Tumours.pdf>

[3] <http://Incidence>