

COSA Neuroendocrine Neoplasms (NENs) Guidelines

CHAPTER 1: BACKGROUND

More than a hundred years have passed since the original description of “karzinoide” by Siegfried Oberndorfer [1,2]. Whilst they were initially thought to be indolent, all of us who have cared for (or been afflicted by) this disease knows that the true story is much more complex. Neuroendocrine neoplasms (NENs) are uniquely disabling. Some patients have fast-growing disease with relatively few treatment options, whilst others have radiologically stable disease but massive disruption to their quality of life and social functioning due to symptoms arising from hormonal oversecretion. With the increasing availability of different modalities, an increasing number of disciplines is required to collaborate to optimally treat patients diagnosed with NENs. Pathology, medical oncology, radiotherapy, nuclear medicine, theranostics, interventional radiology, surgery, nursing, allied health, supportive care. In view of such a long list, a multidisciplinary approach is needed now more than ever.

We acknowledge the initial COSA NET guidelines and the team who published this in 2010. Much of the structure and content still remains relevant today, and indeed the initial guidelines played a pivotal role in shaping the layout of the ones you see here today. However, we sought to update these guidelines for two main reasons. First, we recognised the significant advances made in NEN treatment over the past decade – not only in an increasing understanding of their molecular basis [3,4] but also in the explosion of trials showing the efficacy of various systemic therapies (everolimus, sunitinib, PRRT) over that time [5–8]. Second, we wanted to recognise the increasing evidence base regarding areas such as MEN-1 and supportive care, by expanding the scope of the guidelines.

These guidelines are not intended to be definitive or to replace the excellent work done by other societies such as ENETs, ESMO, NANETS or CommNETs [9–12]. Rather, it is intended to provide a guide to fellow oncologists and patients regarding the Australian context and local evidence-informed practice. We intend this to be a “living document” that can be easily updated to accommodate any new advances that will surely come in the next 10 years.

We hope that you enjoy reading and interacting with this as much as we have enjoyed working together to make this project happen.

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On behalf of the COSA NENs guidelines writing group

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