

## National Institute for Health and Care Excellence

### IP1314 - Selective internal radiation therapy for neuroendocrine tumours that have metastasised to the liver

IPAC date: 14 March 2024

Com. no.	Consultee name and organisation	Sec. no.	Comments	Response
1.	NHS Clinician		Excellent recommendations. I completely agree with them. Thank you for listening to our evidence.	Thank you for your comment.
2.	Terumo Europe (Company)		Terumo Europe thanks NICE and the Interventional Procedures Appraisal Committee for the draft guidance and recommendations. We have no comment to make.	Thank you for your comment.
3.	Neuroendocrine Cancer UK	Draft recommendations 1.1	As a patient co-founded and focused organisation, we, at Neuroendocrine Cancer UK, sincerely welcome these draft recommendations - with the hope for a positive outcome i.e. approval.	Thank you for your comment.
4.	Neuroendocrine Cancer UK	Draft recommendations 1.2	Strongly agree with this recommendation: experience and expertise in managing neuroendocrine tumours is essential for safe and effective delivery and follow up of SIRT in this cohort of patients. It is also essential to ensure truly informed consent and patient education pre/peri and post treatment.	Thank you for your comments.
5.	Neuroendocrine Cancer UK	Draft recommendations 1.3	Strongly agree with this recommendation: SIRT requires an expert NET MDT, nuclear medicine department expert at therapeutics, medical physicist, radiologist, nuclear physicians, and interventional radiologists.	Thank you for your comment.
6.	Neuroendocrine Cancer UK	Draft recommendations 1.4	Strongly agree: with NET expertise informing dataset and to include the capture of patient experience/reported outcomes, alongside quality of life monitoring.	Thank you for your comment.

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7.	Neuroendocrine Cancer UK	The condition 2.1	A subset of those with Carcinoid Syndrome, particularly where hormonal control maybe difficult to achieve, will go on to develop Carcinoid Heart Disease and/or mesenteric fibrosis, which can adversely affect prognosis, quality of life - which in turn can limit potential treatment options.	Please respond to all comments  Thank you for your comment. The following text was added to section 2.1: " <u>Some people with uncontrolled carcinoid syndrome may develop carcinoid heart disease and mesenteric fibrosis. This can reduce quality of life and prognosis, and limit what treatments can be offered.</u> "
8.	Neuroendocrine Cancer UK	The evidence 3.5	Comments related to treatment tolerance within patient response to this consultation - align with findings related to treatment tolerability from published study by Li et al (2022)Patient-Defined Goals and Preferences Among Adults With Advanced Neuroendocrine Tumors. J Natl Compr Canc Netw. 2022 Dec;20(12):1330-1337.e3. (The study was limited to 60 patients but one of the first of it's kind on this very important topic), findings related to QoL (within published data) and anecdotal patient reports to Neuroendocrine Cancer UK.	Thank you for your comment.  The study does not include people who had SIRT so will not be included in the evidence for the overview.
9.	Neuroendocrine Cancer UK	Committee comments 3.8	Compared with currently approved cohorts : those with NETs are often non-cirrhotic and may have lower incidence of hyperbilirubinaemia and/or chemo-related steatosis.	Thank you for your comment.
10.	Neuroendocrine Cancer UK	Unmet need	White et al (2022) Incidence and survival of neuroendocrine neoplasia in England 1995–2018: A retrospective, population-based study. The Lancet: regional Health-Europe. <a href="https://doi.org/10.1016/j.lanepe.2022.100510">https://doi.org/10.1016/j.lanepe.2022.100510</a>	Thank you for your comment.
11.	Neuroendocrine Cancer UK		Patient's views on the procedure are consistent with anecdotal reports to Neuroendocrine Cancer UK via helpline, support groups and shared experiences: in terms of tolerability and symptom control. Equitable access (compared with currently approved	Thank you for your comments.  The consultee acknowledges significant unmet need in this group

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			cohorts) is a significant unmet need. Concur with expert submissions regarding replacement / addition to standard of care and identified cohorts (particularly as stated by Drs Stedman, Manoharan and Seager) - and envisage up to 200 patients/year could benefit from this modality of treatment - particularly those with syndromic symptoms.	Please respond to all comments of people. The committee recommendations will increase access for this group.
12.	NHS clinician		No comments but I agree with the recommendations	Thank you for your comment.
13.	BSCI		No comments but I agree with the recommendations	Thank you for your comment.
14.	Sirtex Medical (Company)		No comments but I agree with the recommendations	Thank you for your comment.

*"Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees."*