



**CONCLUSION:** Because details vary from center to center, a possible future HNF project is to develop an online profile of centers listing key measures, such as are outlined in this survey, that are voluntarily provided by centers as a resource for patients seeking advanced care and as a resource for centers striving to improve care.

**Table 1: Highlights of the HNF Advanced NET Center Survey Results**

CATEGORY	RESULTS	RESULTS (cont.)	RESULTS (cont.)
New Patient Numbers per year GEP-NETs & Non-GEP-NETs	17 of 19: > 80 New GEP-NETs per year (threshold to be considered for CoE)	9 of 19: > 50 Non-GEP-NETs per year 6 of 19: 20-50 Non-GEP-NETs per year 3 of 19: <20 Non-GEP NETs per year	
Specializations with NET Experience/Expertise & Dedicated Professionals	19 of 19: specialized surgery (pancreas, liver, GI), pathology, radiology, nuclear medicine, interventional radiology 18 of 19: thoracic surgery, gastroenterology 17 of 19: medical/pediatric oncology, nutritional support 16 of 19: medical genetics 14 of 19: pulmonology, endocrinology, cardiology	Is there a dedicated oncology nurse or nurse coordinator for GEP-NETs? 14 of 19: Yes* 3 of 19: No 1 of 19: Actively recruiting 1 of 19: Maybe *One center additionally has nurse for Pheo/Para and for GI Oncology	19 of 19: Have a physician or physicians recognized as neuroendocrine specialists committed to providing care for NET patients
Tools & Treatments Available	19 of 19: NETSPOT (Ga-68 dotatate PET), CT, MRI, liver-directed therapies, advanced endoscopy 18 of 19: Octreoscan, Lutathera®/PRRT/ interventional radiology	Additional technologies reported by individual centers: Radio-guided surgery, SBRT, MIBG, I131-MIBG, molecular profiling (DNA sequencing)	

Table 1 (continued)

<p>Tumor Board Characteristics</p>	<p>6 of 19: 90-100% of new NET patients are discussed initially in tumor board 13 of 19: &lt;90% of new NET patients are discussed initially in tumor board</p>	<p>Specialties regularly represented at Tumor Board: 19 of 19: Radiology, Surgery 17 of 19: Pathology, Medical/ Pediatric Oncology 16 of 19: Nuclear Medicine 11 of 19: Gastroenterology 9 of 19: Medical Genetics 7 of 19: Endocrinology 6 of 19: Dietitian/ Nutritionist</p>	<p>Individual centers additionally report: Interventional Radiology (4) Radiation Oncology (2) Nephrology Pharmacy Nurse Navigator Hepatobiliary Surgery Bringing in specialists for specific cases</p>
<p>Multidisciplinary Care</p>	<p>Do administrative policies support the integration of care across disciplines? 12 of 19: Yes 5 of 19: No 1 of 19: Don't know 1 of 19: ""Yes in theory""</p>	<p>How do the multi-discipline specialists interact? Summary of respondent descriptions: 12: Tumor board 9: Personal communication (email, phone, text, in person) 7: Same day and/or same campus or clinic 3: Navigators/navigation Also mentioned: Agreed upon general principles of care; shared medical record and one quarterback; integration at the Cancer Institute level (development of pathways, quality)</p>	<p>How quickly is the treatment algorithm built? Summary of respondent descriptions: 5: Within a week or at weekly meeting (several mentioned weekly meeting to confirm algorithm) 4: Same day or very quick</p>
<p>Administrative Policy &amp; Practices</p>	<p>Does each discipline have standard operating procedures codified in the policies of the medical center? 5 of 19: Yes 12 of 19: No 2 of 19: Don't know</p>	<p>Mechanisms in place for measuring patient satisfaction? 16 of 19: Yes 3 of 19: No</p>	<p>If ""yes"" on measuring patient satisfaction, are there high ratings on communication? 13: Yes 2: ""Communication"" not separated out 2: Don't know</p>

Table 1 (continued)

<p>Connections Beyond the Center</p>	<p>Clinical Trial Participation          6 of 19: 10-50% of new patients participate          13 of 19: &lt;10% of new patients participate</p>	<p>Is there a commitment to educating patients &amp; physicians outside the NET center setting?          17 of 19: Yes          2 of 19: No</p>	<p>How do you find connecting with NET colleagues (scholarly and clinical level)?          8 of 19: Very easy          9 of 19: Easy          2 of 19: Neither easy nor difficult</p>
<p>Hurdles to Adding Elements to Existing Care Program</p>	<p>Summary of hurdles respondents described at their centers:          6: Funding/budget limitations          4: Gaps in staffing (specialists in specific disciplines, support staff)          3: Institutional bureaucracy          3: Issues with insurance</p>		