

# O-1

## Distinct Sociodemographic, Symptom, and HRQoL Profiles in Early-Onset Neuroendocrine Tumors: Insights from the NET-PRO Study

Udhayvir Singh Grewal, MD<sup>3,4</sup>; Tao Xu, PhD<sup>1,4</sup>; Rhonda R. DeCook, PhD<sup>1</sup>; Bradley D. McDowell, PhD<sup>1,2,4</sup>; Brian M. Gryzlak, MSW, MA<sup>1</sup>; Nicholas J. Rudzianski, BS<sup>1</sup>; Kimberly C. Serrano, BA<sup>1</sup>; Abigail M. Wehrheim, BS<sup>1</sup>; Chandrikha Chandrasekharan, MBBS<sup>3,5</sup>; Joseph S. Dillon, MB BCh<sup>3,4</sup>; Thorvardur R. Halfdanarson, MD<sup>6</sup>; T. Clark Gambelin, MD<sup>7</sup>; Lindsay G. Cowell, PhD<sup>8</sup>; Tobias Else, MD<sup>9</sup>; Heloisa P. Soares, MD, PhD<sup>10</sup>; Vineeth Sukrithan, MD<sup>11</sup>; Sravani Chandaka, PhD<sup>12</sup>; Hanna K. Sanoff, MD<sup>13</sup>; Fiona C. He, MD<sup>14</sup>; David Geller, MD<sup>15</sup>; Robert A. Ramirez, DO<sup>16</sup>; Mei Liu, PhD<sup>17</sup>; William Lancaster, MD<sup>18</sup>; Josh A. Mailman, MBA<sup>19</sup>; Heather Moran, MEd<sup>20</sup>; Maryann Wahmann<sup>21</sup>; Elyse Gellerman, MHS<sup>22</sup>; Elizabeth A. Chrischilles<sup>14</sup>; Michael O'Rourke, PhD<sup>14</sup>; NET-PRO Study Investigators.

<sup>1</sup>College of Public Health, Department of Epidemiology, University of Iowa, Iowa City, Iowa, USA; <sup>2</sup>Population Research Core, Holden Comprehensive Cancer Center, University of Iowa, Iowa City, Iowa, USA; <sup>3</sup>Department of Internal Medicine, Carver College of Medicine, University of Iowa, Iowa City, Iowa, USA; <sup>4</sup>Holden Comprehensive Cancer Center, University of Iowa, Iowa City, Iowa, USA; <sup>5</sup>Department of Gastrointestinal Medical Oncology, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA; <sup>6</sup>Mayo Clinic, Rochester, Minnesota, USA; <sup>7</sup>Medical College of Wisconsin, Milwaukee, Wisconsin, USA; <sup>8</sup>O'Donnell School of Public Health, UT Southwestern Medical Center, Dallas, Texas, USA; <sup>9</sup>Department of Internal Medicine, Division of Metabolism, Endocrinology and Diabetes, University of Michigan, Ann Arbor, Michigan, USA; <sup>10</sup>Huntsman Cancer Institute, University of Utah, Salt Lake City, Utah, USA; <sup>11</sup>Division of Medical Oncology, Department of Medicine, The Ohio State University Comprehensive Cancer Center, Columbus, Ohio, USA; <sup>12</sup>University of Kansas Medical Center, Kansas City, Kansas, USA; <sup>13</sup>Division of Oncology, Department of Medicine, University of North Carolina at Chapel Hill, Chapel Hill, North Carolina, USA; <sup>14</sup>Allina Health Cancer Institute, Minneapolis, Minnesota, USA; <sup>15</sup>University of Pittsburgh, Pittsburgh, Pennsylvania, USA; <sup>16</sup>Department of Internal Medicine, Division of Hematology/Oncology, Vanderbilt University Medical Center, Nashville, Tennessee, USA; <sup>17</sup>Department of Health Outcomes and Biomedical Informatics, College of Medicine, University of Florida, Gainesville, Florida, USA; <sup>18</sup>Department of Surgery, Medical University of South Carolina, Charleston, South Carolina, USA; <sup>19</sup>NorCal CarciNET Community, Oakland, California, USA; <sup>20</sup>The Healing NET Foundation, Los Angeles, California, USA; <sup>21</sup>Neuroendocrine Cancer Awareness Network, Fort Mill, South Carolina, USA; <sup>22</sup>Neuroendocrine Tumor Research Foundation, Boston, Massachusetts, USA.

### BACKGROUND

The incidence of neuroendocrine tumors (NETs) has increased over the past four decades, particularly among young individuals (age <50 years). Data from other malignancies have demonstrated that earlier onset may be associated with distinct disease biology and unique care needs; however similar data among patients with early-onset NETs (EO-NETs) are lacking. We sought to investigate differences in sociodemographic and clinicopathological profiles, HRQoL and symptoms among patients with EO-NETs compared to average-onset NETs (AO-NETs) using a large multi-institutional cohort.

### METHODS

The Neuroendocrine Tumors–Patient Reported Outcomes (NET-PRO) study is a prospective, multi-institutional U.S. cohort funded by the Patient-Centered Outcomes Research Institute (PCORI). Adults aged ≥18 years with incident gastroenteropancreatic or lung NETs diagnosed from January

2018 through September 2024 were enrolled. Age at diagnosis was categorized (i) as a continuous variable and (ii) dichotomously using a single cut-point: EO (< 50 years) versus AO (≥ 50 years). Effect sizes were quantified with standardized mean differences (SMDs), and between-group significance was tested. Spearman correlations described how each score of HRQoL or symptoms changed with increasing age.

## **RESULTS**

Among 2340 participants, 617 (26.4%) were EO-NETs and 1721 (73.5%) were AO-NETs (mean age 31.5 years and 61.2 years, respectively). Patients in the EO-NETs cohort were more likely to be female (69% vs 53.5%,  $p < 0.001$ ), Hispanic (6.5% vs 1.6%,  $p < 0.001$ ), Non-Hispanic Blacks (4.4% vs 3.8%,  $p < 0.001$ ) and have localized disease at diagnosis (40.6% vs 38.3%,  $p = 0.01$ ). Younger patients also showed significantly lower mean cognitive functioning (74.4 vs 81.1; SMD = 0.29;  $p < 0.001$ ), emotional functioning (68.0 vs 78.8; SMD = 0.47;  $p < 0.001$ ), physical functioning (86.5 vs 82.4; SMD = 0.20;  $P < 0.001$ ) and social functioning (75.2 vs 79.5; SMD = 0.15;  $p < 0.001$ ) compared to their AO counterparts. Notably, patients in the EO-NETs cohort also experienced significantly higher mean financial burden (30.1 vs 15.8; SMD = 0.48;  $p < 0.001$ ). Younger patients had greater symptom burden across domains, including pain, nausea/ vomiting, insomnia, appetite loss and diarrhea ( $p < 0.05$ ). Spearman correlations were consistent with these findings.

## **CONCLUSIONS**

To our knowledge, this is the first and largest analysis analyzing characteristics, symptom burden and HRQoL among EO-NETs. We found that younger patients with NETs have a unique clinicopathological profile and have notably worse symptom burden and HRQoL across various domains. Recognizing these differences underscores the importance of age-tailored supportive care and ongoing assessment in EO-NETs patient population.

## **ABSTRACT ID 33490**