In addition, it provides valuable information on Ki67 grading (WHO grading) for predicting patients’ prognosis to date, and highlights the crucial role of WHO grading (Ki67) for predicting patients’ prognosis. Multivariable analyses show that grade and stage (I: Not reached, II: 225m, III: 160m, IV: 75m) were analyzed, including age, gender, primary organ, grade and stage. Overall survival (OS) was influenced by therapies to 8% and PRRT to 9%. Median OS of all chemotherapy to 20%, molecular targeted therapies to 8%, and external beam radiotherapy to 9%.

The authors thank the national societies, all physicians and patients that contributed to the collection of data.

Conclusions:

• These data represent the largest multinational dataset of NEN patients to date.
• They highlight the crucial role of WHO grading (Ki67) for predicting patients’ prognosis.
• In addition, it provides valuable information on patients’ demographics, tumor characteristics and applied therapies.
• Age, Gender, Primary Organ, Grade and Stage are independent predictors of OS.

### ENETS Registry

Epidemiologic data on Neuroendocrine Neoplasms

1. **Patients**

   - **Age distribution**
     - Median: 62.0
     - Age: Mean (SD) 58.1 (14.2)
   - **Gender**
     - Male (%): 52.0 (31.1)
     - Female (%): 48.0 (41.9)
   - **Event**
     - Death (%): 23.0 (21.6)
     - No Event (%): 77.0 (78.4)
   - **Country**
     - Belgium (%): 77.0 (7.7)
     - Czech Republic (%): 17.0 (16.3)
     - Germany (%): 24.5 (21.0)
     - Greece (%): 20.1 (2.0)
     - Italy (%): 48.0 (6.4)
     - Spain (%): 33.5 (11.5)
     - Switzerland (%): 11.1 (11.1)

2. **Metastases**

   - **Overall survival by stage**
     - **Grade 1**
       - OS 80% (95% CI: 70%, 90%)
       - 5-year OS 70% (95% CI: 60%, 80%)
     - **Grade 2**
       - OS 70% (95% CI: 60%, 80%)
       - 5-year OS 60% (95% CI: 50%, 70%)
     - **Grade 3**
       - OS 50% (95% CI: 40%, 60%)
       - 5-year OS 40% (95% CI: 30%, 50%)

3. **Therapy by stage**

   - **Therapy**
     - Surgery: 71.0%
     - Surgery only: 41.0%
     - Chemotherapy: 42.0%
     - External Beam Radiotherapy: 29.0%
     - PRRT: 5.0%
     - Other: 5.0%

4. **Therapy by grade**

   - **Grade 1**
     - Surgery: 71.0%
     - Surgery only: 41.0%
     - Chemotherapy: 42.0%
     - External Beam Radiotherapy: 29.0%
     - PRRT: 5.0%
     - Other: 5.0%
   - **Grade 2**
     - Surgery: 65.0%
     - Surgery only: 45.0%
     - Chemotherapy: 60.0%
     - External Beam Radiotherapy: 30.0%
     - PRRT: 5.0%
     - Other: 5.0%
   - **Grade 3**
     - Surgery: 55.0%
     - Surgery only: 35.0%
     - Chemotherapy: 75.0%
     - External Beam Radiotherapy: 50.0%
     - PRRT: 5.0%
     - Other: 5.0%

5. **Primary Organ**

   - **Liver**
     - 16%, II in 11% and I in 27%
   - **Lungs**
     - 16%, II in 11% and I in 27%
   - **Intestinal**
     - 26.9% of pts., 80% being carcinoid syndrome.
   - **Brain**
     - 15.6% of pts., 80% being carcinoid syndrome.