Survey of Challenges in Access to Diagnostics and Treatment for NET Patients (SCAN)

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INTRODUCTION
• Neuroendocrine tumors (NETs) are rare and complex neoplasms⁴
• However, NETs incidence and prevalence is increasing worldwide making it one of the fastest growing classes of cancer⁴
• The incidence of NETs may be increasing due to earlier and improved diagnosis¹²
• Limited understanding of the disease and financial constraints mean the current management and availability of treatments for NET patients vary considerably within and across healthcare systems, with many patients experiencing suboptimal care³
• A recent international survey of unmet needs carried out among NET patients and healthcare professionals identified significant disparities in what patients consider available to them in terms of later diagnostic tools and treatments, compared to what their healthcare systems actually offer (Table 1)⁴

METHODS
• The survey starts in September 2019 and is to be conducted via two self-administered online questionnaires, one for NET patients and the other for healthcare professionals (https://incaalliance.org/scan/)
• All medical professionals involved in multidisciplinary care will be addressed, including:
  - Oncologists
  - Endocrinologists
  - Surgeons
  - Gastroenterologists
  - Pathologists
  - Radiologists
  - Psychiatrists
  - Nurses
  - General practitioners
• Both questionnaires will be available in 14 languages:
  - Arabic, Bulgarian, English, German, Dutch/Flemish, French, Japanese, Hindi, Italian, Mandarin (Chinese), Portuguese, Russian, Spanish, Swahili
• The questionnaires will take less than 15 minutes to complete
• To draw statistically reliable conclusions, the survey would use quotas based on:
  - Patient registries, wherever available
  - National registries of the medical professionals by expertise
  - NET medical societies’ registries by region

RESULTS [cont.]
• SCAN results will allow for comparison:
  - with previously gathered data to evaluate changes in NET diagnosis and treatment over time
  - between the perspectives of both NET patients and healthcare professionals
  - by country to deduce any variation in NET diagnostics and treatments based on location
• Full results will be available in the beginning of 2020

CONCLUSION
• The survey would be the first to incorporate the perspectives of all key stakeholders who could be in a position to communicate and provide services to NET patients
• This survey will contribute to positioning NET research on an equal footing with other cancers of similar prevalence
• The results will help ensure better management for NET patients through earlier diagnosis, improving current treatments, and establishing new treatments

REFERENCES

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