

# 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 neoplasms<sup>1</sup>
- However, NETs incidence and prevalence is increasing worldwide making it one of the fastest growing classes of cancer<sup>1</sup>
- The incidence of NETs may be increasing due to earlier and improved diagnosis<sup>1,2</sup>
- 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 care<sup>3</sup>
- 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 the latest diagnostic tools and treatments, compared to what their healthcare systems actually offer (Table 1)<sup>4</sup>

**Table 1: Most common diagnostics and treatments not available<sup>4</sup>**

Diagnostics			
	Patient/family (N=98)	Advocate (N=20)	HCP (N=44)
Gallium-68-Dotatate PET/CT scan, N, (%)	71 (72)	17 (85)	38 (86)
FDG PET, N, (%)	23 (23)	2 (10)	16 (36)
MIGB, N, (%)	18 (18)	1 (5)	10 (23)
Treatments			
	Patient/family (N=107)	Advocate (N=21)	HCP (N=56)
PRRT, N, (%)	45 (42)	20 (95)	43 (77)
Genetic testing/precision medicine, N, (%)	27 (25)	7 (33)	16 (29)
Surgery, N, (%)	20 (19)	0 (0)	9 (16)
Transplantation, N, (%)	15 (14)	2 (10)	25 (45)

CT: computerized tomography; FDG: fluorodeoxyglucose; HCP: healthcare professional; MIGB: meta-iodobenzylguanidine radiopharmaceutical scan; PET: positron-emission tomography; PRRT: peptide receptor radionuclide therapy. The total number of respondents in each participant group differed slightly for each question because participants were allowed to skip questions. Percentages shown are calculated based on actual numbers

- The International Neuroendocrine Cancer Alliance (INCA) is a global organisation consisting of 26 patient advocacy and research groups in 22 countries on 6 continents
- INCA supports NET patients (and their families) by advocating on their behalf to improve diagnosis, care and research

## OBJECTIVE

- This survey (SCAN) aims to measure the global readiness to provide access to diagnostics and treatments for NET patients in terms of:
  - Awareness
  - Availability
  - Quality of servicing
  - Affordability

## 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://incalliance.org/scan/>)
- All medical professionals involved in multidisciplinary care will be addressed, including:



- 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

- SCAN will assess and measure:



Access to NET diagnostics



Access to NET treatments



Financial burden for NET patients



Awareness of clinical trials



Quality of communication with medical teams

- The findings will allow calculation of the financial burden for NET patients globally, *per* region and nationally, based on their socio-economic profile
- SCAN aims to capture the reasons for the existing gaps in diagnostics and care for NET patients in different parts of the world

## 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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