

Managing Online Survey as a Successful Global Rare Disease Patient Community Building Model

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INTRODUCTION

- Neuroendocrine tumors (NETs) are rare and complex neoplasms, affecting various organs, but most commonly the gastrointestinal tract¹
- NETs incidence and prevalence are increasing worldwide making it one of the fastest growing classes of cancer¹
- The International Neuroendocrine Cancer Alliance (INCA) is an umbrella organization representing 26 neuroendocrine tumor (NET) patient groups across 6 continents.

OBJECTIVES

In 2019, INCA championed a Survey of Challenges in Access to Diagnostics and Treatment for NET Patients (SCAN), to:

- mobilize the global NET community, which is relatively small and relies mostly on volunteer involvement;
- help identify new NET patient groups worldwide;
- generate evidence on the challenges that NET patients are facing globally.

METHODS

This survey (SCAN) aimed to measure the global readiness to provide access to diagnostics and treatments for NET patients in terms of:



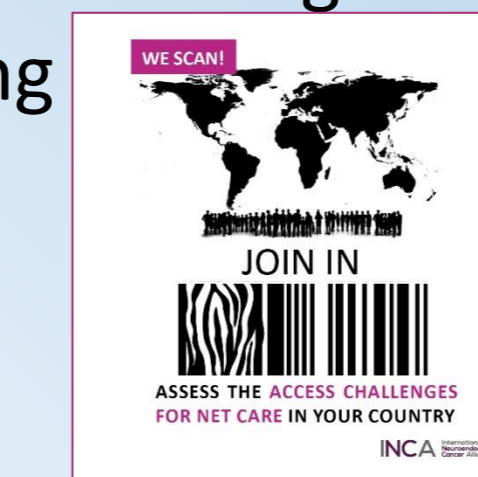
SCAN was developed by INCA in collaboration with NET patients and NET medical experts from around the world. Two questionnaires were designed to address NET patients and healthcare professionals (HCPs) respectively.

In order to ensure optimum accessibility and visibility of the survey, INCA:

- made the survey available in 14 languages: Arabic, Bulgarian, English, German, Dutch/Flemish, French, Japanese, Hindi, Italian, Mandarin (Chinese), Portuguese, Russian, Spanish, Swahili;
- employed networking and communication strategies to position SCAN high on the NET community agenda.

RESULTS

In 2019, the INCA Access Committee started a project named Survey of Challenges in Access to Diagnostics and Treatment for NET Patients (SCAN), which proved to be a powerful community-building tool.



SCAN development included:

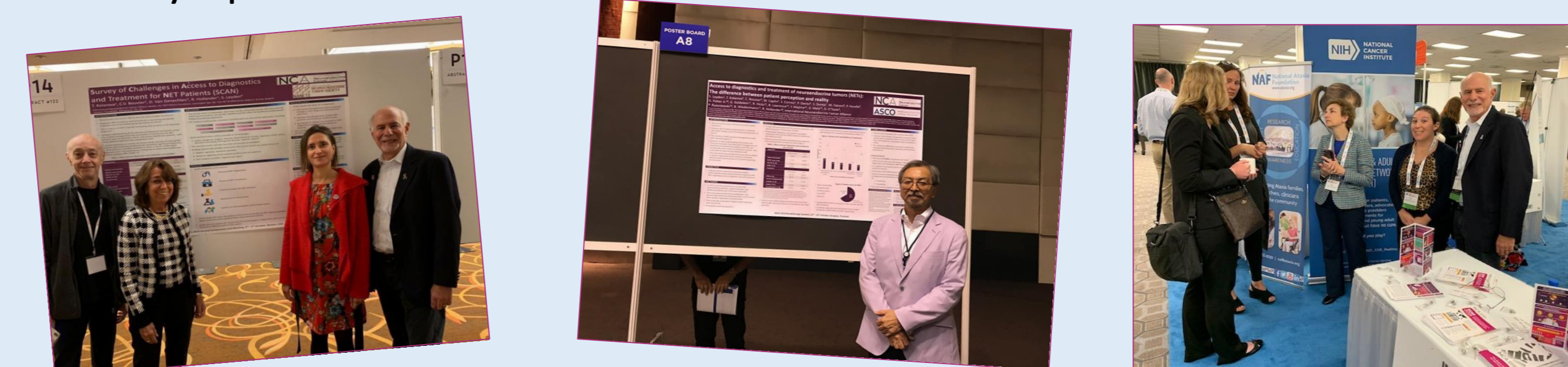
- Extensive internal committee discussions to distill methodologically sound indicators capturing in two questionnaires the challenges that NET patients face globally;
- A pilot phase - to pretest the instrument with 8 NET patients and healthcare professionals from Africa, Europe, and the Americas involved;
- A testing phase with all INCA member organizations.

Launched worldwide on September 16th in 14 languages, the survey concluded on November 30th with:

☐ 2795 respondents from 68 countries across 6 continents.

A concerted communication campaign was strategized, including an INCA communication pack.

- A vast network of partners was mobilized to help field the survey: APNETS, CommNETs, CSNETS, EANM, ECCO, ENETS, EURORDIS, JNETS, MOLNEO, NANETS, NORD, UICC, INCA industry partners and many others.
- Leaflets and posters were presented at the ECCO Summit, NORD Summit, ASCO Breakthrough Summit, NANETS Symposium.



- A targeted 10-day Facebook Ad campaign promoted SCAN in Arabic, Hindi, Swahili, Spanish and Portuguese, with impressive results: social media engagement increased 50-fold – 538 999 reached in total, 144 793 engagements, with cost per post engagement of \$0,01.
- NET patient and medical networks from China and Russia got connected with INCA via SCAN for the first time.

CONCLUSIONS

- Surveys are used widely nowadays, and apart from being the best way to inform evidence-based advocacy they can also be utilized as powerful instruments to build and mobilize a rare patient community globally.
- Positioning the survey in a clear and convincing manner to address the community needs is certainly a priority.
- A collaborative multi-stakeholder approach drives understanding and provides focus on common community goals.
- A detailed piloting phase ensures sound methodology relevant for a global community, which in turn builds trust and drives engagement in all parties involved.
- Availability in many languages, coupled with concerted global communication efforts with specific targets are prerequisites for achieving sound global coverage and meaningful results.
- The online survey tool provides valuable opportunities for global networking and reaching out to new potential partners.
- The collected data effectively generate robust evidence that empowers the wider patient community to make an impact.
- The surge of engagement rates on social media with regards to SCAN messaging is a clear indication that access to healthcare for everyone is a global value that the general audience is ready to stand up for in the case of rare diseases as well.

REFERENCES

1. Dasari A, et al. JAMA Oncol 2017;3:1335-42.

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Learn more at @NETCancerDay www.incalliance.org #wescan #LetsTalkAboutNETs