

FOR NORD SUMMIT Website

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

In 2019, the Survey of Challenges in Access to Diagnostics and Treatment for NET Patients (SCAN), championed by the International Neuroendocrine Cancer Alliance (INCA), mobilized unprecedented global NET community involvement, increased social media engagement 50-fold, helped identify new NET patient groups worldwide, and became the biggest global compendium of NET patient data extant. How was that made possible by an international group advocating for a rare disease community?

INCA applied sound networking and communication strategies to position SCAN high on the NET community agenda. The survey, which consisted of two questionnaires – targeted at NET patients and healthcare professionals, was developed by INCA in collaboration with NET patients and NET medical experts from around the world. It was made available in 14 languages and supported by a concerted communication campaign. It took INCA a year to set up, communicate, launch and conclude this project, notably with remarkable success that translates in 2020 in more visibility evidence-based advocacy.

Surveys are used widely nowadays, but their power to build and mobilize a rare patient community globally is still to be explored by the rare disease community.

All steps INCA undertook to make SCAN such a success are outlined in detail in the INCA poster at NORD Summit 2020.

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About the International Neuroendocrine Cancer Alliance (INCA)

The International Neuroendocrine Cancer Alliance (INCA) is the global voice in support of patients with neuroendocrine cancer and multiple endocrine neoplasia syndromes. INCA is an umbrella organization representing 26 NET patient advocacy and research groups from around the world. Disguised under a variety of symptoms, NETs are difficult to detect with most patients being diagnosed at a late stage of the disease development.

For more information, visit <https://incalliance.org>

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