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Feasibility of e-NET: A Web-Based Health Platform to Investigate Quality of Life in Patients with Neuroendocrine Tumors

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BACKGROUND

Patients with neuroendocrine neoplasms (NENs) have chronic symptoms from hormone overproduction, tumor growth and metastasis, and side effects from prolonged treatment. We assessed the feasibility of using a digital health platform to recruit patients with NENs to evaluate symptoms and quality of life.

METHODS

eNET is a prospective, web-based, cohort study for patients with advanced NENs of any primary site, histologic grade, differentiation, and functional status. Validated surveys (baseline and every 6-12 months for 3 years) are completed online using the Eureka digital health platform, developed at the University of California, San Francisco. Survey topics include medical history, symptoms, lifestyle, and quality of life. Consented participants provide study feedback in a separate Redcap survey.

RESULTS

The eNET study launched in April 2021. As of July 2022, 196 participants of the N=200 pilot cohort have enrolled. Of these, 113 (58%) have completed all surveys in the baseline study visit, with another 20 (10%) study visits still in progress. Demographic characteristics of study participants are shown in the **Table**. A majority (90%) of participants live in the United States, 10% reside in 8 other countries. Most participants (73%) are married or partnered, and 68% have bachelors or higher degree. In terms of NEN history, median time since diagnosis is 4 years (range: <1 to 45). Primary site: gastrointestinal (50%), pancreas (28%), lung (8%), other (5%), unknown (7%), or multiple (2%). Tumors grade: low (42%), intermediate (29%), high (9%), or unknown (20%). At least one feedback survey question was answered by 115 (59%) of participants; 81% were satisfied with participating in the study and 64% felt the surveys effectively captured their experience living with a NEN. Eighteen percent felt too much time was required; 13% suggested removing the fertility survey and 16% the sexual health survey. Participants expressed interest in future research on side effects from NEN treatments.

Table. Participant Demographics

Variable	n (%)
Age (n=196), median [range]	65 years [28, 83]
Biological sex (n=169)	
Female	115 (68%)
Male	54 (32%)
Race (n=170)	
White	156 (92%)
Asian	6 (4%)
Other	3 (2%)
Multiple races	5 (3%)
Hispanic ethnicity (n=170)	6 (4%)

CONCLUSIONS

We demonstrate preliminary feasibility of a novel direct-to-participant, web-based research tool in NENs. The data and feedback from this pilot are being used to develop a larger quality of life cohort study called NET Voices, which will inform subsequent intervention studies. Ongoing efforts are also focused on increasing participant diversity.

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