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Supporting Accurate Patient Information for An Uncommon Malignancy: Evaluation of the Quality of Information on Neuroendocrine Tumors (NETs) on the Internet

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BACKGROUND: Patient information is critical in shared decision-making and patient-centred management for NETs. Most adults search the internet for health issues, with over half considering the information found to be credible. It is important to direct patients towards high-quality websites. We evaluated the quality of online information on NETs.

METHODS: Searching for "Neuroendocrine Tumors", the top 20 websites from Google and top 10 from Yahoo and Bing were retained. Open-access websites written in English were included. Websites identified as advertisements or directed towards healthcare providers were excluded. Each website was evaluated using the JAMA benchmarks (4 factors combined for score 1-4), DISCERN instrument (16 questions scored 1-5, total score 16-80), and the Health On The Net (HON) seal by two independent reviewers.

RESULTS: We included 16 unique websites after removing duplicates. Four were education pages from healthcare institutions, 10 cancer society pages, and 2 general information pages. The average score for JAMA Benchmarks was 2.3; 19% of websites received the highest score of 4. Specifically, 31% met benchmark for authorship, 69% for attribution, 94% for disclosure, and 44% for currency. The average score for DISCERN was 46.5, with no website achieving the maximum of 80 points. The HON Seal was present in 3 out of 16 websites (18%).

CONCLUSION: We identified major issues with the quality of online information for NETs using validated instruments. While websites providing high-quality information exist, the majority of websites identified through common search engines were low-quality. Patients should be informed of the limited quality of online information. High-quality online information is needed to ensure that patients are not misinformed about their diagnosis and management in order to actively participate in their care.

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