

Neuroendocrine Tumor Collaborative Registry

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Background: Neuroendocrine tumors (NET) are a diverse and rare group of diseases that can be: (i) benign or highly malignant; (ii) asymptomatic or cause debilitating syndromes; (iii) indolent or require highly aggressive therapies; and (iii) originated almost anywhere in the body. To increase understanding of NET, it is necessary to create a standardized, user-friendly, HIPAA-compliant registry that will allow researchers from multiple centers to collect, mine, and share NET-related data.

Methods: The Neuroendocrine Tumor Registry (NETR, <http://netr.unmc.edu>) utilizes a multi-tier web-based architecture and a secure web server communication. All Protected Health Information is stored encrypted in an Oracle 11g Database. The system employs a principle of the federated model: all centers input data in the central repository using the same questionnaire and procedures, while each center manages and has access only to its own data. This model protects the confidentiality of each center's data, while laying a foundation for collaborative research. If desired, each center has the capability to share all or selected portions of data.

Results: The NETR has been created and tested. Its questionnaire includes patient socio-demographic, lifestyle, environmental, family history, and clinical forms that are designed with predetermined selection choices to assist users with accuracy and ease of completion. The validation components of the NETR prevent users from entering erroneous information. The NETR's end-users are patients, clinicians, researchers and center administrators that have corresponding levels of authority to enter and use data.

Conclusion: The NETR is ready for implementation. Future developments should include: (i) recruitment of new participating centers and subjects; (ii) creation of a Steering Committee (consisting from representatives from participating centers and a patient advocate) to govern the NETR; (iii) refinement of the NETR's questionnaire by incorporating suggestions from the clinical and research community; (iv) coupling the NETR with a biospecimen management system.