

AbstractID:9116Title:CreatingandImplementingaMulti-institutionalStereotactic
RadiosurgeryPatientRegistry

Purpose: Create an internet-based multi-institutional stereotactic radiosurgery patient registry for the purposes of: 1) tracking patient outcomes, 2) assisting with patient follow-up, 3) comparison of utilization and outcomes data with national averages, 4) reviewing in-house utilization; professional and technical, and 5) tracking patient treatment parameters. **Method and Materials:** A multidisciplinary advisory board was created that included physicians, physicists, nurses, therapists and administrators. Over a period of one year this group was responsible for defining the data to be collected, the structure of the data, the collection and storage methods, the electronic interface to the registry, and ultimately presentation of the data in multiple reports. Particular emphasis was placed on what data to collect; only data with clinical utility value was defined. Patient privacy was also paramount in the registry design. After creating data definitions, requirements were given to a commercial vendor for the database creation. The initial database and interface were evaluated by the board and recommendations for its improvement were made. These recommendations were incorporated into the current design of the registry. Site participation in the registry is voluntary, but IRB approval is required. **Results:** An internet-based patient registry was created. Patient privacy is guaranteed by adhering to HIPAA regulations. Individual site privacy is also maintained. Sites only have access to their data, or national data in aggregate format. Patient data has been entered from multiple centers. **Conclusion:** The patient registry functions as designed and continues to be evaluated for possible improvements. Multiple centers are participating and data continues to accrue. Data abstraction by Cancer Registry personnel at author's center takes approximately 30 minutes. It is our hope that meticulous data collection as described will benefit our patients, increase interest in research and development, and serve as a comprehensive data source for evidence-based treatment disciplines.