



Promoting Patient Centered Care through Precision Therapies: RSSearch® Patient Registry Newsletter

Why are registries important?

Throughout my career in clinical research, I often asked myself “Why are registries important?”. As a former Research Nurse, Research Nurse Supervisor, Research Program Manager and a Senior CRA directly involved in the improvement of patient care, I felt like I was doing it for the betterment of mankind and the fight against cancer. Registries though, this seemed like a different ballgame.

As I considered taking on the role of Clinical Program Manager for the Radiosurgery Society, I quickly came to realize that registries can and do make a big difference in the way diseases are treated. They allow us to gather information on treatments used in a real life setting as opposed to a set of guidelines to which investigators must conform. In clinical research every protocol has a strict list of patient qualifications and a pre-determined treatment to be given. In a registry, we take all patients with no pre-treatment qualifications other than agreeing to participate and the treatment used is determined by the doctors treating them. This “real life” setting gives us information on treatment that happens outside of protocol guidelines and can influence what studies should be done in the future as well as how treatments are used as more and more information is entered and the data is reviewed and written up in journals, presented at scientific meetings, etc.

The summer 2019 issue of **Cure** magazine had a very interesting article about registries that can be found at <https://www.curetoday.com/publications/cure/2019/summer-2019/the-gift-of-cancer-registries-for-your-review>. In the article the author, Marilyn Fenichel talks about the history of registries, the evolution that has taken place in the era of electronic medical records and how this field has evolved. She discusses limitations including which outcomes are measured.

After reading this article, it became evident that what sets the RSSearch Patient Registry apart from the many others mentioned, is the breadth of incredibly important data we collect. We’re capturing data on treatment outcomes like disease free survival, overall survival, local recurrence, distant metastasis, etc. In addition, we get a great deal of pre-treatment information like gender, age, height, weight, type of tumor, pathology, stage, biomarkers, performance status, prior therapies, I could go on and on. Now, with the use of the Vision Tree 360 system, we are also able to gather patient reported outcomes (PRO’s) formerly called Quality of Life information. The system allows centers to collect PRO data using a list of pre-validated questionnaires that each site can set up to be collected at pre-determined timepoints. Once this is set up at the subject’s first visit, the notifications are automatically sent at the specified timepoint and the subject can complete the questionnaire using their email or smart phone without ever having to come in to the clinic. To learn more about this feature and how it can be implemented at your site, please contact us at: registry@therss.org.



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Special points of interest

- RSSearch is the largest SRS/ SBRT dedicated patient registry managed by a non-profit medical professional society.
- Currently, over 27,000 enrolled cases
- Global participation.
- Accepting new participating centers.



Working together as partners

RSSearch Registry Statistics 2019 Update

A July 2019 review of the aggregate data in RSSearch was conducted on the subjects that have been enrolled using the VTOC system at the time of the data merger. This analysis included 26,920 enrolled cases.

At the time of the analysis, the top ten treatment locations (n=26920) reported in RSSearch were brain, spinal cord, cranial nerves (37.3%), lung/bronchus (26.2%), prostate (14.4%), bones/joints (3.4%) and liver (2.8%). Other treatment locations rounding out the top 10 were meninges, pancreas, adrenal gland, kidney, and breast. Men continue to be enrolled at a slightly higher rate than women with the number of men, 14,243 (52.9%) and women, 12401 (46.1%) with 276 (1%) unreported.

The most frequent referrals for SRS/SBRT treatments were from medical oncologists 8,789, and neurosurgeons 3,957, with those two specialties representing more than half of all referrals combined (n=26,920). These were followed by urologists 2,996, radiation oncologists 2,598, and pulmonologists 1,739 making up the top 5 referral sources (see chart at right).

2019 Statistics

26920

Enrolled cases

26

Participating centers

53%

Of cases enrolled are men

37.3%

Of lesions are located in brain, spinal cord or cranial nerve

26%

Of lesions are located in the lung

15%

Of cases are located in the prostate

38%

Of cases were referred by medical oncologists

15%

Of cases were referred by neurosurgeons

RSSearch Registry Press Release—25,000 Cases Reached

The Radiosurgery Society (RSS), a non-profit organization of medical professionals dedicated to advancing the science and clinical practice of stereotactic body radiotherapy (SBRT) and radiosurgery (SRS), announced that its RSSearch® Patient Registry has surpassed 25,000 patient cases treated with SRS/SBRT. The breadth of patient data entered into the multi-institutional registry makes it by far the largest and most robust live database of its kind in the field of SRS/SBRT managed by a professional medical society.

Top 10 Enrolling Centers

1. St. Anthony Hospital, Oklahoma City, OK
2. New Jersey Cyberknife at Community Medical Center, New Brunswick, NJ
3. Sir Charles Gairdner Hospital, Perth, Australia
4. St. Mary's Medical Center, Huntington, WV
5. Mission Hospitals, Asheville, NC
6. Penrose Cancer Center, Colorado Springs, CO
7. Franklin Square Hospital Center, Baltimore, MD
8. St. Francis Hospital, Memphis, TN
9. University of Pennsylvania Hospital, Philadelphia, PA
10. Riverview Medical, Red Bank, NJ

“The RSSearch Registry is a gold mine of data, diligently gathered by dedicated providers across the globe, to provide valuable insight into real-world outcomes of SRS/SBRT treatments. This is exemplified by the significant outcome studies published from this data. For instance, our paper “Stereotactic Body Radiotherapy for Liver Metastasis” has been reported as one of the top 3 most cited articles by the Journal of Radiation Oncology since 2018, providing useful data for patients and providers on the usefulness of SBRT in difficult situations,” stated Anand Mahadevan, MD, Professor and Chairman, Radiation Oncology at Geisinger Health, Geisinger Cancer Institute, Danville, PA.

“Having a comprehensive resource such as RSSearch, which includes both clinical and radiation planning data points has enabled our faculty and residents work on several projects some of which have yielded very interesting findings,” commented Madhur Garg, MD, Clinical Director of Radiation Oncology, Director of Montefiore-Einstein’s Proton Therapy Program and Co-Director of Stereotactic Radiation Therapy Program at Montefiore Medical Center, Bronx, NY.

Data from the RSSearch Patient Registry has fueled 15 publications to date, including a recent publication by Raj Singh et al in the July 2019 issue of the American Journal of Clinical Oncology titled, “Clinical Outcomes Following Stereotactic Body Radiation Therapy (SBRT) for Stage I Medically-Inoperable Small-Cell Lung Carcinoma: A Multi-Institutional Analysis from the RSSearch Patient Registry.”

To see the full press release, please go to: http://www.prweb.com/releases/rssearch_patient_registry_surpasses_25_000_patient_cases_using_stereotactic_body_radiotherapy_stereotactic_radiosurgery/prweb16529809.htm

Is Your Record Complete?

The registry is only as useful as the information it contains, so it is important to enter complete information for screening, treatment and follow-up data. You will be reminded to update your records once a quarter.

With the merger of the VisionTree 360 platform, there are several important changes to be aware of:

- VTOC 360 allows adverse event reporting using both Common Toxicity Criteria Adverse Events Reporting (CTCAE) Versions 3 and 4. It is important to record all treatment-related toxicities. Be sure to include the dates and grade for each toxicity.
- We are now using the newest version of the International Classification of Diseases Oncology codes (ICD-O) Version 10. A drop-down menu list is provided for the treatment location.
- Several additional screening data fields were added to the VTOC 360 platform for prostate, breast, liver, pancreas. Be sure to complete these fields to enhance outcomes analysis.
- The Patient Portal is open and available for all centers to use. Over 20 questionnaires are available for patient-reported quality of life outcomes.

If you have any questions, please contact us at:

registry@therss.org

RSSearch® Patient Registry tips

What is Karnofsky Performance Status and why should I want to record it?

Karnofsky Performance Status (KPS) is a way to measure your patient's ability to carry out life's daily activities. As of July, 2019 the RSSearch Patient Registry database contained information on 26920 patient screenings however, only 69% of the screenings contained KPS percentage information. Why is this information so important? In addition to CT's, MRI's, X-ray's, blood tests, and PET scans, performance status is one of the key instruments that a treating physician can use to determine whether or not the treatment they have given has worked as intended. With nearly 1/3 of the cases having no baseline information, it is impossible to see how this treatment has affected patients' daily lives.

Why is this key data missing and what can we do about it? I think there may be a few different reasons. Below are some suggestions for how we can better capture this vital information.

1) The performance status was not dictated into the patient's notes.

Solution: question the physician and ask them to dictate it into the medical record. Then enter it into the database.

2) This data point was overlooked or is considered unimportant. Solution: reconsider the importance of this information in caring for patients being treated with SRS/SBRT and how it could affect their care as well as what can be learned for patients being treated in the future.

3) Performance Status was dictated using ECOG or WHO performance status and it is unclear how to translate this into Karnofsky values.

Solution: Refer to the chart on the following page and confer with the medical team to see which value would be appropriate to record. Note this in the chart and then enter it into the database.

See the ECOG/Karnofsky comparison chart in table 6.7.3 on the 2nd image on the following page. https://www.researchgate.net/publication/274064386_Europe-an_Association_of_Urology_Guidelines_on_Prostate_Cancer_2015/figures?lo=1.

"The RSSearch® Patient Registry has enabled Sir Charles Gairdner hospital to collect clinical data for SRS/SBRT patients treated at our facility in Australia and has allowed clinicians and research staff to analyse patient and treatment data and to link this with patient-reported outcomes and treatment results. We have already examined our experience treating patients with localised prostate cancer and have published results. Participating in the Registry has also provided the opportunity to evaluate the effectiveness of our local patient management practices and helped us develop data-driven treatment guidelines. The process has been a huge help in working towards prospective clinical trials," stated Tammy Corica, PhD, Clinical Trials Manager, Radiation Oncology Clinical Trials & Research Unit, Sir Charles Gairdner Hospital, Nedlands, Australia.



The RSS Annual Meeting is a collaborative, multi-disciplinary scientific meeting focused on the clinical, scientific and technological advancements of stereotactic radiosurgery (SRS), stereotactic body radiotherapy (SBRT) and advancing therapies for patient care.

Who should attend:

Neurosurgeons, radiation oncologists, surgeons, biologists, medical physicists, nurses, residents, industry, government, administrators and healthcare providers interested in SRS/SBRT and advancing therapies.

Register today at: www.rssevents.org

Regular Registration Rate: July 1- January 31, 2020

Late Registration Rate: February 1, 2020

Hotel Information:

Grand Hyatt Washington

1000 H Street, NW
Washington DC 20001
202-582-1234

Hyatt Place Washington/White House

1522 K Street NW
Washington DC 20001
Reservation Line: 1-888-492-8847

The Radiosurgery Society

PO Box 5631
San Mateo, CA 94402

Phone: 408-385-9411
E-mail: registry@therss.org

2020 MEETING AT A GLANCE *

**Agenda subject to change*

Wednesday, April 1, 7:00 AM – 6:00 PM

Pre-Conference Events:

Registration Open/Exhibitor Set-up
Advancements in GRID/Lattice, Microbeam and FLASH Symposia
Immunology, Immunotherapy & Radiation Oncology Symposia

Thursday, April 2, 7:45 AM – 7:30 PM

Combining Immunotherapy & Stereotactic Radiosurgery
SRS/SBRT for CNS & Extracranial Abstract Presentations
Physics Abstract Presentations
Resident Career and Mentorship Lunch Session
New and Innovative Technology Platforms
Physics Auto Planning Session
Exhibit Hall/Product Demonstrations
Evening Reception/Poster Presentations

Friday, April 3, 7:30 AM – 6:00 PM

Keynote Speaker: David Palma, MD, PhD, “What is the role of stereotactic radiation for metastatic cancer?”
SRS for CNS Lecture Series
Clinical Experience with MRI Linac
Debate I: SBRT for Ultra-Central Lung Tumors
Debate II: SBRT for Prostate Cancer
SRS/SBRT Back to Basics – Treatment Planning & Delivery
Highlights of GRID/Lattice, Flash and Microbeam
Radiotherapy Symposia
Exhibit Hall/Product Demonstrations

Saturday, April 4, 8:00 AM – 4:00 PM

Performance Quality Improvement Case-Based Discussions
Imaging and Targeting for Stereotactic Radiotherapy
Emerging Ablative, Precision Radiation Therapies
SRS/SBRT Quality Assurance
RSS Annual Meeting
SBRT for Liver and Pancreas Workshop
Exhibit Hall/Product Demonstrations