The Multiple Sclerosis Surveillance Registry: A Novel Interactive Database Within the Veterans Health Administration

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The VA MS Surveillance Registry combines a traditional MS registry with individual clinical and utilization data within the largest integrated health system in the US.

Objective: To demonstrate the infrastructure and utility of an interactive health system database for multiple sclerosis (MS), we present the MS Surveillance Registry (MSSR) within the US Department of Veterans Affairs (VA).

Background: Disease specific databases can be helpful in the management of neurologic conditions but few are fully integrated into the electronic health record and linked to health system data. Creating a consistent information technology (IT) architecture and with ongoing support within disease specific registries has been a challenge.

Methods: Building the MSSR was initiated by an iterative process with an IT team and MS health care providers. A common registry platform shared by other VA disease specific registries (eg, traumatic brain injury and cancer) was used to develop the IT infrastructure. MS cases were entered online into the MS Assessment Tool at selected MS Centers of Excellence (MSCoE) clinics in the US. Other large VA databases linked to MSSR are reviewed. Patient demographic and clinical characteristics were compared and contrasted with the broader VA population and other US registry populations.

Results: We have enrolled 1,743 patients with MS in the MSSR through fiscal year 2019 from selected MS regional programs in the VA MSCoE network. The mean age of patients was 56.0 years, with a 2.7 male:female ratio. Among those with definite MS, the mean European Database for MS Disability Score was 4.7 and 75% had ever used an MS disease modifying therapy. A summary electronic dashboard was developed for health care providers to easily access demographic and clinical data for individuals and groups of patients. Data on comorbid conditions, pharmacy and prosthetics utilization, outpatient clinic visits, and inpatient admission were documented for each patient.

Conclusions: The MSSR is a unique electronic database that has enhanced clinical management of MS and serves as a national source for clinical outcomes.

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Disease specific registries can be helpful in the clinical management of neurologic conditions and are critical for studying epidemiologic trends and outcomes. When used within a health care system, they can be a barometer for the provision of treatment and services.[1] Unfortunately, few registries are integrated fully into electronic health records (EHRs) or linked to health system data. Additionally, creating a consistent information technology (IT) architecture with ongoing support within disease specific registries remains challenging.

A number of large registries exist for multiple sclerosis (MS) in North America and Europe. The Scandinavian countries have some of the longest running and integrated MS registries to date. The Danish MS Registry was initiated in 1948 and has been consistently maintained to track MS epidemiologic trends.[2] Similar databases exist in Sweden and Norway that were created in the later 20th century.[3,4] The Rochester Epidemiology Project, launched by Len Kurland at the Mayo Clinic, has tracked the morbidity of MS and many other conditions in Olmsted county Minnesota for > 60 years.[5]

The Canadian provinces of British Columbia, Ontario, and Manitoba also have long standing MS registries.[6-8] Other North American MS registries have gathered state-wide cases, such as the New York State MS Consortium.[9] Some registries have gathered a population-based sample throughout the US, such as the Sonya Slifka MS Study.[10] The North American Research Consortium on MS (NARCOMS) registry is a patient-driven registry within the US that has enrolled > 30,000 cases.[11] The MS-Base is the largest online registry to date utilizing data from several countries.[12] The MS Bioscreen, based at the University of California San Francisco, is a recent effort to create a longitudinal clinical dataset.[13] This electronic registry integrates clinical disease morbidity scales, neuroimaging, genetics and laboratory data for individual patients with the goal of providing predictive tools.

The US military provides a unique population to study MS and has the oldest and largest nation-wide MS cohort in existence starting with World War I service members and continuing through the recent Gulf War Era.[14] With the advent of EHRs in the US Department of

TABLE 1 Data Collected by the MS Surveillance Registry

Categories	Key Variables
Demographic	Age, race, ethnicity, sex, address, health care facility registration
Clinical	Date of MS onset and diagnosis, diagnostic category, onset symptoms, MS subtype, relapses (annual), family history, MS service-connection, European Database on MS disability, all current and past disease modifying therapies, date and cause of death, survey data
Inpatient and outpatient databases	All inpatient and outpatient visits, laboratory, pathology, radiology, problem lists
Pharmacy	All medications and supplies in Veterans Health Administration
Prosthetics	All prosthetic equipment and supplies
Health care economics and cost of care	Cost for pharmacy, prosthetics, outpatient care, inpatient care, nursing home care, fee basis care

Abbreviation: MS, multiple sclerosis.

**TABLE 2** Patient Demographics by VISN in the MS Surveillance Registry

VISNs	Patients, No.	Age, mean (SD), y	Male, No. (%)	White, No. (%)	Black, No. (%)	Other, No. (%)
1	9	61 (8.5)	7 (77.8)	8 (88.9)	1 (11.1)	0
2-3	23	65 (10.9)	19 (82.6)	19 (82.6)	4 (17.4)	0
4	128	58 (12.0)	102 (79.7)	70 (54.7)	51 (39.8)	7 (5.5)
5	473	55 (13.4)	312 (66.0)	201 (42.5)	206 (43.6)	66 (14.0)
6-7	222	52 (11.1)	154 (69.4)	102 (46.0)	85 (38.3)	35 (15.8)
8	1	56	0	0	1	0
9	0	--	--	--	--	--
10	2	46 (0.0)	2 (100.0)	1 (50.0)	1 (50.0)	0
12	0	--	--	--	--	--
15	3	62 (11.0)	3 (100)	2 (66.7)	1 (33.3)	0
16	0	--	--	--	--	--
17	111	51 (12.8)	72 (64.9)	23 (20.7)	19 (17.1)	69 (62.2)
19	137	59 (11.9)	114 (83.2)	112 (81.8)	3 (2.2)	22 (16.1)
20	634	57 (13.1)	490 (77.3)	507 (80.0)	37 (5.8)	90 (14.2)
Total	**1,743**	**56 (12.9)**	**1,275 (73.2)**	**1,045 (60.0)**	**409 (23.5)**	**289 (16.6)**

Abbreviation: VISN, Veterans Integrated Service Network.

Veterans Affairs (VA) Veterans Health Administration (VHA) in the mid-1990s and large clinical databases, the possibility of an integrated registry for chronic conditions was created. In this report, we describe the creation of the VA MS Surveillance Registry (MSSR) and the initial roll out to several VA medical centers within the MS Center of Excellence (MSCoE). The MSSR is a unique platform with potential for improving MS patient care and clinical research.

METHODS
The MSSR was designed by MSCoE health care providers in conjunction with IT specialists from the VA Northwest Innovation Center. Between 2012 and 2013, the team developed and tested a core template for data entry and refined an efficient data dashboard display to optimize clinical decisions. IT programmers created data entry templates that were tested by 4 to 5 clinicians who provided feedback in

FIGURE 1 VA MS Surveillance Registry Data Flow
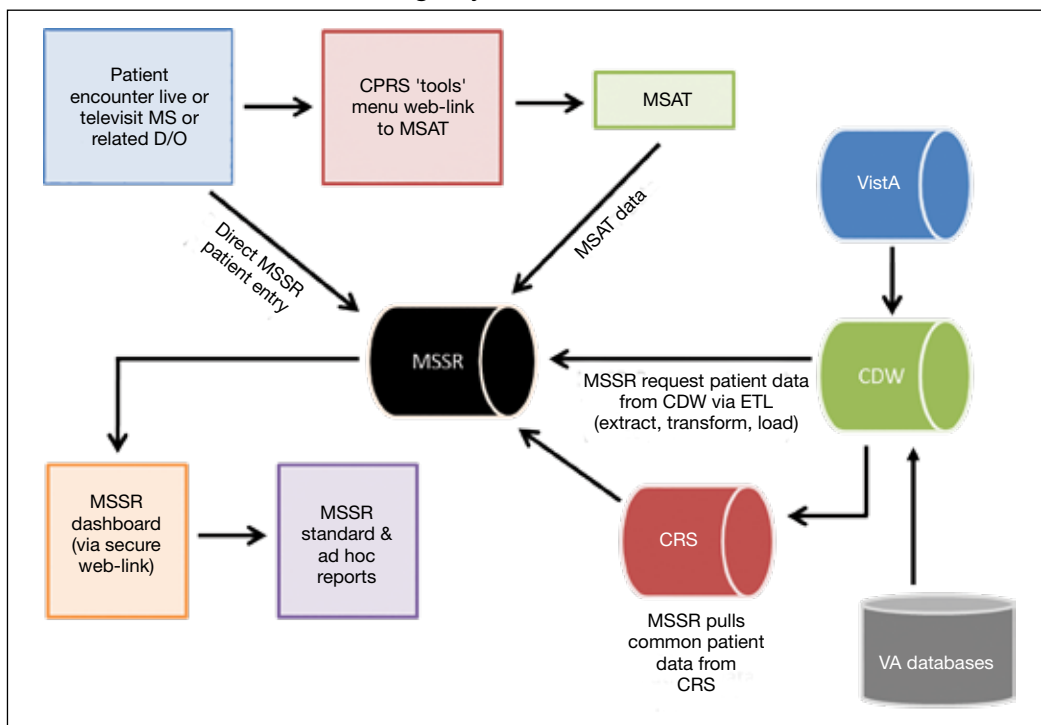
Abbreviations: CPRS, Computerized Patient Record System; CRS, Converged Registries Solution; CDW, Clinical Data Warehouse; D/O, disorder; MS, multiple sclerosis; MSAT, MS Assessment Tool; MSSR, MS Surveillance Registry; VA, US Department of Veterans Affairs; VISTA, Veterans Health Information Systems and Technology Architecture.

biweekly meetings. Technical problems were addressed and enhancements added and the trial process was repeated.

After creation of the prototype MS Assessment Tool (MSAT) data entry template that fed into the prototype MSSR, our team received a grant in 2013 for national development and sustainment. The MSSR was established on the VA Converged Registries Solution (CRS) platform, which is a hardware and software architecture designed to host individual clinical registries and eliminate duplicative development effort while maximizing the ability to create new patient registries. The common platform includes a relational database, Health Level 7 messaging, software classes, security modules, extraction services, and other components. The CR obtains data from the VA Corporate Data Warehouse (CDW), directly from the Veterans Health Information Systems and Technology Architecture (VISTA) and via direct user input using MSAT.

From 2016 to 2019, data from patients with MS followed in several VA MS regional programs were inputted into MSSR. A roll-out process to start patient data entry at VA medical cen-

ters began in 2017 that included an orientation, technical support, and quality assurance review. Twelve sites from Veteran Integrated Service Network (VISN) 5 (mid-Atlantic) and VISN 20 (Pacific Northwest) were included in the initial roll-out.

RESULTS
After a live or remote telehealth or telephone visit, a clinician can access MSAT from the Computerized Patient Record System (CPRS) or directly from the MSSR online portal (Figure 1). The tool uses radio buttons and pull-down menus and takes about 5 to 15 minutes to complete with a list of required variables. Data is auto-saved for efficiency, and the key variables that are collected in MSAT are noted in Table 1. The MSAT subsequently creates a text integration utility progress note with health factors that is processed through an integration engine and eventually transmitted to VISTA and becomes part of the EHR and available to all health care providers involved in that patient's care. Additionally, data from VA outpatient and inpatient utilization files, pharmacy, prosthetics, laboratory, and radiology databases are included in the

TABLE 3 Clinical Features of Multiple Sclerosis Surveillance Registry Patients

VISNs	Patients, No.	Disease Duration, mean (SD), y	Relapsing Remitting, No. (%)[a]	Secondary Progressive, No. (%)	Primary Progressive, No. (%)	EDMUS disability (SD)[b]	Ever on DMT, No. (%)
1	9	24.6 (12.6)	7 (77.8)	2 (22.22)	0 (0.0)	4.4 (1.9)	4 (44.4)
2-3	23	28.7 (17.2)	18 (78.3)	1 (4.35)	4 (17.4)	7.3 (1.5)	4 (17.4)
4	128	22.6 (13.4)	104.0 (81.3)	4 (3.13)	20 (15.6)	4.6 (2.3)	80 (62.5)
5	473	22.7 (13.0)	284 (60.0)	151 (31.92)	38 (8.0)	4.8 (2.5)	298 (63.0)
6-7	222	18.6 (11.1)	142 (64.0)	54 (24.32)	26 (11.7)	4.3 (2.4)	188 (84.7)
8	1	35	0	1	0	7	1
9	0						
10	2	9	2 (100)	0	0	3.5 (3.5)	1 (50.0)
12	0						
15	3	23.5 (21.9)	2 (66.7)	1 (33.33)	0	3.3 (2.5)	3 (100)
16	0						
17	111	17.5 (11.4)	75 (67.6)	26 (23.42)	10 (9.0)	4.1 (2.7)	111 (100)
19	137	20.0 (11.8)	87 (63.5)	37 (27.01)	13 (9.5)	4.4 (2.4)	135 (98.5)
20	634	25.3 (14.0)	410 (64.67)	162 (25.55)	62 (9.8)	4.8 (2.3)	484 (76.3)
Total	**1,743**	**22.7 (13.3)**	**1,131 (64.9)**	**439 (25.2)**	**173 (9.9)**	**4.7 (2.4)**	**1,309 (75.1)**

Abbreviations: DMT, disease modifying therapy; EDMUS, European Database on Multiple Sclerosis; VISN, Veterans Integrated Service Network
[a]Disease duration from year of first symptom onset to 2019.
[b]EDMUS corresponds to Expanded Disability Status Scale where level 6 requires gait aid to walk.

CDW and are included in MSSR. With data from 1998 to the present, the MSAT and CDW databases can provide longitudinal data analysis.

Between 18,000 and 20,000 patients with MS are evaluated in the VHA annually, and 56,000 unique patients have been assessed since 1998. From 2016 to 2019, 1,743 patients with MS or related disorders were enrolled in MSSR (Table 2 and Figure 2). The mean (SD) age of patients was 56.0 (12.9) years and the male:female ratio was 2.7. Racial minorities make up 40% of the cohort. Among those with definite and possible MS, the mean disease duration was 22.7 years and the mean (SD) European Database for MS disability score was 4.7 (2.4) (Table 3). Three-quarters of the MSSR cohort have used ≥ 1 MS disease modifying therapy and 65% were classified as relapsing-remitting MS.

An electronic dashboard was developed for health care providers to easily access demographic and clinical data for individuals and groups of patients (Figure 3). Standard and ad hoc reports can be generated from the MSSR. Lar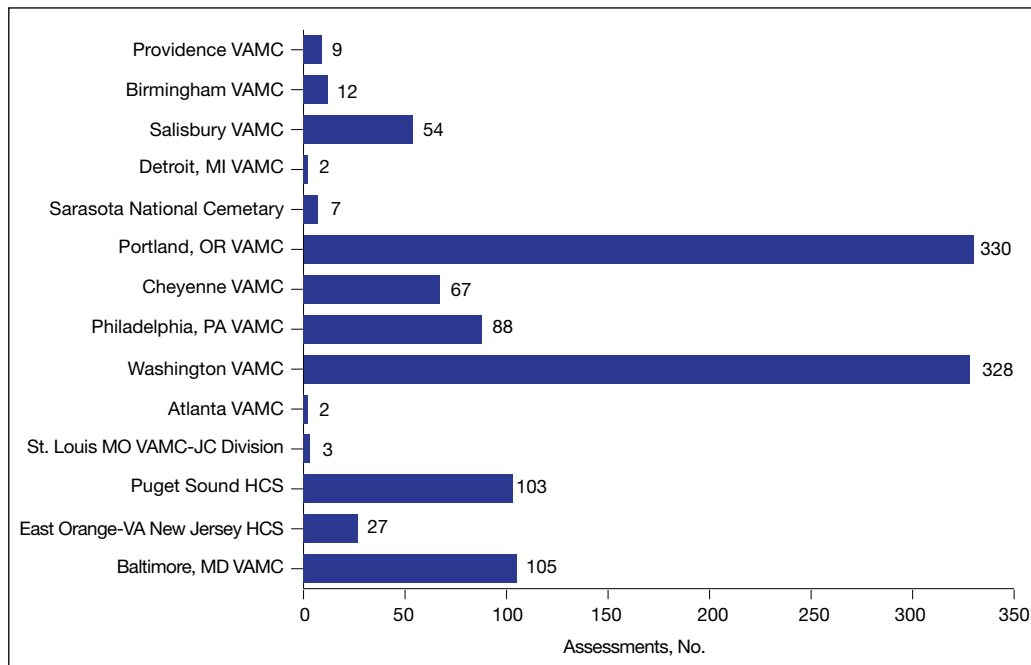ger longitudinal analyses can be performed with MSAT and clinical data from CDW. Data on comorbid conditions, pharmacy, radiology and prosthetics utilization, outpatient clinic and inpatient admission can be accessed for each patient or a group of patients.

In 2015, MSCoE published a larger national survey of the VA MS population.[15] This study revealed that the majority of clinical features and demographics of the MSSR were not significantly different from other major US MS registries including the North American Research Committee on MS, the New York State MS Consortium, and the Sonya Slifka Study.[16-18]

DISCUSSION

The MSSR is novel in that it combines a traditional MS registry with individual clinical and utilization data within the largest integrated health system in the US. This new registry leverages the existing databases related to cost of care, utilization, and pharmacy services to provide surveillance tools for longitudinal follow-up of the MS population within the VHA. Because the structure of the MSAT and MSSR

FIGURE 2 Multiple Sclerosis Assessments Completed by Facility

Providence VAMC — 9
Birmingham VAMC — 12
Salisbury VAMC — 54
Detroit, MI VAMC — 2
Sarasota National Cemetary — 7
Portland, OR VAMC — 330
Cheyenne VAMC — 67
Philadelphia, PA VAMC — 88
Washington VAMC — 328
Atlanta VAMC — 2
St. Louis MO VAMC-JC Division — 3
Puget Sound HCS — 103
East Orange-VA New Jersey HCS — 27
Baltimore, MD VAMC — 105

Assessments, No.

Abbreviations: HCS, health care system; JC, John Cochran; VAMC, US Department of Veterans Affairs Medical Center.

FIGURE 3 Mock Patient Multiple Sclerosis Surveillance Registry Dashboard Report

ies.[20] Still many registries do not have environmental or genetic data to evaluate etiologic questions.[21] Additionally, most registries are not set up to evaluate cost or quality of care within a health care system.

Recommendations for maximizing the impact of existing MS registries were recently released by a panel of MS clinicians and researchers.[22] The first recommendation was to create a broad network of registries that would communicate and collaborate. This group of MS registries would have strategic oversight and direction that would greatly streamline and leverage existing and future efforts. Second, registries should standardize data collection and management thereby enhancing the ability to share data and perform meta-analyses with aggregated data. Third, the collection of physician- and patient-reported outcomes should be encouraged to provide a more complete picture of MS. Finally, registries should prioritize research questions and utilize new technologies for data collection. These recommendations would help to coordinate existing registries and accelerate knowledge discovery.

The MSSR will contribute to the growing registry network of data. The MSSR can address questions about clinical outcomes, cost, quality with a growing data repository and linked biobank. Based on the CR platform, the MSSR allows for integration with other VA clinical registries, including registries for traumatic brain injuries, oncology, HIV, hepatitis C virus, and eye injuries. Identifying case outcomes related to other registries is optimized with the CR common structure.

CONCLUSION

The MSSR has been a useful tool for clinicians managing individual patients and their regional referral populations with real-time access to

were developed in a partnership between IT developers and clinicians, there has been mutual buy-in for those who use it and maintain it. This registry can be a test bed for standardized patient outcomes including the recently released MS Quality measures from the American Academy of Neurology.[19]

To achieve greater numbers across populations, there has been efforts in Europe to combine registries into a common European Register for MS. A recent survey found that although many European registries were heterogeneous, it would be possible to have a minimum common data set for limited epidemiologic stud-

clinical and utilization data. It will also be a useful research tool in tracking epidemiological trends for the military population. The MSSR has enhanced clinical management of MS and serves as a national source for clinical outcomes.

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Disclaimer
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