



Special Communication

Modernization of a Large Spinal Cord Injuries and Disorders Registry: The Veterans Administration Experience



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List of abbreviations: ALS, amyotrophic lateral sclerosis; ARC, Allocation Resource Center; ASIA, American Spinal Injury Association Impairment Scale; BI, Business Intelligence; CDW, Corporate Data Warehouse; CPRS, computerized patient record system; EMR, electronic medical record; GUI, graphical user interface; MIO, Management of Information & Outcomes; MS, multiple sclerosis; RHSCIR, Rick Hansen Spinal Cord Injury Registry; SCD, spinal cord dysfunction; SCI/D, Spinal Cord Injuries and Disorders; SCIDO, Spinal Cord Injury and Disorders Outcomes; SCIMS, Spinal Cord Injury Model Systems; SME, subject matter expert; VHA, Veterans Health Administration; VistA, Veteran Health Information Systems and Technology Architecture; VSR, VHA SCI/D Registry; VSSC, VHA Service Support Center; WOC, Without Compensation. Disclosures: none.

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KEYWORDS

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 Motor neuron disease;
 Multiple sclerosis;
 Population health;
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 Registries;
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 Spinal cord injuries;
 United States;
 Veterans

Abstract Since the 1990s, Veterans Health Administration (VHA) has maintained a registry of Veterans with Spinal Cord Injuries and Disorders (SCI/Ds) to guide clinical care, policy, and research. Historically, methods for collecting and recording data for the VHA SCI/D Registry (VSR) have required significant time, cost, and staffing to maintain, were susceptible to missing data, and caused delays in aggregation and reporting. Each subsequent data collection method was aimed at improving these issues over the last several decades. This paper describes the development and validation of a case-finding and data-capture algorithm that uses primary clinical data, including diagnoses and utilization across 9 million VHA electronic medical records, to create a comprehensive registry of living and deceased Veterans seen for SCI/D services since 2012.

A multi-step process was used to develop and validate a computer algorithm to create a comprehensive registry of Veterans with SCI/D whose records are maintained in the enterprise wide VHA Corporate Data Warehouse. Chart reviews and validity checks were used to validate the accuracy of cases that were identified using the new algorithm. An initial cohort of 28,202 living and deceased Veterans with SCI/D who were enrolled in VHA care from 10/1/2012 through 9/30/2017 was validated. Tables, reports, and charts using VSR data were developed to provide operational tools to study, predict, and improve targeted management and care for Veterans with SCI/Ds. The modernized VSR includes data on diagnoses, qualifying fiscal year, recent utilization, demographics, injury, and impairment for 38,022 Veterans as of 11/2/2022. This establishes the VSR as one of the largest ongoing longitudinal SCI/D datasets in North America and provides operational reports for VHA population health management and evidence-based rehabilitation. The VSR also comprises one of the only registries for individuals with non-traumatic SCI/Ds and holds potential to advance research and treatment for multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), and other motor neuron disorders with spinal cord involvement. Selected trends in VSR data indicate possible differences in the future lifelong care needs of Veterans with SCI/Ds. Future collaborative research using the VSR offers opportunities to contribute to knowledge and improve health care for people living with SCI/Ds.

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Spinal cord injuries and disorders (SCI/Ds) typically cause permanent changes in motor, sensory, and/or autonomic spinal cord functions and require frequent, specialized, and interdisciplinary health care due to impairments and complications that involve almost every system of the body. Paralysis, impaired mobility, sensory impairments that result in pressure injuries, respiratory problems such as impaired cough, cardiovascular dysfunction such as autonomic dysreflexia, and parasympathetic dysregulation that affects bladder and bowel function are common sequelae.¹⁻⁵ Preventing secondary complications is 1 of the important health care and self-care strategies to improve quality of life and reduce mortality for individuals with SCI/D.⁶⁻¹⁴ SCI/Ds often result in a lifetime of physical, psychological, and psychosocial challenges which necessitate frequent access to high-quality primary and specialty health care.^{15,16} One population study using a Canadian registry of individuals with traumatic SCI estimated that lifetime costs of health care range from \$1.5 million to \$3 million per person.¹⁷ The United States Spinal Cord Injury Model Systems (SCIMS) registry currently estimates that approximately 264,000 individuals in the United States (U.S.) are currently living with traumatic SCI/Ds, and over 17,000 new cases have been reported annually since 2015.¹⁸⁻²¹ Over 15% of these people receive health care services from Veterans Health Administration (VHA).^{22,23}

Registries of people living with SCI/D provide essential population health data for rehabilitation, clinical care and decision-making, outcomes, benchmarking, utilization, forecasting, modeling, and research. Comprehensive databases such as the SCIMS and Rick Hansen Spinal Cord Injury Registry (RHSCIR) have contributed significant data to guide policy, enable research collaborations, and develop clinical trials across populations and time points.¹⁸⁻²¹ These contributions have meaningfully advanced knowledge to enable people with SCI/D to live longer and better than at any time in history.²⁴ Similar registries for maternity outcomes, infant development, and diseases such as cancer, tuberculosis, and rheumatic fever have been used to effectively prevent, eradicate, monitor, and intervene to improve population health.²⁵

Since the 1990s, VHA has maintained a registry of Veterans with SCI/D using manual reviews of electronic medical records (EMRs), computer data storage, and management tools to track a cohort of patients who have received care in VHA.^{26,27} These registry data collection methods have drawn on reviews of primary data from patient EMRs to identify and gather clinical information on injury type, duration, and neurologic level. The initial methods and reviews required significant time, costs, training, and staffing to maintain, and they were susceptible to errors, missing data, and reporting delays.²³ Incongruencies in case identification and

clinical variables across data sources and VHA sites limited the generalizability and strength of conclusions that could be drawn.^{23,28}

This manuscript describes the development and validation of an updated VHA SCI/D Registry (VSR) that uses a computer algorithm to identify cases of Veterans with SCI/D across EMRs from 9 million Veterans who receive VHA care.²² A primary objective for updating the VSR was to provide useful, practical, and accurate operational reports for VHA population health management, evidence-based rehabilitation, and life-long SCI/D specialty services for Veterans. The modernized VSR serves as the informatics foundation for supporting Veterans with SCI/D to live independently and maintain the highest quality of life. A second objective was to develop a comprehensive longitudinal database for collaborative research and harmonization with other SCI/D databases to improve health care and the quality of life for individuals living with traumatic and non-traumatic SCI/Ds in the US and around the world.

Background

The overall mission of the VHA SCI/D System of Care is to support, promote, and maintain the health, independence, quality of life, and productivity of individuals with SCI/D throughout their lives.²⁶ The mission is accomplished through rehabilitation; sustaining medical and surgical care; patient and family education; psychological, social, and vocational care; research; education; and professional training. The VHA

SCI/D System of Care is organized as an integrated Hub-and-Spoke network (fig 1) consisting of 25 regional SCI/D Centers or “Hubs,” which are designated centers that provide rehabilitation followed by the full continuum of primary and specialty care by interdisciplinary clinical teams. VHA “Spokes” are VHA medical facilities within a designated Hub catchment area that provide SCI/D primary and limited specialty health care closer to Veterans’ homes.²⁶

History of VHA SCI/D Data Registries

Since the late 1990s, VHA SCI/D Centers have included Veterans in the VHA SCI/D Registry (VSR) based on their eligibility for VHA SCI/D System of Care services.^{23,27} The first VSR data capture method was established in 1994, using manual input of patient-level data into a specially-developed application called the Spinal Cord Dysfunction (SCD) Registry that was entered into Veterans Health Information Systems and Technology Architecture. This initial SCD data collection method included basic identifying information for Veterans with SCI/D and some clinical data such as date of injury or onset of disease, etiology, neurologic level of injury, impairment, and injury category. Although data from all SCI/D Centers were included, case identification and entry rates differed across sites because of burdensome and duplicative input for SCI/D clinical staff and incomplete information for some Veterans.²⁷

While the SCD Registry improved data availability for research and outcomes for SCI/D care, missing data and low

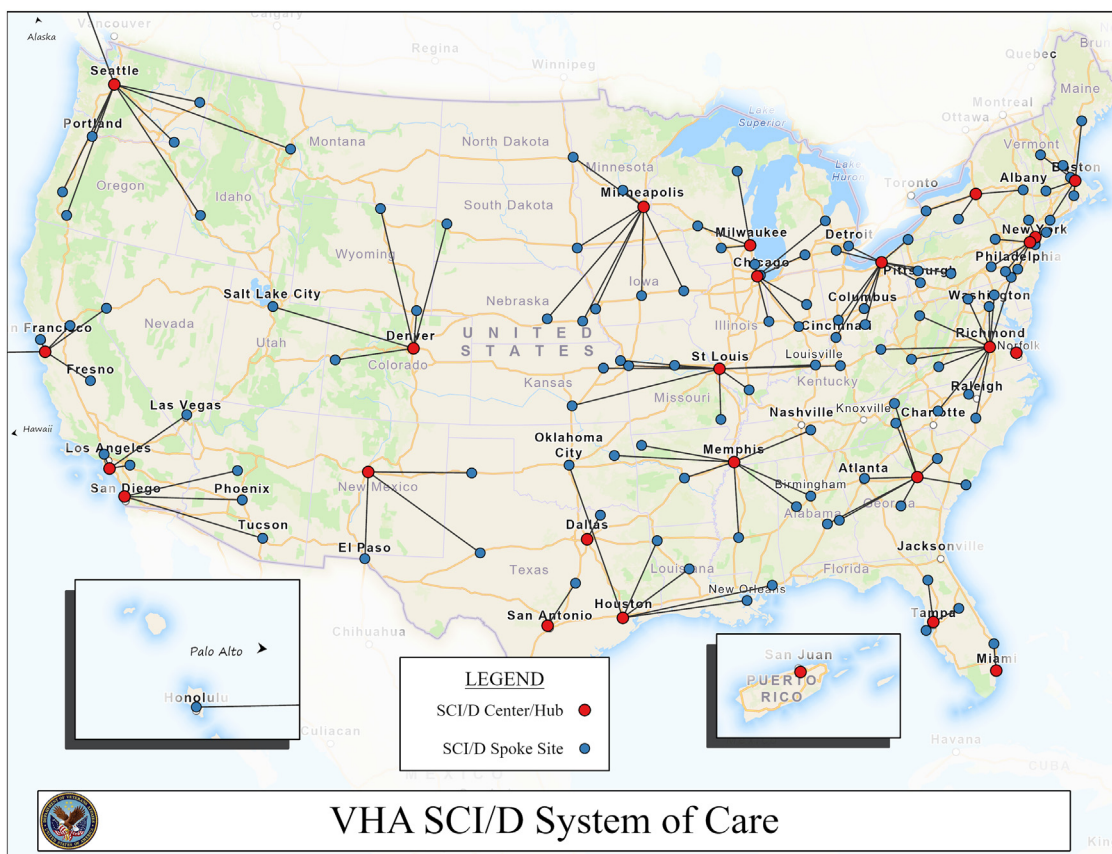


Fig 1 VHA SCI/D Hub and Spoke Map.

agreement on case identification required augmentation from other resources. Smith et al²³ compared case concordance rates for SCI/D-related ICD-9 diagnoses using the SCD Registry and 2 additional VHA primary data cohorts: The VHA Allocation Resource Center, which uses diagnostic codes to determine severity and complexity of care for budgeting purposes, and VHA inpatient record flags used to code for high risk during hospital admissions. They found that less than 30% of Veterans were included in all 3 data sources. In pairwise comparisons, overall agreement between the SCD Registry and inpatient record flags was only 52%, and, of the patients who were included on both the allocation resource center and SCD Registry, many patients were missing key information about date of onset, level of injury, impairment, and etiology.²³ These findings suggest that missing data may limit the validity and generalizability of research conclusions and resource forecasting that could be drawn from the SCD Registry.²⁸

In 2010, the SCD Registry data capture system was replaced by the Spinal Cord Injury and Disorders Outcomes (SCIDO) software application. SCIDO was created by the SCI/D National Program Office, field subject matter experts (SMEs), Veterans Affairs Office of Information & Technology, and a contractor. SCIDO was a graphical user interface with enhanced capabilities, connected to the VHA Enterprise Corporate Data Warehouse (CDW), and created local and national patient databases encompassing VHA SCI/D Hub and Spoke registry data. Most Veteran information for SCIDO was manually entered by Management of Information & Outcomes (MIO) Coordinators at each SCI/D Center using medical record reviews and consultations with clinical care team members. Some information was automatically extracted from the medical record, including body mass index, pre-existing diagnoses, vaccinations, episodes of influenza and pneumonia, ventilator equipment and supplies, and diagnostic tests. MIO Coordinators used chart reviews to identify new SCI/D cases and enter information and outcomes data into the SCIDO application. Twenty standardized instruments were available within SCIDO, including those that were SCI/D-specific, some that were more generally disability-focused, and others that were mandated by VHA. Data spreadsheets were also maintained at SCI/D Centers to identify cases and track outcomes for variables needed for clinical care and operations, but not included in SCIDO. Both SCIDO and spreadsheet data were provided to the SCI/D National Program Office for storage, consolidation, and analysis to allow for national tracking of patients and evaluation of clinical outcomes. Although data input for SCIDO and spreadsheet data were standardized using VHA Directive 1176 (2) SCI/D System of Care requirements and definitions,²⁵ SCI/D Centers' staff used clinical decision processes that focused on care requirements and local operational needs to decide inputs such as which Veterans were included in or removed from the local registry. This clinical expedience resulted in between-Center differences in registry inclusions and exclusions for patients who died, reduced their annual clinical utilization, or moved to a different region. The SCIDO application was decommissioned in September 2015, and SCI/D Centers received spreadsheets with registry patients within their catchment area to that date. Centers maintained data for the

registries locally using team consultations and EMR reviews until the present modernization.

Despite these limitations, the national VHA SCIDO registry had significant strengths for standardizing data collection and data analysis including (1) use of primary clinical data for a large population of patients with SCI/D in the U. S.; (2) use of standardized data collection to identify cases and gather information about impairments, medical complications, function, activities, participation, and satisfaction with life; (3) inclusion of patients with both traumatic and non-traumatic SCI/D; (4) dedicated MIO Coordinators using chart reviews for accurate case identification and tracking; and (5) ability to manually match SCIDO registry patients to VHA CDW data elements for research or national reports.^{29–35}

One important limitation of the SCIDO registry was its lack of direct integration with the VHA EMR and the VHA Enterprise CDW. Although MIO Coordinators reviewed patient EMRs to enter data into SCIDO, the process for identifying cases was idiosyncratic. SCIDO was not integrated with the CDW nor did it add discrete SCI/D-related variables to the CDW. This lack of integration increased the likelihood of missing data, clerical errors, inconsistent entries, and limited standardization. The SCIDO software also offered limited capability for aggregation of national data across sites, affecting data latency and national reporting.

VHA SCI/D Registry

The modernized VSR was developed through a partnership between the VHA SCI/D National Program Office and the VHA Service Support Center (VSSC), a VHA capital tracking service. Registry lists maintained by MIO Coordinators were merged to create a combined national registry data set of Veterans with traumatic and non-traumatic SCI/D, including a subset of Veterans with multiple sclerosis (MS) and motor neuron disease such as amyotrophic lateral sclerosis (ALS). Veterans with MS were included for services in the SCI/D System of Care when providers identified spinal cord involvement in the disease process. A computer algorithm was developed to improve the accuracy, accessibility, and consistency of SCI/D case identification among Veterans enrolled in VHA and to provide operational reports for following Veterans with SCI/D. This paper highlights some of the reports created using the VSR, notes the research and program evaluation benefits of the comprehensive longitudinal cohort, and illustrates the potential of this data for harmonization with other large SCI/D data sets and collaborative research to improve health care and quality of life for people with SCI/Ds.

Method

Data spreadsheets maintained by SCI/D Centers using team consultations and EMR reviews through December 2017 were used to develop and validate a computerized algorithm to identify Veterans for the VSR (fig 2). Some Centers had been retaining Veterans in the locally managed list over years, regardless of deceased status, Veteran's home geographic location, or Veteran's chosen SCI/D specialty care utilization

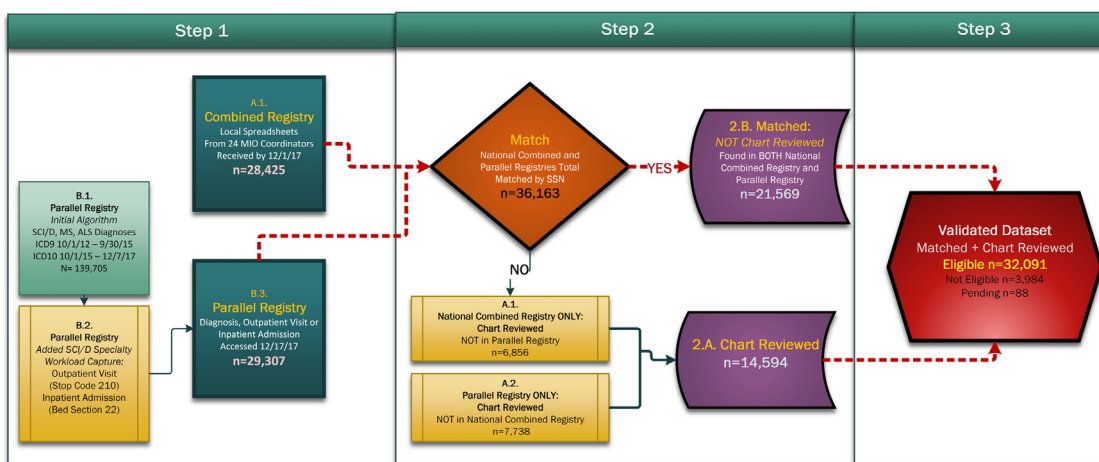


Fig 2 Steps to validate data for the VSR.

patterns. Other centers managed more refined lists reflecting Veterans actively using local SCI/D specialty care. For several years after the decommissioning of the SCIDO system at the end of fiscal year 2015, the MIO Coordinators used nationally standardized, controlled-entry Microsoft Excel spreadsheet templates prepared by the SCI/D National Program Office. This process supported entering local SCI/D registry and outcomes data, managing and analyzing the data locally, and periodically submitting updated spreadsheets to the SCI/D National Program Office. The nationally standardized spreadsheet format was typically adhered to in a manner supporting combining the local registries once or twice per year. Upon receiving the registry data from 24 VHA SCI/D Centers to begin the modernization process, the SCI/D National Program Office conducted a quality review, obtaining correction and validation information from MIO Coordinators as needed until data validation criteria were met.

First, registry data from 24 VHA SCI/D Centers were combined to create a cumulative national SCI/D registry data set of Veterans with traumatic and non-traumatic SCI/Ds, including Veterans with MS and ALS who were served by the SCI/D System of Care because of spinal cord involvement (n=28,425; fig 2, Step 1.A.1). This National Combined Registry included cases identified as SCI/D using ongoing chart reviews of SCI/D specialty care documented in the EMR for patients seen across all VHA SCI/D Centers/Hubs and Spoke sites.

Next, an algorithm was developed using International Classification of Diseases (ICD-9 and ICD-10)³⁴ qualifying diagnostic codes for SCI/D, MS, and ALS within the VHA Enterprise CDW from October 1, 2012, through December 7, 2017. Applying this initial computer algorithm of ICD-9 and ICD-10 codes to CDW data identified 139,705 Veterans (fig 2, Step 1.B.1). VHA SCI/D outpatient (Stop Code 210, indicating an outpatient, face-to-face professional contact between a patient and provider) and inpatient (Treatment Specialty/Bed Section Code 22, indicating admission to the SCI/D specialty inpatient unit) data were then added to ICD diagnoses in the computer algorithm (fig 2, Step 1.B.2), resulting in a Parallel Registry of patients that included a similar number of cases (n=29,307; fig 2, Step 1.B.3) to those found on the National Combined Registry (n=28,425; fig 2, Step 1.A.1).

Patients identified for inclusion in the Parallel Registry by the algorithm were matched with the National Combined Registry using patient social security numbers (fig 2, Step 2). The total matched dataset identified 36,163 unique Veterans, living or deceased, who were diagnosed with a condition which qualified them for VHA SCI/D System of Care services (fig 2, Step 2). Data matching resulted in 3 groups: (1) Patients exactly matched (fig 2, YES) on both the National Combined Registry and the Parallel Registry (n=21,569; fig 2, Step 2.B); (2) patients on the National Combined Registry only (n=6856; fig 2, NO, Step 2.A.1); and (3) those on the Parallel Registry only (n=7738, fig 2, NO, Step 2.A.2).

Patients who appeared on both the National Combined Registry and the Parallel Registry datasets were labeled as eligible for inclusion in the VSR (n=21,569; fig 2, Step 2.B). Cases that appeared on the National Combined Registry only (n=6856; fig 2, Step 2.A.1) or the Parallel dataset only (n=7738; fig 2, Step 2.A.2) were subjected to additional EMR reviews (total n=14,594; fig 2, Step 2.A) by MIO Coordinators. These cases were categorized in the Validated Data Set (fig 2, Step 3) as: *eligible* for VSR inclusion (ie, SCI/D qualifying condition per VHA Directive 1176 [2]); *not eligible* for VSR inclusion because of changes in initial diagnosis (eg, admitted for SCI/D but found to have a different diagnosis), clerical errors, or inaccurate stop codes for visits; or *pending* (ie, insufficient information to determine eligibility). All Veterans with eligible conditions that were validated via MIO Coordinators' EMR reviews (fig 2, Step 2.A) or being found in both the National Combined Registry and the Parallel Registry (fig 2, Step 2.B), were labeled as *eligible* in the Validated Data Set (fig 2, Step 3) regardless of deceased status, geographic location of patient's home, or health care utilization patterns.

The Validated Data Set (fig 2, Step 3) contained 36,163 cases coded as *eligible* (n=32,091, 89%), *ineligible* (n=3984, 11%), and *pending* (n=88, 0%). This Validated Data Set verified eligibility status and was used to perform additional validity checks for the final algorithm.

To create an augmented, final algorithm with optimized scope and accuracy, a panel of SMEs composed of MIO Coordinators, SCI/D clinicians, SCI/D leaders, researchers, and

data programmers from VHA was convened to identify additional CDW data and EMR elements. The full scope of VHA SCI/D System of Care services, and their associated discrete data elements within the VHA Enterprise CDW, was identified: face-to-face outpatient visits, home care, telephone care, VA Video Connect (VVC) telehealth care, inpatient care, and residential care (appendix 1). Additional algorithm inclusion criteria were (1) assignment to a SCI/D primary care team and (2) receipt of SCI/D Annual Exam services.

With these elements added to the algorithm, a Veteran was included in the VSR if they (a) had a qualifying diagnosis and (b) had received 2 or more of the 10 SCI/D specialty outpatient or inpatient services (appendix 1). Two encounters were required as a strategy to minimize patient inclusions in the VSR due to recording errors or potential misapplication of SCI/D clinic stop codes.

Results

To evaluate VSR accuracy, the final algorithm was used to identify cases in the CDW that met the diagnostic and utilization criteria for the period from October 1, 2012, through September 30, 2017. Using this date range, 28,202 unique cases were identified and compared with the Validated Data Set (fig 2, Step 3) to examine the algorithm's classification accuracy. Results indicated that 92% (n=26,035) of Veterans identified by the final algorithm matched cases in the *eligible* category of the Validated Dataset (fig 2, Step 3), 4% (n=1229) matched cases in the *ineligible* category, and 3% (n=914) were not found in the Validated Dataset.

In January 2019, a test version of the VSR report was made available to MIO Coordinators and SCI/D clinicians through the electronic VSSC platform. Over the course of several months, users validated eligibility data and provided interface feedback. During the test period, MIO Coordinators were able to do chart reviews and correct changes in diagnoses, incorrect encounter codes, or other misclassifications. The VSR algorithm was then implemented as a VSSC report for VHA-wide clinical and operational use on April 1, 2019. Subsequently, VSSC analytics and Microsoft Power Business Intelligence software tools³⁶ were used to compile data and create interactive dashboards and operational reports for VHA leaders, clinicians, policymakers, and researchers. VSR data are refreshed monthly to provide information about where individuals with SCI/Ds receive care and what services are being utilized.

At the end of fiscal year 2019, a team of MIO Coordinators and SMEs from the field evaluated VSR accuracy using EMR data for 14,133 VSR cases (10,788 SCI/D, 2680 MS, 665 ALS) across 14 of the 25 SCI/D Centers. The process identified a false-positive rate of 1.59% for all diagnostic categories (SCI/D, MS, and ALS) and 2.0% among the SCI/D-only group. Most of the misclassifications were changes in diagnosis, clerical errors, or inaccurate coding for visits from prior fiscal years. This sample of over half the SCI/D Centers' registry patients demonstrated yet another increase in accuracy (98% or higher) beyond the initial 92% accuracy rate noted through 9/30/2017.

To ensure ongoing accuracy, MIO Coordinators conduct chart reviews of new cases added to VSR with each monthly update. Diagnostic and utilization errors found within a

current fiscal year are corrected using manual inputs with the assistance of local facility health information management staff. This practice, over time, further enhances the VSR accuracy by reducing the number of false positive cases pulled into the VSR.

The VSR report compiles CDW data from the computerized patient record system EMR, as well as VHA facilities that have transitioned to the new VHA Cerner EMR, to include Veterans with SCI/D, MS, and motor neuron disease, both living and deceased, who meet the diagnostic and utilization VSR algorithm criteria (fig 3). The report provides VSR patient data for all VHA SCI/D Hub & Spoke Catchment Areas from October 1, 2012, to the current fiscal year and is updated monthly. Underlined totals in each column offer hyperlinks to data for individual Veterans. Overall VSR data can be sorted (fig 3, a) by fiscal year, diagnostic category (SCI/D, MS, Motor Neuron), deceased status, and most recent utilization (within 3 years or more than 3 years). Each of the 25 catchment areas can be expanded to their individual SCI/D Center/Hub facility and Spoke Site Veteran data (fig 3, b). Data in all columns link to etiology, neurologic level of injury, injury severity (American Spinal Injury Association Impairment Scale, ASIA)^{37,38}, and dates and types of services used by each Veteran. Data in the first column provides unique Veteran information for those who are assigned to a Hub or Spoke facility based on their permanent residence on file with VHA (fig 3, c). Data can also be sorted by the location of a Veteran's most recent service utilization (fig 3, d) and total unique Veterans with SCI/D by closest Hub or Spoke location and recent utilization combined (fig 3, e). A hyperlink in the Demographics column directs users to Veteran data on variables that include sex, age, marital status, disability, caregiver status, employment, religion, race, service connection, and address (fig 3, f). Additional VSSC operational reports using the VSR identified cases are presented in appendix 2 and Supplemental Figs S1 through S6. These include Veteran inpatient status, telehealth utilization, COVID test, and vaccination status. Operational reports are also available for critical population data points such as living setting, caregiver status, ventilator status, bladder management method, education, and employment. Individual Veteran-level data are highly restricted to key personnel, including VHA employees and contracted or without compensation personnel who have cleared VHA background checks, and requires multi-level organizational special permissions to access.

Discussion

The VSR offers a valid, accessible, and accurate resource for clinicians, leaders, and researchers to guide clinical care, advance knowledge, and promote performance improvement for Veterans living with SCI/Ds. Data from the VSR establishes 1 of the largest ongoing longitudinal SCI/D datasets in the U.S. It is also 1 of the few SCI/D registries that include individuals with non-traumatic SCI/D and holds potential to advance research and improve treatment in this group. VSR data are currently being used by VHA national program offices, VHA SCI/D System of Care frontline staff, informatics specialists, and medical providers from other VHA service lines to manage care and resources for the

Level	Total Patients by Closest SCI/D Facility	Total Patients by Most Recent SCI/D Facility Utilization	Total Patients by Closest SCI/D Facility and/or by Most Recent Facility Utilization	View Patient Demographics
ⓓ National	25,002	24,005	25,002	ⓕ
ⓓ Augusta, GA HCS	1,875	2,142	2,225	ⓕ
ⓓ Aurora, CO HCS	353	1,049	1,074	ⓕ
ⓓ Boston, MA (Jamaica P/West Roxbury/Brockton)	1,213	1,214	1,240	ⓕ
ⓓ Bronx, NY HCS	308	490	529	ⓕ
ⓓ Cleveland, OH HCS	1,493	1,672	1,729	ⓕ
ⓓ Dallas, TX HCS	259	949	952	ⓕ
ⓓ East Orange/Lyons, NJ	526	617	654	ⓕ
ⓓ Hampton, VA HCS	224	121	245	ⓕ
ⓓ Hines, IL HCS - All Spoke Sites	1,069	1,021	1,216	ⓕ
ⓓ (515) Battle Creek, MI HCS	124	123	143	ⓕ
ⓓ (537) Chicago, IL HCS	250	126	275	ⓕ
ⓓ (550) Danville, IL HCS	106	111	139	ⓕ
ⓓ (555) North Chicago, IL HCS	52	22	62	ⓕ
ⓓ (578) Hines, IL HCS	225	891	899	ⓕ
ⓓ (583) Indianapolis, IN HCS	124	167	172	ⓕ
ⓓ (610/610A4) Northern Indiana HCS	72	56	84	ⓕ
ⓓ (655) Saginaw, MI HCS	86	49	91	ⓕ
ⓓ Houston, TX HCS	1,135	1,206	1,279	ⓕ
ⓓ Long Beach, CA HCS	342	399	1,079	ⓕ
ⓓ Memphis, TN HCS	1,090	1,180	1,250	ⓕ
ⓓ Miami, FL HCS	518	696	751	ⓕ
ⓓ Milwaukee, WI HCS	449	532	595	ⓕ
ⓓ Minneapolis, MN HCS	1,256	1,404	1,429	ⓕ
ⓓ New Mexico HCS	242	410	444	ⓕ
ⓓ Palo Alto, CA HCS	295	1,171	1,182	ⓕ
ⓓ Richmond, VA HCS	2,059	2,253	2,420	ⓕ
ⓓ San Antonio, TX HCS	581	667	692	ⓕ
ⓓ San Diego, CA HCS	893	1,086	1,119	ⓕ
ⓓ San Juan, PR HCS	352	396	399	ⓕ
ⓓ Seattle/American Lake, WA	366	1,030	1,064	ⓕ
ⓓ St. Louis-John Cochran/Jefferson Barracks, MO	1,109	1,480	1,642	ⓕ
ⓓ Syracuse, NY HCS	204	722	734	ⓕ
ⓓ Tampa, FL HCS	1,239	1,928	2,013	ⓕ
ⓓ Unknown	12	9	9	ⓕ

Fig 3 VSR report provided through VSSC platform, showing VSR cases assigned to SCI/D Hub and Spoke facilities.

Veteran SCI/D population. With 38,022 algorithm-identified cases from 10/1/2012 through 11/2/2022, the VSR includes a large sample of Veterans eligible for, and served by, the VHA SCI/D System of Care. This allows sampling from the VSR database with sufficient statistical power to detect meaningful differences in group or effect sizes for cross-sectional, prospective, and longitudinal studies. The accuracy and validity of the VSR algorithm also minimize the need for data augmentation, complicated data imputation, remediation, and/or triangulation strategies to address missing data to allow accurate inferences and inform future studies. The VSR provides a foundation for reliable analyses, results, and conclusions regarding national VHA trends.³⁹⁻⁴⁷ The consistency and uniformity of VSR data can also facilitate collaboration and harmonization with non-VHA SCI databases to increase the generalizability of results from VSR studies to non-Veteran US and international populations.²³

Analysis of VSR data (appendix 2, Supplemental Figs S1 through S6) reveals important trends in patient demographics and utilization that are important for designing interventions, improving outcomes, and informing resource allocations for future services. For example, VSR data show that male Veterans who are new to VHA SCI/D care tend to be older (65+) and more likely to present with traumatic SCI diagnoses. VSR trends are consistent with census data that show a growing population of women who are volunteering for military service.⁴⁸ VSR data indicate that women are

more likely to receive VHA care for non-traumatic spinal cord diagnoses, which suggests a need for VHA SCI/D Centers that provide not only SCI/D specialized care but also the provision of comprehensive women’s health care for women Veterans with SCI/D. More specifically, women Veterans with SCI/D may need increased resources and support for accessing mammograms and cervical cancer screening. The overall aging VSR population will likely demonstrate increased utilization over time of additional prosthetics, rehabilitation, caregiving resources, and long-term/residential care. These data predict a growing need for long term, geriatric, and residential options for VHA SCI/D System of Care services. VSR data are vital for meaningful guidance of clinical care, quality improvement efforts, research results, and accurate demand forecasting.

Limitations

One limitation of the VSR is its exclusive focus on Veterans, a significant but declining percentage of the U.S. population.⁴⁸ This focus on US Veterans limits the number of individuals who are enrolled each year and restricts the availability of the data to VHA staff and investigators. To balance these constraints, VHA leaders and researchers have established collaborations with SCIMS and RHSCIR to design joint analyses of data and align VSR with other

databases and research. Another limitation is that over 90% of Veterans in the VSR are men. This trend may represent restricted ranges for some variables and affect the robustness of statistical analyses or the types of samples that can be drawn from the data. Finally, the VSR identifies only Veterans who have received VHA SCI/D System of Care services. Future research is needed to determine if Veterans with SCI/D in the VSR who have accessed VHA care (a) differ in significant ways from non-Veterans within or outside the US or (b) differ substantially from Veterans with SCI/D who have not accessed VHA services.

Future directions

Future analyses using the VSR will include longitudinal analyses of patient-level data associated with service utilization and health outcomes. For example, mental and physical health comorbidities and mortality data available in the VHA CDW could be used to predict the frequency of outpatient care, inpatient admissions, and emergency department visits for VSR cases. Mixed-methods research studies might use quantitative surveys and qualitative interviews to assess overall patient satisfaction, SCI/D treatment preferences, barriers to access, and Veteran-driven recommendations for even finer Veteran-centric care. Veteran-centered approaches can be further enhanced by providing aggregated, de-identified data and outcomes to Veterans, families, and organizations to contribute knowledge and assist in making choices for care.

Two areas of study that hold potential for significant advancements in SCI/D knowledge are pre-injury health status for patients with SCI/D and longitudinal tracking of disease progression for patients with non-traumatic SCI/D, including MS and ALS. The VSR's ability to identify cohorts with and without physical and mental health co-morbidities can improve understanding of how these variables affect outcomes such as community participation, life satisfaction, complication rates, and mortality. Longitudinal studies that track individuals in the VSR who access VHA acute rehabilitation services and continue receiving the full complement of SCI/D System of Care Services may hold key insights into the course of recovery, natural history, and outcomes for Veterans with SCI/D.

Future partnerships include a collaboration with the US Department of Defense to determine ways to unify and combine VHA and DoD SCI/D registries consistent with the VA Electronic Health Record Modernization initiative. Partnerships to further harmonize VSR data with SCIMS and other SCI international data sets are on the horizon. Discussions are in progress regarding the possibility of making de-identified, aggregate data sets publicly available. While individual Veteran-level data are highly restricted to key VHA personnel, non-VHA employees who engage with VHA leaders and researchers in partnered projects and initiatives could seek without compensation status with proper clearances in order to access Veteran-level data. Research might also include comparisons of health care outcomes and access to health care resources for individuals receiving care in different SCI/D Systems of Care.

Conclusions

The modernized VSR as 1 of the largest ongoing longitudinal SCI/D datasets in North America and provides best-practice operational reports for VHA population health management and evidence-based care. It serves as the foundation for high-quality operational data products and dashboards, VHA performance measures, and successful program evaluations. The VSR is used by VHA clinician-researchers through partnerships with other longitudinal SCI data sets, such as the US SCIMS and the Canadian RHSCIR. The VSR can now be more easily leveraged to substantially contribute to world-class SCI/D knowledge, population health, and best practices.

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Appendix 1. VHA SCI/D Registry Algorithm Final Criteria (Business Rules)

SCI/D PACT Team:	At least 1 assignment to a SCI/D specialty Patient Aligned Care Team (PACT) in the Patient Centered Management Module (PCMM); prior to June 2017, referred to as Primary Care Management Module (PCMM).
SCI/D Stop Code 210:	At least 2 outpatient encounters (obtained from the CDW) with a primary or secondary stop code assignment of 210 (Spinal Cord Injury) and a qualifying SCI, MS, and/or ALS diagnosis on 2 different calendar days.
SCI/D Stop Code 215:	At least 2 outpatient encounters (obtained from the CDW) with a primary or secondary stop code assignment of 215 (Spinal Cord Injury Home Care Program) and a qualifying SCI, MS, and/or ALS diagnosis on 2 different calendar days.
SCI/D Stop Code 224:	At least 2 outpatient encounters (obtained from the CDW) with a primary or secondary stop code assignment of 224 (Telephone Spinal Cord Injury) and a qualifying SCI, MS, and/or ALS diagnosis on 2 different calendar days.

(continued)

(Continued)

SCI/D PACT Team:	At least 1 assignment to a SCI/D specialty Patient Aligned Care Team (PACT) in the Patient Centered Management Module (PCMM); prior to June 2017, referred to as Primary Care Management Module (PCMM).
SCI/D Stop Code 210:	At least 2 outpatient encounters (obtained from the CDW) with a primary or secondary stop code assignment of 210 (Spinal Cord Injury) and a qualifying SCI, MS, and/or ALS diagnosis on 2 different calendar days.
SCI/D Stop Code 215:	At least 2 outpatient encounters (obtained from the CDW) with a primary or secondary stop code assignment of 215 (Spinal Cord Injury Home Care Program) and a qualifying SCI, MS, and/or ALS diagnosis on 2 different calendar days.
SCI/D Stop Code 224:	At least 2 outpatient encounters (obtained from the CDW) with a primary or secondary stop code assignment of 224 (Telephone Spinal Cord Injury) and a qualifying SCI, MS, and/or ALS diagnosis on 2 different calendar days.
SCI/D Stop Code 225:	At least 2 outpatient encounters (obtained from the CDW) with a primary or secondary stop code assignment of 225 (Spinal Cord Injury Telehealth Virtual) and a qualifying SCI, MS, and/or ALS diagnosis on 2 different calendar days.
SCI Dx:	At least 1 outpatient encounter (obtained from the CDW) with a qualifying provider type , or 1 inpatient episode (obtained from the patient treatment file (PTF) records from the VSSC workload data-mart) or 1 central Fee payment file episode of care for both inpatients and outpatients with a primary and/or secondary qualifying SCI diagnosis.
MS Dx:	At least 1 outpatient encounter (obtained from the CDW) with a qualifying provider type , or 1 inpatient episode (obtained from the PTF records from the VSSC workload data-mart) or 1 central Fee payment file episode of care for both inpatients and outpatients with a primary and/or secondary qualifying MS diagnosis.
ALS Dx:	At least 1 outpatient encounter (obtained from the CDW) with a qualifying provider type , or 1 inpatient episode (obtained from the PTF records from the VSSC workload data-mart) or 1 central Fee payment file episode of care for both inpatients and outpatients with a primary and/or secondary qualifying ALS diagnosis.
SCI/D Treating Specialty:	At least 1 inpatient episode (obtained from the PTF records from the VSSC workload data-mart) in specialty Spinal Cord Injury (22) or specialty Spinal Cord Injury Observation (23) and/or specialty Nursing Home Long Stay Spinal Cord Injury (46).
SCI/D Annual Exam:	At least 1 SCI Annual Exam (obtained from the CPRS note title 'SCI Annual Exam' in the CDW).

Appendix 2. Additional Operational Reports

An operational dashboard was created from the VSR VSSC report data (Supplemental Fig S1, available online only at <http://www.archives-pmr.org/>). This dashboard links to a gallery of tables, graphs, and charts that describe Veterans' demographics, SCI/D etiology, level of neurologic impairment, geographic location, and living/deceased status. The dashboard monitors national trends, demographics, panel sizes by area, and demographics. The dashboard trends menu (Supplemental Fig S2, available online only at <http://www.archives-pmr.org/>) monitors changes in VSR Veterans over time. As shown on the left, these data can be filtered by multiple categories, including fiscal year, sex, facility, diagnosis, etiology, race, ethnicity, rurality, and point of care.

Another VSR-based dashboard (Supplemental Fig S3, available online only at <http://www.archives-pmr.org/>) provides a view identifying the proportion of patients per catchment area during FY22. This graph illustrates the wide variation in the number of Veterans who are served by each facility because of the geographic location of patients' homes and Veterans' utilization choices. The menu shown on the left of this dashboard allows users to filter cases by closest facility or by utilization to view numbers of Veterans according to Veterans' closest SCI/D Hub or Spoke. The graph can also be filtered by diagnosis, sex, age, and period of military service. These descriptive data allow facility,

region, and national leaders to consider trends for resource allocation, staffing, and growth by catchment area.

As of the end of fiscal year 2021 (Supplemental Fig S4, available online only at <http://www.archives-pmr.org/>), diagnoses for living patients are 73% SCI/D, 20% MS, and 7% MN. Sixty-eight percent (68%) of VSR Veterans are over the age of 60, including 32% who are 70-79 years old and 58.63% who are 65-84 years. Most Veterans with SCI/D in the VSR (92%) are men.

The Registry Trends dashboard (Supplemental Fig S5, available online only at <http://www.archives-pmr.org/>) allows users to filter the VSR by sex "women." The report shows that most living and deceased women Veterans as of August 2022 are 45-64 years old (45%), 53% served during the Persian Gulf period of service, and almost half (49%) have a diagnosis of non-traumatic SCI/D (ie, MS). The same dashboard can be filtered (Supplemental Fig S6, available online only at <http://www.archives-pmr.org/>) by sex "men." The graphs show that as of August 2022, compared with women Veterans, only 29% of men Veterans living and deceased are age 45-64 years, only 22% served during the Persian Gulf War period, and most (72%) have an SCI diagnosis (Supplemental Fig S6). In contrast, VSR trends indicate that men Veterans tend to be older than women Veterans (59% age 65 years old or older), are more likely to be diagnosed with traumatic SCI (72%), and are more likely to have served during the Vietnam Era (52%).

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