Multiple Sclerosis Surveillance Registry: Introduction and Overview

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Disclosures

No interests to disclose-MW

PESG and PVA staff have no interest to disclose.

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Learning Objectives

At the conclusion of this activity, the participant will be able to:

1. List and describe advantages of surveillance registries
2. Describe the major features of the Multiple Sclerosis Surveillance Registry (MSSR)
3. Become familiar with entering patient data into the MS Assessment Tool
4. Describe and discuss the monitoring capabilities of the MSSR
CE/CME Credit

If you would like to receive continuing education credit for this activity, please visit:

http://PVA.cds.pesgce.com
Multiple Sclerosis Surveillance Registry

- MSCoE Clinical Surveillance and Integrated Care
- Converged Registry Solutions in VHA
- MSCoE Clinical Network & Surveillance Goals
- Multiple Sclerosis Surveillance Registry (MSSR) Data Flow
MSCoE Clinical Program Highlights

• MS Policy Handbook (renewal 2016)
  • Create a surveillance registry to track and evaluate patients with MS in the VHA nationally

• Integrated Neurology Project
  • MSCoE, PADRECC, EpilepsyCoE
  • VISN 5-6 & 20
  • Initiate MSAT/MSSR in 4 key MSCoE VAMCs

• NMSS & Outside Collaborations

• MS Disease Modifying Therapy Access & Risk Monitoring

• MS Interdisciplinary Clinics
Integrated Neurology Project

• Provide access to subspecialty care and consultation in Epilepsy, movement disorders, and Multiple Sclerosis

• Choose the means of consultation/treatment appropriate to the clinical issue. *Care delivery modes evaluated will include face-to-face, Telemedicine, Telephone Consults, E-Consults & Secure Messaging, and Multi-disciplinary Clinics*

• Support Primary Care and General Neurology clinicians with complex diagnosis, management, and treatment issues

• When medically appropriate, deliver care from the Centers of Excellence to Veterans at their home, local VAMC or CBOC.
Integrated Neurology Care
Specialty Care and PACT Collaboration

PACT Teams

VAMC Neurologist

SCI

Neurology Specialty Care Networks (MSCoE, ECoE, PADRECC)
Consult options to meet optimize patient & provider communication
MSCoE East & West Network
Benefits of Surveillance
MS Assessment Tool & MSSR

- MSAT & MSSR developed initially by the Northwest Innovation Team-Portland 2012 then supported by VA IT contractor 7Delta after New OI&T Service Request Award was granted in 2013 (MSCoE-East)
- MSAT is a user-friendly portal integrated with CPRS allowing efficient entry of key demographic and clinical variables
- MSSR is a secure web-based database that allows efficient data views and queries
- Data on utilization (outpatient, inpatient, prosthetics), cost and disability evaluations linked to MSSR
Veterans Health Care System
Converged Registries Solutions (CRS)

- Common IT platform for clinical surveillance in VHA
- Data retrieved from common platform: Corporate Data Warehouse (CDW)
- Direct input of data elements from health care providers
- CRS platform used for the following VHA registries: TBI, Oncology, Eye Injury, Embedded Fragments, Implant Tracking & Alert System
MSSR Deployment Architecture
MS Surveillance Registry/MS Assessment Tool
(https://vaww.mssr.registries.aac.va.gov)

VA MS Care Network
- Converged Registries IT support
- Web-based MSAT integrated in CPRS
- National CPRS roll-out
- 1200 MS patients enrolled in 2 US Regions
- Updates to MSAT more efficient
Multiple Sclerosis Assessment Tool

- Annual Assessment (per VA MS Policy Handbook)
- Data captures via live visits, telehealth and telephone
- Variables:
  - Demographics
  - Onset year & symptoms
  - Diagnosis (MS, CIS, NMO, not MS)
  - Relapses
  - Neurological Disability (EDMUS)
  - MS Disease Modifying Therapy History
  - Untoward effects
MSSR Data Flow & System Design

1. **Patient Encounter**
   - Live or Tele-visit
   - MS or Related Q/D

2. **CPRS 'Tools' Menu**
   - Web-link to MS Assessment Tool

3. **MSAT**

4. **MSAT data**

5. **MSSR**

6. **MSSR requests patient Data from CDW via ETL**

7. **Vista**

8. **CDW**

9. **CRS**

10. **MSSR Dashboard (via secure web-link)**

11. **MSSR Standard & Ad Hoc Reports**

12. **VIA-DeD Other Databases (patient, discharge, lab)**
Multiple Sclerosis Surveillance Registry

Conclusions

- Accessible database with core information to meet surveillance goals of MSCoE
- User-friendly health care provider dashboard and tools to improve patient assessments and track progress
- Ongoing IT support provided by VA OI&T contract for updates and repairs
- MSSR will serve as a clinical source for quality improvement and research
Thank you
VHA MULTIPLE SCLEROSIS SURVEILLANCE REGISTRY (MSSR)

William J. Culpepper II, PhD, MA

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MS Center of Excellence – East
and
Assistant Professor, Department of Neurology
University of Maryland School of Medicine
Disclosures

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3. Describe and discuss the monitoring capabilities of the MSSR
MSSR: Overview

- MSSR, along with MSAT, was designed to capture and organize the minimally important clinical data on the VHA MS population.
- These data can be used to describe the epidemiology of a clinic MS population and nationwide once sufficiently populated.
- Data from the MSAT serves as the parent table in MSSR.
MSSR: Overview

• VHA extant data have been incorporated into MSSR

• These data sets include:
  • IP & OP utilization (including Fee-Basis)
  • Pharmacy
  • Laboratory tests & results
  • Radiographic tests & results
  • Prosthetics
MSSR: Overview

• Can display all patients entered via MSAT or display a subset (e.g., females on DMT with EDMUS of 3-6)

• Graphical display of summary data (smart-charts)
  • # patients seen
  • Histogram of EDMUS scores
  • Pie chart of DMT users by type
  • Pie chart of types of assistive devices (e.g., walker)
MSSR access

• Access to MSSR is granted by business owners
  • Once you have MSAT setup within your CPRS system contact us and we’ll enter your information into MSSR user database
  • Joel Culpepper (William.Culpepper@va.gov)
  • Mitch Wallin (Mitchell.Wallin@va.gov)

• For the majority of providers, access will be limited to the MS patients from your VISN

• Access to MSSR is web-based
  • Must be logged into the VHA as VHA credentials needed to authenticate users
  • https://vaww.mssr.registries.aac.va.gov/Patients.aspx
  • PIV/PIN issues are being addressed…..
MSSR access

As of 0800 EST 3/10/2015, You are now accessing new MSSR software.

To report issues

Please follow your local IRM policies for reporting any technical errors.
If they request that you report your issue without their assistance either
Call the VA/CO Helpdesk (866.596.4357)

or

Log a Remedy Ticket for MSSR Registry
Category = Applications-HealthCare-Vista
Type = MSSR Registry
Item = select one from the available list

OK
## MSSR Patients

### Filters
- **Name or SSN**: 
- **Location**: Any Location
- **Source**: Culpepper Alg, Non-MS Assessment, MS Assessment
- **Gender**: Any Gender, Male, Female
- **DMT MS Medications**: 
- **Status**: Any
  - **Timeframe**: Currently
  - **EDMUS Score between**: 0 and 10

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### Demographic and clinical features of the MSSR Pilot Sample from the MSCoE clinic network (n=1,000)

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<th>Location</th>
<th>N</th>
<th>Age (yr. mean)</th>
<th>Gender (% male)</th>
<th>Race (%)</th>
<th>Diagnosis</th>
<th>Relapses in last year (mean)</th>
<th>EDMUS (mean)</th>
<th>DMT (% use)</th>
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MSSR: Enhancements…

- Second enhancement request underway
- Will build upon MSAT & VHA claims data that were added during the first enhancement contract
- Ultimate goal is
  - Turn-key summaries of HC utilization & costs per-patient, per-year
  - Report MS-specific quality indicators (AAN & NMSS)
  - Provide real-world surveillance (DMT monitoring)
MSSR: HC utilization summary

- Aim with this enhancement is to provide a longitudinal summary (per-patient, per-year) of IP/OP HC utilization & costs
  - Draws from the VHA claims data
  - Will provide annual summary of frequency of IP by category (med-surg, SNF, etc.) and length of stay
  - Will provide annual summary of frequency of OP by clinic stop and visit day
  - Will provide annual summary of IP, OP, Rx and prosthetics costs as well as total HC costs
MSSR: MS Quality Indicators

- AAN MS quality measures (2015)
- NMSS Quality Indicators (2005)
- For those measures that can be linked to a diagnosis or procedure code (ICD/CPT)
  - Create indicator variables for each QI annually
  - Develop summary statistics and charts to display longitudinally at the clinic- and patient-level
- Allows assessment of quality of care delivered
- Targets areas for quality improvement activities
MSSR: DMT Surveillance

• Several of the newer oral DMTs can have an unfavorable side-effect profile
  • Pre-screening and routine FU testing recommended to minimize adverse events

• Following the CFUs from PBM
  • Create DMT-specific “dashboards” that chart if appropriate screening/testing was done
  • Generate summary statistics/charts at the clinic/VISN level
  • Generate lists of patients NOT compliant with recommended screening/testing for targeted FU
MSSR Enhancements

• Want feedback from users in the field
  • Please let us know if you find “bugs” in the system
  • If you have suggestions for improvements to the existing system
  • If you have suggestions for new features

• We will be distributing manuals FALL 2016
  • Technical guide to pass on to your local CAC to aid installation and setup
  • User guide to provide instruction on how to access the MSAT/MSSR and perform standard functions
MSSR Enhancements

• We hope that the MSSR will prove valuable for patient management as well as for epidemiologic and research projects
• The MSAT/MSSR is being sustained (funded) under the VHA’s Converged Registries Solution (CRS) platform
• New feature development have to be secured through a competitive proposal process like research grants
• Dollars allocated for enhancements varies
MSSR

• Now that you have seen some of the features and capabilities of the MSSR
• The next presentation will walk you through the process of entering data via the MS Assessment Tool (MSAT)

QUESTIONS
CE/CME Credit

If you would like to receive continuing education credit for this activity, please visit:

http://PVA.cds.pesgce.com
Multiple Sclerosis Surveillance Registry:
ENTERING PATIENTS INTO THE MS ASSESSMENT TOOL (MSAT)

PVA Summit-2016
Orlando, FL

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Assistant Professor of Neurology
Oregon Health & Science University
Disclosures

Rebecca Spain has the following interest to disclose:

- Research support from:
  - VA Rehabilitation, Research & Development Service (B7493-W)
  - National MS Society
  - Conrad Hilton Foundation
  - Medical Research Foundation of Oregon
  - Race to Erase MS
  - OCTRI (UL1TR000128)
- Honoraria from the National MS Society and the MS Society of Portland

PESG and PVA staff have no interest to disclose.

This continuing education activity is managed and accredited by Professional Education Services Group in cooperation with PVA. PESG, PVA, and all accrediting organization do not support or endorse any product or service mentioned in this activity.
Learning objectives

At the conclusion of this activity, the participant will be able to:

1. Describe how to enter patient data into the MS Assessment Tool

2. Recognize the ease of entering annual updates to the MSAT
Access the MSAT from CPRS
Confirm the patient with SSN on the MSAT website

[Image of the MSAT website interface with a highlighted area showing the input field for patient SSN and the instruction to confirm the correct patient.]
Select note Title
Select “Multiple Sclerosis Assessment Tool”
Select “scheduled clinic appointment choice”
Enter assessment date and start demographics

Multiple Sclerosis Assessment Tool

Assessment Date: *

Assessment Type *
- Baseline
- Annual
- Interim
- Medications Only

Interview Completed by *
- Telephone
- Clinical Video Teleconferencing
- In-person Assessment

Date Of Death

Cause Of Death
- MS
- Natural
- Combat
- Unknown

1. Race, as defined by patient *
   - American Indian or Alaskan Native
   - Asian
   - Black or African American
*Tip: have 2 screens open to reference your clinic notes*
Enter demographics

2. Ethnicity, as defined by patient *
   - Hispanic
   - Not Hispanic

3. Gender *
   - Male
   - Female

4. Biological family history of Multiple Sclerosis? *
   - Unknown
   - None
   - Yes
Enter MS history

5. Biological family history of Clinically Isolated Syndrome? *
   - Unknown
   - None
   - Yes

6. Biological family history of Neuromyelitis Optica/Devic's Disease? *
   - Unknown
   - None
   - Yes

7. Diagnosis History *
   - Multiple Sclerosis
   - Possible Multiple Sclerosis
   - Clinically Isolated Syndrome (CIS)
   - Neuromyelitis Optica/Devic's Disease (NMO)
   - Determined NOT to have Multiple Sclerosis

8. Type of initial MS/NMO symptom (check all that apply) *
   - Motor
   - Sensory
   - Brainstem
   - Cerebellar
   - Optic Neuritis
   - Cognitive
   - Bowel/Bladder
   - Spinal Cord
Enter MS history drop-down options

7. Diagnosis History *
- Multiple Sclerosis
- Possible Multiple Sclerosis
- Clinically Isolated Syndrome (CIS)
- Neuromyelitis Optica/Devic’s Disease (NMO)
- Determined NOT to have Multiple Sclerosis

Date of first neurological sign/symptom (if known) [Select a month] [Select a year] *

Date of MS diagnosis [Select a month] [Select a year]

8. Type of initial MS/NMO symptom (check all that apply) *
- Motor
- Sensory
- Brainstem
- Cerebellar
- Optic Neuritis
- Cognitive
- Bowel/Bladder
- Spinal Cord
9. **Multiple Sclerosis Subtype** *
   - Relapsing-Remitting (RRMS)
   - Secondary Progressive (with or without relapses; SPMS)
   - Primary Progressive (PPMS)
   - Progressive-Relapsing (PRMS)
   - Not applicable (CIS or NMO)

10. **MS Service-Connection Status** *
    - Patient is service-connected for MS
    - Patient is not service-connected for MS

11. **Current MS or NMO Disability** *
    - 1 = No disability: minimal signs on neurological examination
    - 2 = Minimal and not ambulation-related disability; able to run
    - 3 = Unlimited walking distance without rest but unable to run, or a significant not ambulation-related disability
Enter MS history drop-down options

9. **Multiple Sclerosis Subtype** *
   - Relapsing-Remitting (RRMS)
   - Secondary Progressive (with or without relapses; SPMS)
   - Primary Progressive (PPMS)
   - Progressive-Relapsing (PRMS)
   - Not applicable (CIS or NMO)

   **Date transitioned**
   - Select a month
   - 2012

10. **MS Service-Connection Status** *
    - Patient is service-connected for MS
    - Patient is not service-connected for MS
11. **Current MS or NMO Disability** *
   - 1 = No disability: minimal signs on neurological examination
   - 2 = Minimal and not ambulation-related disability; able to run
   - 3 = Unlimited walking distance without rest but unable to run, or a significant not ambulation-related disability
   - 4 = Walks without aid; limited walking distance, but greater than 500 meters without rest
   - 5 = Walks without aid; walking distance less than 500 meters without rest
   - 6a = Walks with permanent unilateral support; walking distance less than 100 meters without rest
   - 6b = Walks with permanent bilateral support; walking distance less than 100 meters without rest
   - 7 = Home-restricted; a few steps with wall or furniture assistance; walking distance less than 20 meters without rest
   - 8 = Chair-restricted; unable to take a step; some effective use of arms
   - 9 = Bedridden and totally helpless

   If applicable, year patient reached an EDMUS disability score of 6 (walks with unilateral or bilateral support)
   - January
   - 2012

12. **Number of relapses** * over the past twelve months *
   - 0
   *relapse = worsening neurological symptoms for > 24hrs that stabilize or resolve
Enter MS disease-modifying therapies

<table>
<thead>
<tr>
<th>Medications</th>
</tr>
</thead>
<tbody>
<tr>
<td>13. MS or NMO medications (for baseline, be sure to document ALL medications)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Azathioprine (Imuran)</th>
<th>Never Taken</th>
<th>Current Use / Past Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cyclophosphamide (Cytoxan)</td>
<td>Never Taken</td>
<td>Current Use / Past Use</td>
</tr>
<tr>
<td>Daclizumab (Zenapax)</td>
<td>Never Taken</td>
<td>Current Use / Past Use</td>
</tr>
<tr>
<td>Dimethyl Fumarate (Tecfidera)</td>
<td>Never Taken</td>
<td>Current Use / Past Use</td>
</tr>
</tbody>
</table>
Enter MS disease-modifying therapies

Fingolimod (Gilenya)
- Never Taken
- Current Use / Past Use

- Past Use
  - Dispensing Pharmacy:
    - VA Pharmacy
    - Non-VA Pharmacy
  - Approximate date started: January 2014
  - Approximate date stopped: February 2015
  - Reason Stopped:
    - Ineffective
    - Intolerance to medication (e.g. cardiac toxicity, infection, macular edema)
    - Significant adverse event
    - Other reason stopped

- Adverse Events
  - Adverse Events Description: (75 chars max)
Enter MS disease-modifying therapies

Interferon beta-1a (Rebif)

- Never Taken
- Current Use / Past Use

- Current Therapy

- Past Use
  - Dispensing Pharmacy:
    - VA Pharmacy
    - Non-VA Pharmacy

  - Approximate date started: [Select a month] [Select a year]
  - Approximate date stopped: [Select a month] [Select a year]
  - Reason Stopped:
    - Ineffective
    - Intolerance to medication (e.g. Injection site reaction, flu-like symptoms, depression)
    - Significant adverse event
    - Other reason stopped

- Adverse Events
  - Adverse Events Description: [75 chars max]
Enter MS disease-modifying therapies

<table>
<thead>
<tr>
<th>Mitoxantrone (Novantrone)</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Never Taken</td>
</tr>
<tr>
<td>☑ Current Use / Past Use</td>
</tr>
</tbody>
</table>

Past Use

- Dispensing Pharmacy:
  - VA Pharmacy
  - Non-VA Pharmacy

- Approximate date started: [Select a month] [Select a year]
- Approximate date stopped: [Select a month] [Select a year]

- Number of doses taken: [Enter number] (50 chars max)

Reason Stopped:
- ☑ Maximum dose reached
- ☑ Ineffective
- ☑ Intolerance to medication (e.g. diminished cardiac ejection fraction, infection, nausea)
- ☑ Significant adverse event
- ☑ Other reason stopped

- ☐ Adverse Events

Is patient being monitored for cardiotoxicity?
- ☑ Yes
- ☑ No
Enter MS disease-modifying therapies

**Other Medication:**

**Other DMTs**
- Never Taken
- Current Use / Past Use

- Name of Medicine: [ ] (50 chars max)
  - Current Therapy
  - Past Use
  - Adverse Events

**Corticosteroids Medication:**

**Corticosteroids** (only include those used for maintenance therapy, not relapse therapy)
- Never taken
- Current use / Past use
Save and Prepare note

Save Draft  Save and Prepare Note  Cancel

Note Preview:
Update

Health Factors Preview:
Update

Source: SPAIN.REBECCA
Resulting note in CPRS

Question 1: Ethnicity, as defined by patient
   - Not Hispanic

Question 2: Gender
   - Female

Question 3: Biological family history of Multiple Sclerosis?
   - None

Question 4: Biological family history of Clinically Isolated Syndrome
   - None

Question 5: Biological family history of Neuromyelitis Optica
   - None

Question 6: Diagnosis History
   - Multiple Sclerosis
   - Date of first neurological sign/symptom (if known)
     - 1980
   - Date of MS diagnosis
     - 1996

Question 7: Type of initial MS/NMO symptom (check all that apply)
   - Bowel/Bladder

Question 8: Multiple Sclerosis Subtype
   - Relapsing-Remitting (RRMS)

Question 9: MS Service-Connection Status
It’s seems like a lot of work…but…next time it looks like this:

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Ethnicity, as defined by patient *</td>
<td>Asian, Black or African American, Native Hawaiian or other Pacific Islander, White, Other</td>
</tr>
<tr>
<td>3. Gender *</td>
<td>Male, Female</td>
</tr>
<tr>
<td>4. Biological family history of Multiple Sclerosis? *</td>
<td>Unknown, None, Yes</td>
</tr>
<tr>
<td>5. Biological family history of Clinically Isolated Syndrome? *</td>
<td>Unknown, None, Yes</td>
</tr>
<tr>
<td>6. Biological family history of Neuromyelitis Optica/Devic's Disease? *</td>
<td>Unknown, None, Yes</td>
</tr>
<tr>
<td>7. Diagnosis History *</td>
<td>Multiple Sclerosis, Possible Multiple Sclerosis, Clinically Isolated Syndrome (CIS), Neuromyelitis Optica/Devic's Disease (NMO), Determined NOT to have Multiple Sclerosis</td>
</tr>
<tr>
<td>Date of first neurological sign/symptom (if known)</td>
<td>January, 2009</td>
</tr>
<tr>
<td>Date of MS diagnosis</td>
<td>November, 2009</td>
</tr>
</tbody>
</table>
It seems like a lot of work…but…next time it looks like this:

9. **Multiple Sclerosis Subtype** *
   - * Relapsing-Remitting (RRMS)
   - * Secondary Progressive (with or without relapses; SPMS)
   - * Primary Progressive (PPMS)
   - * Progressive-Relapsing (PRMS)
   - * Not applicable (CIS or NMO)

10. **MS Service-Connection Status** *
    - * Patient is service-connected for MS
    - * Patient is not service-connected for MS

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    - * 7 = Home-restricted; a few steps with wall or furniture assistance; walking distance less than 2
    - * 8 = Chair-restricted; unable to take a step; some effective use of arms
    - * 9 = Bedridden and totally helpless

    If applicable, year patient reached an EDMUS disability score of 6 (walks with unilateral or bilateral support):
    - April 2014

12. **Number of relapses** * over the past twelve months *
    - 0

*relapse = worsening neurological symptoms for > 24hrs that stabilize or resolve
It seems like a lot of work…but…next time it looks like this:

<table>
<thead>
<tr>
<th>Medication</th>
<th>Status</th>
<th>Current Therapy</th>
<th>Dispensing Pharmacy</th>
<th>Reason Stopped</th>
<th>Approximate Date Started</th>
<th>Approximate Date Stopped</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Azathioprine (Imuran)</strong></td>
<td>Never Taken</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Current Use / Past Use</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Dispensing Pharmacy</td>
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<tr>
<td></td>
<td>VA Pharmacy</td>
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<td></td>
<td>Non-VA Pharmacy</td>
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<tr>
<td></td>
<td>Approximate Date Started</td>
<td>July 2014</td>
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<tr>
<td></td>
<td>Approximate Date Stopped</td>
<td>October 2014</td>
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</tr>
<tr>
<td></td>
<td>Reason Stopped</td>
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<tr>
<td></td>
<td>Ineffective</td>
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<tr>
<td></td>
<td>Intolerance to medication (e.g. nausea, flushing, infection)</td>
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<tr>
<td></td>
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MS Assessment Tool

Learning objectives:

At the conclusion of this activity, the participant will be able to:

1. Describe how to enter patient data into the MS Assessment Tool
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