

Know RND and CORE TM

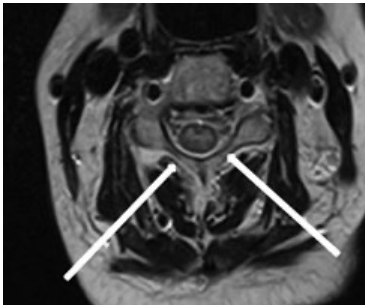
Kyle Blackburn, MD

Receiving an accurate diagnosis is not straight path when you have a rare condition

Review symptoms and perform examination

Determine 'where' in the nervous system damage is occurring ("localize the lesion")

Obtain Appropriate Testing



Enterovirus:
POSITIVE



"Spinal Cord"

Acute Flaccid
Myelitis

The reality



Back Pain



Send Home



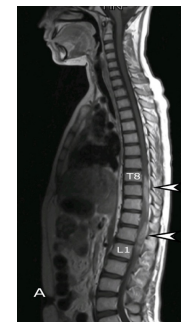
“Not sure”

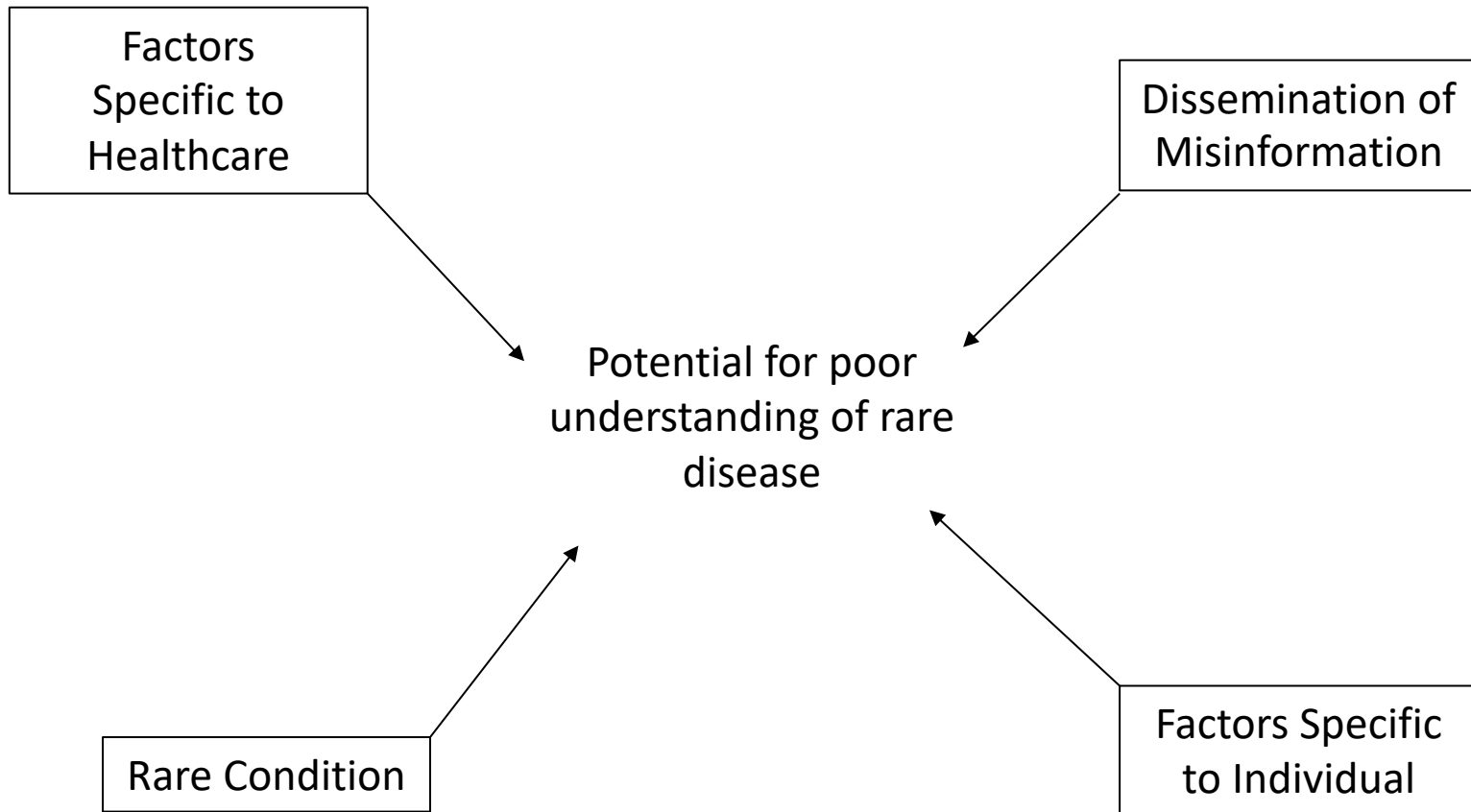


Refer to
Neurologist



“MS....maybe”





Knowledge is Power

- Knowledge of one's health condition is important to manage disease and prevent complications.
- Studies of common diseases like heart disease and diabetes demonstrate that those with better knowledge of their condition are more likely to accurately manage their medications and adhere to preventive recommendations.



Know RND: Bridging the Gap

Objectives:

Measure condition-specific knowledge and identify opportunities for learning interventions among individuals diagnosed with rare neuroimmune disorders.



Methods

Step 1: Develop measure of knowledge.

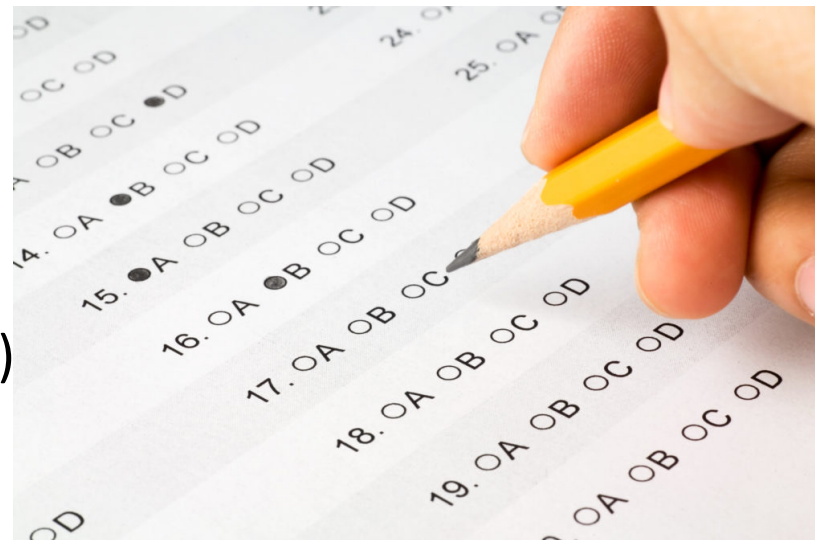
Step 2: Pilot test measure in small sample and refine measure.

Step 3: Administer measure to population of individuals with rare neuroimmune disorders.

Step 1: Develop Measure

Measure Development:

- Team: Clinicians, psychologist, SRNA.
- Domains covered:
 - Neuroanatomy (1 Question)
 - Symptoms (8 questions)
 - Disease Etiology (2 questions)
 - Relapses and Treatment (6 questions)
- Additional questions on:
 - History of diagnosis and follow-up, demographic and education.
 - Measure of Health Literacy



Step 2: Pilot Testing

- Underway! Planned for five adults.
- Each participant completes procedures, participates in interview to provide feedback.
- 4 of 5 completed (idiopathic TM).
- Upon completion, measure will undergo revisions prior to final sample.

Step 3 to come soon!

- Once measure is finalized, measure will be administered in individuals with rare neuroimmune disorders .
 - Targeting 100 individuals, roll out early 2023.
- Opportunity for individuals to consent virtually and participate via RedCap (keep an eye out!).

CORE TM

Comprehensive

Outcomes

Registry

Exploring

Transverse

Myelitis

Spinal cord injury impacts more than just motor functions

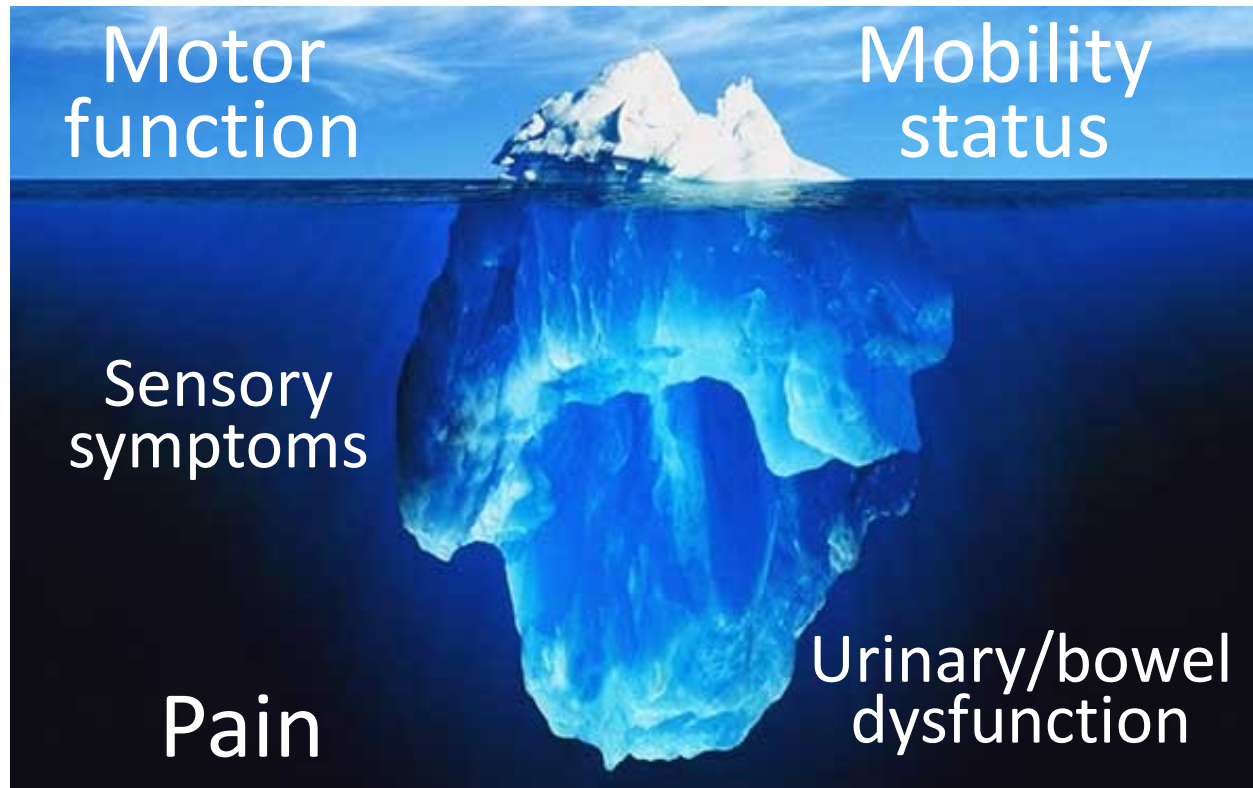


Table 2: Modified Rankin Scale for Measuring the Degree of Disability or Dependence in the Daily Activities of People who experience a Stroke

Level	Description
0	No symptoms
1	No significant disability, despite symptoms; able to perform all usual duties and activities
2	Slight disability; unable to perform all previous activities but able to look after own affairs without assistance
3	Moderate disability; requires some help, but able to walk without assistance
4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5	Severe disability; bedridden, incontinent and requires nursing care and attention

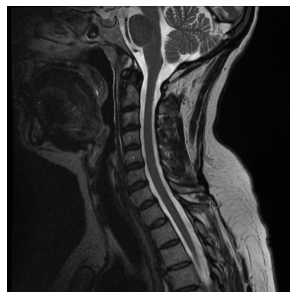
Adapted from Rankin, 1957²⁰ and van Swieten et al., 1988²¹

Study details: greater than 2 years from onset

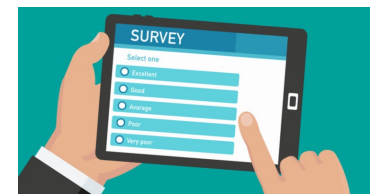
Establish a registry of patient-reported outcomes for patients with idiopathic TM and AFM.



1. Express interest and submit informed consent



2. Submit MRI images from onset on a CD. Submit medical records from diagnosis.



3. Complete surveys

Current State of CORE TM

~110 Expressed interest

16 Consented

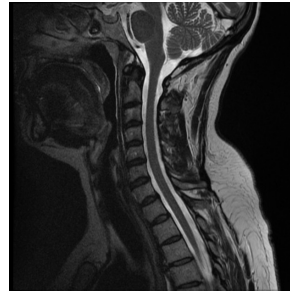
12 Completed study procedures

Adults (#)	10
Current age, years (median)	26
Median PDDS (nadir)	4 (Range 1-6)
Median PDDS (current)	1 (Range 0-6)
Immunotherapy	
Steroids	10
IVIg	2
Received PLEX	3

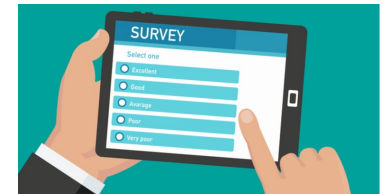
Difficulties with record collection and submission have been one of our biggest hurdles to the registry.



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Future Directions

- Streamline registry procedures for interested subjects.
 - Create virtual consenting process.
 - Remove medical record requirements.
 - Optional MRI.
- Expand outcome measures.
- Expand to other disease states.

THANK YOU!

