



MS PATHS Informatics

August 2018

Enhance The Standard of Care Through a Learning Health System



- A demonstration project supported by Biogen in collaboration with a number of MS centers
- Seeking to improve MS outcomes through real-world data and insight generation
- Leveraging technology to enable the creation of a data repository of deeply phenotyped patients
- Exploring new technologies (e.g., advanced wearables) to generate and collect patient data outside of the clinical practice setting to be made available at the point of care

MS PATHS Shared Vision: By pooling data, this network of technology-enabled MS centers will create a system of continuous learning – a way to learn from clinical practice and generate insights that can be used to inform decision making at the point of care.

MS PATHS: Enable Standardized Data Generation & Analytics



Background Information

- Demographics
- MS disease-modifying medications
- Disease type and duration



Quantitative MRI

- New and enlarging T2 lesion number*
- Brain atrophy and brain atrophy change*

*Technology for point-of-care is metrics under development.



Neuroperformance Testing

- Walking Speed Test - time
- Processing Speed Test – number correct
- Manual Dexterity Test – time
- Low Contrast Letter Acuity Test – number correct



Patient Reported Data (NeuroQol)

Physical

– Function/Health:

- Upper Extremity Function (Fine Motor, ADL)
- Bowel Function
- Urinary/Bladder Function
- Lower Extremity Function (Mobility)

Physical

– Symptoms:

- Fatigue
- Sleep Disturbance

Mental

– Emotional Health:

- Depression
- Anxiety
- Stigma
- Positive Affect and Well-Being
- Emotional and Behavioral Dyscontrol

Mental

– Cognitive Health:

- Applied Cognition-General Concerns
- Applied Cognition-Executive Function

Social:

- Satisfaction with Social Roles and Activities
- Ability to Participate in Social Roles and Activities

These data are collected on every patient at each visit as part of routine care. Long term value for MS Community

Challenges



Cultural

- Pharmaceutical company interested in data from the medical centers
- MSPT in clinical workflow



Legal

- Patient consent into MS PATHS
- Business Associate Agreements



Privacy

- Hosting MSPT identifiable information
- Data deidentification
- MS PATHS support



Regulatory

- MSPT medical device in US and EU
- EU regulations



Technical

- HIE features and integrations
- Site systems need to be upgraded to enable Gateway
- MSPT Device, LHS data curating

Backup



High Level Solution Data Flow

