

ORIGINAL ARTICLE

Using rasch motor FIM individual growth curves to inform clinical decisions for persons with paraplegia

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Study Design: A longitudinal retrospective study.

Objective: To better understand individual-level temporal change in functional status for participants with paraplegia in the National Spinal Cord Injury Database (NSCID), as measured by Rasch Transformed Motor Functional Independence Measure (FIM) scores.

Setting: Multicenter/Multistate longitudinal study across the United States.

Methods: Non-linear random effects modeling, that is, individual growth curve analysis of retrospective data obtained from the National Institute on Disability and Rehabilitation Research (NIDRR) NSCID.

Results: We generated non-linear individual level trajectories of recovery for Rasch Transformed Motor FIM scores that rise rapidly from inpatient rehabilitation admission to a plateau. Trajectories are based on relationships between growth parameters and patient and injury factors: race, gender, level of education at admission, age at injury, neurological level at discharge, American Spinal Injury Association Impairment Scale (AIS) at discharge, days from injury to first system inpatient rehabilitation admission, rehabilitation length of stay, marital status and etiology. On the basis of study results, an interactive tool was developed to represent individual level longitudinal outcomes as trajectories based upon an individual's given baseline characteristics, that is, information supplied by the covariates and provides a robust description of temporal change for those with paraplegia within the NSCID.

Conclusions: This methodology allows researchers and clinicians to generate and better understand patient-specific trajectories through the use of an automated interactive tool where a nearly countless number of longitudinal paths of recovery can be explored. Projected trajectories holds promise in facilitating planning for inpatient and outpatient services, which could positively impact long term outcomes.

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INTRODUCTION

Spinal cord injury (SCI) rehabilitation outcomes are typically evaluated at the group level based on cross-sectional analysis for a specific point in time, such as at discharge from inpatient rehabilitation.^{1–3} Such methodologies can be informative about the group studied at that time point, but do not provide information about how an individual progresses over time. Recently, researchers have adopted sophisticated techniques to evaluate individual level temporal change, which can be modeled by linear or curvilinear functions or by more complex non-linear functions, depending on the nature of change and the time frame of interest.^{4–9} This type of modeling also allows for examination of associations between characteristics of the person, the injury or other factors and the pattern of temporal change, that is, an individual's trajectory as measured by the outcome. This approach is known as individual growth curve (IGC) analysis.⁴ Clinicians and researchers can benefit from IGC models because they provide a 'custom tailored' understanding of patient recovery,⁵ which could be used to inform clinical planning decisions for new patients.^{5–8}

The study aim is to use the longitudinal information contained within the National Spinal Cord Injury Database (NSCID) and

employ IGC analysis to improve the understanding of functional independence for individuals with paraplegia. Our primary goal is to use IGC analysis to construct an interactive tool that provides a detailed description of individual level change as measured by the motor subscale of the Functional Independence Measure (FIM) Instrument for persons with paraplegia represented in the NSCID. Our secondary goal is to discuss how the interactive tool may be applied clinically to inform decision making.

MATERIALS AND METHODS

Primary outcome measure

The motor FIM is a 13-item measure of burden of care associated with physical functioning. Each item is rated on an ordinal scale ranging from 1 (Total Assistance) to 7 (Complete Independence). We adopted the 11-item Rasch transformed motor FIM scale (11-RTMFS) based on the analysis reported for the SCIREhab project.^{9,10} The SCIREhab study applied practice-based evidence methodology to summarize associations of patient characteristics and rehabilitation and treatment interventions to outcomes for a cohort of 1376 persons with SCI enrolled from six SCI Model Systems starting in Fall 2008.¹¹ Rasch analysis of FIM scores was conducted on a data set with a random sample of one third of participants' admission scores, a random sample without replacement of another third of participants'

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Table 1 Participant demographics (*n* = 4504)

Categorization	Percentage/mean (s.d.)
Female	21%
White	69%
Education (less than high school)	14%
Education (high school)	57%
Education (greater than high school)	29%
Neurological level (L2–S3)	10%
Neurological level (T10–L1)	41%
Neurological level (T7–T9)	15%
Neurological level (T1–T6)	34%
AIS A	61%
AIS B	10%
AIS C	14%
AIS D	15%
Marital status (married)	32%
Marital status (other)	12%
Marital status (single)	56%
Etiology (vehicular)	43%
Etiology (violence)	24%
Etiology (sports/recreation)	3%
Etiology (other)	26%
Etiology (medical/surgery)	4%
Age at injury (years)	32 (s.d. = 13)
Admission FIM motor score	32 (s.d. = 11)
Injury to rehabilitation admission (days)	23 (s.d. = 26)
Rehabilitation length of stay (days)	51 (s.d. = 33)

Abbreviation: AIS, American Spinal Injury Association impairment scale.

discharge scores and the follow-up scores for the remaining third (each participant represented once).^{9,10} The SCIREhab Rasch FIM subscales represent a subset of recent SCI Model Systems participants measured across time, and thus provides a suitable model for our study. Analysis of the motor FIM scores suggests that bowel and bladder management items do not fit a unidimensional scale and therefore were removed. For improved interpretability, we converted the interval-level 11-RTMFS into a 0 to 100 point scale. Bode *et al.*^{10,12} describe how to interpret the Rasch transformed scores and convert them to raw motor FIM scores, which may help clinicians to better translate IGC results to clinical action.

Covariates

Covariates were selected *a priori* and based on previously established associations between the covariate(s) and motor FIM scores.^{1–3,9,13} Candidate covariates include race² (*white and other), gender¹³ (*female and male), level of education at admission¹ (*less than high school, high school or greater than high school), age at injury,^{1–3,9,13} neurological level at discharge (T1–T6, T7–T9, T10–L1, *L2–S5), American Spinal Injury Association Impairment Scale (AIS)^{3,9,13,14} at discharge (A, B, C, *D), days from injury to first system inpatient rehabilitation admission⁹ (DFITRA), rehabilitation length of stay^{9,13} (RLOS), injury marital status (single*, married and other), etiology (vehicular*, violence, sports/recreation, medical/surgery and other), and preinjury employment (employed*, unemployed). Neurological level was calculated using both the right and left side levels where, if values differed, the higher score was reported. Reference categories are marked with an asterisk and all continuous covariates are centered about their respective means.⁵

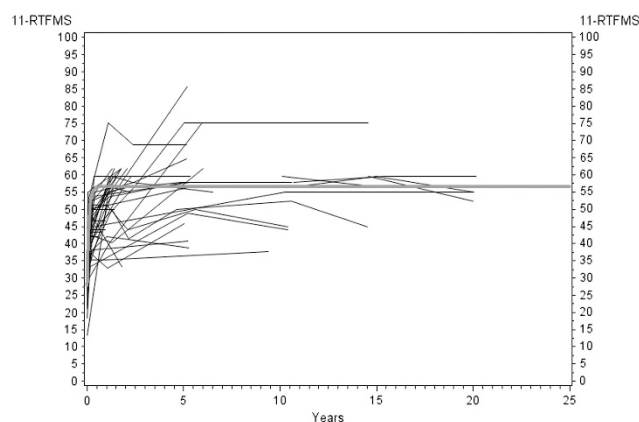
Data source

Data were retrieved from the NSCID, which captures information from approximately 13% of new SCI cases every year in the United States.¹⁵ Since its inception in 1973, 28 federally funded SCI Model System centers have contributed data to the database where the motor FIM is collected at inpatient rehabilitation admission and discharge, and at post-injury years 1, 5 and every 5 years thereafter.¹⁶ More details about this database including data collection

Table 2 NEF growth parameter estimates for the 11-RTMFS sample trajectory (unconditional model)

Growth Parameter	Estimate (unconditional model)	P-value	Lower 95% confidence limit	Upper 95% confidence limit
Asymptote	56.6	<0.0001	56.2	57.0
Pseudo intercept	27.8	<0.0001	27.6	28.1
Rate	10.4	<0.0001	10.1	10.7
Days until asymptote	199	—	—	—

Abbreviation: NEF, negative exponential function.

**Figure 1** Group trajectory and random sample of individual patterns.

procedures, forms, instructions and a complete data dictionary can be found on the National Spinal Cord Injury Statistical Center's web site at <https://www.nscisc.uab.edu>.¹⁷ We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during data collection and throughout the ensuing research process.

Study participants

The present analyses are limited to NSCID participants with T1–S3 injuries and FIM data obtained between 1995 and 2011. Participants were included if data were collected for at least three time points for any combination of rehabilitation admission, discharge or follow-up records. Analyses included only those participants with a complete set of covariate values resulting in a sample of 4504 individuals. Sample characteristics are summarized in Table 1.

Statistical procedures

Pretz *et al.*⁶ outlines numerous options for modeling longitudinal outcomes. By applying this methodology, we determined the negative exponential function (NEF), which rises rapidly to a plateau, provides the best description of how the 11-RTMFS changes over time. Details regarding the NEF are found in Pretz (2013) and Singer and Willett.^{4,6} The NEF is comprised of three growth parameters; the pseudo intercept, asymptote and rate.⁶ The pseudo intercept represents the 11-RTMFS at admission to rehabilitation and the asymptote identifies the 11-RTMFS at which the measure reaches a point of relative stability (that is, plateau). The term relative stability is used because change at this point is markedly less pronounced in comparison with change occurring before relative stability is achieved. The rate for the NEF, which represents the rate at which the asymptote is approached, does not conform to the traditional definition of change in outcome per unit of time. Consequently we report the number of days to reach relative stability, which is more easily interpreted and clinically relevant.

Table 3 NEF growth parameter/covariate pair estimates for the 11-RTMFS group (reduced conditional model)

Growth parameter/covariate/(reference group)	Estimate (conditional model)	P-value	Lower 95% confidence limit	Upper 95% confidence limit
Pseudo intercept	28.94	<0.0001	28.04	29.84
Rate	8.01	<0.0001	7.67	8.34
Asymptote	72.12	<0.0001	70.77	73.47
Pseudo intercept/age	-0.041	<0.0001	-0.061	-0.02
Rate/age	0.027	0.0032	0.009	0.045
Asymptote/age	-0.33	<0.0001	-0.36	-0.30
Pseudo intercept/gender (female)	0.94	0.0018	0.35	1.53
Asymptote/gender (female)	2.58	<0.0001	1.87	3.30
Asymptote/high school (less than high school)	1.14	0.0012	0.45	1.82
Asymptote/greater than high school (less than high school)	2.74	<0.0001	1.73	3.75
Asymptote/Non-White/ (White)	-2.07	<0.0001	-2.75	-1.40
Pseudo intercept/T1 to T6/ (L2 to S3)	-4.13	<0.0001	-5.01	-3.25
Asymptote/T1 to T6/ (L2 to S3)	-8.89	<0.0001	-10.00	-7.79
Pseudo intercept/T7 to T9/(L2 to S3)	-2.78	<0.0001	-3.76	-1.81
Asymptote/T7 to T9/ (L2 to S3)	-7.53	<0.0001	-8.76	-6.29
Pseudo intercept/T10 to L1/(L2 to S3)	-2.12	<0.0001	-2.92	-1.31
Asymptote/T10 to L1/ (L2 to S3)	-5.23	<0.0001	-6.27	-4.19
Pseudo intercept/AIS A/(AIS D)	-0.94	0.0019	-1.53	-0.3482
Rate/AIS A/(AIS D)	2.48	<0.0001	1.94	3.02
Asymptote/AIS A/(AIS D)	-16.25	<0.0001	-17.20	-15.30
Pseudo intercept/AIS B/(AIS D)	-1.48	0.0009	-2.36	-0.60
Rate/AIS B/(AIS D)	1.68	0.0005	0.73	2.63
Asymptote/AIS B/(AIS D)	-14.83	<0.0001	-16.08	-13.58
Asymptote/AIS C/(AIS D)	-8.31	<0.0001	-9.39	-7.23
Pseudo intercept/injury to rehabilitation admission	0.028	<0.0001	0.019	0.036
Asymptote/injury to rehabilitation admission	-0.049	<0.0001	-0.061	-0.037
Pseudo intercept/rehabilitation length of stay	-0.056	<0.0001	-0.064	-0.048
Rate/rehabilitation length of stay	-0.028	<0.0001	-0.029	-0.027
Asymptote/rehabilitation length of stay	-0.061	<0.0001	-0.070	-0.051
Asymptote/married/(single)	1.85	<0.0001	1.05	2.65
Asymptote/married other/(single)	2.13	<0.0001	1.10	3.16
Pseudo intercept/etiology/violence/(vehicular)	2.94	<0.0001	2.31	3.56
Rate/etiology violence/(vehicular)	1.73	<0.0001	0.94	2.52
Pseudo intercept/etiology sports and recreation (vehicular)	2.54	0.0001	1.26	3.81
Asymptote/etiology sports and recreation (vehicular)	3.14	<0.0001	1.60	4.68
Pseudo intercept/etiology/medical and surgery/(vehicular)	3.61	<0.0001	2.34	4.88
Rate/etiology medical surgery/(vehicular)	1.93	0.0160	0.36	3.49
Pseudo intercept/etiology other/(vehicular)	1.20	0.0002	0.58	1.82

Abbreviations: AIS, American Spinal Injury Association impairment scale; NEF, negative exponential function.

Analyses were performed using SAS 9.3 (Cary, NC, USA). In the first step of the analysis, an unconditional model (free of covariates) was utilized to establish the relationship between outcome and time. Next, a conditional model was constructed, which considers all covariates and determines which covariate/growth parameter relationships are significant using type III sums of squares. We retained covariates that had *P*-values < 0.05, to form a reduced conditional model. In addition to identifying significant covariates, the percent of variability in the growth parameters explained by the covariates is reported along with the interrelationships between growth parameters themselves. Although model diagnostics were performed, due to the nature of the analytic procedure and the descriptive focus of the study, no data alterations were made.

RESULTS

The growth parameter estimates for the unconditional model describe how the 11-RTMFS changes over time without considering covariate associations (Table 2). The trajectory in Figure 1 (gray curve) illustrates the general pattern of change for sample. In addition, it is no accident that the shape of the sample trajectory mirrors the

individual response patterns as seen by comparing the trajectory with a random sample of 30 different response patterns (black lines).

The sample trajectory begins with an 11-RTMFS score of 28 points (pseudo intercept) and plateaus near a score of 57, where it takes an estimated 199 days before relative stability is achieved. The sample trajectory provides an appropriate overall description of the sample but lacks detailed information about individuals. To produce individual level trajectories, covariates with significant associations to one or more of the growth parameters are necessary; these relationships are provided in Table 3. Reference categories are supplied for each categorical covariate.

The narrow width of the 95% confidence intervals about the growth parameters attests to the accuracy of the estimates.

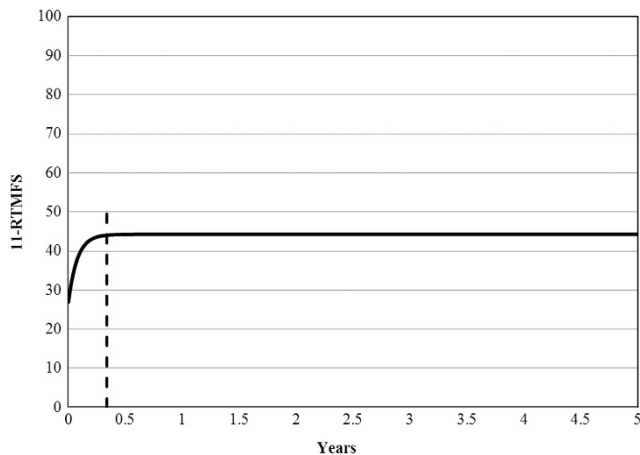
The covariates explain about half of the variability in the admission and plateau 11-RTMFS scores, and near half of the variability in rates (Table 4). However, significant *P*-values suggest that covariates not included in this model account for large amounts of parameter variability. The significant covariance estimates between growth

Table 4 Variance estimates and % of variability explained by the covariates

Variance estimate of growth parameter	Estimate (unconditional model)	P-value	Estimate (reduced conditional model)	P-value	Percent of variability explained
Asymptote	165.8	<0.0001	86.2	<0.0001	48%
Pseudo intercept	13.4	<0.0001	5.9	<0.0001	56%
Rate	32.4	<0.0001	19.0	<0.0001	41%

Table 5 Covariances between growth parameters

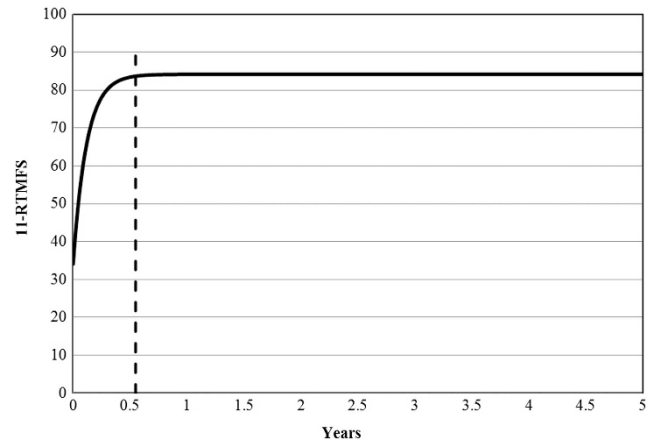
Growth Parameters	Estimate	P-value	Lower 95% confidence limit	Upper 95% confidence limit
Asymptote and pseudo intercept	13.26	<0.0001	10.77	15.74
Asymptote and rate	-25.73	<0.0001	-29.37	-22.08
Pseudo intercept and rate	2.61	0.0016	0.99	4.23

**Figure 2** Individual level trajectory for Case no. 1.

parameters indicate that the growth parameters also covary with each other (Table 5).

The positive covariance between the asymptote and pseudo intercept suggest that individuals with higher baseline 11-RTMFS scores tend to reach higher levels of functional independence. Likewise, higher baseline 11-RTMFS scores tend to be associated with faster recovery from admission to plateau. Rates and asymptotes are negatively associated, meaning those with slower recoveries tend to reach higher levels of functional independence. In other words, their recovery tends to take longer, but their plateaus tend to be higher in comparison to those with more rapid recoveries. The relationships between the various growth parameters are reflected in the results produced by the interactive tool as discussed in the ensuing paragraph.

As the intricate relationships between growth parameters and covariates are difficult to conceptualize based solely on the information in Table 3, an interactive tool that visually depicts individual level changes was created. The interactive tool generates individual-level trajectories based on specified covariate values and is provided in an online supplement. To fully appreciate the vast amount of

**Figure 3** Individual level trajectory for Case no. 2.

information available regarding individual level change, we encourage the user to investigate how different combinations of covariate values produce different trajectories. In addition, even though in reality the plateau extends to 25 years as shown in Figure 1, to better highlight initial change, the interactive tool displays a plateau that extends only to 5 years. As an example, the following cases highlight two of countless possible trajectories.

Case no. 1

The first case signifies the trajectory for female individuals who are married, 45 years old, white, have a high school education, sustained injuries resulting from vehicular incidents, have a DFITRA of 25 days; and at discharge have a T1 to T6 neurological level of injury, an AIS grade of A and a RLOS of 40 days (Figure 2). Individuals with these characteristics are projected to have an 11-RTFMS score at admission to inpatient rehabilitation near 24, which plateaus at 44, about 123 days after admission (indicated by the dashed vertical line in Figure 2). By comparing this trajectory to the sample (Figure 1), the current trajectory begins and plateaus at lower 11-RTFMS values, and reaches a plateau faster.

Case no. 2

The second case represents male individuals who are single, 21 years of age, white, have greater than high school education, sustained injuries resulting from sporting accidents, have DFITRA of 15 days; and at discharge, have L2 to S5 neurological levels of injury, with an AIS grade of D and RLOS and 25 days (Figure 3).

In comparison with the sample and Case no. 1, such individuals are projected to have a better prognosis. Those with the Case no. 2 profile have baseline scores 10 points higher than the sample and reach stability 30 points higher at about 200 days post admission (indicated by the dashed vertical line in Figure 3).

DISCUSSION

The interactive tool can be used to access a wealth of information about individual level change for a nearly limitless array of personal and injury characteristic combinations, where the cases above provide examples of just two of numerous trajectories that can be explored and used for comparative purposes. Although our primary goal is to provide a means of describing how outcomes change over time for individuals with paraplegia within the NSCID, our secondary goal is to open the door to the potential this abundance of information provides, which until now, has been unavailable to clinicians and researchers alike. For instance, consider the cases highlighted above. Along with judgment and experience, clinicians traditionally made decisions about intervention and goal setting for specific patients based on group-averaged outcomes estimated for a single time point, such as at inpatient discharge. However, through use of the interactive tool, clinicians can now base intervention planning and goal setting on a temporal projection of individual level information. Specifically, clinicians can make informed decisions based on a projected admission score, plateau, and time expected to reach plateau.

For instance, a clinician can generate a trajectory based on a new patient's values for all but three covariates provided the limitations discussed shortly are considered. That is, demographic characteristics and etiology can be entered upon admission to inpatient rehabilitation, whereas neurological level, AIS grade and RLOS values at discharge must be estimated (for example, based on facility norms) or entered as admission values. Note that if admission values are used, the resulting trajectory likely represents a conservative estimate of recovery, as neurological levels and AIS categories may improve from admission to discharge. Once information is entered, the trajectory generated can be used as a point of reference, as statistically, this trajectory is the 'best estimate' of how similar individuals progress over time. Upon obtaining the estimate, the clinician can compare the actual admission FIM score to the projected score and determine how well the values align. If they coincide, information from the trajectory can be used to assess a likely plateau and time until the plateau is reached, where the clinician can consider these estimates as future patient benchmarks and intervention and can be adjusted accordingly. Likewise, depending upon the relative position of the actual and projected admission score, benchmarks can be adjusted to better reflect those which are appropriate. This is just one of many potential clinical applications of the interactive tool.

One foreseeable challenge to a clinician in employing the interactive tool is one of interpretability. To enhance interpretability, the 11-RTFMS can be converted into raw motor FIM scores (ranging from 11–77) using the conversion scale supplied in the online supplement. In addition, clinicians can use the Rasch KeyForm that corresponds to the 11-RTFMS provided by Bode *et al.*,¹⁰ which provides an additional layer of understanding by allowing for item level comparisons at admission, plateau, or at any point in between. More specifically, KeyForms facilitate comparison of individual variations in components of motor functioning, which may cue the clinician to change the intensity or the focus of intervention strategies. Consequently, used in conjunction with a corresponding trajectory, information from the KeyForms can enhance goal setting and decisions regarding care management for individual patients.

In addition to providing individual-level projected recovery for patients with paraplegia, the interactive tool may also inform research planning and implementation. For instance, the tool could be used to define study inclusion and exclusion criteria. As an example, research may have previously set eligibility criteria to include only subjects

with chronic SCI, defined as 6 months post discharge from inpatient rehabilitation. However, at 6 months, some individuals may not have reached the chronic phase of recovery (Case 2) whereas others have (Case 1). Hence, transition to chronicity may be better defined at the time to reach stability as this is where chronic SCI seemingly begins, based on fitting the NEF to the NSCID data. Clinicians, researchers and other stakeholders are likely to develop many applications for the interactive tool.

Limitations

A number of limitations should be considered when using the interactive tool.

- (1) Trajectories are estimates based on participants that meet previously established inclusion/exclusion criteria as dictated by both entry into the NSCISC and the analytic approach. Owing to these constraints, results may not fully represent more recently injured participants or those who fail to meet the NSCISC inclusion criteria.
- (2) Trajectories produced by the interactive tool are descriptive, and as a result, comparison between trajectories should be made based on clinical relevance alone.
- (3) Trajectories are mathematical projections based on relationships between covariates and growth parameters. As such, clinicians, patients and families should be aware that many factors such as concomitant medical conditions, complications, family support, resilience, motivation and so on are not included in the modeling process, and as a result, individuals with paraplegia are not constrained to fit their corresponding trajectory.
- (4) Relationships between covariates and the growth parameters do not imply causality.
- (5) The focus of this study is to model the 11-RTFMS over the full range of data collection, and therefore, the modeling process may not be sensitive enough to assess change across the entire timeline of recovery. For instance, the point of relative stability assumes change becomes stagnant, and, although change is greatly diminished at this point, change still occurs. Thus, future studies are encouraged to investigate change beyond the point of relative stability.
- (6) Caution should be exercised when extrapolating beyond the range of data as resulting trajectories will not reflect an actual individual (or group of individuals). For instance, a trajectory based on a person with a DFITRA of 200 days and a RLOS of 1 day is likely not authentic because it is doubtful an individual with an DFITRA of 200 days and a RLOS of 1 day exists. Thus, clinical expertise and judgment should be implemented so that valid trajectories are produced.

CONCLUSION

This study provides a detailed descriptive account of functional change as measured by the Rasch transformed 11-item FIM in NSCID participants with paraplegia. More specifically, with assistance from the interactive tool, individual level trajectories can be generated based on known baseline characteristics. These individual level trajectories provide an understanding of how individuals may progress over time respect to the 11-RTMFS. Access to individual level change can help clinicians and researchers better understand what factors effect or influence such change. Similarly, understanding individual level change allows clinicians to better assess outcome so that outcome enhancing action can be administered.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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Supplementary Information accompanies this paper on the Spinal Cord website (<http://www.nature.com/sc>)