

# Progress Report: Preference For Recovery Of Walking Function In Incomplete Spinal Cord Injured (SCI) Consumers At Two Year Follow Up

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## Abstract

**Objective:** To illustrate longitudinal preferences for recovery in incomplete SCI consumers at two year follow-up.

**Design:** Direct observation of a constrained consensus building process with the same individuals in a repeated measures design at one, two and five years post injury

**Participants/methods:** A modified version of Steinman's Feature Trade-off Consensus Building tool was utilized to assess consumer preference for recovery among 14 functional status items of the modified Functional Independence Measure (MFIM), comparing walking to the other dimensions of the motor functional domains of the FIM. The method involved trading levels of independence (resources) across different items (features). The panel consisted of 5 incomplete SCI patients assessed at one year post injury and 3 of the same individuals again at two years post injury. Concentric pie charts (CPC) illustrate preferences.

**Results:** Preference for walking recovery in incomplete SCI consumers remains equal to bowel and bladder recovery and remains constant over one and two years post injury.

**Conclusions:** It is well known that recovery of bowel and bladder is primary in preference for recovery of function among incomplete SCI consumers. This is the first study that suggests walking is also of prime value. Five year follow-up will be reported at a future date.

## Introduction

Consumer preference needs careful study to determine the importance of mobility to persons with spinal cord injury. This was illustrated by consumer reaction to a television commercial aired during the 2001 Super bowl which showed a person with SCI getting up from a wheelchair and walking across the stage. The commercial implied such a goal was achievable in the future with proper investment of research funds. Many individuals commented that this offered hope and was a very inspiring message, where as others were upset at a message of false hope and the implication that individuals in wheelchairs needed to walk. Consumer preference and satisfaction are important and essential components of the new paradigm defined and described in the Long Range Plan of the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education.<sup>1</sup> Stineman<sup>2</sup> recently reported a discrepancy between consumers and clinicians rating of dimensions of disability. The study not only showed differences, but also facilitated a discussion between consumers and clinicians that allowed the clinicians to more openly consider the consumers value judgments. An adaptation of Stineman's methodology was developed for this study. The purpose of the study was to examine longitudinal preferences for recovery of walking function in incomplete SCI consumers at one and two years post injury.

## Methods

The Features Game developed by Stineman to demonstrate consumer/staff preference for recovery was applied to spinal cord injury. Consumer/staff preference for walking was compared to the other dimensions of a modified Functional Independence Measure (MFIM), which separated walking and wheelchair mobility. Thus, six items of self-care, two items of sphincter control, and six items of mobility (wheelchair, walking, stairs, chair, tub, and toilet transfers) will comprise the MFIM.

The study involved the direct observation of a constrained consensus building process in a panel of 5 individuals with incomplete spinal cord injury assessed at one year post injury and three of the same individuals again at two years post injury.

The objective of the Features Game is to establish the relative value of alternative functional status states. The features being traded here will be the 14 MFIM. Resource trade-off is the imagined level of

## Results

Consumers with incomplete spinal cord injury advanced walking to complete independence by Stage 4 and was equally as important as

independence achieved among the various tasks. The game uses the nominal group process<sup>3</sup> that is clearly integrated with concepts from economic utility analysis<sup>4</sup>. This process assures that each panelist has equal opportunity for input.

The game involves a continuous two-step process of building imagined recovery patterns until all stages are completed. The specific steps to form each stage are as follows:

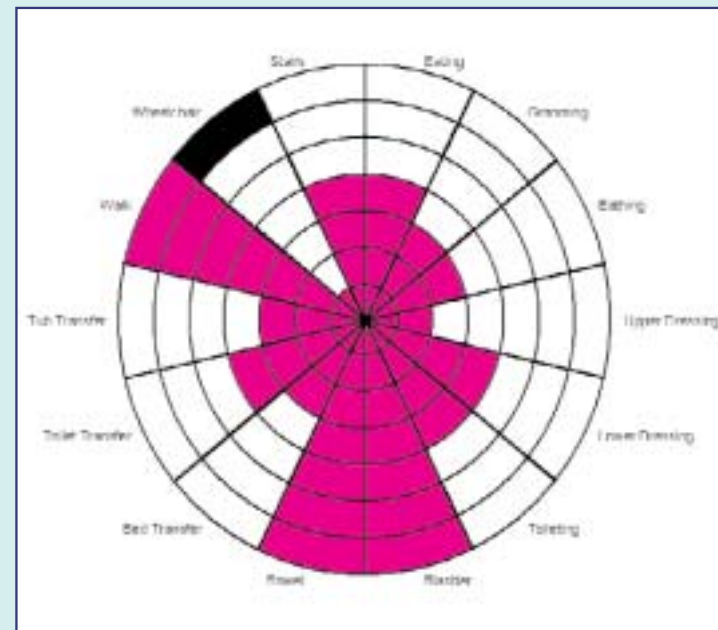
Step 1 – The Free Movement Phase

Step 2 – Zero-Sum Exchange with Individual Discussions and Voting

Step 1 and 2 are repeated until the five interim stages are defined.

The preference stages developed by each panel are illustrated by concentric pie charts consisting of slices profiling panelists' preferences for functional achievement in the 14 MFIM (Figures 1 and 2).

bowel and bladder function. This preference remained constant over one and two year post injury (Figures 1 and 2).



**Figure 3** Concentric pie chart depicting Stage 4 for the incomplete SCI consumers at one year post injury



**Figure 4** Concentric pie chart depicting Stage 4 for the incomplete SCI consumers at two year post injury

## Discussion

This is the first study that suggests walking is as important as the recovery of bowel and bladder function among incomplete subjects with SCI and remains constant over the first two years post injury. It has been well documented that recovery of bowel and bladder is primary in preference for recovery<sup>5</sup>. Further research is needed to support our hypothesis that there may be a difference of preference for recovery in individuals with SCI depending on the time since injury. Other groups of consumers with SCI need to be evaluated according to their preferences and are currently are being studied by this approach. A five-year follow-up on this same group will be reported at a future date. Additionally, cross sectional groups at one, two and five years post injury will be examined.

## Bibliography

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