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## **Development and Validation of a Patient-Assessed Disease Activity Index in Systemic Sclerosis**

Dr. Marie Hudson from the Jewish General Hospital, Montreal, Quebec, is working on developing the first Patient-Assessed Disease Activity Index in systemic sclerosis (SSc). Patient reported disease activity scales have been shown to perform well in other rheumatic diseases. They measure health status from the patient's perspective and provide valuable information to supplement traditional biomedical assessments, such as physician assessments and clinical information. Potential items to be included in the Index will be determined both through patient interviews and caregiver focus groups. A pilot instrument will then be pre-tested in a small sample of physicians and patients. After performing necessary modifications, it will then be tested in a larger sample of patients, to assess data quality, perform item reduction and scaling, and obtain weights for the items using multiple regression. The final Index will be provided to all patients in the Canadian Scleroderma Research Group (CSRG) Registry at their baseline and one-year visit to measure test-retest reproducibility, internal consistency, construct validity, responsiveness to change, interpretability and ease of use. This Index will be a useful tool in epidemiological research to identify important and potentially reversible aspects of SSc and to establish eligibility and measure outcome in clinical trials. Furthermore, this index has the potential to be used in clinical practice to guide decision-making and for regulatory documentation.