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## **The Scleroderma Patient-centered Intervention Network (SPIN) Cohort**

### **Appendix 1: SPIN Core Measures**

The Scleroderma Patient-centered Intervention Network (SPIN) Core Measures currently include six questionnaires that assess overall quality of life and function across a number of areas important to patients with systemic sclerosis (SSc).

Overall health status will be assessed with the Patient Reported Outcomes Measurement Information System-29 (PROMIS-29).[1] The PROMIS-29 measures 7 domains related to pain, fatigue, depression, anxiety, sleep, physical function, and sexual function. For each domain, 4 items are scored on a 5-point scale, and pain intensity is assessed using an 11-point rating scale. A score of  $50 \pm 10$  represents the mean  $\pm$  SD of the general US population for each domain (except pain rating). For the anxiety, depression, fatigue, pain interference, and sleep disturbance domains, higher scores represent worse symptoms, and for physical functioning and social role, higher scores represent better functioning (thus, higher scores represent more of the domain being measured).

Functional disability from SSc will be measured using the Scleroderma Health Assessment Questionnaire (SHAQ)[2] which consists of the Health Assessment Questionnaire - Disability Index (HAQ-DI) and 6 numerical rating scales to assess functional disability due to SSc-related symptoms. The HAQ-DI is a self-report questionnaire designed to assess functional disability in patients with arthritis and is the most widely used instrument among patient-reported measures of functional status in SSc.[3] The HAQ-DI has 8 domains that inquire about hand activities, dexterity, and lower extremity function. It has found to have acceptable feasibility, reliability, and validity including sensitivity to change and predicts survival in SSc.[2, 4-6] A higher

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score on the HAQ-DI indicates a greater level of functional disability with a total score range of 0 (no disability) to 3 (severe disability).

The numerical rating scales assess SSc-related functional disability due to Raynaud's phenomenon, finger ulcers, breathing problems, gastrointestinal problems, pain, and overall SSc, and are anchored between "did not limit activities" to "very severe limitation". We will also assess itch using numerical rating scales, which was found to be a common symptom of SSc.[7] Transition questions are added for all symptoms (*Compared to your last assessment, how would you rate your [insert symptom]*) and are scored on a 7-point Likert scale (*very much better to very much worse*).

Depressive symptoms will be assessed with the Patient Health Questionnaire-8 (PHQ-8).[8-10] The PHQ-9 [11] is a 9-item measure of depression symptoms that has been widely used in primary care and medical populations and rates the frequency of depressive symptoms over the past 2 weeks on a 0-3 Likert-type scale (*not at all to nearly every day*). The PHQ-9 exhibits good sensitivity/specificity and has been found to be sensitive to changes in depression over time.[12] Overall, the PHQ-9 has been translated into at least 25 languages and been shown to be as accurate as longer tools for identifying major depression in a range of settings, countries, and patient populations.[13, 14] An important shortcoming of the PHQ-9, however, is that its 9<sup>th</sup> item asks about both self-harm and passive thought about "being better off dead." In medical populations, as many as 20% of patients may endorse this item, but most are responding to the passive thoughts part of the item rather than active thoughts of self-harm. Thus, increasingly, the PHQ-8 is preferred in research studies [9], including SSc.[10]

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Body image concerns due to changes in appearance from SSc will be assessed with the Satisfaction with Appearance Scale (SWAP)[15-17]. The 14-item SWAP [15] was developed to measure non-weight related body image dissatisfaction among burn survivors. The SWAP has been validated for SSc.[17] Respondents to the SWAP rate the degree to which they feel each item reflects their thoughts and feelings about their appearance on a 7-point scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). The SWAP has a two-factor structure, Perceived Social Impact, reflecting social discomfort, and Subjective Dissatisfaction, reflecting dissatisfaction with various body parts. High scores indicate greater body image dissatisfaction.

The Cochin Hand Function Scale (CHFS)[18] will be used to measure limitations in hand function. The CHFS is a questionnaire with 18 items concerning daily activities that require hand function and designed to assess limitations in hand function due to rheumatic disease. Each question is scored on a scale of 0 (*performed without difficulty*) to 5 (*impossible to do*). The total score is obtained by adding the scores of all items (range 0-90). The CHFS has been validated in rheumatoid arthritis,[18, 19] hand osteoarthritis,[20] and SSc.[21]

Self-efficacy for coping and disease management will be measured using the Self-Efficacy for Managing Chronic Disease Scale.[22] This scale measures the confidence individuals have in their ability to use self-management techniques to cope with the consequences of chronic disease. Various versions of this scale have been used with many different populations and disease groups.[22] The 6-item brief version was developed for use in clinical trials in order to reduce the respondent questionnaire burden. It measures confidence in one's ability to manage fatigue, pain, emotional distress and

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other symptoms as well as to reduce the need for medical care and reliance on medications. Each item is rated on a numerical scale ranging from 1 (*not confident at all*) to 10 (*totally confident*). The score for the scale is the mean of all items. The scale has been shown to be sensitive to change in self-management trials.[23, 24]

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