

Supplementary Table 1: Overview of all suggested tools for the 10 domains from Delphi survey step 3

	Symptoms	Clinical examination	Imaging/ para clinic	Function assessment	Activity assessment
1.Lung	Dyspnea Cough Sputum Hemoptysis Chest pain with respiration Functional class (NYHA) Shortening of breath, Unableness to sleep	Auscultation Leg edema	Chest x-ray Lung ultrasound HRCT	Lung function tests (FVC, DLCO, lung volumes) Borg's dyspnea scale VAS scale as part of SHAQ SO ₂	6 minutes walking test Borg's dyspnea scale Mahlers questionnaire VAS (SHAQ)
2.Heart	Shortness of breath Palpitation Chest pain Orthopnea Peripheral edema Dyspnea Unable to sleep well Edema Concurrent heart disease	Heart rate Blood pressure Auscultation Leg edema	Chest x-ray MR cor Right heart catheterization	EKG Echocardiography (sPAP, diastolic dysfunction, LVEF, RVEF, size of RA, pericardium) Tissue Doppler Echo Functional class (NYHA) Holter monitor NT-pro BNP	6 minutes walking test
3.GI	Weight loss Nausea/vomiting Night time/day time heart burn/reflux Dyspepsia Stomach pain Abdominal distension Bloating Diarrhea Dysphagia Constipation Fecal soilage Need of parental	Weight	BaSO ₄ X-ray esophagram Gastroscopy, EGD w duodenal culture Esophageal manometry Colonoscopy GI capsule endoscopy Glucose Hydrogen Breath test (SIBO)	Blood test (Anemia, albumin, cholesterol) Anorectal manometry Sarcopenia screening Suction splash	Weight UCLA -GIT questionnaire Specific PRO for digestive involvement SarQoL VAS (SHAQ)

	<p>nutrition</p> <p>Body mass index</p> <p>Malabsorption,</p>				
4.RP	<p>Frequency and severity of Raynaud's</p> <p>Triggering factors (cold, emotion),</p> <p>Claudication of lower limbs</p>	<p>Nail fold capillary abnormalities</p>	<p>Nailfold capillaroscopy</p> <p>Doppler ultrasound of peripheral pulses</p> <p>Arteriography</p>		<p>Frequency of Raynaud's</p> <p>Severity by VAS (SHAQ)</p> <p>Specific PRO for Raynaud</p> <p>Raynaud's condition score</p>
5. DU	<p>Tenderness at fingertips</p> <p>Distal pulses</p> <p>Presence or absence of distal finger ulcers</p> <p>Number of ulcers</p> <p>Pitting scars</p> <p>Number of pitting scars</p> <p>Gangrene</p> <p>Amputation</p> <p>Leg ulcer</p> <p>Foot pain and toe lesion</p> <p>Development of new ulcers during the last year</p> <p>Presence of acroosteolysis</p> <p>Co-existing conditions like diabetes,</p> <p>Problems of major arteries</p> <p>Smoking</p>	<p>Digital pitting</p> <p>Digital ulcer</p> <p>Gangrene</p> <p>Ulcer on MCP, elbow ,knee</p> <p>Amputation</p> <p>Leg and Foot examination</p>	<p>Hand x-ray</p> <p>MRI of hands</p>	<p>Handicap due to digital ulcer</p> <p>Pain or inability to walk due to foot lesion?</p>	<p>New onset of ulcer</p> <p>Healed ulcer</p> <p>VAS (SHAQ)</p> <p>Cochin hand function scale</p>
6. Skin, Mucosa	<p>Puffy hand</p> <p>Skin thickening</p> <p>Extension of skin thickening</p> <p>Pruritus</p> <p>Telangiectasia on hands/</p>	<p>MRSS</p> <p>Measure mouth opening</p> <p>Fat pad atrophy</p> <p>Periungal</p>	<p>Ultrasound of skin thickness</p>	<p>Measure mouth opening</p> <p>Finger to palm distance</p> <p>Fingers extension</p>	<p>MRSS, Skin involvement including single areas</p> <p>Changes in skin hardness</p> <p>Change in</p>

	face/lips Skin worsening or improving (patients reported) Sicca symptoms including vaginal involv. Erectile dysfunction morphea, vasculitis sign pigmentary changes oral ulcers	erythema Calcinosis Finger to palm distance Fingers extension			numbers of telangiectasia VAS (SHAQ) SF36,
7.Renal	Headache confusion	Blood pressure	Urine analysis BUN Creatinin Ultrasound abdomen Proteinuria	24 hours urine test Protein / creatinine ratio	
8.Lab, Biomarkers	Scleroderma specific auto antibodies (ATA, ACA, anti Pol 3, ANA by IF for pattern, Antiphospholipids panel) Acute phase reactants (ESR, CRP) Hematology (WBC, Plt, leuc) NT-pro BNP and troponin CK Renal (GFR, Creatinin, Proteinuria, uric acid, BUN) Liver function tests, Serum albumin Clinical chemistry (Na, K) 25OH vitD, B12, folate Fecal calprotectin Complements Trace elements				
9.Treatment	Date of initiation and finalization of every drug Type of treatment Co-morbidities and co-treatment interactions Type and duration of physiotherapy Type and duration of occupational therapy				

10. Musculo skeletal.	Hand and finger edema Puffy fingers Joint pain Joint contracture Arthritis Tender/swollen joints Tendon Friction rub	Muscle weakness and stiffness Muscle strength (MRC sum score) Calcinosis	CK, ESR,CRP, LDH, Aldolase RF, anti-CCP x-ray hands Ultrasound Muscle power grading (0-5) MRI muscle Muscle biopsy EMG		SSc-adapted ABILHAND questionnaire Cochin Hand Function Scale MMT8 and FI2 Score if evidence for potential arthritis DAS 28 HAQ-DI VAS (SHAQ)
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