

## Longitudinal follow-up

Visit date:

Physician:

### Patient

Name:

Date of birth:

Sex:  female  male

**All questions are defined as “symptoms since last visit” unless specified otherwise**

Domains and tools	Result
<b>1. Domain: Raynaud’s phenomenon</b>	
Frequency and severity of attacks	/Attacks/week /10 for severity on VAS scale
<b>2. Domain: Skin and mucosa</b>	
Skin changes (worsening or improvement; patient reported)	<input type="checkbox"/> worsening <input type="checkbox"/> stabilization <input type="checkbox"/> improvement
Puffy fingers	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
modified Rodnan Skin Score (mRSS)	/51
Teleangiectasias	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Calcinosis	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
<b>3. Domain: Musculoskeletal</b>	
Muscle weakness and stiffness	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
<i>If yes</i> , proximal muscle weakness not explainable by other causes	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Joint contractures	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Clinical signs of arthritis ( $\geq 2$ tender AND swollen joints)	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Tendon friction rubs	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
<b>4. Domain: Digital ulcers</b>	
Total number of digital ulcers (current)	<input type="checkbox"/> unknown
Localization of digital ulcers (current)	<input type="checkbox"/> Fingertip <input type="checkbox"/> on bony prominence <input type="checkbox"/> unknown
Number of new digital ulcers (not present at last visit)	<input type="checkbox"/> unknown
Co-existing conditions relevant for hypoperfusion (i.e. diabetes)	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown Type:

Smoking status	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
<b>5. Domain: Lung</b>	
Dyspnoea	<input type="checkbox"/> yes ( <input type="checkbox"/> Worsening <input type="checkbox"/> Stable) <input type="checkbox"/> no
Functional class (NYHA 1-4)	<input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> unknown
Basal lung crackles on auscultation	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Lung function test including DLCO	Restrictive defect <input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown FEV1 (%predicted) <input type="checkbox"/> unknown DLCO/SB (%predicted) <input type="checkbox"/> unknown DLCO/VA (%predicted) <input type="checkbox"/> unknown FVC (%predicted) <input type="checkbox"/> unknown TLC (%predicted) <input type="checkbox"/> unknown
<b>6. Domain: Heart</b>	
Concurrent heart disease	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Heart rate (beat/minute)	<input type="checkbox"/> unknown
Blood pressure (mmHg)	<input type="checkbox"/> unknown
Leg oedema	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
<b>ECG</b>	<input type="checkbox"/> unknown
Conduction blocks	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Right bundle branch block	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Right axis deviation	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Right ventricular hypertrophy	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Ventricular arrhythmias	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Q waves	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
<b>Doppler-echocardiography</b>	<input type="checkbox"/> unknown
Left ventricular ejection fraction (%)	<input type="checkbox"/> unknown
Pulmonary arterial hypertension	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Tricuspid regurgitation velocity (m/sec)	<input type="checkbox"/> unknown
Pericardial effusion	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
RV/LV ratio	<input type="checkbox"/> unknown
Right atrium area (cm <sup>2</sup> )	<input type="checkbox"/> unknown
Right ventricular area (cm <sup>2</sup> )	<input type="checkbox"/> unknown
TAPSE	<input type="checkbox"/> unknown
Diastolic dysfunction	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
PAP sys (mmHg)	<input type="checkbox"/> unknown
<b>7. Domain: Gastro intestinal</b>	
Night and day time heart burn/reflux	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown

Dysphagia	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Diarrhea	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Body weight (kg)	<input type="checkbox"/> unknown
<b>8. Domain: Renal</b>	
Serum creatinine (µmol/L)	<input type="checkbox"/> unknown
Glomerular filtration rate (GFR)	<input type="checkbox"/> unknown
Proteinuria (urinary dipstick)	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
<b>9. Domain: Laboratory</b>	
CRP (mg/l)	<input type="checkbox"/> unknown
ESR rate (mm/hr)	<input type="checkbox"/> unknown
CK elevation	<input type="checkbox"/> yes <input type="checkbox"/> no <input type="checkbox"/> unknown
Creatine kinase (U/L)	<input type="checkbox"/> unknown
Hb (g/dl)	<input type="checkbox"/> unknown
Uric acid (µmol/L)	<input type="checkbox"/> unknown
ASAT (U/L)	<input type="checkbox"/> unknown
ALAT (U/L)	<input type="checkbox"/> unknown
<b>10. Domain: Treatment</b>	
Type of treatment (generic and name of drug)	
Route of administration	<input type="checkbox"/> po <input type="checkbox"/> iv <input type="checkbox"/> unknown
Date of initiation	
Date of finalization	
Dose (mg/d)	Yes/medication withdrawn/no/unknown
Adverse events	
Type of treatment (generic and name of drug)	
Route of administration	<input type="checkbox"/> po <input type="checkbox"/> iv <input type="checkbox"/> unknown
Date of initiation	
Date of finalization	
Dose (mg/d)	
Adverse events	Yes/medication withdrawn/no/unknown
Type of treatment (generic and name of drug)	
Route of administration	<input type="checkbox"/> po <input type="checkbox"/> iv <input type="checkbox"/> unknown
Date of initiation	
Date of finalization	
Dose (mg/d)	
Adverse events	Yes/medication withdrawn/no/unknown