Supplementary Table 1: Comparison of patients with teleangiectacias and patients without teleangiectacias for determinants for immunosuppressive medication, vascular complications and gastrointestinal interventions

<table>
<thead>
<tr>
<th></th>
<th>Teleangiectacias absent, n=93 (41%)</th>
<th>Teleangiectacias present, n= 133 (59%)</th>
<th>P value</th>
</tr>
</thead>
<tbody>
<tr>
<td>mRSS, mean (SD)</td>
<td>6.2 (10)</td>
<td>4.7 (6)</td>
<td>ns</td>
</tr>
<tr>
<td>Interstitial lung disease, n (%)</td>
<td>48 (52%)</td>
<td>65 (49%)</td>
<td>ns</td>
</tr>
<tr>
<td>Diffuse cutaneous SSc, n (%)</td>
<td>35 (38%)</td>
<td>38 (29%)</td>
<td>ns</td>
</tr>
<tr>
<td>Disease duration, years; mean (SD)</td>
<td>4.7 (6.4)</td>
<td>8.3 (8.4)</td>
<td>0.001</td>
</tr>
<tr>
<td>Additional pulmonary function test</td>
<td>19 (20%)</td>
<td>14 (11%)</td>
<td>0.038</td>
</tr>
<tr>
<td>discussed within 12 months after care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pathway, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Calcinosis, n (%)</td>
<td>6 (7%)</td>
<td>33 (25%)</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Digital Ulcers, n (%)</td>
<td>21 (23%)</td>
<td>22 (17%)</td>
<td>ns</td>
</tr>
<tr>
<td>Estimated SPAP by cardiac ultrasound</td>
<td>18 (26%)</td>
<td>38 (34%)</td>
<td>ns</td>
</tr>
<tr>
<td>&gt; 35 mmHg, n (%)*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discussion of patient’s case in</td>
<td>5 (5%)</td>
<td>18 (14%)</td>
<td>0.049</td>
</tr>
<tr>
<td>multidisciplinary PAH meeting, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Additional cardiac ultrasound</td>
<td>1 (1%)</td>
<td>7 (5%)</td>
<td>0.09</td>
</tr>
<tr>
<td>indicated within 12 months after care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pathway, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Start of medication for peripheral</td>
<td>18 (19%)</td>
<td>40 (30%)</td>
<td>0.069</td>
</tr>
<tr>
<td>vascular complications, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Referral to gastro-enterologist,</td>
<td>14 (15%)</td>
<td>21 (16%)</td>
<td>ns</td>
</tr>
<tr>
<td>including requests for specific</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>additional investigations</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Start of proton pump inhibitor or</td>
<td>13 (14%)</td>
<td>16 (12%)</td>
<td>ns</td>
</tr>
<tr>
<td>laxantia</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

mRSS = modified Rodnan Skin score, SPAP = systolic arterial pulmonary pressure; PAH = pulmonary arterial hypertension; * available in n = 182
Translation of questionnaire

Organisation

1. Did you get sufficient information on the health care program beforehand?
   - Yes, sufficient
   - No, not sufficient.
   - No opinion.

   In case you were not adequately informed, which aspects did you not know of beforehand?

2. Did you get sufficient information specific medical diagnostic tests beforehand, including cardiac ultrasound, pulmonary function test etc?
   - Yes, sufficient
   - No, not sufficient.
   - No opinion.

   In case you were not adequately informed, which aspects did you not know of beforehand?

3. Was the care pathway in line with your health care needs, as evaluated by the questionnaire?
   - Yes
   - No.
   - No opinion.

   Remarks:

4. What was your opinion about the time schedule during the 2 days?
   - Sufficient
   - Insufficient.
   - No opinion.

   Remarks:

5. Did the physician make an appointment with you to discuss the results?
   - Yes
   - No
Health care
For next questions we would like you to give your opinion on a scale from 1 to 5, with 5 = very satisfactory, and 1 = very unsatisfactory.

6. Were you satisfied about the way you was welcomed?

Very unsatisfied                            very satisfied
1                          2                          3                          4                          5

Remark:

What should be changed?

7. Were you satisfied about the heath care providers?

Very unsatisfied                            very satisfied
1                          2                          3                          4                          5

Remark:

What should be changed?

8. Were you satisfied about the diagnostic tests performed?

9. Were you satisfied about the specific knowledge on systemic sclerosis of the health care providers?

Very unsatisfied                            very satisfied
1                          2                          3                          4                          5

Remark:

Is there a specific area where there is lack of knowledge?

11. Were you satisfied about the:

Rheumatologist

Very unsatisfied                            very satisfied
1                          2                          3                          4                          5
Remark:

What should be changed?

**Specialized nurse**

Very unsatisfied

| 1 | 2 | 3 | 4 | 5 |

Remark:

What should be changed?

If applicable:

**Physical therapist**

Very unsatisfied

| 1 | 2 | 3 | 4 | 5 |

Remark:

What should be changed?

**Occupational therapist**

Very unsatisfied

| 1 | 2 | 3 | 4 | 5 |

Remark:

What should be changed?

**Social worker**

Very unsatisfied

| 1 | 2 | 3 | 4 | 5 |

Remark:

What should be changed?
How would you grade the care pathway in general, including organisation, health care providers and food and drinks, and if applicable your stay in the hospital?

Very unsatisfactory  1  2  3  4  5  6  7  8  9  10  highly satisfactory

What should be changed?

12. Do you have any other remarks or suggestions?