

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

	Teleangiectacias absent, n=93 (41%)	Teleangiectacias present, n= 133 (59%)	P value
mRSS , mean (SD)	6.2 (10)	4.7 (6)	ns
Interstitial lung disease, n (%)	48 (52%)	65 (49%)	ns
Diffuse cutaneous SSc, n (%)	35 (38%)	38 (29%)	ns
Disease duration, years; mean (SD)	4.7 (6.4)	8.3 (8.4)	0.001
Additional pulmonary function test indicated within 12 months after care pathway, n (%)	19 (20%)	14 (11%)	0.038
Calcinosis, n (%)	6 (7%)	33 (25%)	< 0.001
Digital Ulcers, n (%)	21 (23%)	22 (17%)	ns
Estimated SPAP by cardiac ultrasound > 35 mmHg, n (%)*	18 (26%)	38 (34%)	ns
Discussion of patient's case in multidisciplinary PAH meeting, n (%)	5 (5%)	18 (14%)	0.049
Additional cardiac ultrasound indicated within 12 months after care pathway, n (%)	1 (1%)	7 (5%)	0.09
Start of medication for peripheral vascular complications, n (%)	18 (19%)	40 (30%)	0.069
Referral to gastro-enterologist, including requests for specific additional investigations	14 (15%)	21 (16%)	ns
Start of proton pump inhibitor or laxantia	13 (14%)	16 (12%)	ns
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. Very unsatisfied very satisfied
1 2 3 4 5

Remark:

What should be changed?

10. 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

