

**Appendix 1.**

## List of questions

**[q1]** Do you have any type of psoriasis or psoriatic arthritis?

- <1> Yes, and I have been diagnosed by a physician
- <2> Yes, but I have not been diagnosed by a physician
- <3> I don't have any type of psoriasis or psoriatic arthritis
- <4> I don't know

**[q2]** Which type of psoriasis or psoriatic arthritis have you been diagnosed with by a physician?

- <1> Psoriasis on the skin, nails or scalp
- <2> Psoriatic arthritis
- <3> Both psoriasis (on skin, nails or scalp) and psoriatic arthritis
- <4> I don't know

**[q3]** How long after your first symptoms were you diagnosed by a physician?

*Separate answers for "Psoriasis (skin, nails or scalp)" and "Psoriatic arthritis"*

- <1> Within one year
- <2> 1-2 years after
- <3> 2-4 years after
- <4> 5-9 years after
- <5> 10-14 years after
- <6> 15-19 years after
- <7> 20-29 years after
- <8> 30 years or more
- <9> I don't know

**[q4]** Have you ever seen a dermatologist for your psoriasis?

- <1> Yes
- <2> No

**[q5]** How many times within the past two years have you seen a dermatologist for your psoriasis? If you can't remember the precise number, please indicate your best guess.

*If yes to question 4.*

- <1> 0 times
- <2> 1 time
- <3> 2 times
- <4> 3 times
- <5> 4 times
- <6> 5 times
- <7> 6 times
- <8> 7 times
- <9> 8 times
- <10> 9 times
- <11> 10 times
- <12> More than 10 times

**[q6]** Are you regularly seeing a dermatologist for your psoriasis?

- <1> Yes, more often than 6 months
- <2> Yes, every 6 to 18 months

- <3> Yes, more rarely than every 18 months
- <4> Yes, when flare/ when needed/ at request
- <5> No

**[q7]** Have you ever been examined by a rheumatologist?

- <1> Yes
- <2> No

**[q8]** How many times within the past two years have you seen a rheumatologist? If you can't remember the precise number, please write your best guess.

*If yes to question 7.*

- <1> 0 times
- <2> 1 time
- <3> 2 times
- <4> 3 times
- <5> 4 times
- <6> 5 times
- <7> 6 times
- <8> 7 times
- <9> 8 times
- <10> 9 times
- <11> 10 times
- <12> More than 10 times

**[q9]** Are you regularly seeing a rheumatologist?

*If yes to question 7.*

- <1> Yes, more often than 6 months
- <2> Yes, every 6 to 18 months
- <3> Yes, more rarely than every 18 months
- <4> Yes, when flare/ when needed/ at request
- <5> No

**[q10]** How would you rate the severity of your [ "psoriasis", "psoriatic arthritis"] the past 12 months?

*Separate answers for "Psoriasis (skin, nails or scalp)" and "Psoriatic arthritis"*

- <1> Not severe at all
- <2> Not particularly severe
- <3> Quite severe
- <4> Very severe
- <5> Extremely severe
- <6> Don't know

**[q11]** Which symptoms or problems have you had in the past 12 months due to your psoriasis? Please indicate all relevant options.

- <1> Itching
- <2> Flaking
- <3> Scales
- <4> Burning
- <5> Pain
- <6> Staining
- <7> Redness

- <8> Pustules (pus-filled blisters)
- <9> Bleeding
- <10> Nail psoriasis
- <11> Swollen entire finger or toe (sausage digit)
- <12> Tender or swollen tendon (e.g. at heel or elbow)
- <13> Depression or anxiety
- <14> Fatigue
- <15> Other symptoms, inconveniences or problems
- <16> I have not had any symptoms, inconveniences or problems in the past 12 months
- <17> I don't know

**[q12]** Where on the body have you had psoriasis (on skin, nails or scalp) in the past 12 months? Please indicate all relevant options.

- <1> Scalp
- <2> Ears
- <3> Neck
- <4> Shoulders
- <5> Back
- <6> Chest
- <7> Armpits
- <8> Genitals
- <9> Skinfolds (inverse psoriasis)
- <10> Hips
- <11> Knees
- <12> Elbows
- <13> Elbow pits
- <14> Wrist
- <15> Ankles
- <16> Heels
- <17> Palms or foot soles
- <18> Fingers
- <19> Toes
- <20> Nails
- <21> Other parts of the body
- <22> I have not had symptoms/psoriasis in the past 12 months
- <23> I don't know

**[q13]** If you use your palm as a measure, how big an area with psoriasis would you say that you currently have on your entire body?

- <1> None
- <2> Less than 1 palm
- <3> 1–3 palms
- <4> 4–9 palms
- <5> 10–19 palms
- <6> 20 palms or more
- <7> Don't know/do not wish to answer

The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK.

[q14] Over the last week, how **itchy, sore, painful** or **stinging** has your skin been?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much

[q15] Over the last week, how **embarrassed** or **self conscious** have you been because of your skin?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much

[q16] Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden**?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much
- <5> Not relevant

[q17] Over the last week, how much has your skin influenced the **clothes** you wear?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much
- <5> Not relevant

[q18] I Over the last week, how much has your skin affected any **social** or **leisure** activities?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much
- <5> Not relevant

[q19] Over the last week, how much has your skin made it difficult for you to do any **sport**?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much
- <5> Not relevant

[q20] Over the last week, has your skin prevented you from **working** or **studying**?

- <1> Yes
- <2> No
- <3> Not relevant

[q21] If "No", over the last week how much has your skin been a problem at **work** or **studying**?

*If "No" to question 20*

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much

[q22] Over the last week, how much has your skin created problems with your **partner** or any of your **close friends relatives**?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much
- <5> Not relevant

[q23] Over the last week, how much has your skin caused any **difficulties**?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much
- <5> Not relevant

[q24] Over the last week, how much of a problem has the **treatment** for your skin been, for example by making your home messy, or by taking up time?

- <1> Not at all
- <2> A little
- <3> A lot
- <4> Very much
- <5> Not relevant

[q25] Have you experienced pain in your joints or tendons?

- <1> Yes, I have it now
- <2> Yes, within the past 12 months
- <3> Yes, more than a year ago
- <4> No never
- <5> I don't know

[q26] Where have you experienced pain in your joints or tendons?

- <1> Neck
- <2> Back
- <3> Shoulders
- <4> Hips
- <5> Elbows
- <6> Knees
- <7> Wrists
- <8> Ankles
- <9> Heel
- <10> Foot soles
- <11> Fingers
- <12> Toes
- <13> Other parts of the body
- <14> I don't know

[q27] We want you to indicate how much your psoriatic arthritis impacts your health. Please tell us how you have been feeling this last week.

*Patients with PsA and PsO with pain now only*-[q27\_1]        **Pain**

Indicate the number that best describes the pain you felt due to your psoriatic arthritis during the last week

-[q27\_2]        **Fatigue**

Indicate the number that best describes the overall level of fatigue due to your psoriatic arthritis you have experienced during the last week

-[q27\_3]        **Skin problems**

Indicate the number that best describes the skin problems including itching you felt due to your psoriatic arthritis during the last week

-[q27\_4]        **Work and/or leisure activities**

Indicate the number that best describes the difficulties you had to participate fully in work and/or leisure activities due to your psoriatic arthritis during the last week

-[q27\_5]        **Functional capacity**

Indicate the number that best describes the difficulty you had in doing daily physical activities due to your psoriatic arthritis during the last week

-[q27\_6]        **Discomfort**

Indicate the number that best describes the feeling of discomfort and annoyance with everyday tasks due to your psoriatic arthritis during the last week

-[q27\_7]        **Sleep disturbance**

Indicate the number that best describes the sleep difficulties (i.e., resting at night) you felt due to your psoriatic

-[q27\_8]        **Coping**

Considering your psoriatic arthritis overall, how well did you cope (manage, deal, make do) with your psoriatic arthritis during the last week?

-[q27\_9]        **Anxiety, fear and uncertainty**

Indicate the number that best describes the level of anxiety, fear and uncertainty (for example about the future, treatments, fear of loneliness) due to your psoriatic arthritis you have experienced during the last week

<1> 0 – None

<2> 1

<3> 2

<4> 3

<5> 4

<6> 5

<7> 6

<8> 7

<9> 8

<10> 9

<11> 10 – Extreme

**[q28]** Are you at the moment able to (concerning your psoriatic arthritis/musculoskeletal pain):

*Patients with PsA and PsO with pain now only*

-[q28\_1]        Dressing yourself, including shoelaces and buttons?

-[q28\_2]        Shampoo your hair?

-[q28\_3]        Stand up from a straight chair?

-[q28\_4]        Get in and out of bed?

-[q28\_5]        Cut your meat?

- [q28\_6] Lift a cup or glass to your mouth?
- [q28\_7] Open a new milk carton?
- [q28\_8] Walk outdoors on flat ground?
- [q28\_9] Climb up five steps?
- [q28\_10] Wash and dry your body?
- [q28\_11] Take a tub bath?
- [q28\_12] Get on and off the toilet?
- [q28\_13] Reach and get down a 2 kg object from above your head?
- [q28\_14] Bend down and pick up clothing from the floor?
- [q28\_15] Open car doors?
- [q28\_16] Open previously open jars?
- [q28\_17] Turn faucets on and off?
- [q28\_18] Run errands and shop?
- [q28\_19] Get in and out of a car?
- [q28\_20] Do chores such as vacuuming or garden work?
- [q28\_21] Walk 3 kilometres, if you wish (over the last week)?
- [q28\_22] Participate in recreational activities and sports as you would like, if you wish (over the last week)?
- [q28\_23] Get a good night's sleep (over the last week)?
- [q28\_24] Deal with feelings of anxiety or being nervous (over the last week)? If you have not been anxious or nervous answer the question with 'Without any difficulty'.
- [q28\_25] Deal with feelings of depression or feeling blue (over the last week)? If you have not been feeling depressed or blue answer the question with 'Without any difficulty'.

- <1> Without any difficulty
- <2> With some difficulty
- <3> With much difficulty
- <4> Unable to do

**[q29]** Please indicate which statement best describes your health today.

**Mobility**

- <1> I have no problems in walking about
- <2> I have slight problems in walking about
- <3> I have moderate problems in walking about
- <4> I have severe problems in walking about
- <5> I am unable to walk about

**[q30]** Please indicate which statement best describes your health today.

**Self-care**

- <1> I have no problems washing or dressing myself
- <2> I have slight problems washing or dressing myself
- <3> I have moderate problems washing or dressing myself
- <4> I have severe problems washing or dressing myself
- <5> I am unable to wash or dress myself

**[q31]** Please indicate which statement best describes your health today.

**Usual activities** (e.g. work, study, housework, family or leisure activities)

- <1> I have no problems doing my usual activities
- <2> I have slight problems doing my usual activities

<3> I have moderate problems doing my usual activities

<4> I have severe problems doing my usual activities

<5> I am unable to do my usual activities

**[q32]** Please indicate which statement best describe your own health state today.

**Pain/Discomfort**

<1> I have no pain or discomfort

<2> I have slight pain or discomfort

<3> I have moderate pain or discomfort

<4> I have severe pain or discomfort

<5> I have extreme pain or discomfort

**[q33]** Please indicate which statement best describe your health today.

**[q34] Anxiety/Depression**

<1> I am not anxious or depressed

<2> I am slightly anxious or depressed

<3> I am moderately anxious or depressed

<4> I am severely anxious or depressed

<5> I am extremely anxious or depressed

**[q35]** We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

100 means the best health you can imagine. 0 means the worst health you can imagine.

Mark on the scale to indicate how your health is today.

- Thermometer, scale from 0-100, Point 0 = “The worst health you can imagine”, point 100 = “The best health you can imagine”

**[q36]** Are you using any of the following treatments for your psoriasis/psoriatic arthritis?

-[q36\_1] Moisturizers (such as creams or ointments without cortisone)

-[q36\_2] Alternative treatments (e.g. from health food stores)

-[q36\_3] Light treatment (e.g. UV treatment)

-[q36\_4] Tablet (oral) or injectable (with a syringe) methotrexate

-[q36\_5] Tablet (oral) medication (other than methotrexate)

-[q36\_6] Injectable or intravenous biologic medication

-[q36\_7] Other treatment

<1> Yes, I am currently using it

<2> No, I tried it but stopped

<3> No, I have never tried it

<4> I don't know

**[q37]** In all, how satisfied or dissatisfied are you with the treatment of your [ “psoriasis”, “psoriatic arthritis”]?

Separate answers for "Psoriasis (skin, nails or scalp)" and "Psoriatic arthritis"

<1> Very dissatisfied

<2> Dissatisfied

<3> Neither dissatisfied nor satisfied

<4> Satisfied

<5> Very satisfied

<6> I don't know



**[q38]** How tall are you (without your shoes on)?

Write your height in centimetres

- Free text answer

**[q39]** What is your weight (without clothes on)?

<1> Less than 40 kg

<2> 40-49 kg

<3> 50-59 kg

<4> 60-69 kg

<5> 70-79 kg

<6> 80-89 kg

<7> 90-99 kg

<8> 100-109 kg

<9> 110-119 kg

<10> 120-129 kg

<11> 130 kg or more

<12> I don't know

**[q40]** What is your current work status?

<1> Working/studying (full- or part-time)

<2> Retired

<3> Sick leave

<4> Early retiree

<5> Government subsidised job

<6> Unemployed

<7> Other

**[q41]** How much alcohol do you use per week?

<1> 0 standard drinks

<2> 1-7 standard drinks

<3> 7-14 standard drinks

<4> More than 14 standard drinks

<5> I don't know