Appendix S1. Full list of questions

Question 1: Do you have any type of psoriasis or psoriatic arthritis?
   i) Yes, and I'm diagnosed by a physician
   ii) Yes, but I'm not diagnosed by a physician
   iii) No, I don't have any type of psoriasis
   iv) Don't know/do not wish to answer

Question 2: Which type of psoriasis have you been diagnosed for by a physician?
   i) Psoriasis on the skin, on nails or on the scalp
   ii) Psoriatic arthritis
   iii) Both psoriasis (on skin, nails or scalp) and psoriatic arthritis
   iv) Don't know/do not wish to answer

Question 3: How long after your first symptoms were you diagnosed by a physician?
   Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"
   i) Within 1 year
   ii) One year after
   iii) 2–4 years after
   iv) 5–9 years after
   v) 10–14 years after
   vi) 15–19 years after
   vii) 20–29 years after
   viii) 30 years after or more
   ix) Don't know/do not wish to answer

Question 4: If you think about the past 12 months, how would you rate the severity of your … ?
   Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"
   i) Not severe at all
   ii) Not particularly severe
   iii) Quite severe
   iv) Very severe
   v) Extremely severe
   vi) Don't know/do not wish to answer

Question 5: Please describe in which way your psoriasis (on skin, nails or scalp) is quite, very or extremely severe
   – Free text answer

Question 6: Please describe in which way your psoriatic arthritis is quite, very or extremely severe
   – Free text answer

Question 7: Which symptoms or troubles due to your psoriasis (on skin, nails or scalp) have you experienced in the past 12 months?
   i) Bleeding
   ii) Burning
   iii) Depression or anxiety
   iv) Fatigue
   v) Flaking/scales
   vi) Itching
   vii) Pain
   viii) Plaque
   ix) Pustules (pus-filled blisters)
   x) Redness
   xi) Swollen fingers or toes (e.g. sausage digits, so called dactylitis)
   xii) Tender or swollen tendons (e.g. on the heal, so called enthesitis)
   xiii) Nail psoriasis
   xiv) Other symptoms
   xv) I have not experienced any symptoms in the past 12 months
   xvi) Don't know/do not wish to answer

Question 8: Where on the body have you had symptoms of psoriasis (on skin, nails or scalp) in the past 12 months?
   i) Ankles
   ii) Arm pit
   iii) Back/spine
   iv) Chest
   v) Elbow
   vi) Fingers
   vii) Genitals
   viii) Heels
   ix) Hips
   x) In skin folds (inverse psoriasis)
   xi) Knees
   xii) Nails
   xiii) Neck
   xiv) Scalp
   xv) Shoulders
   xvi) The bend of the arm
   xvii) Palm of hands or sole of feet
Question 9: Based on the amount of psoriasis that could be covered by the palm of your hand, about how many palms would you say that you currently have across your entire body?

i) None
ii) Less than 1 palm
iii) 1–3 palms
iv) 4–9 palms
v) 10–19 palms
vi) 20 palms or more
vii) Don't know/do not wish to answer

Question 10: How often have you had relapses or flare-ups of your psoriasis (on the skin, nails or scalp) in the past 3 years? With relapse or flare-up, we mean periods when symptoms have worsened.

i) I've had constant symptoms, with no remission
ii) Every week
iii) Every month
iv) Every quarter
v) Every 6 months
vi) Every year
vii) Every 2 years
viii) Every 3 years (once in the past 3 years)
ix) I haven't had any flare-up or relapses in the past 3 years
x) Don't know/do not wish to answer

Question 11: Have you experienced pain or soreness in any of your joints?

i) Yes
ii) Yes, I have it currently
iii) Yes, in the past 12 months
iv) Yes, more than 1 year ago
v) No, never
vi) Don't know/do not wish to answer

Question 12: On which body locations is/were your joint pain or soreness most bothersome?

i) Ankles
ii) Back/spine
iii) Elbow
iv) Fingers/hands
v) Heel
vi) Sole of foot
vii) Hips
viii) Knees
ix) Neck
x) Shoulders
xi) Toes
xii) Wrist
xiii) Other body location
xiv) Don't know/do not wish to answer

Question 13: To which extent do you agree that you have experienced the following in the past 12 months due to your psoriasis?

Each statement scored from 1 (do not agree at all) to 5 (totally agree)

i) I've felt embarrassed or self-conscious because of my skin symptoms
ii) The topical treatment (such as ointments or creams) of my skin has been taking up too much time
iii) The topical treatment (such as ointments or creams) of my skin has been inconvenient or messy

Question 14: To which extent do you agree that you have experienced the following in the past 12 months due to your psoriasis/psoriatic arthritis?

My disease has ...

i) ... caused sleeping disorders/lack of sleep.
ii) ... prevented me from maintaining a good hygiene (e.g. showering or brushing the teeth)
iii) ... interfered with my daily routines such as getting out of bed, eating, cleaning, shopping or cooking
iv) ... prevented me from wearing specific clothes/ shoes
v) ... prevented me from participating in a social activity
vi) ... prevented me from doing sports or a leisure activity
vii) ... made me feel depressed or anxious
viii) ... prevented me from having an active sex life
ix) ... created difficulties in the relationship with my partner, family, close friends or relative
x) ... created difficulties in the relationship with acquaintances such as new friends or colleagues

Question 15: Have you experienced any trouble doing different activities in the past 12 months due to your psoriatic arthritis?

i) Yes, getting dressed, including tying shoelaces and doing buttons
ii) Yes, getting in and out of bed
iii) Yes, lifting a full cup or glass to my mouth
iv) Yes, walking outdoors on flat ground
vj) Yes, washing and drying my body
vii) Yes, bending down to pick up something from the floor
viii) Yes, turning faucets on and off
ix) Yes, getting in and out of a car
xi) Yes, having sex
xj) Yes, other difficulties, what?
xii) No, I haven't had any trouble
xii) Don't know/do not wish to answer

Question 16: Have you been absent from work or school in the past 12 months due to your psoriasis/psoriatic arthritis?
i) Yes, I've been on a long term sick leave
ii) Yes, a couple of days per week
iii) Yes, a couple of days per month
iv) Yes, a couple of days in the past year
v) Yes, only once in the past 12 months
vi) No
vii) I didn't work or go to school in the past 12 months
viii) Don't know/do not wish to answer

Question 17: To which extent has your psoriasis/psoriatic arthritis had negative impact on your work/career or education since you developed the first symptoms?
i) No impact at all
ii) Quite low impact
iii) Impact

Question 18: Which types of healthcare professionals have you seen in the past 3 years for your …?
Separate answers for ”Psoriasis (on skin, nails or scalp)” and ”Psoriatic arthritis”
i) Allergist
ii) General practitioner
iii) Dermatologist
iv) Rheumatologist
v) Nurse
vi) Physiotherapist
vii) Orthopaedist
viii) Other healthcare professional
ix) I haven't seen any healthcare professionals
x) Don't know/do not wish to answer

Question 19: What is the medical specialty of the healthcare professional that you see most often for your …?
Separate answers for ”Psoriasis (on skin, nails or scalp)” and ”Psoriatic arthritis”
i) Allergist
ii) General practitioner
iii) Dermatologist
iv) Rheumatologist
v) Nurse
vi) Physiotherapist
vii) Orthopaedist
viii) Other healthcare professional
ix) I don't have a specific healthcare professional that I see most often
x) Don't know/do not wish to answer
xi) Don't know/do not wish to answer

Question 20: When did you last see a dermatologist for your psoriasis (on skin, nails or scalp)?
i) In the past week
ii) In the past month
iii) In the past quarter
iv) In the past 6 months
v) In the past year
vi) In the past 2 years
vii) Three years ago or more
viii) I never saw a dermatologist
ix) Don't know/do not wish to answer

Question 21: When did you last see a rheumatologist for your psoriatic arthritis?
i) In the past week
ii) In the past month
iii) In the past quarter
iv) In the past 6 months
v) In the past year
vi) In the past 2 years
vii) Three years ago or more
viii) I never saw a rheumatologist
ix) Don't know/do not wish to answer
Question 22: If you think about the last time you were in contact with a physician for your psoriasis (on skin, nails or scalp). What were the main reasons that you were in contact with the physician? You may choose several options below.

i) Renewal of a prescription

ii) My symptoms had worsened

iii) General follow-up

iv) To talk about possible side-effects from medication

v) I had side-effects from a medication

vi) To discuss about treatment options

vii) To discuss test results

viii) To take tests (such as blood test)

ix) Psychological reasons (e.g. depression or anxiety)

x) Other reason, what?

xi) Don't know/do not wish to answer

Question 23: If you think about the last time you were in contact with a physician for your psoriatic arthritis. What were the main reasons that you were in contact with the physician? You may choose several options below.

i) Renewal of a prescription

ii) My symptoms had worsened

iii) General follow-up

iv) To talk about possible side-effects from medication

v) I had side-effects from a medication

vi) To discuss about treatment options

vii) To discuss test results

viii) To take tests (such as blood test)

ix) Psychological reasons (e.g. depression or anxiety)

x) Other reason, what?

xi) Don't know/do not wish to answer

Question 24: Overall, how satisfied or dissatisfied are you with the healthcare’s system and treatment of your … ?

Separate answers for “Psoriasis (on skin, nails or scalp)” and “Psoriatic arthritis”

i) Very dissatisfied

ii) Neither dissatisfied nor satisfied

iii) Quite satisfied

iv) Very satisfied

v) Don't know/do not wish to answer

Question 25a: Why are you dissatisfied with the healthcare’s system or treatment of your psoriasis (on skin, nails or scalp)?

- Free text answer

Question 25b: Why are you satisfied with the healthcare’s system or treatment of your psoriasis (on skin, nails or scalp)?

- Free text answer

Question 26a: Why are you dissatisfied with the healthcare’s system or treatment of your psoriatic arthritis?

- Free text answer

Question 26b: Why are you satisfied with the healthcare’s system or treatment of your psoriatic arthritis?

- Free text answer

Question 27: Have you ever changed physician because you were dissatisfied with the management or treatment of your … ?

Separate answers for “Psoriasis (on skin, nails or scalp)” and “Psoriatic arthritis”

i) Yes, once

ii) Yes, several times

iii) No, I never had the reason to change

iv) No, I never had the option to change

v) Don't know/do not wish to answer

Question 28: Have you had a dialogue with your physician about using any of the below treatment options for your psoriasis/psoriatic arthritis?

Treatment options:

- Oral (tablet) or injectable methotrexate

- Oral (tablet) medications (other than methotrexate)

- Injectable or intravenous biologic medication

i) We discussed it but I never used it

ii) We discussed it and I used it/will use it

iii) We never discussed about it

iv) Don't know/do not wish to answer

Question 29: Why did you decide not to use an oral (tablet) or injectable methotrexate?

- Free text answer

Question 30: Why did you decide not to use an oral (tablet) medication (other than methotrexate)?

- Free text answer

Question 31: Why did you decide not to use an injectable or intravenous biologic medication?

- Free text answer
Question 32: Are you using any of the following treatments for your psoriasis/psoriatic arthritis?

Treatment options:
- Emollients (such as creams or ointments without cortisone)
- Topical cortisone treatments (topical steroids)
- Alternative treatments (e.g. from health food stores)
- Light treatment (e.g. UV treatment)
- Oral (tablet) or injectable methotrexate
- Oral (tablet) medications (other than methotrexate)
- Injectable or intravenous biologic medication
- Other treatment

i) Yes, I'm currently using it
ii) No, I used it but stopped
iii) No, I never used it
iv) Don't know/do not wish to answer

Question 33: For how long did you take the oral (tablet) or injectable methotrexate before you stopped?

i) A week or less
ii) Two to 3 weeks
iii) A month
iv) A quarter (3 months)
v) Half a year
vi) One year
vii) Two years
viii) More than 2 years
ix) Don't know/do not wish to answer

Question 34: In general, how satisfied or dissatisfied are/were you with using the oral (tablet) or injectable methotrexate?

i) Very dissatisfied
ii) Quite dissatisfied
iii) Neither dissatisfied nor satisfied
iv) Quite satisfied
v) Very satisfied
vi) Don't know/do not wish to answer

Question 35: Why are/were you dissatisfied with the oral (tablet) or injectable methotrexate?

i) I experienced side-effects, e.g. nausea, vomiting, diarrhoea or fever
ii) I currently have/I got problems with my liver
iii) I have/I had to change my lifestyle too much, e.g. limit the alcohol intake or follow a specific diet
iv) I don't/I didn't get enough effect
v) I don't/I didn't get any effect at all
vi) I'm not/I wasn't able to keep up with my daily activities (e.g. missed work; missed family/personal time)
vii) I am/I was concerned about the long term safety
viii) It's too difficult to remember to take the medication
ix) Other
x) Don't know/do not wish to answer

Question 36: For how long did you take the injectable or intravenous biologic medication before you stopped?

i) A week or less
ii) Two to 3 weeks
iii) A month
iv) A quarter (3 months)
v) Half a year
vi) One year
vii) Two years
viii) More than 2 years
ix) Don't know/do not wish to answer

Question 37: When you first were prescribed the biologic medication, was it mainly yourself requesting the treatment or was it the doctor's suggestion?

i) The doctor first suggested that I use the treatment
ii) I was the one first suggesting that I use the treatment
iii) Both the doctor and I suggested that I use the treatment
iv) None of the above
v) Don't know/do not wish to answer

Question 38: How satisfied or dissatisfied are/were you with using the biologic medication?

i) Very dissatisfied
ii) Quite dissatisfied
iii) Neither dissatisfied nor satisfied
iv) Quite satisfied
v) Very satisfied
vi) Don't know/do not wish to answer

Question 39: Why are/were you dissatisfied with the biologic medication?

i) I experienced side effects, e.g. nausea, vomiting, diarrhoea or fever
ii) I have/I had to change my lifestyle too much, e.g. limit the alcohol intake or follow a specific diet
iii) I don't/I didn't get enough effect
iv) I don't/I didn't get any effect at all
v) I'm not/I wasn't able to keep up with my daily activities (e.g. missed work; missed family/personal time)
vii) I don't like to self-inject
viii) I am/I was concerned about the long-term safety
ix) I get/I got injection-site reactions
x) Other
xi) Don't know/do not wish to answer

Question 40: How would you evaluate the following treatment types in regards to health risks of long-term use?
Treatment types
– Topical steroids, e.g. cortisone salves or creams
– Oral (tablet) or injectable methotrexate
– Oral (tablet) medications (other than methotrexate)
– Injectable or intravenous biologic medication

i) No health risks at all
ii) Quite low health risks
iii) Some health risks
iv) Quite large health risks
v) Very large health risks
vi) Don't know

Question 41: Do you think there is a good or bad range of treatment options available today for your … ?
Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"

i) Very bad range
ii) Quite bad range
iii) Neither bad nor good range
iv) Quite good range
v) Very good range
vi) Don't know

Question 42: If you think about your psoriasis/psoriatic arthritis as a whole, what is most important to you in terms of support or treatment?
– Free text answer

Question 43: Where do you get most of your information about psoriasis/psoriatic arthritis? You may choose a maximum of 3 options below.

i) Doctors
ii) Nurses
iii) Other health professionals
iv) Other patients
v) Family or friends
vi) Patient organizations
vii) Books
viii) Library
ix) Internet – search engines (such as Google)
x) Internet – specific disease related sites
xi) Internet – forums
xii) Internet – other
xiii) Television
xiv) Radio
xv) Newspapers
xvi) Magazines
xvii) Other, what?
xviii) Don't know

Question 44: Are you a member of any patient organization for psoriasis or psoriatic arthritis?

Sweden
i) Yes, Psoriasisförbundet
ii) Yes, Reumatikerförbundet
iii) Yes, another organization
iv) No
v) Don't know/do not wish to answer

Norway
i) Yes, Psoriasis- og eksemforbundet
ii) Yes, Norsk Revmatikerforbund
iii) Yes, another organization
iv) No
v) Don't know/do not wish to answer

Denmark
i) Yes, Danmarks Psoriasis Forening
ii) Yes, Gigtforeningen
iii) Yes, another organization
iv) No
v) Don't know/do not wish to answer