All statements divided in concepts from the AXIAL SPONDYLOARTHRITIS workshops

	Frequency of rating*					Statement		Concept	
Statements	**1**	**2**	**3**	**4**	**5**	**Mean**	**Median**	**Mean**	**Median**
Consequences/Limitations in work-life									
I use my energy wrong. I use it all on work.		1			2	4,0	5	**3.7**	**4**
I have felt compelled to tell colleagues that I have some limitations due to Bechterew's disease		1	1	1		3,0	3		
I had to tell and be very open about my disease at work			3			3,0	3		
Openness at work has been necessary to be understood			3	1		3,3	3		
I have to decline jobs because of my disease		1	1	1		3,0	3		
It limits me with regard to new work		1		1	1	3,7	4		
Is there anyone who wants to hire me, if they know about my disease?			2		1	3,7	3		
I never told I had Bechterew's disease at work. I want to be judged for my work and not my disease			3			3,0	3		
I will always tell my employer about my disease		1	2			2,7	3		
I arrange my work-life so that I can keep up with it and recharge			1	2		3,7	4		
I have worked part-time to prioritize my disease and family life in order to have enough energy		1			2	4,0	5		
I have reduced my work hours and thus my salary, so it costs money to be ill		1	1	1		3,0	3		
The options for pension and flexjob are very limited in relation to knowledge about disease in the public sector				2	1	4,3	4		
I have gone from 110 per cent to 90 per cent because of my disease			1	1	1	4,0	4		
All treatment and physiotherapy take place during the day, which then affects my workday			1	1	1	4,0	4		
I have made a conscious career change from "fast pace" in the private sector to a position in the public sector to take my disease into account		1			2	4,0	5		
Home working days due to covid have given increased flexibility in everyday life				2	1	4,3	4		
Can I work and be active in the future or will I have to live differently?				1	2	4,7	5		
I had to arrange my work-life so that I could rest		1			1	3,5	4		
Due to my disease, I retired earlier than expected		1			1	3,5	4		
The first three months of my early retirement were the longest of my life				1	1	4,5	5		
My work-life stopped very abruptly				1	1	4,5	5		
Worries now and in the future									
Worry about whether I can keep up with my work-life			1		2	4,3	5	**3.6**	**4**
Uncertainty about the future			3			3,0	3		
Will I be able to start a family?			1	1	1	4,0	4		
Uncertainty with the new unpredictability in my life		1		2		3,3	4		
I am worried about passing it on to my children		1	1		1	3,3	3		
I am worried about getting diseases related to Bechterew's disease			2	1		3,3	3		
What does the medicine do to my body in the long run?			1	1	1	4,0	4		
It is unpredictable who will have effect of the medicine and how long it works			3			3,0	3		
Worried that my back is growing together			2		1	3,7	3		
Concerned about the development of the disease over time				2	1	4,3	4		
Does fatigue increase over time?				2	1	4,3	4		
Do back and joint stiffness increase?				2	1	4,3	4		
I am worried whether I can continue my sport if the disease develops			2		1	3,7	3		
I am worried whether my daughter will inherit the disease	1			1	1	3,3	4		
I am worried that my stiff neck will result in me losing my driver's licens	1			1	1	3,3	4		
I am worried about the biological medicine stop working and I have a relapse		1			2	4,0	5		
Those who are close to me do not need to worry. I leave that to the healthcare professionals	2				1	2,3	1		
Take responsibility for your own situation									

Openness to family and friends about the disease			1		2	4,3	5	**3.8**	**4**
You must take responsibility for your own situation and not sit back			1	2		3,7	4		
You can do something yourself				3		4,0	4		
Recreation and interests are very important so that the disease does not take up so much				2	1	4,3	4		
You have to get input, e.g., socially and culturally, so that the disease gets less space				1	2	4,7	5		
Mental health becomes charged with positive things				1	2	4,7	5		
Now that there is limited medical treatment available, positive distractions are even more important		1		1	1	3,7	4		
It is important to set goals including sub-goals		1		1	1	3,7	4		
I ride my bike a lot and I am really happy about that. I would be sad if I could not do that			1	1	1	4,0	4		
Being able to run every day makes me really happy. It gives me a boost in everyday life			1	1	1	4,0	4		
It is good to have a routine so that I get up and go out every morning	1			2		3,0	4		
It is important to be open to yourself, also in relation to alternative treatment			1	2		3,7	4		
Am I doing enough myself to manage my disease?			1	2		3,7	4		
Can I counteract the development of my disease myself?			1	2		3,7	4		
Quality of life and content are very important				1	2	4,7	5		
Should I be patient-ignorant or take responsibility and thus be an expert?	1		2			2,3	3		
It is an advantage to be prepared before the appointment at the hospital				2	1	4,3	4		
I solve the challenges I face with my disease		1	1			2,5	3		
Identity/recognition/accept									
I cannot do everything I would like to and have a hard time accepting that				1	2	4,7	5	**3.2**	**3**
My disease does not matter much. Has become a part of my life			2	1		3,3	3		
The disease affects social life. Makes it awkward		1	1	1		3,0	3		
It has been a process to tell others I don’t know, that I have a disease			1	2		3,7	4		
When you are not ill, you have the privilege of being normal		1	1		1	3,3	3		
When you are ill, you are both ill and have to put yourself in a vulnerable situation of having to tell colleagues about it			3			3,0	3		
I work full time so no one will say I am sick			1	2		3,7	4		
At times you can feel a little self-pity			1	1	1	4,0	4		
Why me?			1	2		3,7	4		
I have opted out of being part of patient associations in order not to be a patient	2		1			1,7	1		
My identity is not to be a patient, on the other hand, I am 100 per cent something else	1		1		1	3,0	3		
It has always been my trademark to be physically strong and the disease will not change that		1		1	1	3,7	4		
I have said no to paid physiotherapy because then I am not a patient and have chosen private physiotherapy instead	2		1			1,7	1		
I have learned more about myself - for better or for worse			2		1	3,7	3		
I have gained insight into what is important for me to be able to do and what matters				3		4,0	4		
My sister didn’t want to take medicine because she then felt ill	2	1				1,3	1		
I have not felt a deprivation due to my disease because I do not know what I have missed out on		1	2			2,7	3		
My boyfriend got another package	1		1		1	3,0	3		
My boyfriend gets involved in the treatment by, for example, having to tape a shoulder and he should not have to	2				1	2,3	1		
I see my wife's concern as support more than a worry			1	1	1	4,0	4		
The heredity of the disease has played a role in having children, but not decisively	1			1	1	3,3	4		
Surrounding's/relatives understanding and “good” advice									
People find it difficult to accept my situation and its limitations		1	1		1	3,3	3	**3.2**	**3**
People have considered me to be a hypochondriac			1	2		3,7	4		

I cannot stand other people's worries			2		1	3,7	3		
My wife does not worry, on the contrary, she paces me a little	2				1	2,3	1		
I experience understanding for my disease when I talk about it			2		1	3,7	3		
People find it difficult to accept my situation and its limitations			1	1	1	4,0	4		
People are not aware of and do not understand that I need, for example, to rest in the afternoon	1			1	1	3,3	4		
I experience a discrepancy between the understanding of pain versus fatigue			1	1	1	4,0	4		
Now stop that nonsense			1	1		3,5	4		
You just have to…			1	1		3,5	4		
There is an incredible amount of good advice		1		1		3,0	3		
The good advice is probably well-intentioned	1		1			2,0	2		
I think my boyfriend is overprotective of me		1	1			2,5	3		
I am made more vulnerable than I am		1	1			2,5	3		
My wife worries about me more than I do		1	1			2,5	3		
Diagnosis/medicine/treatment									
I am glad that I can tolerate my medicine				1	2	4,7	5	**3.4**	**4**
When I can no longer take NSAIDs, I will have to take Codipar, which is perhaps not appropriate for driving	2				1	2,3	1		
I wish there was a better alternative to painkillers that do not affect my driving	2				1	2,3	1		
When I experienced treatment failure, I learned why I take the medicine		1			2	4,0	5		
I stopped feeling ill after I stopped taking the medicine		1		1	1	3,7	4		
The disease is so significant if I do not get medicine so there is no alternative		1			2	4,0	5		
I do not worry about side effects to the medicine as the effect far exceeds the side effects		1			2	4,0	5		
I never felt like I needed medicine other than a little painkiller	1	1			1	2,7	2		
I think about whether the progression of my disease would have been different if I had received medicine earlier	1	1	1			2,0	2		
Many people experience a long process before they get their diagnosis	1		1		1	3,0	3		
The experience until you get the diagnosis is a bit random compared to whom you meet on your way		1	1		1	3,3	3		
I don't know if I could have benefited from medication via the hospital	1	1			1	2,7	2		
Before my diagnosis, the pain was the focus of my everyday life					2	5,0	5		
It was a relief to get the diagnosis				1	1	4,5	5		
I thought I was crazy before I got the diagnosis			1	1		3,5	4		
I was given hope that my pain would go away when I was diagnosed				1	1	4,5	5		
I had an expectation that something could be done when I received my diagnosis				1	1	4,5	5		
I am thinking about how long my body can take this medicine		1		1		3,0	3		
It is probably not completely harmless to take medicine for a long time		1		1		3,0	3		
Medicine is good for something and maybe not good for something else		1		1		3,0	3		
I go less to the hospital after I have switched to medication, I can take at home			1	1		3,5	4		
I am incredibly happy to go to the hospital to receive my medicine	1		1			2,0	2		
I find it scary how dependent I am on that medicine			1		1	4,0	4		
Five days before I have to get my medicine, I can feel my disease			1	1		3,5	4		
I have experienced worse treatment in outer Denmark		1		1		3,0	3		
Lack of understanding/to be heard and seen by healthcare professionals									
No one listened to me when my symptoms started			1	1	1	4,0	4	**4.0**	**4**
There is a lack of openness and recognition regarding alternative treatment options in the healthcare system		1	1	1		3,0	3		
In the time before my diagnosis, I have lost trust in the health care professionals				1	1	4,5	5		
I did not feel heard or seen until I was diagnosed				1	1	4,5	5		
I was asked to exercise more even though I was already exercising			1		1	4,0	4		

I did not feel I got help to solve my challenges			1		1	4,0	4		
You just need to take some painkillers (symptom treatment)			1		1	4,0	4		
I was not examined when I came with my pain				1	1	4,5	5		
I had the feeling that others thought it was something I was imagining		1			1	3,5	4		
Everyday life with Bechterew's disease									
There are many things I would like to do. And sometimes I push myself too much				3		4,0	4	**3.5**	**4**
Wish I had more energy in my spare time				2	1	4,3	4		
Fatigue is paramount for me			1	2		3,7	4		
Træthed har været årsag til at jeg har skiftet job	1			1	1	3,3	4		
I have had to put myself aside		1	1	1		3,0	3		
I have to spend a lot of time on mobility exercises and physiotherapy that others don’t have to		1	2			2,7	3		
I have to opt out because my disease takes time		1	1		1	3,3	3		
It is not fair that I have to spend time on e.g. exercises when others don’t have to		1		2		3,3	4		
My spare time is filled with disease obligations instead of what I want to do		1		1	1	3,7	4		
If I don’t exercise, I don’t have the energy to do what I have to do. It is unfair		1	1	1		3,0	3		
I limit myself in terms of hard physical work in everyday life due to the disease		1	2			2,7	3		
For me, cold means inactivity due to joint pain	1	1		1		2,3	2		
If I am too active, it costs me energy the next day		1	1	1		3,0	3		
Definitely, a need to rest in the afternoon to function well					3	5,0	5		
I had to constantly balance the things I wanted to do with my pain		1			1	3,5	4		
What does it cost in terms of pain to do what I want to do?		1		1		3,0	3		
You only have a certain amount of energy to spend each day				1	1	4,5	5		
I cannot do housework				1	1	4,5	5		
It annoys me endlessly that I cannot do work at home				1	1	4,5	5		
Things in everyday life are challenging for me due to Bechterew's disease			1		1	4,0	4		
It annoys me that I am not so flexible in my body				1	1	4,5	5		
I am stiff in the body and that limits me in terms of swimming			1		1	4,0	4		
I do not worry about my disease		2				2,0	2		
Sometimes there is too much focus on my situation/Bechterew's disease		1	1			2,5	3		
I can no longer tolerate alcohol as a result of my disease		1		1		3,0	3		
Meeting the hospital/healthcare system									
You must not let yourself be taken over by the system			2	1		3,3	3	**3.3**	**3**
Rheumatologists also considered me to be a hypochondriac			2		1	3,7	3		
There are unrealistic expectations of what the doctor thinks I can achieve in my everyday life in terms of exercise		1	2			2,7	3		
If you have Bechterew’s disease, it is almost a guarantee that you will not get Crohn’s disease	1		1	1		2,7	3		
Much focus is placed on pain in relation to the disease			3			3,0	3		
Lack of information about what the consequence of the medicine is			1	2		3,7	4		
I feel seen and heard by my doctor				2	1	4,3	4		
At the doctor's, it is a lot about medicine			1	2		3,7	4		
Danbio is a good tool in the meeting with the doctor				2	1	4,3	4		
Especially the nurses see and hear me			1	1	1	4,0	4		
Exchange of your regular doctor can be a challenge			1	2		3,7	4		
It is a good thing to be able to write directly to the doctor if in doubt				1	2	4,7	5		
I have generally felt really well taken care of and met by competent healthcare professionals			2		1	3,7	3		
My strategy is to let the doctor worry about the disease and not me		1	1		1	3,3	3		
I have confidence in healthcare professionals in general regarding my disease			1	2		3,7	4		
I have experienced a shift in confidence - felt alone with the disease	1	1			1	2,7	2		
I stopped at the physiotherapist as I did not feel he could do anything for me that I could not do myself	2		1			1,7	1		

I think it is reasonable after paying taxes for forty years, that I use the healthcare system	1		1		1	3,0	3		
I feel I am burdening the public sector because of a banality	2		1			1,7	1		
I cost the public sector a lot of money	1	1	1			2,0	2		
I feel that I inconvenience the public system unnecessarily	2		1			1,7	1		
I have great chemistry with my doctor and that makes me feel safe			1		1	4,0	4		
I feel my doctor sincerely listens and hears what I say				1	1	4,5	5		
It is important that my doctor continues		1			1	3,5	4		
My doctor made me aware of my rights			1		1	4,0	4		
It is important that you, as a patient, feel free to speak up against the system you have become a part of			1	1		3,5	4		
Life with Bechterew's disease									
Difficult to plan your life for the long term			3			3,0	3	**3.6**	**4**
It gives me less confidence that the disease can suddenly overwhelm me			2	1		3,3	3		
The mind and the physical are connected			1		2	4,3	5		
The unpredictability can lead to worries which can lead to a depressive state		1			2	4,0	5		
Being ill offers the opportunity to seek financial compensation, but it costs energy			2	1		3,3	3		
I have joined the patient association to meet others with the disease		1		2		3,3	4		
Stress has a big impact on my disease			1	2		3,7	4		

*Rating - 1: ‘Not important at all’, 2: ‘A little important’, 3: ‘Somewhat important’, 4: ‘Very important’ and 5: ‘Of great importance’.

All statements divided in concepts from the PSORIATIC ARTHRITIS workshops

	Frequency of rating*					Statement		Concept	
Statements	**1**	**2**	**3**	**4**	**5**	**Mean**	**Median**	**Mean**	**Median**
Concerns in relation to my illness/unanswered questions									
What must I do? If I feel pain, must I stop what I'm doing?					3	3.0	3	**3.7**	**4**
What makes my condition worse or better?				1	2	4.7	5		
I have many unanswered questions.				2	1	4.3	4		
I would like more information as regards what I can do myself			2		2	4.0	4		
Is my illness at a standstill, - should I resign myself to where I am now?			1	3		3.8	4		
It's hard to know whether I should continue when it hurts		2		2		3.0	3		
Thinking about whether I can stay in my apartment because my knees were so sore				1	1	4.5	5		
What are my prospects				2	2	4.5	5		
The pain has not improved after I took my medication (MTX)				1	1	4.5	5		
Concerned for the future				3	1	4.3	4		
Worried about experiencing more pain				3	1	4.3	4		
It worries me that my mobility may be reduced				3	1	4.3	4		
If it becomes worse - I will feel like I'm in deep trouble				4		4.0	4		
How bad will it become - will I end up in a wheelchair?			1	2	1	4.0	4		
Worries about my physical condition in general			1	2	1	4.0	4		
What can it develop into	1			1	2	3.8	5		
I'm concerned about the limitations the illness forces on my everyday			2	1	1	3.8	4		
When I was diagnosed, I was afraid I would end up in a wheelchair	1	1		1	1	3.0	3		
Could not get a clear overview of the consequences the illness might possibly result in? Lose my apartment, be fired, etc?			1	1	1	3.0	4		
Worry about whether I can still be active with my kids, if I feel worse	2			1	1	2.8	3		
What worries me is not being able to interact with my children	2	1			1	2.3	2		
I'm concerned that I might need help getting out of bed for example	2		1	1		2.3	2		
The development of my illness - will it get worse?				1	3	4.8	5		
I could not return to the job I had before the illness				1	2	4.7	5		
What job opportunities are there if I do not have a job?			1	1	2	4.3	5		
Worry about whether my current job is too physically demanding	1			2		2.3	3		
Financial worries	1		1	1		2.0	2		
How long can I continue to work	1				2	2.8	3		
Consequences of pain and fatigue, what I will be subjected to, feelings about that									
Worsening of pain				1	3	4.8	5	**3.7**	**4**
Before I had biological medication, I could not get up from the floor				1	2	4.7	5		
Difficulty with cutting because of the pain				1	2	4.7	5		
Had a hard time getting up because of pain in fingers and wrist				2	2	4.5	5		
Wake up with severe pain at night				2	1	4.3	4		
Hurts a lot - dietary does not help	1		2		1	3.0	3		
My arthritis is very much influenced by the fluctuating Danish weather	1	1	1	1		2.5	3		
It's a vicious cycle I have fallen into				1	2	4.7	5		
It is stressful because they (the system) do not do anything to help me				2	2	4.5	5		
My husband is also affected by me receiving chemotherapy (MTX)				2	1	4.3	4		
My husband is anxious on my behalf because I am receiving chemotherapy (MTX)				2	1	4.3	4		
I hide my hands				2	1	4.3	4		
When I am in pain, I do not use my body as I would like, - affects me a lot				3	1	4.3	4		
I turn the anger inward so as not to upset anybody			1	2	1	4.0	4		
Mental impact - the illness dampens my mood			2	1	1	3.8	4		
The pain associated with psoriatic arthritis is great			1	3		3.8	4		
Feel guilty about not doing what I know I can to feel better			2	1	1	3.8	4		
Suffering from psoriatic arthritis is a full-time job		1	1	2		3.3	4		
Loss of vigour for periods	1		1	2		3.0	4		
Consequences of not being able to use my body - the basic level is deteriorating more and more			1	2	1	4.0	4		

My body is becoming more and more twisted (due to illness/inactivity)	1			2	1	3.5	4		
I have to sleep for a few hours when I get home from work	2	1			1	2.3	2		
I am very much affected by fatigue				1	2	4.7	5		
Increased fatigue				2	2	4.5	5		
I am very tired - use up all my energy at work	1	1	1		1	2.8	3		
My pain restricts my participation in Yoga etc. (physical activity)			2	1	1	3.8	4		
Lose things	1			2	1	3.5	4		
Constantly losing things, - very frustrating	1			2	1	3.5	4		
Difficulty performing work because of arthritis	1			1	1	3.3	3		
Many limitations as regards being with my children - need help from others	2		1		1	2.5	2		
Limitations as regards my grandchildren	3					1.0	1		
Have difficulty climbing stairs - no strength in my joints (hard)			1	1	1	4.0	4		
Medication (effects and adverse effects)									
Concerns about the medication					4	5.0	5	**3.8**	**4**
Does the medication work?			1		3	4.5	5		
Decreases the effect (of the medication) over time				2	2	4.5	5		
What impact does the medication have on me				3	1	4.3	4		
There are many adverse effects from all the medications I take because of my illness(es)				3	1	4.3	4		
You never hear any good stories about MTX - why should I take it?			1	1	1	4.0	4		
I worry a lot about whether the biological medication I receive can cause cancer		1		1	2	4.0	5		
If the medication does not work - will I be on a roundabout for the rest of my life	1			2	1	3.5	4		
Concerned about whether I can have children because of the medication	2				2	3.0	3		
The medication causes hair loss (Arava)				1	2	4.7	5		
The frequency of the arthritis attacks has increased markedly after I received MTX				1	1	4.5	5		
I am mentally affected by medication				2	2	4.5	5		
Hair loss (adverse effect)				2	2	4.5	5		
It's annoying that I have to howl all the time (adverse effect)				2	1	4.3	4		
I get angry over nothing - snarling all the time				2	1	4.3	4		
I don't want to read the leaflet about the adverse effects, as I'll just feel bad			1	1	2	4.3	5		
Get sore ankles and swollen toes (arthritis) from MTX			1	1	2	4.3	5		
Become more tired when I take the medication (MTX)			1	1	1	4.0	4		
After I started the MTX, I become very sad			1	2	1	4.0	4		
I think I get a fever from the MTX (adverse effect) - my bedclothes are dripping wet after I take it			1	1	1	4.0	4		
After I started taking MTX I feel that I suffer flu-like symptoms			1	2	1	4.0	4		
Adverse effects from the medication (MTX)			1	1	2	4.3	5		
I become aggressive for the first few days I take MTX (adverse effect)		1		2	1	3.8	4		
Adverse effects from the medication (MTX)	1			1	2	3.8	5		
I am emotionally affected by the medication			2	2		3.5	4		
The medication (MTX) and something else was stopped, as my liver countsincreased a lot	3				1	2.0	1		
If it gets worse I will stop taking MTX			1	2	1	4.0	4		
I have tried to stop taking the medication (but it did not go as well as I had hoped				4		4.0	4		
Has my condition improved while I took the medication....... could I possibly do without it?			2	2		3.5	4		
I tried to stop taking MTX, but I became very poorly	2			1	1	2.8	3		
I have thought about whether I could do without the medication				3	1	4.3	4		
I've finally received biological medication	2			1	1	2.8	3		
I have high expectations for my biological medication	1			1	2	3.8	5		
The medication works very differently on different people. Many also have great success stories	1		1	2		3.0	4		
Can I get the medication I want		1		2	1	4.0	5		

I have tested many of the biological preparations - but they had no effect or I could not tolerate them	2		1	1		2.3	2		
Frustrated about having to take MTX for a long time, without it having worked				2	2	4.5	5		
My own approach (I do something myself)									
I am not overly affected by the illness, such that I can tolerate it if it does not get worse				1	2	4.7	5	**3.6**	**4**
I have difficulty performing everyday objects at home - but I will find a solution		1		3		3.5	4		
One finds a way			2	1	1	3.8	4		
Everything is possible, a way is found			2	1	1	3.8	4		
I find a solution to the problems - so that they do not take over			1	3		3.8	4		
I refuse to spend my time worrying about myself - otherwise I couldn’t do anything		1	1	2		3.3	4		
Exercise improves my mood		1		1	2	4.0	5		
I think a lot about my illness before I go to the doctor		1		1	2	4.0	5		
When I was diagnosed, I tried many alternative methods	1		1		2	3.5	4		
What can I do myself?			2	1	1	3.8	4		
I am amazed that there has been no focus on diet	1	1			2	3.3	4		
Heat helps my illness	1			1	2	3.8	5		
When I have been in the sun for 14 days, I can do things I otherwise cannot	1				3	4.0	5		
Dietary changes can help a person’s general condition		1	2	1		3.0	3		
Did not have the patience to wait for the alternative methods to work	1		2	1		2.8	3		
Very dry heat helps my arthritis a lot	1			2	1	3.5	4		
I am not physically active - but I am active with many other things, which keeps me going				2	1	4.3	4		
The patient against the bureaucracy (Doctors’ authority – they have the power)/ Patientization (not a person, but just someone in the system)/Powerless/Frustration									
Feel that the doctor must "dot the i’s" - very bureaucratic		1		1	2	4.0	5	**3.2**	**3**
It seems odd (I feel stupid) that I must first go through several different drugs before I get the biological medication	1			2	1	3.5	4		
I do not like the fact that I have to try different medication before I get the biological one	1		1	1	1	3.3	4		
Very difficult to get biological medication	2				2	3.0	3		
They wear white coats, - so they must know what they are saying	1	1	2			2.3	3		
You can feel like an experimental animal	1	1	1	1		2.5	3		
Some doctors have a personal interest in issuing the medication they say you have to take	1	1	1	1		2.5	3		
I have received lots of treatments that did not work	1			2		3.0	4		
I've been lucky, doctors have believed in me				1	3	4.8	5		
If I have to increase the dosage, I tell him (the doctor) I will not				2	1	4.3	4		
If you are a strong patient (know what you want), you can get suggest some things - you are taken seriously		1		2	1	3.8	4		
I do not want MTX - even if they force me to take it - I will find another solution	1	2		1	1	3.0	3		
I wonder if they really can force me to take MTX or biological medication	2				2	3.0	3		
The doctor says that if I do not do as he says, he will not visit me	3				1	2.0	1		
Meeting with the system (municipality)									
No consideration is given to my situation as regards what I can do now, and which jobs are open to me				1	2	4.7	5	**3.3**	**3**
The municipality does not believe what I say			1		3	4.5	5		
The system (the municipality) does not believe what the doctors say is wrong with me				2	2	4.5	5		
The cash system has no understanding of my situation				2	1	4.3	4		
It cannot be right that you go and say you hurt everywhere (says the municipality)			1	1	2	4.3	5		

Trying to get help from the unemployment benefit system - but it is very hard				1	2	4.7	5		
It is scary that it is not the same for everyone - but hard to see how it could be different			2	1	1	3.8	4		
Very hard to get aids from Copenhagen municipality - depending on where you live	1		1	1	1	3.3	4		
I would like to be offered training (they do not want to be liable for me in the gym)		2		2		3.0	3		
Everything is about the economy	1		2	1		2.8	3		
Tried to get help for babies from the municipality, but I couldn’t	2	1			1	2.3	2		
Difficult to get further training because of the economy	1		1		1	3.0	3		
Applying for a flexible job was a struggle	2				1	2.3	1		
Contact with the public system is gruelling	1			1	1	3.3	4		
You have to be mentally prepared to do battle with the system (the municipality)		1		1	1	3.7	4		
You are constantly confronted with the limitations of the illness in everyday life				3		4.0	4		
While applying for flexible jobs, I was constantly asked how sick I really am	2				1	2.3	1		
Difficult having an invisible disability									
I have a difficulty saying that I cannot do the same things as before				2	1	4.3	4	**3.4**	**3**
Hard to tell people that I have psoriatic arthritis			1	1	1	4.0	4		
Annoying that you have to give a long scientific report if you cannot drink a glass of wine		1	1	1	1	3.5	4		
People misunderstand the reason why you cannot drink alcohol		1	1		1	3.3	3		
People have trouble understanding that I cannot drink a beer or a glass of wine as before, due to the medication		1	2		1	3.3	3		
You have to justify why you cannot drink a glass of wine		1	2		1	3.3	3		
If you tell people that you are receiving chemotherapy (MTX), they become frightened		1	1	1	1	3.5	4		
Can feel that some people are reluctant to touch me because of my illness				2	1	4.3	4		
Get the feeling that people feel sorry for me		1	1	1	1	3.5	4		
Feel I am not being taken seriously	1	1	1	1		2.5	3		
People have difficulty understanding how sick I am, since you cannot see it				2	1	4.3	4		
Difficult having an invisible disability				2	1	4.3	4		
Hard to explain to people how much pain I’m in				1	2	4.7	5		
A lot of the arthritis pain is difficult to explain				2	1	4.3	4		

*Rating - 1: ‘Not important at all’, 2: ‘A little important’, 3: ‘Somewhat important’, 4: ‘Very important’ and 5: ‘Of great importance’.

All statements divided in concepts from the PSORIASIS workshops

	Frequency of rating*					Statement		Concept	
Statements	**1**	**2**	**3**	**4**	**5**	**Mean**	**Median**	**Mean**	**Median**
Social and psychological problems, the shame									
It scares me to show my illness to strangers				1	4	4.8	5	**4.0**	**4**
The shame of skin flaking			1		4	4.6	5		
Self-esteem disappears			2		3	4.2	5		
I was terrified to talk to girls (as a teenager)	2		1		2	3.0	3		
It goes beyond my vanity			2		3	4.2	5		
Do not want to display it in public			2	1	2	4.0	4		
Ashamed of the impression the illness makes (must shake the sheets after sleeping in the homes of others)		1			4	4.4	5		
It affected me socially			3		2	3.8	3		
My nails look like they've been hit with a hammer				1	4	4.8	5		
Do not show it to others (if, for example, I sleep in a hotel room with others)	1				4	4.2	5		
Hated physical education in school	1			2	2	3.8	4		
Socially hampered me greatly	1		2		2	3.4	3		
Build barriers to protect myself	2		1		2	3.0	3		
Life before biological treatment -→ I would not wear t-shirts or shorts	1		2	2		3.0	3		
Felt like a leper	1	2			2	3.0	2		
Was very modest	1		4			2.6	3		
I have to prepare myself mentally for a few days beforehand if I have to show myself/my illness in public		2		1	2	3.6	4		
Do not wear t-shirts	1		2	2		3.0	3		
You shut yourself in	2		1		1	2.5	2		
Genes, pain, symptoms									
It itches all the time				1	3	4.8	5	**3.7**	**4**
Bleeding wounds - hurts			1		3	4.5	5		
The wounds are very painful			1		3	4.5	5		
Painful when wounds cracks			2		3	4.2	4		
Cannot help scratching			2		2	4.0	4		
The nails come loose (very fragile)				1	4	4.8	5		
Affects the nails - nails take on another shape				1	4	4.8	5		
Can be hard to sleep due to pain					5	5.0	5		
The cracks are very painful			3		1	3.4	3		
Wake up because you feel it all the time				2	3	4.6	5		
It's a kind of hell for us			2	1	2	4.0	4		
"don't scratch it" - it's really hard!		2		3		3.2	4		
I have become thin-skinned			2	1	1	3.8	4		
The skin cracks if I bend down, - very painful		1	1	1	1	3.5	4		
Often have difficulty walking and running (bottom of feet crack)					5	5.0	5		
Cutting nails f**king hurts	2			1	2	3.2	4		
Constantly in pain				3	2	4.4	4		
Constant inflammation in the elbows. I chose not to protect myself (due to my work)		1	2	1		3.0	3		
The clothes can be troublesome - feels painful			3	2		3.4	3		
Itching can become pain			4	1		3.2	3		
Burning and stinging underfoot, mostly at night - wake in the night			2	2	1	3.8	4		
Outbreaks make eyes sensitive to light	2		2	1		2.6	3		
I think it has been a serious disability	1	1			2	3.3	4		
At the doctor/the doctor knows my body									
The doctors must listen to what I say				3	2	4.4	4	**3.7**	**4**
It is a matter of being taken seriously as a person				3	2	4.4	4		
I know my body better than anyone else			2	1	2	4.0	4		

It is infinitely annoying that doctors focus on numbers and not on what the individual patient wishes			3		2	3.8	4		
There is no understanding that I know my body better - "try to investigate what I think the problem is"			1	2	2	4.2	4		
(the doctor) lacks understanding of the individual			3		2	3.8	4		
Seems annoying constantly having to tell the same story again and again			3		2	3.8	4		
Hard to relate to "numbers" the doctor uses...			3		2	3.8	4		
When I'm standing half naked in Bispebjerg - many people come in looking for/asking about something - it bothers me!		1	1	1	1	3.5	4		
Panicked about the fact that no one knew what was wrong with me				3	1	4.3	4		
It's tough fighting the system			3		2	3.8	4		
A year and six months passed before I was diagnosed - even though I had psoriasis all over me				2	2	4.5	5		
From the beginning, I was bounced around the system - they had no idea what was wrong		1	1	1	1	3.5	4		
My GP had no idea what was wrong with me and recommended I try all sorts of creams - to no effect!	1	1		1	1	3.0	3		
Long wait for treatment	1		1	1	1	3.3	4		
How do I know if I'm getting the best treatment?				2	3	4.6	5		
We are subjected to a lot of different things - how do I know that it is the best treatment			2	1	2	4.0	4		
I don't think that my treatment is good enough (apply cream, tar ointment, steroid creams + pellets)	2			2	1	3.0	4		
Felt that doctors were uncertain as to which treatment was best			1	3		3.8	4		
Doctors are sometimes searching in the dark			1	3		3.8	4		
I told my doctor that it doesn't seem good enough	2			1	2	3.2	4		
The doctor thinks we have to wait and see... and then maybe change treatment	2		2	1		2.4	3		
Continuing to try new medications - because the effect wears off		1	1	1	1	3.5	4		
Feel like the doctors are experimenting on me		1	1	2		3.3	4		
You have to hurry when you are in discussions with the doctor	1		2		1	3.0	3		
Was diagnosed... I thought what now... did not know much about the illness				2	2	4.5	5		
Not nice when the dermatologist does not say that the hormone cream enters the bloodstream	1				3	4.0	5		
I have read that inadequate treatments can lead to complications			2		3	4.2	5		
I don't know the reason behind the sudden flare up			4	1		3.2	3		
I thought of all the pictures I had seen and thought about it a lot			1	2	1	4.0	4		
I have not been told the adverse effects of biological medication (from the doctor/hospital)	1		1		2	3.5	4		
Worried about sequelae (e.g. arthritis)			4		1	3.4	3		
Spreading makes me uneasy (I've got it in more places than just on my hands and feet)		2	2		1	3.0	3		
I do not know the adverse effects of biological medication	1	1	1	1		2.5	3		
MTX → adverse effect - is said that you can die from it				2	3	4.6	5		
I was terrified when I was diagnosed, - had seen some terrible images		1	1	2		3.3	4		
I have no idea why I got the illness		2	3			2.6	3		
Have been told that the illness reduces length of life by 2 years			4	1		3.2	3		
Medication and treatment									
I noticed that all of my symptoms disappeared within 14 days (with biological medication)					5	5.0	5	**3.5**	**4**
Biological treatment is a miracle!				1	4	4.8	5		
What happens if the medication does not work any more - or if I do not get it any more				1	3	4.8	5		
Am I guaranteed to receive Humira forever				1	3	4.8	5		
Subsidies are continuously being cut - concerned about continuing to receive Humira				1	3	4.8	4		
May be concerned about money for biological treatment running out			2		3	4.2	5		
Will I get the illness again (major concern)				2	2	4.5	5		

I am a little cautious (medication) about what I put in my body				2	2	4.5	5		
I would not take MTX due to adverse effects - did not say in the leaflet what was good about MTX			3		2	3.6	8		
This is not the end (if this treatment does not work, then it's on to the next)	1		1		2	3.5	4		
Must take medication for the rest of my life		2		3		3.2	4		
I think the hospital I am affiliated to is great	1			1	2	3.8	5		
It flares up immediately if I miss a treatment (biological treatment)			1	2	2	4.2	4		
I do not think about it in my day to day life any more - my treatment works	2			1	1	2.8	3		
I am not in pain	4		1			1.4	1		
Do not like wasting my time on discussions with the doctor (feel good) - would rather the doctor spent time on those who need it		4				2.0	2		
I tolerate MTX			2		2	4.0	4		
Individually what the body can tolerate			4	1		3.2	3		
I put on weight after the MTX treatment - it is a side effect.	1			1	2	3.8	5		
Biological medication also affects the liver	1			1	2	3.8	5		
I could not tolerate MTX	1		1		2	3.5	4		
The skin peeled off my heels (received MTX)	1		1	1	1	3.3	4		
My skin has become thinner, because I have applied all sorts of creams		1	2		1	3.3	3		
I am bad all over (open sores), - do not know if it is an adverse effect	1		2	1		2.8	3		
Could not tolerate MTX	2			1	2	3.2	4		
Was quite mad about MTX	2			1	2	3.2	4		
Must be more aware of how I move (easily bruised)	1	2	1			2.1	2		
Suffered adverse effects from previous treatments (steroid cream) - bruising	2	1	1			1.8	2		
Nausea after MTX	3			1		1.8	1		
Relationship with partner/others									
Lack of discussion with others in the same situation	2				3	3.4	5		
Would love to participate in network groups	2				3	3.4	5		
No one understands the illness			3		2	3.8	3		
Do not understand why there is no network groups (the psoriasis association)	2		2		1	2.6	3		
Feel all alone with the illness			4		1	3.4	3		
No one who knows the illness			3		2	3.8	3		
Intimate relationships - what do partners think?	1			1	2	3.8	5		
My own thoughts about myself as regards being intimate with others	1			1	2	3.8	5		
What do partners think - they think it's disgusting	1			1	2	3.8	5		
Affects my sex life (no fun if you have cream applied all over one’s body)	1	2			2	3.0	2		
Enjoy less sex during treatment - also affects me mentally	2		2	1		2.4	3		
Concern when starting a new relationship	1		1	1	1	3.3	4		
What does my partner think about how I look ("my butt looks like a baboon’s")	1		1	1	1	3.3	4		
There are days when you do not feel like sex		3	2			2.4	2	**3.2**	**3**
Will I get a girlfriend/wife	1		2		1	3.0	3		
It's not contagious	1			2	1	3.5	4		
Others are afraid of touching me. They think it’s contagious		2		1	1	3.3	3		
Feel that people seem scared	2		1		2	3.0	3		
Feel that people keep a distance	2		1		2	3.0	3		
Kept my distance from having a social life with others	3				2	2.6	1		
I've met people that would not shake my hand	2		2	1		2.4	3		
Are you contagious/non-contagious...	2		3			2.2	3		
Everyone stares	1	2			1	2.5	2		
Others are afraid that it is contagious		2	2			2.5	3		
People look at me funny	2	1			1	2.3	2		
When you go to work, you feel very dirty (hair made greasy by treatment/tar)		1		1	2	4.0	5		
Friends think it is helping, but it is not - it's f**king annoying when they comment on my flaky/oatmeal skin		2			2	3.5	4		

It looks ugly	1	1			2	3.3	4		
I think it is uncomfortable for others (girlfriend/wife) to hold my hand	2		2	1		2.4	3		
Confronted with my illness everyday	3				1	2.0	1		
Must always explain why you do not have a shot with your coffee		4	1			2.2	2		
Many offer me good advice - know-it-alls	2		3			2.2	3		
No understanding of the limitations caused by the illness (cannot drink a little schnapps)		4	1			2.2	2		
"It's not an illness that can kill you," but that does not alter the illness’s impact on life	1	1	1	1		2.5	3		
Own attitude/personal perception									
The sooner you accept the illness the better			1	2	1	4.0	4	**3.2**	**3**
The illness controlled my life more before I learned to accept it			2	1	2	4.0	4		
In my teenage years, I always had an answer ready if someone asked about the illness	2		3			2.2	3		
Will have to accept the illness	1			1	2	3.8	5		
Depends on the stage of your life when you are diagnosed (how old you are) as regards accepting the illness		1		2	1	3.8	4		
You must be careful that it does not take over your life	1		2	1		2.8	3		
I was dressed up in the summer - would not show myself due to the illness	1		2		1	3.0	3		
Will my children also suffer this illness?	1		1		2	3.5	4		
Decided early on that I would not bring children into the world - do not want them to experience the same thing			4		1	3.3	3		
When you reach the stage of daring to expose yourself, then you have won a battle			2	1	2	4.0	4		
I believe you have to be honest and speak about it			2	2		3.5	4		
I have decided that it is not my problem what others think	1			2	1	3.5	4		
I don’t want to hear about my "oatmeal"	1	1		1	1	3.0	3		
I don’t want to hear that it is contagious or it's disgusting	1	1		1	1	3.0	3		
I told my friends that I do not want to constantly hear about the illness	2			1	1	2.8	3		
I won’t cover myself up - if they want, they can just ask me	3				1	2.0	1		
It would be fine if my psoriasis remains stable - I can live with itching		2			3	3.8	5		
You learn to live with it		2	1		2	3.4	3		
Only learned to accept the illness at the age of 40			2	1	2	4.0	4		
Men are not as meticulous as women as regards appearance			3	1		3.3	3		
You cannot be cured of the illness		2		1	2	3.6	4		
"To be looked at and touched is very nice"	1		1	2		3.0	4		
I have to vacuum constantly (white flakes over everything)	2		2			2.0	2		
"Kids thought I had burned myself in a fire"	3				1	2.0	1		
I have never experienced itching	3		1			1.5	1		
Nivea cream can combat the worst dryness	1	4				1.8	2		
The impact of the illness/the illness itself									
There were jobs that I did not get because of my illness (was turned down by the Military - could not wear a helmet because I had psoriasis)			1		3	4.5	5		
People really focused on my hands (due to the illness) as regards my job (working with people)		1		1	2	4.0	5		
Jobs don’t grow on trees (especially with illness)		2	1	2		3.0	3		
Absenteeism for treatment can be a problem		2	1	2		3.0	3		
My illness has prevented me from taking some jobs	1	1	1		1	2.8	3		
Psoriasis is triggered by stress			2		2	4.0	4		
I cannot tolerate alcohol - the illness flares up		2	2	1		2.8	3		
Stress can trigger the symptoms	2		1		2	3.0	3		
I think that psoriasis can be controlled through diet	1		3			2.5	3		
It is a lifelong treatment - it limits the joy when it works		2			3	3.8	5		
Due to large patches on my buttocks, it was hard to sit on the bus etc.				2	2	4.5	5		
Can I move to Aarhus and get my medication there?	1		1	1	1	3.3	4		
You must always take the medication	1	1	1		1	2.8	3		

When planning holidays, it must be taken into account when the medication must be taken etc.	1	1	1	1		2.5	3		
It is too difficult to bring the medication on vacation - we plan our vacation on that basis	1	1	1	1		2.5	3		
I would like to get a tattoo - but do not dare - imagine it caused the illness to come back	1		3			2.5	3		
I think about my illness, since it requires logistics (must be retrieved, brought along, etc.)	1	1	1	1		2.5	3		
I cannot just leave on my boat for long periods, because I must have the treatment	2		3			2.2	3		

*Rating - 1: ‘Not important at all’, 2: ‘A little important’, 3: ‘Somewhat important’, 4: ‘Very important’ and 5: ‘Of great importance’.