

ONLINE SUPPLEMENTAL FILE I

Task 1 – all about you!

1: Are you..... (Please tick a box)

- Male
- Female

2: What is your age? ----- Years

3: How many years is it since your RA was diagnosed? ----- Years

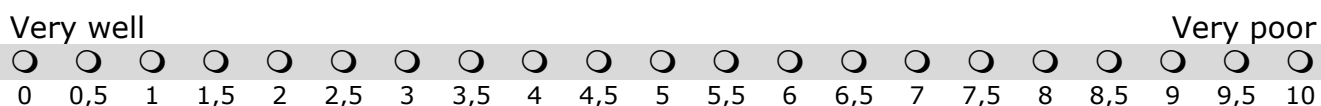
4: Have you **ever** experienced a period of very low disease activity, in which you had the idea that your disease activity was “as good as gone”?

- No
- Yes

5: Would you say that, **at this moment**, your disease activity is “as good as gone”?

- No
- Yes

6: Considering all of the ways your arthritis has affected you, how do you feel your arthritis is today?



7: Have you been diagnosed with any other disease besides rheumatoid arthritis?

- No
- Yes, please write down all your diagnosed illnesses:

.....

.....

8: Do you have any of the following: joint(s) with strongly reduced mobility, with deformities, or joint replacement surgery?

- No
- Yes

9: Is it possible for you to distinguish between pain due to inflammation and pain due to damage to the joints?

- No
- Yes

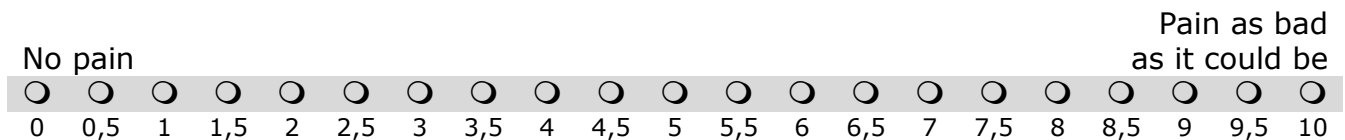
10: Please list all the RA medications you take: -----

11: Please check one best answer for your abilities at this time:

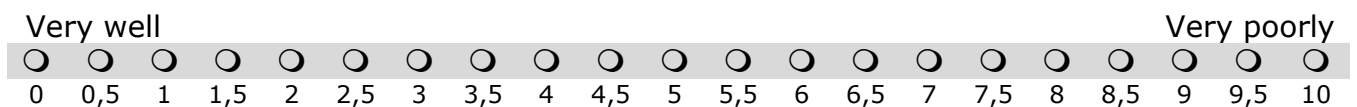
Over the last week were you able to:

	Without any difficulty	With some difficulty	With much difficulty	Unable to do
A Dress yourself, including tying shoelaces and doing buttons?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B Get in and out of bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C Clift a full cup or class to your mouth?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D Walk outdoors on flat ground?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E Wash and dry your entire body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
F Bend down to pick up clothing from the floor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
G Turn regular faucets (taps) on and off?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
H Get in and out of a car, bus, train, or airplane?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I Walk two miles or three kilometres if you wish?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
J Participate in recreational activities and sports as you would like, if you wish?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
K Get a good night's sleep?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
L Deal with feelings of anxiety or being nervous?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
M Deal with feelings of depression or feeling blue?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12: How much pain have you had because of your condition **over the past week?**
Please indicate below how severe your pain has been:



13: Considering all the ways in which illness and health conditions may affect you **at this time**, please indicate below how you are doing:



14: Are you completing this survey..... (Please tick a box)

- during your clinic visit
- through mail
- through e-mail

Task 2 Features of a period in which your disease activity is 'as good as gone'

We would like you to define the **most important features** of a period in which your disease activity is 'as good as gone'. With disease activity we mean the active disease in your joints, NOT the damage that has possibly been done to your joints.

If you **have** experienced a period in which your disease activity was 'as good as gone', please answer the questions with that period in mind.

If you **have not** experienced such a period, please answer the questions according to your expectations of such a state.

Below is a chart with **2 columns**: 1.Importance, 2. Level. On the left side of the chart are 26 features that might describe a period in which your disease activity was as good as gone. These are in no particular order.

We ask you to do 3 things:

- 1: Look at each feature and tick in the first column ("Importance") whether it is
 - **NOT IMPORTANT** or **IMPORTANT** or **ESSENTIAL** to you for characterising a period when your disease activity was as good as gone. If you think of additional features, please fill them out and grade them as well.
- 2: Of all features that you tick as **'important' or 'essential'** → tick in the second column ("Level") if it is
 - **LESS** or **ALMOST ABSENT** or **GONE** in case of features that need to decrease for characterising a period when disease activity as good as gone
 - **BETTER** or **ALMOST NORMAL** or **NORMAL** in case of features that need to improve or increase for characterising a period when disease activity as good as gone
- 3: After completing columns 1 and 2, think of your personal **top three most important features** of a period when your disease is as good as gone. List your top 3 at the end of the survey.

For example: (to avoid influencing your answers, we give an example of how to fill in the survey by replacing features with letters).

In periods in which my disease activity is as good as gone, I don't have much aaaa, I feel more cccc and I dddd better. These features are essential to me when characterizing periods when my disease activity is as good as gone. bbbb is important to me as well, but eeee is not.

To me, the 3 most important features of periods when my disease activity is as good as gone are the total absence of aaaa, an improvement in dddd and almost normal feeling of cccc:

Features	1: Importance				2: Level		
	Not important	Important	essential		less	almost absent	gone
Aaaa			X	→			X
Bbbb		X		→	X		
Cccc			X	→	better	almost normal	normal
Dddd			X	→	X		
Eeee	X						

3: Top three of most important features:

- 1: Aaaa
- 2: Cccc
- 3: Dddd

Please now complete the columns 1 and 2. Think about a period when your disease activity was as good as gone, or your expectations of such a period in case you have never experienced this.

Features	1: Importance			2: Level		
	In deciding whether I have a period in which my disease activity is as good as gone, this feature is..			If important or essential: This feature needs to be...		
	Not important	Important	essential	Less	almost absent	Gone / stopped
Pain						
Swelling						
Morning stiffness (eg. after rising)						
Stiffness (eg. during the day)						
Variability (eg. one day disease activity is absent, the next day it is active)						
Fatigue (eg. lack of energy, tiredness)						
Unpredictability (the ability to predict when your disease is active and when not)						
Flares (eg. periods of increased disease activity that make you want to contact a health care provider)						
Use of anti-rheumatic drugs (eg. methotrexate, corticosteroids, but not painkillers)						
Use of painkillers (eg: ibuprofen, diclofenac, paracetamol)						

Features	1: Importance			2: Level		
	In deciding whether I have a period in which my disease activity is as good as gone, this feature is..			If important or essential: This feature needs to be...		
	Not important	Important	essential	better	almost normal	normal
Mood (eg feeling enthusiastic or depressed)						
Socialize (eg visiting friends, going out)						
The way other people see me						
Being mobile (eg going out for a walk)						
Strength (eg. physical power when lifting something)						
Grip (eg. holding a cup of coffee)						
Physical functioning (basic activities – eg. standing up, getting dressed or washing yourself)						
Fine motor skills (eg. writing a note by hand)						
Performing everyday activities (eg. chores, errands)						
Perform my normal family role (eg. take care of children)						
Being able to work (the number of hours that you would want to work)						
Doing leisure time activities (hobbies or sports)						
Being independent; (not needing to ask for help from family /friends /neighbours or colleagues)						
Feeling as normal as other people around you						
Being treated as normal as others by people around you						
Mental power; (eg the ability to cope with life-events)						

