

## Patient Uncertainty Questionnaire - Rheumatology (PUQ-R)

This questionnaire includes questions about issues related to your arthritis/lupus

(Depending on population of administration the word arthritis or lupus is used through the questionnaire).

Please answer each question according to **HOW CERTAIN OR UNCERTAIN** you are about each of these issues.

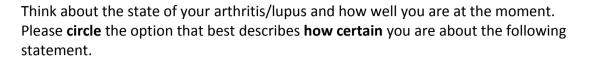
Please answer all of the questions. If you are not sure, make your best guess.

The following questions relate to your arthritis/lupus symptoms. Thinking about your arthritis/lupus, how certain are you that you understand which symptoms are arthritis/lupus symptoms and which are not? Please **circle** the option that best describes **how certain** you are about the following statements.

 $\sim$ 

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I can tell straight away when I am experiencing an arthritis/lupus symptom.	1	2	3	4
I can tell apart everyday arthritis/lupus symptoms from flares.	1	2	3	4
I can tell which symptoms are specific to arthritis/lupus.	1	2	3	4
I can judge how serious my arthritis/lupus symptoms are.	1	2	3	4
I can tell apart arthritis/lupus symptoms from the natural symptoms of getting older.	1	2	3	4
I can tell arthritis/lupus symptoms apart from side-effects caused by the medication I am taking.	1	2	3	4
I know all the different symptoms related to my arthritis/lupus.	1	2	3	4
I know when to expect an arthritis/lupus symptom.	1	2	3	4
I know how long my arthritis/lupus symptoms last.	1	2	3	4
I know what triggers my arthritis/lupus symptoms.	1	2	3	4

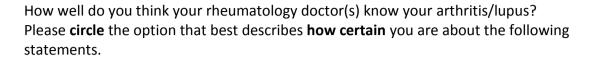
For additional information please contact sophie.cleanthous@gmail.com



	Very	Somewhat	Somewhat	Very
	Uncertain	Uncertain	Certain	Certain
My arthritis/lupus is under control at the moment.	1	2	3	4

Think about the medications you are taking for your arthritis/lupus at the moment. Please **circle** the option that best describes **how certain** you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain	Not Applicable
I need the medication I am currently taking for my arthritis/lupus.	1	2	3	4	na
The medications I am taking are helping my arthritis/lupus symptoms.	1	2	3	4	na
The medication I am taking is controlling my arthritis/lupus.	1	2	3	4	na
I do NOT need a stronger dose of medication for my arthritis/lupus.	1	2	3	4	na
I do NOT need additional medication for my arthritis/lupus.	1	2	3	4	na
I do NOT need alternative medication for my arthritis/lupus.	1	2	3	4	na



	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain	Not applicable
My doctor(s) know which medication(s) and dose(s) are the best for me.	1	2	3	4	na
My doctor(s) know which medication will work best for me.	1	2	3	4	na
My doctor(s) know how to help me control the physical aspects of my arthritis/lupus.	1	2	3	4	na
My doctor(s) know exactly what's wrong with me.	1	2	3	4	na
My doctor(s) know exactly how physically active I should be.	1	2	3	4	na
My doctor(s) know how to help me with the non- physical aspects of my arthritis/lupus (e.g. feeling low).	1	2	3	4	na
My doctor(s) know what caused my arthritis/lupus.	1	2	3	4	na
My doctor(s) know exactly how my arthritis/lupus will progress in the future.	1	2	3	4	na



Think about the management of your arthritis/lupus and how well you understand it. Please circle the option that best describes how certain you are about the following statements.

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain	Not applicable
I understand my doctor's/nurse's questions, comments and recommendations.	1	2	3	4	na
I understand what my medical test results mean.	1	2	3	4	na
I know which symptoms I need to report to my doctor.	1	2	3	4	na
I know which types of physical activity I should avoid.	1	2	3	4	na
I know exactly how to manage my arthritis/lupus.	1	2	3	4	na
There are things I can do to help control my arthritis/lupus (e.g. avoid or recover from flares).	1	2	3	4	na

Thinking about how people react to your arthritis/lupus, how certain are you about revealing your diagnosis? Please **circle** the option that best describes **how certain** you are about the following statement.

	Very	Somewhat	Somewhat	Very	Not
	Uncertain	Uncertain	Certain	Certain	Applicable
I can confidently reveal my arthritis/lupus diagnosis to others (e.g. social circle & workplace)	1	2	3	4	na

Think about the future development of your arthritis/lupus and how easy it is for you to predict it. Please **circle** the option that best describes **how certain** you are about the following statements.

 $\overline{\mathbf{m}}$ 

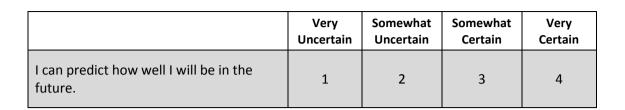
	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain
I know that my arthritis/lupus will flare- up at some time in the future.	1	2	3	4
I know what type of flare-ups I will experience.	1	2	3	4
I can predict when I will experience a flare-up.	1	2	3	4
I can predict how arthritis/lupus will affect me in the future.	1	2	3	4
I can predict how severe my flare-ups will be.	1	2	3	4
I can predict how often I will experience a flare-up.	1	2	3	4

## Think about how your arthritis/lupus will develop in the future. Please **circle** the option that best describes **how certain** you are about the following statements.

	Very	Somewhat	Somewhat	Very
	Uncertain	Uncertain	Certain	Certain
The symptoms of my arthritis/lupus will stay the same in the future.	1	2	3	4

	Very	Somewhat	Somewhat	Very
	Uncertain	Uncertain	Certain	Certain
The severity of my arthritis/lupus will stay the same in the future.	1	2	3	4

For additional information please contact sophie.cleanthous@gmail.com



ШП

Think about the effectiveness of your medication in the future. Please **circle** the option that best describes **how certain** you are about the following statement.

In the future	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain	Not Applicable
The medication I am taking will help my arthritis/lupus symptoms.	1	2	3	4	na
The medication I am taking will control my arthritis/lupus.	1	2	3	4	na
I will NOT need a stronger dose of medication for my arthritis/lupus.	1	2	3	4	na
I will NOT need additional medication for my arthritis/lupus.	1	2	3	4	na
I will NOT need alternative medication for my arthritis/lupus.	1	2	3	4	na

Think about what additional treatments for your arthritis/lupus you might need to have in the future. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very	Somewhat	Somewhat	Very
	Uncertain	Uncertain	Certain	Certain
I will NOT need to have surgery related to my arthritis/lupus in the future.	1	2	3	4

## Think about what effect (if any) the medication you are taking for arthritis/lupus could have on your body. Please **circle** the option that best describes **how certain** you are about the following statement.

	Very	Somewhat	Somewhat	Very	Not
	Uncertain	Uncertain	Certain	Certain	Applicable
The medication I am taking will NOT cause any severe side effects in the future.	1	2	3	4	na

Think about the arthritis/lupus-care team that looks after you (e.g. rheumatology doctors or nurse). Please **circle** the option that best describes **how certain** you would feel about the following statement.

	Very	Somewhat	Somewhat	Very
	Uncertain	Uncertain	Certain	Certain
It would not be a problem if my arthritis/lupus care team (e.g. different doctor or hospital) changed.	1	2	3	4

Think about how your arthritis/lupus might develop. How certain are you that you will be able to manage your arthritis/lupus in the future? Please **circle** the option that best describes **how certain** you are about the following statement.

	Very	Somewhat	Somewhat	Very
	Uncertain	Uncertain	Certain	Certain
I will be able to manage my arthritis/lupus in the future.	1	2	3	4

Think of how arthritis/lupus may affect aspects of your personal life. Please **circle** the option that best describes **how certain** you are about the following statements.

Ŵ

	Very Uncertain	Somewhat Uncertain	Somewhat Certain	Very Certain	Not applicable
Arthritis/lupus will NOT affect my ability to plan my life (e.g. housework)	1	2	3	4	na
Arthritis/lupus will NOT affect my ability to complete my education	1	2	3	4	na
Arthritis/lupus will NOT affect my relationship with my partner or a future partner.	1	2	3	4	na
Arthritis/lupus will NOT affect my ability to care for my children.	1	2	3	4	na
Arthritis/lupus will NOT affect my functionality (e.g. ability to dress, do the house chores).	1	2	3	4	na
Arthritis/lupus will NOT affect my finances.	1	2	3	4	na
Arthritis/lupus will NOT affect my ability to exercise.	1	2	3	4	na
Arthritis/lupus will NOT affect my job prospects.	1	2	3	4	na
Arthritis/lupus will NOT affect my mobility (e.g. my ability to walk).	1	2	3	4	Na
Arthritis/lupus will NOT affect my pregnancy.	1	2	3	4	Na

For additional information please contact sophie.cleanthous@gmail.com



Thinking about practical and emotional support, how certain are you that your family and loved ones will support you in the future? Please **circle** the option that best describes **how certain** you are about the following statements.

	Very	Somewhat	Somewhat	Very
	Uncertain	Uncertain	Certain	Certain
My family and loved ones will help me manage my arthritis/lupus.	1	2	3	4