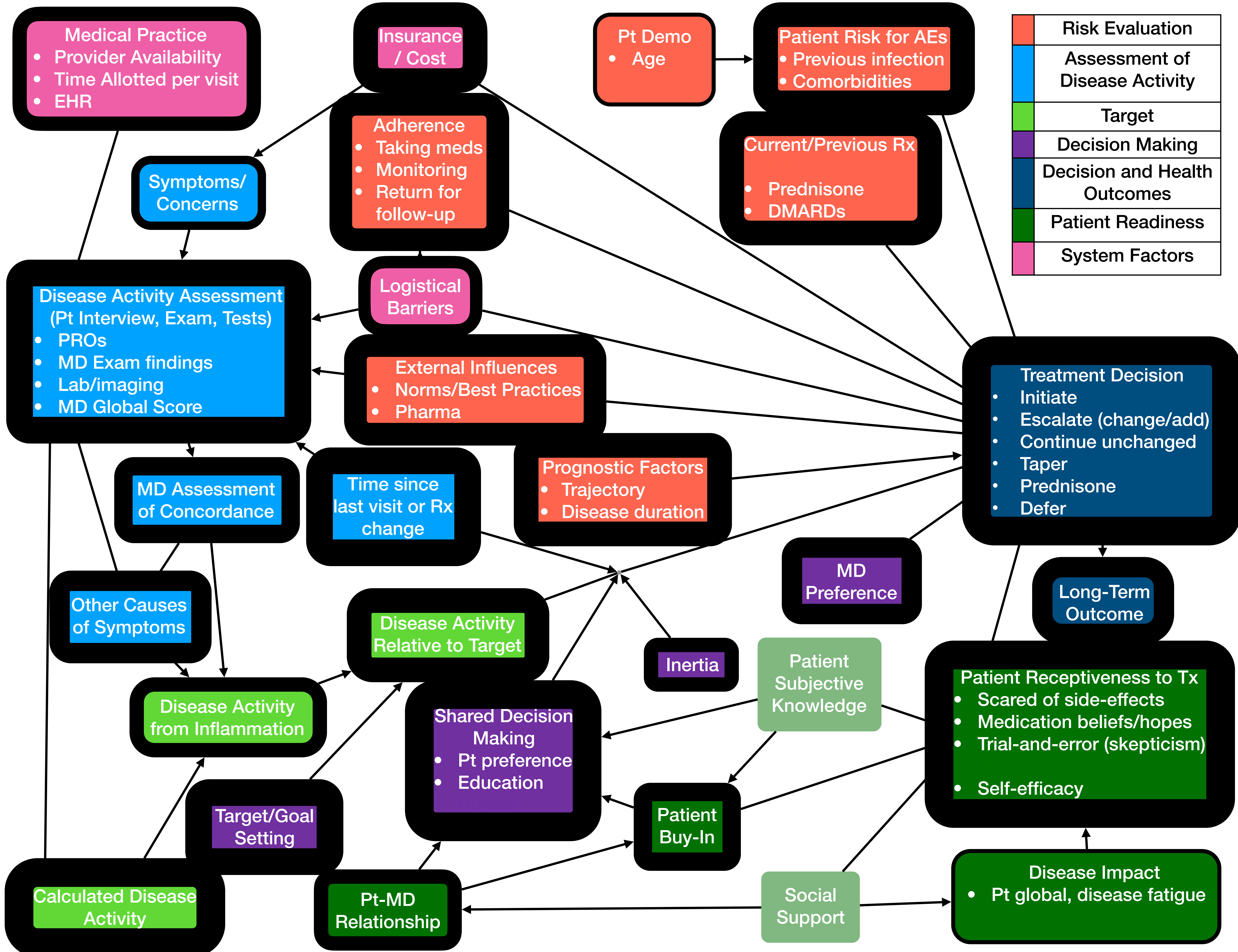
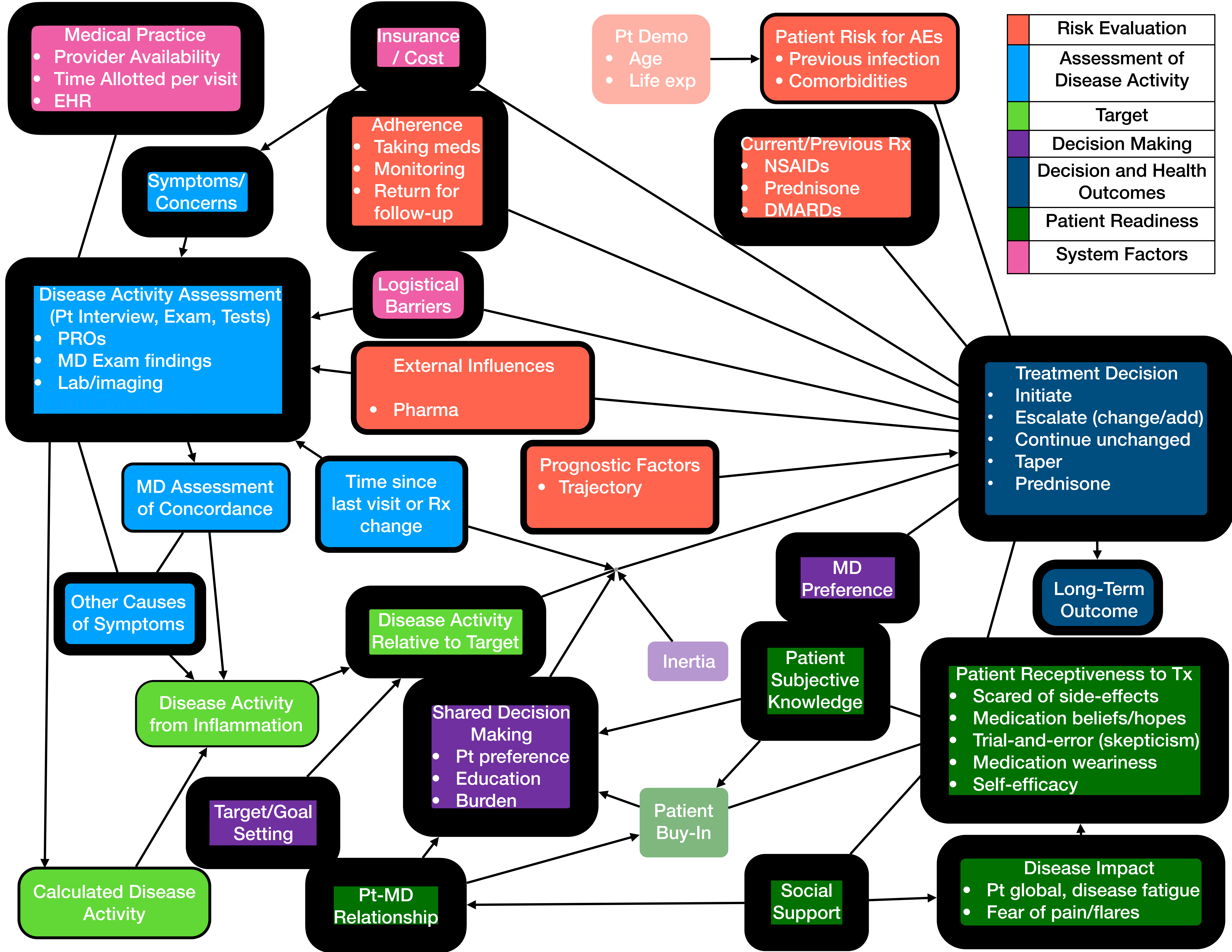


Figure 2. Rheumatologist Mental Model of TTT



	Risk Evaluation
	Assessment of Disease Activity
	Target
	Decision Making
	Decision and Health Outcomes
	Patient Readiness
	System Factors

Figure 3. Patient Mental Model of TTT



intro

Welcome to the Survey!

We are trying to better understand how people living with RA feel about treatment. In this survey, you will be asked questions about Rheumatoid Arthritis, or RA, and how it has affected your life. Your answers will help us improve communication between patients and their doctors. There are no right or wrong answers. When we ask about medication, we are referring to disease modifying drugs (DMARDs) like methotrexate, biologics, and JAK inhibitors (i.e. not prednisone).

Click the arrow on the bottom right of your screen to continue.

accessing care

The questions below are about accessing care for your RA. Thinking about your experiences with your current or previous rheumatologists, please indicate the most difficulty you have had (or ever have had).

	Not at all difficult	A little difficult	Moderately difficult	Very difficult
Finding a rheumatologist.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Scheduling an appointment to see a rheumatologist for the first time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting to my rheumatology appointments (considering all factors that may affect you).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Not at all difficult	A little difficult	Moderately difficult	Very difficult

rheumatologist if I have to cancel.	-	-	-	-
Scheduling an appointment with my rheumatologist right away if my disease flares up.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Getting clear, complete answers in a timely manner from my rheumatologist (by email or telephone) in- between appointments if I have questions or concerns.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

It is very important that you read all question text, even if the questions look similar.

These next questions ask about getting information. Thinking about your experiences with your current or previous rheumatologists, please indicate how much of the time each of the following have (or ever have) occurred for you.

	Never	Rarely	Sometimes	Most of the time	Always
My rheumatologist gives me enough time to ask questions during my visits.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel like I have enough information from all sources to make good decisions about my medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Never	Rarely	Sometimes	Most of the time	Always
I do my own research before changing my medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My rheumatologist gives me enough information to decide which medication to take.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

feel about meds

These next questions ask how you feel about medication for RA. Please indicate how much you agree with each of the following statements. If not sure of your answer, please give your best guess.

	Do not agree at all	Slightly agree	Moderately agree	Strongly agree	s
Medication is needed to keep my RA under control.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
The right diet, vitamins or supplements could allow (or has allowed) me to reduce the dose or stop some of my medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
The right diet,					

my symptoms.					
	Do not agree at all	Slightly agree	Moderately agree	Strongly agree	s
My life would be a real challenge without my RA medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
My RA medication protects me from getting worse.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
I expect that one day I will be able to stop taking all RA medication for good.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

side effects

These next questions ask how you feel about side effects. Please indicate how much you agree with each of the following statements. If not sure of your answer, please give your best guess.

	Do not agree at all	Slightly agree	Moderately agree	Strongly agree
I have underlying health problems that put me at higher risk than most RA patients for getting a serious side effect from RA medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel RA medication is too risky to take.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Do not agree	Slightly	Moderately	Strongly

hear about from other patients (in person or online) make it hard to take RA medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bad experiences I learn about (from the drug manufacturers, doctors or other sources) make it hard to take RA medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

changing meds

These next questions ask how you feel about decisions to change your medication. Please indicate how much you agree with each of the following statements. If not sure of your answer, please give your best guess.

	Do not agree at all	Slightly agree	Moderately agree	Strongly agree
Rheumatologists need to use a trial and error approach because it's impossible to know which medication will work for each patient.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need to be in a lot of pain before I would be willing to change my RA medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I sometimes think it is better				

	Do not agree at all	Slightly agree	Moderately agree	Strongly agree
It is hard to decide whether to switch medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is hard to decide whether to add medication to the ones I am already taking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is hard to take a medication for weeks before even knowing if it will work or not.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These next questions ask how you feel about managing RA over long periods of time. Please indicate how much you agree with each of the following statements.

	Do not agree at all	Slightly agree	Moderately agree	Strongly agree
Taking RA medication for years is hard for me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am tired of taking medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Lack of support from family and/or friends makes it hard to take my RA medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Do not agree at all	Slightly agree	Moderately agree	Strongly agree

people at work makes it hard to take my RA medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't think I need to see my rheumatologist as often as recommended.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I think I need to see my rheumatologist more frequently (either in person or by telehealth).	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

worries

These next questions ask about worries some patients have. Please indicate how much you agree with each of the following statements. If not sure of your answer, please give your best guess.

I worry about:

	Do not agree at all	Slightly agree	Moderately agree	Strongly agree	Very strong agree
I worry about changing medication because I don't know if a new medication will work as well or any better than the one(s) I'm already taking.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
I worry about changing					

new (or more) side effects.					
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Please indicate how much of the time you worry about each of the following. If not sure of your answer, please give your best guess.

I worry about:

	Never worry	Rarely worry	Sometimes worry	Worry most of the time	Always worry
I worry about what will happen if the medication I am on stops working for my RA.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

physical damage that RA can do.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	Never worry	Rarely worry	Sometimes worry	Worry most of the time	Always worry
I worry about the negative impact RA medication can have on my body in the long-term.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

treatment decisions

These next questions ask about some treatment decisions you have made with your current or previous rheumatologist(s). Please indicate how often of the time each of the following occurs for you. If not sure of your answer, please give your best guess.

	Never	Rarely	Sometimes	Most of the time	All the time
I take less medication than recommended because of cost or insurance.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
I delay (or would delay) changing medication because of worries about side effects.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
I decide to reduce or stop taking my RA medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

I take the medication that my rheumatologist recommends.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	Never	Rarely	Sometimes	Most of the time	Al
I feel like I don't have much of a say in making decisions about treating my RA.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
My rheumatologist wants me to stay on a medication even though I want to switch.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
My rheumatologist wants me to					

My
rheumatologist
wants me to
change
medication
even though I
think it is
working well
enough.



labwork

The following questions ask about blood work. Please indicate how much you agree with each of the following statements for you. If not sure of your answer, please give your best guess.

	Do not agree at all	Slightly agree	Moderately agree	Strongly agree	st
Blood work shows if my RA is progressing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
Blood work shows whether I need more or different medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
	Do not agree at all	Slightly agree	Moderately agree	Strongly agree	st
Blood work shows whether my medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

doesn't always reflect that I am in a lot of pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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The following questions ask about x-rays. Please indicate how much you agree with each of the following statements for you. If not sure of your answer, please give your best guess.

	Do not agree at all	Slightly agree	Moderately agree	Strongly agree	st
X-rays show if my RA is progressing.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
X-rays show whether I need more or different medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

	agree at all	Slightly agree	moderately agree	strongly agree	SI
X-rays show whether my medication is working.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
goals X-rays don't always reflect that I am in a lot of pain.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

The following questions ask about goals. How much of a priority is each of the following for you?

	Not at all a priority	Low priority	Moderate priority	High priority	Very high priority
To manage my RA without medication.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
To manage my RA with as low a dose of medication or as few medications as possible.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	
To be entirely free of pain, fatigue and stiffness even if it means taking more medication from currently	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	

open

Is there anything else you'd like to mention that wasn't covered in this survey?

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