

Supplemental Table S1. Concepts, preliminary versions, and final version of items on reasons for nonadherence chosen by the lupus clinic advisory group.

Reasons for Nonadherence Concept	Preliminary versions: I missed my lupus medication(s) because...	Version Chosen by Advisory Group
Experiencing side effects	...the medications caused side effects	X
Difficulty obtaining medications	...I could not get the medications filled on time	X
	...I did not have a way to get to the pharmacy	
Efficacy of medicine	...the medicine was not working since I still felt bad	X
Affording medication	...the medicine cost too much	X
Long term consequences	...I am concerned about possible side effects or long-term effects of the medicine	X
	...I worry about taking them for the rest of my life	
	...I was afraid of becoming dependent on them	

	...I was afraid the medicine would interact with other medications or make another condition I have worse	
	...I am concerned that the medicine would affect my ability to have children in the future	X
	...I don't want to be on birth control	
Meeting dietary requirements	...I need to take the medications with food but could not eat at the time	X
	...the medication instructions were hard to follow	X
Missing doses	...I forgot or I was busy	X
	...I did not have my medicines with me	
	...I was too late with my dose	
Medication unnecessary when feeling good	...I don't think I need my lupus medicine when I feel fine	
	...I didn't have any symptoms	X
	...I felt well	X
Tired of taking medicines everyday	...I am tired of taking medicines everyday	X
	...I want to lead a normal life again	

	...it reminds me that I have an illness	
	...I wish I wasn't sick	
Trust in outside information	...my family or friends suggested for me to not take the medicine	X
	...I heard that someone else had a bad experience from taking the medicine	X
Physical fatigue and stiffness	...I was physically too tired or too stiff to take my medicine	X
	...I was asleep	
	...there was no one to help me or remind me	
No immediate consequence of stopping medicine	...sometimes I skip a dose to see if the medicine is still needed	
	...when I skip a dose I don't feel any difference	X
Defeatist attitude	...I feel that nothing will get better even if I take my lupus medications	X
	...I could not get answers to my questions about the medication	
	...I did not have enough information about the medication	

Lack of trust in providers or health system	...I don't have confidence in my doctor or the health system	
	...I am worried that my doctor didn't prescribe the right medicine	X
Lack of understanding	...I don't understand why I need to take the medicine	X
Depressed or overwhelmed	...I feel too depressed or overwhelmed to take my medicine	X
Pill burden	...I have a hard time swallowing my pills	X
	...I take too many pills	X
Irregular schedule	...I do not have a regular schedule	X
	...the medication schedule doesn't fit with my lifestyle	
Prescription error	...there was a mistake in my prescription	
Unready to prioritize health	...taking lupus medications is not a high priority in my daily routine	
Trust in religion	...I would rather depend on prayer or try something more natural	
	...I think there may be alternatives or something else I could take	
Insurance issues	...I had insurance issues	

Supplemental Table S2. Reasons for nonadherence concepts covered in the original DOSE-Nonadherence questionnaire, concepts relevant for patients with SLE, and actions taken based on feedback from the advisory group meeting and patient cognitive interviews.

Reasons for Nonadherence Concept	Original DOSE- nonadherence <i>reasons</i> items	Draft items reviewer with advisory group	Action after advisory group meeting	Action after 1st round of cognitive interview	Action after 2nd round of cognitive interview	Retained after quantitative evaluation
Experiencing side effects	x	x	Retained			x
Difficulty obtaining medications	x	x	Retained			x
Efficacy of medicine	x	x	Retained			x
Affording medication	x	x	Retained			x
Long term consequences	x	x	Retained and added item for “concern			x

			about fertility”; felt to be more specific	
			Retained and added item for “difficult to follow instructions”; felt to be more comprehensive	
Meeting dietary requirements	x	x		x
Missing doses	x	x	Retained	x
Feeling too sick to take oral medications	x			x
Meeting dosing schedule	x			
Dealing with comorbidities	x			
Interfering with sex life	x			

Making it part of your routine	x			
Fear of stigma	x			
Getting blood test results	x			
Hard on family	x			
Sleeping through dose	x			
Accessing provider	x			
Having social support	x		Added; felt to be a missing concept	x
Medication unnecessary when feeling well		x	Retained	x
Tired of taking medicines everyday		x	Retained	x

Trust in outside information	x	Retained and split into 2 items		x
Physical fatigue and stiffness	x	Retained	Split into 2 items	x
No immediate consequence of stopping medicine	x	Retained		x
Defeatist attitude	x	Retained		x
Lack of trust in providers or health system	x	Retained		x
Lack of understanding	x	Retained		x
Depressed or overwhelmed	x	Retained	Removed "overwhelmed"; reflected by "tired"	

 of taking

medicines"

Pill burden	x	Retained	x
Irregular schedule	x	Retained	x
Prescription error	x	Removed; felt to be rare occurrence	
Unready to prioritize health	x	Removed; felt to represent prioritizing paying for medicines and is covered by affordability	
Trust in religion	x	Removed; felt to be offensive and reflects "worry about side effects"	
Insurance issues	x	Removed; covered by affordability	

Hard to open bottles	Added; felt to be a missing concept	Removed; covered by "too stiff" and "no one to help"	
Most challenging 3 barriers	Added; showed that the doctor cares and allows patients to prioritize barriers	Added to help capture any additional barriers	x
Open ended answer choice		Added to help capture any additional barriers	x

Supplemental Table S3. Final version of DOSE-Nonadherence-SLE.

For one reason or another, many people can't or don't always take all of their medications as prescribed. We want to know how often you have missed your lupus pills. If you took your pills later than usual, do not count it as a missed dose.

Over the past 7 days...	None of the time	A little of the time	Some of the time	Most of the time	Every time
I missed my medicine(s).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I skipped a dose of my medicine(s).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I did not take a dose of my medicine(s).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

People miss doses for various reasons. Please tell us which reasons contribute to you missing a dose of your lupus pills. We recognize that the past 7 days may not represent what you do over longer time periods. However, we are only interested in the past 7 days. When responding, please think only about your lupus pills.

Over the past 7 days...	<div style="display: flex; justify-content: space-between;"> Not at Very </div> <div style="display: flex; justify-content: space-between; margin-top: 10px;"> all Much </div>				
I missed my lupus pills because I felt well.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I am tired of taking medicines every day.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because my family or friends suggested I not take them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I heard that someone had a bad experience taking them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I am worried about possible side effects.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I am worried that they would affect my ability to have children in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I was too tired.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I was too stiff.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I missed my lupus pills because I had no one to help me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I still felt so bad I thought the medicine was not working.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because when I skip a dose I don't feel any difference.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I feel that nothing will get better even if I take them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I am worried that my doctor did not prescribe the right medicine for me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I do not understand why I need to take them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I felt too depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because they cost too much.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I could not fill the medicine on time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I missed my lupus pills because I forgot or I was busy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because they caused side effects.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I had a hard time swallowing them.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I take too many pills.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I do not have a regular schedule.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because the medication instructions were hard to follow.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I needed to take them with food but could not eat at the time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I missed my lupus pills because I was feeling too sick to take it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I missed my lupus pills for another reason not listed above: _____

Of the reasons listed above, please mark 3 that you feel are the biggest challenges for you.