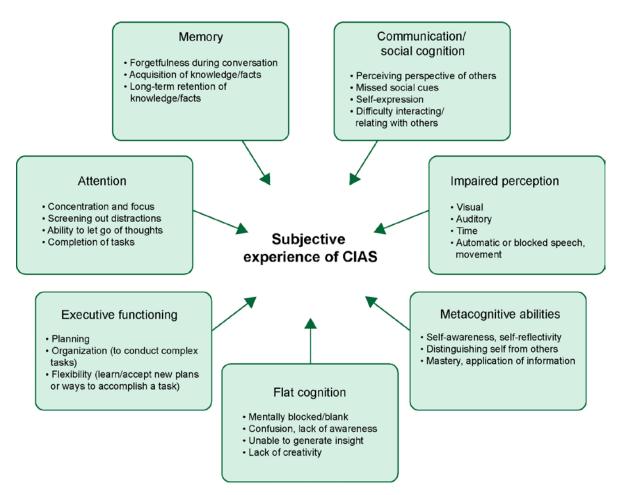
# Initial development of a patient-reported outcome measure of experiences with cognitive impairment associated with schizophrenia



Supplemental Figure (S1) Initial conceptual model based on existing knowledge.

**Table S1** Patient-Reported Experience of Cognitive Impairment in Schizophrenia (PRECIS): item tracking grid **ITEMS** 

Domain/ subdomain	Illustrative respondent description	Original item pool (v1.0; 7/10/2014)	Expert review of Version 1.0 (v1.1; 7/15/2014)	Revisions based on cognitive debriefing (v2.0; 9/4/2014)	Expert review of Version 2.0 (v2.1; 9/12/2014)	Final item for psychometric testing (9/15/2014)
Memory Location of items	"I'm notorious for putting my keys down and forget where I put them." (222035)  "Yeah, 'cuz I was looking for this phone for three days and it was right by the bed and I couldn't see it, and it was right there." (333024)  "I mean, a lot of times, I might be just difficult on myself, but like trying to remember where I put things, like my glasses, I can't find my glasses sometimes." (222040)	Remembering where I put things (like my keys, phone, glasses, or other items) was	unchanged	Remembering where I put things (for example, my keys, phone, glasses, or other items) wasReplaced "like" with "for example" to enhance clarity that the specific items are examples of the broader concept	unchanged	Remembering where I put things (for example, my keys, phone, glasses, or other items) was
Memory Acquisition of information	"Like today. I read something; I forget what I readIt's not a problem. I just forget what I read I mean, it bothers me because, you know, if, if, people ask questions, about the paper and all that and they read the same paper, no conversation there because I don't remember what I read. So papers and everything else, short-term memory" (444001)  "I can tell you what show I, I watched the next day, but if you have to tell me what the show is about, I wouldn't be able to remember." (444017)	Remembering information from a short time ago, (like what I read or watched in a movie or TV show) was	unchanged	When I wanted to remember information from a short time ago (for example, what I read or watched in a movie or TV show), it wasReplaced "like" with "for example" to enhance clarity that the specific items are examples of the broader concept	unchanged	When I wanted to remember information from a short time ago (for example, what I read or watched in a movie or TV show), it was
	"I can usually focus on the movie but for					

	some reason sometimes I can't remember all the parts in the movie." (333026)					
<b>Memory</b> Acquisition of information	"That has been a problem. Sometimes like I, I can meet somebody and you always want to make sure you don't forget somebody's name, but sometimes it's hard to remember people's name when you meet them." (222034)	Recalling people's names was	unchanged	unchanged	unchanged	Recalling people's names was
	"I've always had difficulty remembering, umm people's names with their faces." (222015)					
Memory Long-term retention	I: "So, in your own words can you explain any difficulties that you might have with memory?"  R: "Um, remembering stuff You know, like remembering stuff from like a couple years ago." (111004)  "I can't remember 100% like all the math that I had learned. And maybe some of the science, all of that too." (222031)  "Like, like another thing isremembering just events and places; I don't remember my last birthday." (444013)	Recalling something from a couple years ago when I wanted to (like information I used to know or an important event) was	unchanged	Recalling something from a couple years ago when I wanted to (for example, information I used to know or an important event) wasReplaced "like" with "for example" to enhance clarity that the specific items are examples of the broader concept. Added underlining to "years ago" as a contrast to "short time" ago in the previous item	Recalling something from a couple of <u>years ago</u> when I wanted to (for example, information I used to know or an important event) wasMade a minor grammatical change	Recalling something from a couple of years ago when I wanted to (for example, information I used to know or an important event) was
<b>Memory</b> Agenda/tasks	"But sometimes, like if I'm supposed to do something, somebody reminds me to do something, and I do forget. Like if they tell me, 'You have to buy this' or 'You have to do this within a certain time,' I may forget. I do have a forgetful memory." (111010)	Remembering what I was supposed to do or buy was	unchanged	unchanged	unchanged	Remembering what I was supposed to do or buy was
	"Well, going to the store sometimes,					

	sometimes I have a hard time trying to remember what to, what to get." (222025)					
Memory Forgetfulness during conversation	"I, I tend to forget sometimes with where I'm, with what I was talking about and what I was gonna say." (333025)  Like every other conversation I guess, something like that. But I'll just forget. Like, 'Oh, wait, what, what was I going to say?" (333012)	Remembering what I wanted to say was	unchanged	unchanged	unchanged	Remembering what I wanted to say was
Memory Forgetfulness during conversation	"Like if I, if somebody's talking and I want, I want to think of a response sometimes like if, if when I'm multi, multitasking in my mind like that, I'll, I'll lose, lose information. That happenswhen I'm listening to somebody" (333018)  "Sometimes when my girlfriend of mine starts talking a lot, it could be hard to remember everything they were saying." (222010)	Remembering what someone else was saying or asking me was	unchanged	Remembering what someone else was saying wasRemoved the phrase "asking me" because three respondents appeared to interpret that as someone trying to persuade them to do something, which was not the intended meaning	unchanged	Remembering what someone else was saying was
<b>Memory</b> Directions	"I, I did, I try to get to Walmart and I had to ask somebody. I, I remembers Georges, we have to take Georges Road but I took, I took Livingston so I forgot how to get to Walmart." (333004)	Remembering how to get somewhere when I wanted to was	unchanged	Remembering how to get someplace that I wanted to go wasReplaced the word "somewhere" with "someplace" because two respondents interpreted "to get somewhere" to mean a personal goal rather than a physical place	unchanged	Remembering how to get someplace that I wanted to go was
<b>Memory</b> Agenda/tasks	"Well, I was gonna do something and I forgot what I was gonna do." (222026)	Remembering what I was doing or going to do was	unchanged	Remembering what I was just about to do wasModified to clarify the intent	unchanged	Remembering what I was just about to do was

	"Say I was cooking and after I put my stuff in the oven I went to do laundry, and then I come backfrom laundry, I sat down for a while to do my schoolwork. And then the bell rings for the oven and I do the oven, and laundry is only 36 minutes and I forgot it." (222012)			of remembering what I was just about to do because four respondents interpreted the phrase "going to do" as referring to remembering what is on one's agenda or to-do list		
<b>Memory</b> General	R: "It's hard for me to remember certain things and how to express myself on it." I: "Okay. What kind of things?" R: "I don't know, it could be anything." (333001)	Remembering things in general was	unchanged	dropped -Item dropped because most respondents (18 of 19) reported that they interpreted it to refer to the same memory difficulties reflected in the other questionnaire items		
Communication/ social cognition Difficulty interacting/ relating with others	"I mean I, they'll talk about something, I respond, but then they keep on talking about different things and it's like I'm trying to race to, to catch up to what they're talking about because I'm still thinking about the first thing we were talking about." (444014)  "I guess if I'm you know sort of concerned about a specific thing, it just sort of makes it a little more difficult to like keep up with the conversation or something like that." (222035)	Keeping up with a conversation when I wanted to was	unchanged	dropped -Item dropped because 4 respondents interpreted it as asking about a different concept (having sufficient conversation skills to keep a conversation going) and there was not an apparent revision that would reduce the ambiguity without increasing the reading comprehension level		
Communication/ social cognition Difficulty interacting/ relating with others	"Sometimes like when people are talking to me, it's like they're talking at me, rather than me being able to ascertain what they're talking about. And so it's important for me to stop and say, 'Can you tell me that again please?" (222011)	Understanding what someone was talking about even when I heard the words was	unchanged	Understanding what someone was talking about wasModified because the phrase "even when I heard the words" caused confusion and was not needed to maintain the	unchanged	Understanding what someone was talking about was

	"Sometimes I could understand them but sometime it's hard to understand what they, what they're saying and what they, what they mean Sometimes when, when I'm at home and my parents, they talk, I don't understand what they're talk [chuckles]; so I just, you know, keep to myself." (444017)			item's meaning		
Communication/ social cognition Difficulty interacting/ relating with others	"Uh, sometimes I feel blocked. Um, I don't, I'm not able to express myself as I, I'd like to Um, um, it's just like, can't really explain it. It's just like I, I feel like I can't communicate properlyHard time coming up with something." (222036)  "I like communicating when I got something to say and we could talk about it. Now I get upset if I see people who talk and I can't find, get into the conversation with, that bothers meI be saying, well I wanted to say something too but don't nothin' pop up, you know?" (222019)	Coming up with something to say when I wanted to was	unchanged	unchanged	unchanged	Coming up with something to say when I wanted to was
Communication/ social cognition Difficulty interacting/ relating with others	"It's hard to meet new people too, for them to understand what I'm trying to say or where, understand where I'm coming from. With old people, older, well not, old people, it's easier because I, I grew up with them and they know me and so they know what I'm trying to say or how I'm trying to say it." (222017)  I: "It sounds like you have, sometimes there are challenges when you're talking to people in your family, both of	Interacting with people I don't know well was	unchanged	unchanged	unchanged	Interacting with people I don't know well was

	them. Is there a particular, is it harder with one of those two groups?" R: "Mostly harder with outside of the familyLike, like, for me like if I ever met a person, anybody, you know, I don't know what to say." (333004)					
Communication/ social cognition Difficulty interacting/ relating with others	"When I mingle with people, sometimes I think I can't mingle because I might not say the right things to people." (111001)  "Sometimes I don't know what to sayI say the wrong things." (444012)	Talking with people when I thought I might not say or do the right things was	unchanged	dropped -Item dropped because it did not meet comprehension threshold		
Communication/ social cognition Self-expression: meaning	"I think that it's hard, it's hard to get the, your point across. Always, in any conversation it's going to be difficult to explain exactly what you mean." (333019)  "I have a hard time explaining myself so somebody can understand what I'm saying. Like some people could speak in front of a general population and they can do it clearly. And sometimes if I do it, I couldn't, I think you can't understand what I'm sayingIt makes me think that if I don't get my point across, I think that makes me like crazy or I'm more depressed. I just, I don't know I can't explain myself that good." (111002)	Explaining what I meant in a way that other people knew what I was trying to say was	unchanged	Explaining myself well so that other people know what I mean was  -Item modified to simplify the language in response to respondent comments that the wording was complicated and made the item difficult to understand	Explaining myself well so that other people knew what I meant wasMinor grammatical change in tense	Explaining myself well so that other people knew what I meant was
Communication/ social cognition Self-expression: speech	"Yeah, it's sometimes hard to find words, yeahLike sometimes you'll be talking to a guy and then like you, you know the word's like on the tip of your tongue and you just can't get it out." (333026)	Finding the words to say what I meant to was	unchanged	Finding words to say what I mean wasMinor grammatical change	unchanged	Finding words to say what I mean was

	"In terms of usage, there were times I couldn't even, I couldn't use the proper term because I couldn't remember the, the right, the correct words. And I'm not talking about like, you know, an advanced vocabulary. I'm talking about simple words. I do it today." (444003)					
Communication/ social cognition Self-expression: speech	"Like I can have together what I'm going say in groups, like when it's my turn, and then when it's my turn to say, it's like I get, you know, I can't express, I can't say what I had been thinking the whole time while everybody else was sharing. I know my turn is coming and I had it all together and ready to say it and then I can't get it out the way I want to say it. I don't know why that is." (333008)  "But I know I want to say specific words, but they just don't come out quick enough sometimes Umm, embarrassed because I, I know what I'm trying to say; it just doesn't surface."	Getting my words to come out even though I knew what I wanted to say was	unchanged	dropped -Item dropped because it did not meet comprehension threshold		
Communication/ social cognition Self-expression: speech	(222004)  "Like, that's what I'm saying like my words be slurred or something like that. I don't even know why though, but that's how they be. I don't know why."  (111003)  "I can't speak that well. I, I mumble up my words." (444014)	Getting my words out clearly was	unchanged	Dropped -Item dropped because it did not meet comprehension threshold		
Communication/ social cognition Missed social cues	"But actually like interpreting like body language and stuff like that, I'm, I'm, I have very little understanding." (333007)  "I'm not good at like certain social	Understanding body language, gestures, or other hints from people without them telling me in words was	unchanged	unchanged	Understanding body language, gestures, or other hints from people without them telling	Understanding body language, gestures, or other hints from people without them telling me how they

	situations. I'm not good also at like reading cues and getting the hint about things. I mean unless someone says it." (222031)  "It's like a look somebody would give you sometimes or a gesture. Or sometimes I could take it wrong and that they could just be doing that, too." (222023)				me how they felt in words was  -The phrase "how they felt" was added for clarity	felt in words was
Metacognitive abilities Self-control	R: "They know generally what it is, but then they'll say something and it's like poke a prod at me, and I'll say something else but it's kind of inappropriate."  I: "You say it to sort of get them angry or?"  R: "No, no, no. It just slipsJust I don't want them to know anything at all, but sometimes it comes out even if I don't want it to." (444009)  "When I'm pretty much saying something that I don't want to say." (222008)	Keeping things from slipping out when I didn't want to say it was	unchanged	unchanged	unchanged	Keeping things from slipping out when I didn't want to say it was
Metacognitive abilities Self-control	"Well with me I have a problem with judgment. Like I don't always, like I can't think clearly before I act, and so that can get you into trouble You can make, like it's better to think things through and also to be accurate, you know." (222031)  "Yeah, that's how, that's also happened, making, just letting the first thing that comes to your mind just come right out instead of really thinking about it and processing what you're going to say. I'm working, as you see, I'm working on that	Thinking through things before saying or doing them was	unchanged	Stopping to think through things before saying or doing them was  -Modification was made to emphasize the concept of self-control, which four respondents did not gather from the original wording	unchanged	Stopping to think through things before saying or doing them was

	too" (333008)					
Metacognitive abilities Self-control	"One thing that I'm known for is saying inappropriate things, and it has to do with what's in the back of my head, the inappropriate thought. It's telling me 'Don't say it, don't say it, don't say it,' and it comes out." (444003)  "But I keep making the same silly mistakes doing stupid things. I would stand there doing stupid stuff and I can't help it. It's like the devil made me do it all the time." (333024)  "I can be mad at somebody and I'll call them a name and I'll say, you know, 'I, I, I, why didn't I just keep my mouth shut?'I wish, you know, just can't keep my mouth shut, it was the wrong thing to	Stopping myself from saying or doing something wrong or inappropriate was	unchanged	unchanged	unchanged	Stopping myself from saying or doing something wrong or inappropriate was
Metacognitive abilities Self-control	say." (333009)  "I regret some things that I would say just because it came out as an, when I was upset Uh sometimes yeah, once I get going and everything just starts coming out, and then I'm, 'Oh my God, did I just say that?" (222017)  "When I get mad I get impulsive and I'll come out and I'll say something stupid." (444011)	When I was upset, stopping myself from saying or doing something I wish I hadn't was	unchanged	dropped -Item dropped because it did not meet comprehension threshold		
Metacognitive abilities Understanding/ distinguishing self from others	"Well I understand they're saying to save their money, but I wouldn't understand their point of view, I would understand mine." (444007)  " I'm so focused on my own way of thinking, I just allow people to think	Seeing someone else's point of view, especially if I didn't agree with it, was	unchanged	dropped -Item dropped because a revision to address the confusion of some respondents was not identified		

	whatever they want to think, and just go through it that way. Because trying to take on somebody else's view, viewpoints, especially if I don't necessarily agree with them, is impossible." (444009)			
Metacognitive abilities Understanding/ distinguishing self from others	I: "Can you understand their perspective, why they were mad at each other?" R: "Yeah, because he said that she has too many clothes. Men do that to women sometimes. My ex-husband did the same thing to me." I: "Okay, what about the woman's perspective, can you understand where she was coming from?" R: "No, because I don't do that." (333002)	When people disagreed, seeing it from both sides was	unchanged	dropped -Item dropped because a revision to address the confusion of some respondents was not identified
Metacognitive abilities Understanding/ distinguishing self from others	I: "Like somebody told me that they planned actually similar to what you're saying, they planned a birthday party for someone And then the day beforethe party, the person called to say, "Oh, my mom got sick, she's in the hospital, I have to cancel" How would you do with something like that, how would you handle it?"  R: "I would cry because it is, I would feel that it was my fault that something happened."  I: "To his mother?"  R: "I don't know. I would blame myself." (444014)	When other people had problems that I didn't cause, believing that it wasn't my fault was	unchanged	dropped -Item dropped because it did not meet comprehension threshold
Metacognitive abilities	"I, I do take things people say very personally, even, like say the situation	To avoid taking what other people did or said	unchanged	dropped -Item dropped because it did
Understanding/	with my parents about them saying	personally was		not meet comprehension

distinguishing self from others	about my sister not meaning that she was calling me a bad parent. In my head she was calling me a bad parent. And that really, really upset me." (444009)			threshold		
Executive functioning Planning and organization of steps	"I don't, I don't know. I don't really know how, how to plan things outI, I think, I think that would be hard for me to do. I, I don't think I would be able to do that very well. I mean, I, I, if I had someone else to do that with and let them do all the work [LAUGHTER], that would be the best thing." (111010)	Without someone's help, planning ahead of time for an event or to get to a goal was	unchanged	Without someone's help, planning ahead for an event or how to get to a goal was  -Modification made to simplify the language	unchanged	Without someone's help, planning ahead for an event or how to get to a goal was
	<ul> <li>R: "Planning, uh, it's very difficult for me"</li> <li>I: "What do you think makes it difficult?"</li> <li>R: "Planning itYou have to be a step ahead, I guess Everything has to be like ahead of things, I guess." (444017)</li> </ul>					
	"For my husband's birthday, I tried to plan something for him. But it seems difficult. It's like I can't do itI wanted to make him a little party and have a little dinner and whatever. But I don't, I, I just can't seem to get around to doing it. I, I, I told my daughter to help me." (444014)					
Executive functioning Planning/ organization of steps	R: "It's, it's trouble organizing it sometimes I'll give you an example of making Thanksgiving Dinner. Yeah, I cook it, okay, but the day you've got, I've got to prepare certain, certain stuff. And like prepare the sweet potatoes, peel them and all that stuff. And I'll, you know, I have prob, you know, problems with when to put stuff	Organizing things that had a lot of steps was	unchanged	dropped -Item dropped because it did not meet comprehension threshold		

	in and get it all out on the table at the same time." I: "I mean do you miss some steps of doing things?" R: "Yeah. Putting the butter in or the milk in for the sweet potatoes when I'm cooking it. Or forgetting to preheat the oven." (444011)					
Executive functioning Flexibility	"It's not a good thing. Like, it's like your whole life is being thrown off balance Because you're used to things happening a certain way and then when something is out of place, it's not good." (333024)  "I'm not don't get me wrong, I mean, I don't fly off the handle and smash things and break them [LAUGHS] like a child, but I'm, I'm, I am definitely a creat, a creature of habit." (222034)	When things that usually happen in a certain way got changed, it was	unchanged	When things don't happen the way they usually do, it wasModification was made in response to respondents commenting that the wording was confusing	unchanged	When things don't happen the way they usually do, it was
Executive functioning Flexibility	"Well, I hate when they change at the last minute. I, that's when, it'd get me upset. It's be like, "Look, I thought we supposed to be doin' this. Wait a minute, what?! We have something else to do." And he says he's going to change the plans right like that in the last second of the minute? I don't know, I don't know, it's been like that." (333023)  "She'd come over at workto visit us because we used to work together, and she would, you know, said we'll go to the restaurant And you know I put aside; I put aside, then wouldn't bring in my lunch and all that stuff. And then all of a sudden she calls me last minute and cancels, you know, because she	When someone I know changed our plans at the last minute, it was	unchanged	unchanged	unchanged	When someone I know changed our plans at the last minute, it was

	can't make it out or whatever, and I get frustrated." (444011)					
functioning Creativity in problem solving/ thinking "outside the box"	"Sometimes I don't come up with the solutions so it's kind of frustrating." (333004)  "No, I don't solve problems. I don't." (444016)	Coming up with solutions to problems was	unchanged	unchanged	unchanged	Coming up with solutions to problems was
Executive functioning Creativity in problem solving/ thinking "outside the box"	"I don't come up with new ideas, solve problems." (111011)	Coming up with a new or different way to get something done was	unchanged	Figuring out a new way to get something done wasReplaced "coming up with" with "figuring out" to more closely reflect the intended meaning of "thinking outside the box"; the word "different" was interpreted as any change (rather than something new) and therefore was dropped	unchanged	Figuring out a new way to get something done was
Executive functioning Seeing the full picture	"I get stuck with the details sometimes." (444006)  "I can't always see the bigger picture, but I think if my parents were around, they, they really have good perception so they would, they'd be able to understand everything that's kind of going on." (222031)	Seeing beyond the details of a situation and understanding the bigger picture or broad view was	Seeing the overall causes or bigger picture of a situation rather than focusing on just one detail of it was  -Modified to replace "broad view" with the more common phrase "overall causes" and to clarify that "focusing on just one detail" is the opposite	dropped -Item was dropped owing to low comprehension and no apparent way to revise the wording to reflect a complicated concept in a short statement		

			of the main concept			
Executive functioning Seeing the full picture	"Usually I don't even think about it. I just, I, I do it anyway. So I don't, I wouldn't think that further down the line how it would affect me in the future." (222036)	Understanding how something happening now would affect me in the future was	unchanged	Understanding how something happening now will affect me in the future wasReplaced the word "would" with "will" to avoid suggesting a hypothetical situation	unchanged	Understanding how something happening now will affect me in the future was
				Note: Item was retained with the goal of maintain the concept in the survey; however, given the difficulty of the concept and the confusion among some respondents, the item requires special attention during the quantitative phase to assess consistency		
Attention Mind wandering	"Even if I like a person if they start talking sometimes my mind just drifts off to something else." (222019)  "And I'm afraid of going [to college] because of staying focused. When I try to, you know, I'm sure, I think college is going to be a lot of reading and writingAnd I'm, I'm afraid because I can't focus, my mind just drifts off in so many different places" (333008)	My mind drifted off when I wanted to pay attention.	unchanged	unchanged	unchanged	My mind drifted off when I wanted to pay attention.
Attention Screening out distractions	"And like when I take tests, I really do much better when there's less sounds 'cause I won't be, I can focus enough; even if I don't study, I can make a good grade But it's like if I know that I	I got distracted by things around me, like noises or people talking.	unchanged	I got distracted by things going on around me (for example, other people talking or making noise).  -Replaced "like" with "for	I got distracted by things going on around me (for example, other people talking or	I got distracted by things going on around me (for example, other people talking or

	didn't stu, I, I, I hear the sound, hear the voices of other people as I'm trying to take the test, and that really distracts me. Even though it's supposed to be quiet, I still hear the pencils moving." (333013)  "Say if I was doing something like reading a book and I might hear a song, and the song might trigger me. I might start reading a book, turn on the radio, listen to the song, and my, my thing is I want to get back to reading that book but I might go start doing something else." (333006)			example" to enhance clarity that the specific items are examples of the broader concept. Added the word "other" to clarify that the item refers to external stimuli (ie, people in the respondent's environment making noises or talking)	making noise, or the radio or TV playing)Additional examples added to further clarify that the item is referring to external stimuli	making noise, or the radio or TV playing).
Attention Mind wandering	"Well, well, usually like my roommate, she'll talk to me and I keep saying 'What? Wait, say that again. What?' You know, I'm interested in what she's saying. I just wander off for the moment. And then I turn around and I say, 'What? What did you?'" (333003)  "Usually when somebody's talking to me, I would say 50% of the time I'm thinking about something else and I catch parts of their words in the sentences, and I try to put it all together at the end, you know, while I'm thinking about something else. And usually I get in trouble because sometimes when I put it together, it becomes that's not what they said." (444003)	When I was talking with people, my mind wandered off to other things even when I wanted to stay in the conversation.	unchanged	dropped -Item dropped because the phrase "wandered off" was interpreted by a respondent to mean physically wandering off, there was duplication with another item, and the conditional phrase increased the complexity of the sentence		
Attention Completion of tasks	"My difficulty's staying focused and concentration, sometimes setting out goals and staying on task. Like trying to do it by myself and staying on task and	It was hard to stay on task to finish things.	unchanged	It was hard to focus on something so I could finish it.  -Item modified to explicitly mention staying focused	unchanged	It was hard to focus on something so I could finish it.

	trying to do it is a little bit difficult." (222027)  "Late, lately it's my writing and poetry. Like I get stuck. And I'm trying to get into, to this contest, but it's really hard for me to, to sit down and write, so I, so like I get preoccupied and I don't really stay on task with that." (444013)			because two respondents did not interpret the original item as about focus		
Attention Ability to let go of thoughts	"You know, a lot of stuff gets in my head and all, it's kind of hard to let go." (111008)  "Yeah, sometimes things would just bother me. It would keep like on my mind. Like something bothers me, I wouldn't be able to let it go. I wouldn't be able to like sleep and stuff." (333019)	I kept thinking about things even when I wanted to let them go.	unchanged	unchanged	unchanged	I kept thinking about things even when I wanted to let them go.
Attention Racing/ disorganized thoughts	"I'll be thinking about one thing and several other things are racing through my mind at the same time." (111011)  "It's very upsetting and especially if you've been lying down most of the night and you look at the clock and it's like 4 or 5 AM and you haven't slept. You're like why can't I go to sleep, and then you go right back to thinking and it's just like speeding, and speeding, and speeding. You can't get out of it." (333007)	I had trouble with my thoughts racing and speeding through my mind.	I had trouble with my thoughts racing and speeding through my mind faster than I wanted.  -Modified to clarify that the item is asking about an experience that is counter to what the person would like to have (i.e., some element of bother).	My thoughts were racing and speeding through my mind faster than I wanted.  - Deleted the phrase "I had trouble with" because four respondents interpreted having "trouble with" something as different than something being "hard/difficult"	unchanged	My thoughts were racing and speeding through my mind faster than I wanted.

Sharpness of thought Fogginess/ cloudiness/lack of clarity	"Well, actually, I'm, sometimes my head gets all cloudy and foggy." (111008)  "Oh, it, it's just like a bunch of clouds that's going through my head. A hazy morning, because I'm not wearing my glasses. That's the cloudiness. When I put them back on that's the clearness. You know?" (333023)	My thinking was unclear, cloudy, or foggy.	unchanged	unchanged	unchanged	My thinking was unclear, cloudy, or foggy.
Sharpness of thought Fogginess/ cloudiness/lack of clarity	"Up until now, up until now since I got on the Abilify, it's been better. But precursor to that, I've had, I would describe my, my way of thinking as a crowded train station, and I'm the only person with directionsIf, if you ever went to like Times Square and the Information Booth, I feel like I'm in the Information Booth and everybody's lost, and I'll feel that way in conversation. Like there's just too much stuff going on in my own head for me to even focus on what people are sayingLet's, let's say if I'm doing something, everybody has input in what I'm doing. So the, the, yeah, um hmm, being bombarded with a lot of information, yeah." (444009)  "I don't like letting a lot of information inside, but right now it's kind of cluttered." (222008)	My thinking felt crowded or cluttered with thoughts going on in the background.	unchanged	dropped -Item dropped because it did not meet comprehension threshold		
Sharpness of thought Slow processing	"Yeah, I feel like sometimes I'm in slow motion. When I went out on that date, I had to think about things to talk about and it, it felt like, it went quick but it felt in my mind forever. It felt forever because I had to, I had to think of what I was going to say." (444011)	My thoughts were coming to me slower than I wanted.	My thoughts were coming to me more slowly than I wanted.  -Grammatical revision made to	dropped -Item dropped because it did not meet comprehension threshold		

			enhance clarity			
	"I can't think that fast, do it like that. So, it's like I know, I memorized the thing, but trying to do it, I get blanked sometimes." (333020)					
Sharpness of thought Slow processing	"Yes. It's like, it's like, it's like if I'm thinking, if I'm around certain people, you know, a group of people, whatever, and we're talking and having a good time or whatever, my thoughts would not catch on to some of the things they thinkin' about, because I don't catch it as fast as they do I, I would say it's, it's slower when I'm around a lot of people you know what I'm saying?" (333025)  "Now I could remember why I say I'm slow thinking sometimesLike right now I'm doing cashiering, and so I feel like I get into a custom more where I would be like counting real slow. Can you go faster, you know, like this." (222013)	I felt like I was not thinking as fast as other people.	unchanged	I felt like my thinking was not as fast as other people's.  -Item modified because a respondent interpreted the phrase "was not thinking" to mean that someone was not considering the consequences rather than the intended meaning of the process of thinking	unchanged	I felt like my thinking was not as fast as other people's.
Sharpness of thought Slow processing	"Uh, words do come up slower than I want them to come up. 'Cause I have to think about it first." (222017)  I: "Okay. What about feeling like your thinking is slower than usual or it's just taking longer for your thoughts to come together?"  R: "Yeah, that's what I have. It's quite a bit Yeah, like when I want to tell my boss something and I was, I thought, thought it over for a couple days and just took a couple days to get my thoughts organized. And it was still wasn't as, as,	I couldn't get my thoughts together fast enough because I had to really think about it first.	unchanged	dropped -Item dropped because the concept is addressed by another item and there was no apparent revision to address respondent's confusion about the phrase "because I had to really think about it first"		

	good as I had hoped, you know." (222036)					
Sharpness of thought Slow processing	"Sometimes when I get tired things stopUmm, everything just slow down." (222012)  "I'm a slow thinker I, the only time I've really been like that is if I'm tired and I guess that would be the reason why I'm thinking slowly." (444005)	When I was tired, I had trouble with my thinking slowing down.	unchanged	When I was tired, my thinking slowed down more than I wanted it to.  - Modified to avoid using the phrase "I had trouble with" because four respondents interpreted having "trouble with" something as different than something being "hard/difficult." The phrase "more than I wanted it to" was added to communicate that the item is asking about an experience that is counter to what the person would like to have (ie, some element of bother)	unchanged	When I was tired, my thinking slowed down more than I wanted it to.
Sharpness of thought Mentally blocked/ blank	"The block is like, what happens is that you're just not, like for me, I guess, I just don't know what to say next. I am just, I'm just definitely just out there. I mean like nothing is coming." (222013)  I: "And it does sound like when you said it does sound like it makes it harder to carry on a conversation sometimes."  R: "Yeah, because nothing really comes to mind, so you really don't like know what to say sometimes." (333020)	It was hard to think of what to say, as if my thoughts were blocked and nothing was coming to my mind.	unchanged	I felt like my thoughts were blocked and nothing was coming to my mind.  -The phrase "it was hard to think of what to say" was deleted to simplify the item and maintain focus on the idea of blocked thinking rather than communicating	unchanged	I felt like my thoughts were blocked and nothing was coming to my mind.
Metacognitive abilities Unmooring of	"Sometimes I'm not there, out somewhere in the universe. But lately I've been, I, I, I've been focused on my	I felt like I wasn't really there in my surroundings; I was awake, but I felt like I	unchanged	dropped -Item dropped because many of low rates of		

thought from context	surroundings and things. I know what's going on and I'm aware of my surroundings, too." (111012)  "You know, sometimes things are pleasant to think about, you know, outside. Sometimes trying to like, to sort of leave reality." (222008)  "It was like I, like I was walking on the street and like I felt I wasn't even there. Like I could feel my body moving but it's like I wasn't there." (333007)  "a lot of times when I'm in a fogit's like I'm lost. I'm already thinking different scenarios of things happening, you know I'm like dreaming. My, my mind is like dreaming." (444003)	was dreaming or had left reality.		comprehension and similarity to positive symptoms		
Metacognitive abilities Unmooring of thought from context	"And I got disoriented like, like I was talking and I couldn't understand what he was saying. I just like, 'Yeah, yeah, okay;' I'm not hearing what he said." (222008)  "Like when I'm so spent, like, like, like I'm so, so, so, so tired. Yeah, that's a point of disorientation completely. That's part of the problem, you know, 'cuz that's when you start to feel like, um, altered is such a different feeling, you know. Your brain isn't working." (222034)	I felt disoriented and I couldn't understand what was going on around me, like I was in an altered state.	unchanged	dropped -Item dropped because many of low rates of comprehension and similarity to positive symptoms		
N/A	N/A	Overall in the past week, how much have your experiences with thinking	unchanged	Overall in the past week, how much have your experiences with the items in this survey	unchanged	Overall in the past week, how much have your

		bothered you?	bothered you?  -Item modified because  some respondents did not  focus on the types of  thinking in the questionnaire  with the original wording of  the item	experiences with the items in this survey bothered you?
N/A	N/A	If your current experiences with thinking stayed the same for the rest of your life, how much would that bother you?	If your recent experiences with the items in this survey stayed the same for the rest of your life, how much would that bother you?  -Item modified because some respondents did not focus on the types of thinking in the questionnaire with the original wording of the item. The word "current" was replaced with "recent" to better align with the 1-week recall period of the questionnaire. The words "stayed the same" were underlined for emphasis	If your recent experiences with the items in this survey stayed the same for the rest of your life, how much would that bother you?

### **INSTRUCTIONS**

Original wording (v1.0; 7/10/2014)	Expert review (v1.1; 7/15/2014)	Cognitive debriefing (v2.0; 9/4/2014)	Expert review (v2.1; 9/12/2014)	Final item for psychometric testing (9/15/2014)
People with schizophrenia have different types of symptoms or experiences related to the condition. The following questions are about experiences with your thinking – positive or negative. Any difficulties with thinking that you might experience can be part of schizophrenia or a reaction to other things.	unchanged	unchanged	People with schizophrenia have different types of symptoms or experiences related to the condition. The following questions are about experiences with your thinking – positive or negative. Please answer based on your experience with each question, whether or not you think it is related to schizophrenia.  -Modified the last sentence to more directly state the intended meaning of asking respondents to answer the questions regardless of whether they attribute symptoms to schizophrenia	People with schizophrenia have different types of symptoms or experiences related to the condition. The following questions are about experiences with your thinking – positive or negative. Please answer based on your experience with each question, whether or not you think it is related to schizophrenia.
Please note: For this survey, "experiences with thinking" do not include delusions, hallucinations, or paranoia. These types of symptoms are very important but are not part of this survey.	unchanged	Please note: For this survey, "experiences with thinking" do not include experiences caused by paranoia, delusions, or hallucinations (for example, do not include "hearing voices" that no one else can hear). These types of symptoms are very important but are not part of this surveyModified to further clarify that the survey is not asking about positive symptoms. This change was in response to a subset of respondents mentioning the experience of hearing voices in relation to their thinking	Please note: For this survey, "experiences with thinking" do not include experiences caused by paranoia, delusions, or hallucinations (for example, "hearing voices" that no one else can hear). These types of symptoms are very important but are not part of this surveyModified to simplify language	Please note: For this survey, "experiences with thinking" do not include experiences caused by paranoia, delusions, or hallucinations (for example, "hearing voices" that no one else can hear). These types of symptoms are very important but are not part of this survey.
Please read or listen to each item	unchanged	Please read or listen to each item	unchanged	Please read or listen to each item

carefully and choose the ONE number that best describes you.		carefully and choose the ONE number from easiest (1=not at all hard) to hardest (5=very hard) that best describes you. If an item does not apply to you or asks about an experience you have not had, "choose "not at all hard."  -Modified because a respondent did not initially understand that the response categories were orderable. The instruction on how to answer if an item does not apply was added for clarity and to communicate to respondents that it is expected that each item may not apply to every person (particularly in Section 2 regarding difficulties with attention or sharp thinking)		carefully and choose the ONE number from easiest (1=not at all hard) to hardest (5=very hard) that best describes you. If an item does not apply to you or asks about an experience you have not had, "choose "not at all hard."
Section 1 In this section, please tell us whether the following situations have been hard for you in the past week. Take into account your overall experience during the week.	unchanged	unchanged	unchanged	Section 1 In this section, please tell us whether the following situations have been hard for you in the past week. Take into account your overall experience during the week.
Section 2 In this section, please tell us how much each statement has applied to you in the past week. Take into account your overall experience during the week. For each item, choose ONE number.	unchanged	In this section, please tell us how much each statement has applied to you in the past week. Take into account your overall experience during the week.  Please read or listen to each item carefully and choose the ONE number from lowest (1=not at all) to highest (5=very much) that best describes you. If an item does not apply to you or asks about an experience you have not had, choose "not at all."	unchanged	Section 2 In this section, please tell us how much each statement has applied to you in the past week. Take into account your overall experience during the week.  Please read or listen to each item carefully and choose the ONE number from lowest (1=not at all) to highest (5=very much) that best describes you. If an item does not apply to you or asks about an
		Please note: For this survey, do not		experience you have not had, choose "not at all".

include experiences caused by paranoia. delusions, or hallucinations (for example, Please note: For this survey, do not do not include "hearing voices" that no include experiences caused by paranoia, delusions, or one else can hear). hallucinations (for example, do not -Modified to include a reminder that include "hearing voices" that no one the survey is not asking about positive symptoms because this else can hear). section asks about attention (which was the most common point in the survey in which the experience of hearing voices was mentioned by respondents) and to be consistent with earlier instruction about the orderable nature of the response items Section3 unchanged Section 3 Section3 Section3 For this section, please take into For this section, please take into For this section, please take For this section, please take into account account your experiences with into account your your experiences with all the types of account your experiences with all thinking as a group and tell us how experiences with all the types thinking asked about in this survey and the types of thinking asked about in much they bother you overall. For of thinking asked about in this tell us how much they bother you this survey and tell us how much this survey, being "bothered" by overall. For this survey, being "bothered" they bother you overall. For this survey and tell us how much your experience means that you feel by your experience means that you feel survey, being "bothered" by your they **bother you overall**. For annoyed or concerned about them. this survey, being "bothered" annoyed, uncomfortable, or concerned experience means that you feel by your experience means about them. annoyed, uncomfortable, or that you feel annoyed or concerned about them. concerned about them. Please note: For this survey, do not -Modified to specify that include experiences caused by paranoia, Please note: For this survey, do not the phrase "as a group" delusions, or hallucinations. include experiences caused by -Added the word "uncomfortable" paranoia, delusions, or meant types of thinking hallucinations. asked about in the survey because a respondent suggested this meaning of "bother"; added the reminder that the survey does not include positive symptoms in order to be consistent with other instructions

#### Table S2 Draft Patient-Reported Outcome Instrument

People with schizophrenia have different types of symptoms or experiences related to the condition. The following questions are about *experiences with your thinking*—positive or negative. Please answer based on your experience with each question, whether or not you think it is related to schizophrenia.

*Please note:* For this survey, "experiences with thinking" <u>do not include experiences caused by paranoia, delusions, or hallucinations</u> (for example, hearing voices that no one else can hear). These types of symptoms are very important but are not part of this survey.

Please read or listen to each item carefully and **choose the ONE number** from easiest (1=not at all hard) to hardest (5=very hard) that best describes you. If an item does not apply to you or asks about an experience you have not had, choose "not at all hard."

#### Section 1

In this section, please tell us whether the following situations have been hard for you in the past week. Take into account your <u>overall</u> experience during the week.

#### MEMORY: Remembering what I want to

Overall, in the past week	Not at all hard	A little bit hard	Somewhat hard	Quite hard	Very hard
Recalling people's names was	1	2 □	3 □	4 □	5 □
Remembering what I was supposed to do or buy was	1	2 □	3 □	4 □	5 □
Remembering where I put things (for example, my keys, phone, glasses, or other items) was	1	2	3 □	4 □	5 □
When I wanted to remember information from a <u>short time</u> ago (for example, what I read or watched in a movie or TV show), it was	1 □	2 □	3 □	4 □	5 □
Recalling something from a couple of years ago when I wanted to (for example, information I used to know or an important event) was	1	2 □	3	4 □	5 □
Remembering what I wanted to say was	1	2 □	3 □	4 □	5 □
Remembering what someone else was saying was	1	2	3 □	4 □	5 □
Remembering how to get someplace that I wanted to go was	1 □	2 □	3 □	4 □	5 □
Remembering what I was just about to do was	1	2 □	3 □	4 □	5 □

# **COMMUNICATION: Talking and interacting with others**

Overall, in the past week	Not at all hard	A little bit hard	Somewhat hard	Quite hard	Very hard
Understanding what someone was talking about was	1	2	3 □	4	5
Coming up with something to say when I wanted to was	1	2 □	3 □	4 □	5 □
Interacting with people I don't know well was	1	2 □	3 □	4 □	5 □
Explaining myself well so that other people knew what I meant was	1 □	2 □	3 □	4 □	5 □
Finding words to say what I mean was	1	2 □	3 □	4 □	5 □
Understanding body language, gestures, or other hints from people without them telling me how they felt in words was	1 □	2 □	3 □	4 □	5 □

# **CONTROL: Saying and doing what I mean**

Overall, in the past week	Not at all hard	A little bit hard	Somewhat hard	Quite hard	Very hard
Keeping things from slipping out when I didn't want to say it was	1	2 □	3 □	4 □	5 □
Stopping to think through things before saying or doing them was	1	2 □	3 □	4 □	5 □
Stopping myself from saying or doing something wrong or inappropriate was	1	2 □	3 □	4 □	5 □

## **PLANNING: Making and changing plans**

Overall, in the past week	Not at all hard	A little bit hard	Somewhat hard	Quite hard	Very hard
Without someone's help, planning ahead for an event or how to get to a goal was	1	2 □	3 □	4 □	5 □
When things don't happen the way they usually do, it was	1	2 □	3 □	4 □	5
When someone I know changed our plans at the last minute, it was	1	2 □	3 □	4	5 □

# HANDLING PROBLEMS: Coming up with solutions & taking the future into account

Overall, in the past week	Not at all hard	A little bit hard	Somewhat hard	Quite hard	Very hard
Coming up with solutions to problems was	1	2	3 □	4 □	5
Figuring out a new way to get something done was	1 □	2 □	3 □	4 □	5 □
Understanding how something happening now will affect me in the future was	1	2	3 □	4 □	5

#### Section 2

In this section, please tell us how much each statement has applied to you in the past week. Take into account your overall experience during the week.

Please read or listen to each item carefully and choose the **ONE number** from lowest (1=not at all) to highest (5=very much) that best describes you. If an item does not apply to you or asks about an experience you have not had, choose "not at all".

<u>Please note</u>: For this survey, <u>do not include experiences caused by paranoia, delusions, or hallucinations</u> (for example, do not include "hearing voices" that no one else can hear).

### ATTENTION: Paying attention to what I want to

Overall, in the past week	Not at all	A little bit	Somewhat	Quite a bit	Very much
My mind drifted off when I wanted to pay attention.	1	2	3	4	5
I got distracted by things going on around me (for example, other people talking or making noise, or the radio or TV playing).	1	2 □	3 □	4 □	5 □
It was hard to focus on something so I could finish it.	1	2 □	3 □	4 □	5
I kept thinking about things even when I wanted to let them go.	1	2 □	3 □	4 □	5 □
My thoughts were racing and speeding through my mind faster than I wanted.	1	2 □	3 □	4 □	5 □

### SHARP THINKING: Thinking that is clear, fast, and easy

Overall, in the past week	Not at all	A little bit	Somewhat	Quite a bit	Very much
My thinking was unclear, cloudy, or foggy.	1	2 □	3 □	4	5
I felt like my thinking was not as fast as other people's.	1	2 □	3 □	4 □	5 □
When I was tired, my thinking slowed down more than I wanted it to.	1	2 □	3 □	4 □	5 □
I felt like my thoughts were blocked and nothing was coming to my mind.	1 □	2 □	3 □	4 □	5 □

#### Section 3

For this section, please take into account your experiences with all the types of thinking asked about in this survey and tell us how much they **bother you overall**. For this survey, being bothered by your experiences means that you feel <u>annoyed</u>, <u>uncomfortable</u>, <u>or concerned</u> about them.

*Please note:* For this survey, <u>do not include experiences caused by paranoia, delusions, or hallucinations</u>.

	Not at all	A little bit	Somewhat	Quite a bit	Very much
Overall in the past week, how much have	1	2	3	4	5
your experiences with the items in this survey bothered you?					
If your recent experiences with the items in this survey stayed the same for the rest of your life, how much would that bother you?	1	2 □	3 □	4 □	5 □