

Supplementary Online Content

Nestsiarovich A, Hurwitz NG, Nelson SJ, Crisanti AS, Kerner B, Kuntz MJ, Smith AN, Volesky E, Schroeter QL, DeShaw JL, Young SS, Obenchain RL, Krall RL, Jordan K, Fawcett J, Tohen M, Perkins DJ, Lambert CG. Systemic challenges in bipolar disorder management: a patient-centered approach.

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Supplementary Material 1: Focus groups script

Supplementary Table 1: Demographic characteristics of participants of the three focus groups.

Race	Male (n=17)	Female (n=17)	Total (n=34)
American Indian/ Alaska Native	0	1	1
Asian	0	0	0
Black/ African American	1	2	3
Hawaiian/ Pacific Islander	0	0	0
White	13	11	24
Multi-race	2	0	2
Unknown	1	3	4
Ethnicity	Male (n=17)	Female (n=17)	Total (n=34)
Hispanic (Latino/Latina)	3	2	5
Non-Hispanic	21	8	29
Age range	Male (n=17)	Female (n=17)	Total (n=34)
Age 20s	3	2	5
Age 30s	4	2	6
Age 40s	2	2	4
Age 50s	3	9	12
Age 60s	2	3	5
Age 70s	1	1	2

Supplementary Table 2: Categories of questions generated in focus groups and their mapping to 10 broad themes.

Original focus group categories	Summary rank score	Broad themes	Summary rank score
Alternatives and adjuncts to medication	4	Alternatives and adjuncts to pharmacotherapy	41
Drug alternatives	3		
Other treatments	20		
Holistic options	12		
Lifestyle	2		
Medications	23	Pharmacotherapy	35
Medications and adherence	3		
Pharmacology	4		
Side effects	5		
Sexuality	0		
Doctor communication/collaboration	16	Provider relations	24
Provider relations	8		
Understanding bipolar	2	Understanding BD	23
Causes of bipolar	3		
Education	12		
Symptoms	0		
Behaviors	6		
Support/Advocacy	9	Support	21
Social and family support	3		
Support resources	1		
Family dynamics	8		
Healthcare system navigation	3	Health care system navigation	14
Treatment assessment/cost	11		
Criminal justice system	0		
Diagnosis and research	10	Diagnosis	13
Diagnosis/screening	3		

Symptom management	4	BD coping/management	8
Crisis management	4		
Coping	0		
Social bias and stigma	6	Social bias and stigma	8
Stigma	2		
Big Ideas	8	Other (these groups contained miscellaneous questions covered by themes above)	8
Children	6		6

Supplementary Table 3: Ten questions top-rated by researcher and patient stakeholders.

#	10 top-ranked questions by both researcher and patient stakeholders		10 top-ranked questions by researcher stakeholders		10 top-ranked questions by patients stakeholders	
	Questions	Average score	Questions	Average score	Questions	Average score
1	What can be done to eliminate suicidal thoughts with some medications?	4.750	What can be done to eliminate suicidal thoughts with some medications?	4.750	Medications don't always work the same for everyone. Medications: how do you get the right cocktail? What can be done to stop, "take this and see if it works" policy? How do I know this treatment option will work? How do I know what medication will work for me?	5.000
2	For the BD brain to not be medicated, what are the consequences? I wish I had information about why I need medication. What are the risks of takings medications or not? Why do I have to take this? Explain please?	4.688	For the BD brain to not be medicated, what are the consequences? I wish I had information about why I need medication. What are the risks of takings medications or not? Why do I have to take this? Explain please?	4.625	Drug side effects. What are all the side effects of my medication? What are the side effects of medicines? What is a side effects of this medication? What's the safest medications to take first? How to make sure your love one is taking his medications; what will be the side effects? What kind of side effects do I need to be aware of? How do I deal with the side effects of my medication when I'm re-entering the work force, social environments, etc.? More details on medication metabolization, effect duration, risks of overdose, ramp up times.	5.000

3	Medications don't always work the same for everyone. Medications: how do you get the right cocktail? What can be done to stop, "take this and see if it works" policy? How do I know this treatment option will work? How do I know what medication will work for me?	4.688	What is the efficacy of my treatment?	4.500	When is too much medication. Why do they prescribe so many medications?	4.875
4	Drug side effects. What are all the side effects of my medication? What are the side effects of medicines? What is a side effects of this medication? What's the safest medications to take first? How to make sure your love one is taking his medications; what will be the side effects? What kind of side effects do I need to be aware of? How do I deal with the side effects of my medication when I'm re-entering the work force, social environments, etc.? More details on medication metabolization, effect duration, risks of overdose, ramp up times.	4.688	Would have been good to know severity of symptoms, especially dangers.	4.500	For the BD brain to not be medicated, what are the consequences? I wish I had information about why I need medication. What are the risks of takings medications or not? Why do I have to take this? Explain please?	4.750
5	When is too much medication. Why do they prescribe so many medications?	4.563	How will the drugs interact with each other?	4.375	How should I manage the manic episode?	4.750

6	What is the efficacy of my treatment?	4.563	Medications don't always work the same for everyone. Medications: how do you get the right cocktail? What can be done to stop, "take this and see if it works" policy? How do I know this treatment option will work? How do I know what medication will work for me?	4.375	I take lithium, "Geodon", "Buspar", hydroxyzine, and "Lyrica". My question is which antipsychotic works best for bipolar disorder?	4.750
7	Would have been good to know severity of symptoms, especially dangers.	4.563	Drug cravings vs. different medications? Real discussion about medications interactions with substances. What are these?	4.375	What are therapeutic treatment windows? How do these affect how I take medications? More information about medication and dosages.	4.750
8	How should I manage the manic episode?	4.500	Drug side effects. What are all the side effects of my medication? What are the side effects of medicines? What is a side effects of this medication? What's the safest medication to take first? How to make sure your love one is taking his medications; what will be the side effects? What kind of side effects do I need to be aware of? How do I deal with the side effects of my medication when I'm re-entering the work force, social environments, etc.? More details on medication metabolism, effect duration, risks of overdose, ramp up times.	4.375	What can be done to eliminate suicidal thoughts with some medications?	4.750

9	I take lithium, "Geodon", "Buspar", hydroxyzine, and "Lyrica". My question is which antipsychotic works best for bipolar disorder?	4.500	[Are] side effects different for young children? I want to know how puberty affects medication efficacy.	4.375	What happens when people do not want to be medicated? How can you help them? (I have read [book]: I am not sick, I don't need help). Have people been healed without drugs? What options do I have outside of drug treatment? Are there studies of people who do alternative therapies to medication who succeed? What are all of my treatment options? What are available treatments? What are treatment choices? What kinds of therapy should I try? What type of therapy is good for mental illness? When should I take medicine vs therapy for my bipolar?	4.625
10	How will the drugs interact with each other?	4.500	What happens when people do not want to be medicated? How can you help them? (I have read [book]: I am not sick, I don't need help). Have people been healed without drugs? What options do I have outside of drug treatment? Are there studies of people who do alternative therapies to medication who succeed? What are all of my treatment options? What are available treatments? What are treatment choices? What kinds of therapy should I try? What type of therapy is good for mental illness? When should I take medicine vs therapy for my bipolar?	4.250	How will the drugs interact with each other?	4.625

Supplementary Table 4: Rating of questions related to the “Alternatives and adjuncts to pharmacotherapy” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
For the BD brain to not be medicated, what are the consequences? I wish I had info about why I need medication. What are the risks of takings medications or not? Why do I have to take this? Explain please?	4.688	For the BD brain to not be medicated, what are the consequences? I wish I had info about why I need medication. What are the risks of takings medications or not? Why do I have to take this? Explain please?	4.625	For the BD brain to not be medicated, what are the consequences? I wish I had info about why I need medication. What are the risks of taking medications or not? Why do I have to take this? Explain please?	4.750
What happens when people do not want to be medicated? How can you help them? (I have read [book]: I am not sick, I don't need help). Have people been healed without drugs? What options do I have outside of drug treatment? Are there studies of people who do alternative therapies to medication who succeed? What are all of my treatment options? What are available treatments? What are treatment choices? What kinds of therapy should I try? What type of therapy is good for mental illness? When should I take medicine vs therapy for my bipolar?	4.438	What happens when people do not want to be medicated? How can you help them? (I have read [book]: I am not sick, I don't need help). Have people been healed without drugs? What options do I have outside of drug treatment? Are there studies of people who do alternative therapies to medication who succeed? What are all of my treatment options? What are available treatments? What are treatment choices? What kinds of therapy should I try? What type of therapy is good for mental illness? When should I take medicine vs therapy for my bipolar?	4.250	What happens when people do not want to be medicated? How can you help them? (I have read [book]: I am not sick, I don't need help). Have people been healed without drugs? What options do I have outside of drug treatment? Are there studies of people who do alternative therapies to medication who succeed? What are all of my treatment options? What are available treatments? What are treatment choices? What kinds of therapy should I try? What type of therapy is good for mental illness? When should I take medicine vs therapy for my bipolar?	4.625
Alcohol helps symptoms in short term. What are long term damages? What effect will alcohol have on my treatment?	4.063	Alcohol helps symptoms in short term. What are long term damages? What effect will alcohol have on my treatment?	4.125	One treatment, center for education, diet, medication, job placements, training.	4.375

How does the substance abuse reinforce the disease? What do I need to know about interactions with pot, alcohol, LSD, etc.? What do others abuses look like?	3.875	How does the substance abuse reinforce the disease? What do I need to know about interactions with pot, alcohol, LSD, etc.? What do others abuses look like?	4.000	How can one incorporate diet, exercise, mindfulness, etc.? Why aren't these part of treatment plan?	4.250
Do I have any options to try first before psychotropic medications?	3.813	Do I have any options to try first before psychotropic medications?	3.875	Effect of stressors +sleep hygiene	4.125
Effect of stressors +sleep hygiene	3.750	Effect of stressors +sleep hygiene	3.375	Classes, structure, life skills	4.000
How can one incorporate diet, exercise, mindfulness, etc.? Why aren't these part of treatment plan?	3.688	How can one incorporate diet, exercise, mindfulness, etc.? Why aren't these part of treatment plan?	3.125	Alcohol helps symptoms in short term. What are long term damages? What effect will alcohol have on my treatment?	4.000
One treatment, center for education, diet, medication, job placements, training.	3.625	How nutrition could affect condition? Caffeine, vitamins, alcohol, etc.	3.125	How nutrition could affect condition? Caffeine, vitamins, alcohol, etc.	3.875
Classes, structure, life skills.	3.500	Are there research studies on the horizon incorporating CBD [Cannabidiol] therapy for BD? THC [Tetrahydrocannabinol]? Oil/Smoke - - Knock off mania -- relax depression. What are side effects of smoking marijuana for [a] bipolar person?	3.125	Do I have any options to try first before psychotropic medications?	3.750
How nutrition could affect condition? Caffeine, vitamins, alcohol, etc.	3.500	Classes, structure, life skills.	3.000	How does the substance abuse reinforce the disease? What do I need to know about interactions with pot, alcohol, LSD, etc.? What do others abuses look like?	3.750
How can lifestyle changes help? Is dairy a known trigger? What research is being done on special diet therapy for BD ketogenic? Diet.	3.250	How can lifestyle changes help? Is dairy a known trigger? What research is being done on special diet therapy for BD ketogenic? Diet.	3.000	How can lifestyle changes help? Is dairy a known trigger? What research is being done on special diet therapy for BD ketogenic? Diet.	3.500

Are there research studies on the horizon incorporating CBD [Cannabidiol] therapy for BD? THC [Tetrahydrocannabinol]? Oil/Smoke -- Knock off mania -- relax depression. What are side effects of smoking marijuana for [a] bipolar person?	3.188	One treatment, center for education, diet, medication, job placements, training.	2.875	Are there research studies on the horizon incorporating CBD [Cannabidiol] therapy for BD? THC [Tetrahydrocannabinol]? Oil/Smoke -- Knock off mania -- relax depression. What are side effects of smoking marijuana for [a] bipolar person?	3.250
Bipolar and LSD?	2.688	Bipolar and LSD?	2.375	Bipolar and LSD?	3.000

Supplementary Table 5: Rating of questions related to the “Pharmacotherapy” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
What can be done to eliminate suicidal thoughts with some medications?	4.750	What can be done to eliminate suicidal thoughts with some medications?	4.750	Medications don't always work the same for everyone. Medications: how do you get the right cocktail? What can be done to stop, "take this and see if it works" policy? How do I know this treatment option will work? How do I know what medication will work for me?	5.000
Medications don't always work the same for everyone. Medications: how do you get the right cocktail? What can be done to stop, "take this and see if it works" policy? How do I know this treatment option will work? How do I know what medication will work for me?	4.688	What is the efficacy of my treatment?	4.500	Drug side effects. What are ALL the side effects of my medication? What are the side effects of medicines? What is a side effects of this medication? What's the safest medications to take first? How to make sure your love one is taking his meds; what will be the side effects? What kind of side effects do I need to be aware of? How do I deal with the side effects of my medication when I'm re-entering the work force, social environments, etc.? More details on medication metabolization, effect duration, risks of overdose, ramp up times.	5.000

<p>Drug side effects. What are ALL the side effects of my medication? What are the side effects of medicines? What are the side effects of this medication? What's the safest medications to take first? How to make sure your love one is taking his meds; what will be the side effects? What kind of side effects do I need to be aware of? How do I deal with the side effects of my medication when I'm re-entering the work force, social environments, etc.? More details on medication metabolization, effect duration, risks of overdose, ramp up times.</p>	4.688	How will the drugs interact with each other?	4.375	When is too much medication. Why do they prescribe so many medications?	4.875
<p>When is too much medication. Why do they prescribe so many medications?</p>	4.563	Medications don't always work the same for everyone. Medications: how do you get the right cocktail? What can be done to stop, "take this and see if it works" policy? How do I know this treatment option will work? How do I know what medication will work for me?	4.375	I take lithium, "Geodon", "Buspar", hydroxyzine, and "Lyrica". My question is which antipsychotic works best for bipolar disorder?	4.750
<p>What is the efficacy of my treatment?</p>	4.563	Drug cravings vs. different meds? Real discussion about medications interactions with substances. What are these?	4.375	What are therapeutic treatment windows? How do these affect how I take meds? More information about medication and dosages.	4.750

I take lithium, "Geodon", "Buspar", hydroxyzine, and "Lyrica". My question is which antipsychotic works best for bipolar disorder?	4.500	Drug side effects. What are ALL the side effects of my medication? What are the side effects of medicines? What is a side effects of this medication? What's the safest medications to take first? How to make sure your love one is taking his meds; what will be the side effects? What kind of side effects do I need to be aware of? How do I deal with the side effects of my medication when I'm re-entering the work force, social environments, etc.? More details on medication metabolization, effect duration, risks of overdose, ramp up times.	4.375	What can be done to eliminate suicidal thoughts with some medications?	4.750
How will the drugs interact with each other?	4.500	I take lithium, "Geodon", "Buspar", hydroxyzine, and "Lyrica". My question is which antipsychotic works best for bipolar disorder?	4.250	How will the drugs interact with each other?	4.625
"Invega" shot.	4.375	"Invega" shot.	4.250	What is the efficacy of my treatment?	4.625
What are therapeutic treatment windows? How do these affect how I take meds? More information about medication and dosages.	4.313	When is too much medication. Why do they prescribe so many medications?	4.250	"Invega" shot.	4.500
Drugs --> Birth defects, obesity, elevated appetite, diabetes	4.313	When on multiple drugs how to be sure they're safe together?	4.125	One drug at a time -- so I know side effects of each one	4.500

How can one best understand side effects, benefits of a drug & how to mitigate undesired side effects, like weight gain? I am experiencing weight gain from this medication and what alternatives may I have? I would like to have known more about side effects. Getting fat!!Why do some medications make a person so hungry?	4.250	What's the effect on a bipolar patient's recovery when having taking an antidepressants versus not?	4.125	How can one best understand side effects, benefits of a drug & how to mitigate undesired side effects, like weight gain? I am experiencing weight gain from this medication and what alternatives may I have? I would like to have known more about side effects. Getting fat!!Why do some medications make a person so hungry?	4.500
Drug cravings vs. different meds? Real discussion about medications interactions with substances. What are these?	4.250	Drugs --> Birth defects, obesity, elevated appetite, diabetes	4.125	Drugs --> Birth defects, obesity, elevated appetite, diabetes	4.500
Medication makes me physically ill. Would be nice to have medications that don't	4.188	Medication makes me physically ill. Would be nice to have medications that don't	4.000	Medication makes me physically ill. Would be nice to have medications that don't	4.375
When on multiple drugs how to be sure they're safe together?	4.188	What is the best way to get a streamline on all medications that could work for several different issues?	4.000	Is it advisable to go off antipsychotics if a person has a predisposition to diabetes? If so, what would be alternative?	4.375
Is it dangerous to change meds?	4.188	Is it dangerous to change meds?	4.000	How can I know if it's my medications making me sick or my disease?	4.375
Better explanation of side effect times vs medicinal effect	4.188	Better explanation of side effect times vs medicinal effect	4.000	What is the best way to wean off meds?	4.375
One drug at a time -- so I know side effects of each one	4.188	What will help me sleep without making me psychotic?	4.000	Is it dangerous to change meds?	4.375

What will help me sleep without making me psychotic?	4.188	How can one best understand side effects, benefits of a drug & how to mitigate undesired side effects, like weight gain? I am experiencing weight gain from this medication and what alternatives may I have? I would like to have known more about side effects. Getting fat!!Why do some medications make a person so hungry?	4.000	Better explanation of side effect times vs medicinal effect	4.375
How can I know if it's my medications making me sick or my disease?	4.125	Are there shots or implants for effective BD treatment?	4.000	What will help me sleep without making me psychotic?	4.375
How many times a night did patients waken on different meds?	4.063	What are therapeutic treatment windows? How do these affect how I take meds? More information about medication and dosages.	3.875	Why do my hands shake so much?	4.375
What kind of med combos are common and why?	4.063	How can I know if it's my medications making me sick or my disease?	3.875	What kind of med combos are common and why?	4.375
What about the drug and alcohol abuse? How do you help the person to overcome that when in conjunction with mental illness?	4.063	How safe is "Depakote"?	3.875	Connection between ADHD and akathisia?	4.375
What's the effect on a bipolar patient's recovery when having taking an antidepressants versus not?	4.000	One drug at a time -- so I know side effects of each one.	3.875	When on multiple drugs how to be sure they're safe together?	4.250
How safe is "Depakote"?	4.000	How many times a night did patients waken on different meds?	3.875	How many times a night did patients waken on different meds?	4.250
Are there shots or implants for effective BD treatment?	4.000	What are my alternative treatment options when the past 2-3 rounds of medications have had limited success?	3.875	What about the drug and alcohol abuse? How do you help the person to overcome that when in conjunction with mental illness?	4.250

Is it advisable to go off antipsychotics if a person has a predisposition to diabetes? If so, what would be alternative?	3.938	What about the drug & alcohol abuse? How do you help the person to overcome that when in conjunction with mental illness?	3.875	How safe is "Depakote"?	4.125
What is the best way to get a streamline on all medications that could work for several different issues?	3.938	How long does it take for the medications to kick in?	3.750	What happens when your son says the medicine makes him feel so sick? He would rather not be on it because it produces a sizzle effect on the brain? ("Zyprexa")	4.125
Why do my hands shake so much?	3.938	What kind of med combos are common and why?	3.750	Drug cravings vs. different meds? Real discussion about medications interactions with substances. What are these?	4.125
What are my alternative treatment options when the past 2-3 rounds of medications have had limited success?	3.938	Some medications have life-long deleterious effects or life threatening side effects. Better testing to prevent this would be nice	3.750	Is lithium making a comeback as a choice of treatment?	4.125
What can a bipolar woman do to help mood during menopause? Besides medication, is hormone treatment okay or not advised, etc.?	3.813	What can a bipolar woman do to help mood during menopause? Besides medication, is hormone treatment okay or not advised, etc.?	3.625	What can a bipolar woman do to help mood during menopause? Besides medication, is hormone treatment okay or not advised, etc.?	4.000
What is the best way to wean off meds?	3.813	Why is there side effects to this medication?	3.625	Are there shots or implants for effective BD treatment?	4.000
Why is there side effects to this medication?	3.750	Should I change my diet if I'm on meds?	3.625	How often is LAB test on drug metabolism ever done?	4.000
Some medications have life-long deleterious effects or life threatening side effects. Better testing to prevent this would be nice.	3.750	How long will side effects last?	3.500	What are my alternative treatment options when the past 2-3 rounds of medications have had limited success?	4.000
How long will side effects last?	3.688	Is it advisable to go off antipsychotics if a person has a predisposition to diabetes? If so, what would be alternative?	3.500	How long will side effects last?	3.875

How long does it take for the medications to kick in?	3.688	Why do my hands shake so much?	3.500	What is the best way to get a streamline on all medications that could work for several different issues?	3.875
Connection between ADHD and akathisia?	3.688	What about sexual dysfunction as side effect?	3.500	What's the effect on a bipolar patient's recovery when having taking an antidepressants versus not?	3.875
What happens when your son says the medicine makes him feel so sick? He would rather not be on it because it produces a sizzle effect on the brain? ("Zyprexa")	3.625	What happens when you see that a small dose of "Abilify" did help stabilize, but then our son did not want to continue with the medication? (and it seemed hopeful)	3.250	How the medication affects your libido? What effects will you have on childbirth?	3.875
Should I change my diet if I'm on meds?	3.625	What is the best way to wean off meds?	3.250	Why is there side effects to this medication?	3.875
Is lithium making a comeback as a choice of treatment?	3.563	What happens when your son says the medicine makes him feel so sick? He would rather not be on it because it produces a sizzle effect on the brain? ("Zyprexa")	3.125	Some medications have life-long deleterious effects or life threatening side effects. Better testing to prevent this would be nice	3.750
What about sexual dysfunction as side effect?	3.500	How the medication affects your libido? What effects will you have on childbirth?	3.000	How long does it take for the medications to kick in?	3.625
How the medication affects your libido? What effects will you have on childbirth?	3.438	Is lithium making a comeback as a choice of treatment?	3.000	Should I change my diet if I'm on meds?	3.625
How often is lab test on drug metabolism ever done?	3.438	Connection between ADHD and akathisia?	3.000	What happens when you see that a small dose of "Abilify" did help stabilize, but then our son did not want to continue with the medication? (and it seemed hopeful)	3.500
What happens when you see that a small dose of "Abilify" did help stabilize, but then our son did not want to continue with the medication? (and it seemed hopeful)	3.375	How often is lab test on drug metabolism ever done?	2.875	MRI, CT scans, how often are these utilized in determining treatment for BD?	3.500
MRI, CT scans, how often are these utilized in determining treatment for BD?	3.000	And what with all the night time peeing!?	2.750	What about sexual dysfunction as side effect?	3.500

And what with all the night time peeing!?	2.875	I wish I had known about the dry mouth from Lithium	2.750	And what with all the night time peeing!?	3.000
I wish I had known about the dry mouth from Lithium.	2.813	MRI, CT scans, how often are these utilized in determining treatment for BD?	2.500	I wish I had known about the dry mouth from Lithium.	2.875

Supplementary Table 6: Rating of questions related to the “Provider relations” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
How can you better understand my condition and what information will help you in "fine tuning" my treatment?	4.313	How can you better understand my condition and what information will help you in "fine tuning" my treatment?	4.000	How can you better understand my condition and what information will help you in "fine tuning" my treatment?	4.625
Poor relationship with psychiatrist. Non-compliant.	3.750	How come doctors don't spend more time with patients? Most therapy hours only last 15 min.	3.250	Poor relationship with psychiatrist. Non-compliant.	4.250
How come doctors don't spend more time with patients? Most therapy hours only last 15 min.	3.688	Poor relationship with psychiatrist. Non-compliant.	3.250	How come doctors don't spend more time with patients? Most therapy hours only last 15 min.	4.125

Supplementary Table 7: Rating of questions related to the “Understanding BD” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
Would have been good to know severity of symptoms, especially dangers.	4.563	Would have been good to know severity of symptoms, especially dangers.	4.500	What will happen to me?	4.625
What will happen to me?	4.313	Are there common physical symptoms or issues that commonly co-occur with bipolar?	4.125	Education at the start of treatment structured, i.e. NAMI etc. for patient/consumer.	4.625
Are there common physical symptoms or issues that commonly co-occur with bipolar?	4.313	What will happen to me?	4.000	Would have been good to know severity of symptoms, especially dangers.	4.625
What is bipolar? Expand. Knowledge of bipolar disorder.	4.125	Does NOT being treated+ having psychotic events+ hallucinations worsen bipolar or decrease you IQ?	4.000	What is bipolar? Expand. Knowledge of bipolar disorder.	4.500
Does NOT being treated+ having psychotic events+ hallucinations worsen bipolar or decrease you IQ?	4.125	What is co-occurring?	4.000	Are there common physical symptoms or issues that commonly co-occur with bipolar?	4.500
What is co-occurring?	4.125	What happens to the brain/body after multiple psychiatric breaks?	3.875	Better education of consumer on side effects/benefits of med choices	4.375
Education at the start of treatment structured, i.e. NAMI etc. for patient/consumer	4.063	I was told that bipolar in men becomes just depression as they age? If true, why not women? - Menopause	3.875	Is BD specific to genetics, environmental and or traumatic events? What are my triggers? What research is being done on the environmental impact of BD (pesticides etc.)?	4.375
Can a medication trigger a manic episode?	4.063	Sleep apnea. Obstructive and/or central.	3.875	Does NOT being treated+ having psychotic events+ hallucinations worsen bipolar or decrease you IQ?	4.250
Better education of consumer on side effects/benefits of med choices.	4.000	Can a medication trigger a manic episode?	3.875	What is co-occurring?	4.250

I was told that bipolar in men becomes just depression as they age? If true, why not women? – Menopause.	3.938	What is bipolar? Expand. Knowledge of bipolar disorder.	3.750	Can a medication trigger a manic episode?	4.250
Is BD specific to genetics, environmental and or traumatic events? What are my triggers? What research is being done on the environmental impact of BD (pesticides etc.)?	3.938	Why did I get bipolar disorder?	3.750	SAD [Seasonal affective disorder]	4.125
What happens to the brain/body after multiple psychiatric breaks?	3.875	Can you please go deeper into explaining this illness?	3.750	How do illegal drugs affect onset of mental illness?	4.125
How do illegal drugs affect onset of mental illness?	3.875	Better education of consumer on side effects/benefits of med choices	3.625	Can Bipolar be a result of early childhood trauma? Is childhood trauma a factor of getting bipolar?	4.125
Percent of BD on stimulants? Analysis of stimulant type vs. other drugs the person is on?	3.813	Percent of BD on stimulants? Analysis of stimulant type vs. other drugs the person is on?	3.625	Are there symptoms beyond mania and depression that are commonly experienced, like explosiveness or irritability?	4.000
Can you please go deeper into explaining this illness?	3.813	What tends to mask the symptoms of bipolar?	3.625	Percent of BD on stimulants? Analysis of stimulant type vs. other drugs the person is on?	4.000
Sleep apnea. Obstructive and/or central.	3.813	How do illegal drugs affect onset of mental illness?	3.625	Can severe BD be triggered by PTSD?	4.000
Are foods, substances i.e. alcohol a known trigger?	3.750	Education at the start of treatment structured, i.e. NAMI etc. for patient/consumer.	3.500	Are foods, substances i.e. alcohol a known trigger?	4.000
Am I really bipolar or is it caused by antidepressants?	3.750	Education of significant others at start of treatment. I would have asked for more education for all family members including siblings (under 18).	3.500	I was told that bipolar in men becomes just depression as they age? If true, why not women? - Menopause	4.000
What tends to mask the symptoms of bipolar?	3.750	Are foods, substances i.e. alcohol a known trigger?	3.500	Am I really bipolar or is it caused by antidepressants?	4.000
SAD [Seasonal affective disorder].	3.688	Am I really bipolar or is it caused by antidepressants?	3.500	Interaction of comorbid BD and Major Depression.	4.000

Can Bipolar be a result of early childhood trauma? Is childhood trauma a factor of getting bipolar?	3.688	Is BD specific to genetics, environmental and or traumatic events? What are my triggers? What research is being done on the environmental impact of BD (pesticides etc.)?	3.500	What happens to the brain/body after multiple psychiatric breaks?	3.875
Does trauma in vitro [sic. in utero] affect the baby?	3.688	Does trauma in vitro [sic. in utero] affect the baby?	3.500	Explain effects of disease. Not attack me, I am not my disease.	3.875
Why did I get bipolar disorder?	3.625	Can severe BD be triggered by PTSD?	3.250	Can you please go deeper into explaining this illness?	3.875
Education of significant others at start of treatment. I would have asked for more education for all family members including siblings (under 18).	3.625	Tired of feeling like crap, when will it stop?	3.250	What tends to mask the symptoms of bipolar?	3.875
Can severe BD be triggered by PTSD?	3.625	SAD [Seasonal affective disorder].	3.250	Does trauma in vitro [sic. in utero] affect the baby?	3.875
Interaction of comorbid BD and Major Depression.	3.625	Can Bipolar be a result of early childhood trauma? Is childhood trauma a factor of getting bipolar?	3.250	Education of significant others at start of treatment. I would have asked for more education for all family members including siblings (under 18).	3.750
Are there symptoms beyond mania and depression that are commonly experienced, like explosiveness or irritability?	3.563	Interaction of comorbid BD and Major Depression.	3.250	Tired of feeling like crap, when will it stop?	3.750
Tired of feeling like crap, when will it stop?	3.500	Are there symptoms beyond mania and depression that are commonly experienced, like explosiveness or irritability?	3.125	Sleep apnea. Obstructive and/or central.	3.750
Explain effects of disease. Not attack me, I am not my disease.	3.438	Explain effects of disease. Not attack me, I am not my disease.	3.000	Effect of condition on personality matrix.	3.750
Effect of condition on personality matrix.	3.375	Effect of condition on personality matrix.	3.000	Why did I get bipolar disorder?	3.500

What happens when your son just smokes cigarettes incessantly and you worry about his health?	3.125	What happens when your son just smokes cigarettes incessantly and you worry about his health?	2.750	What happens when your son just smokes cigarettes incessantly and you worry about his health?	3.500
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Supplementary Table 8: Rating of questions related to the “Support” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
I wish they would of shown me where to find support when suicidal.	4.063	I wish they would of shown me where to find support when suicidal.	3.875	I wish they would of shown me where to find support when suicidal.	4.250
Where can you go to get support for substance abuse, bipolar, schizophrenia, therapy, housing? Sometimes it feels like there is no one to help.	3.813	Where can you go to get support for substance abuse, bipolar, schizophrenia, therapy, housing? Sometimes it feels like there is no one to help.	3.625	Where/how to find an excellent counselor?	4.125
How does the family support loved ones choice of treatment if episodic events continue to occur? Support groups are nowhere to be found (except online) for family or patients. How can my family support me with mental illness?	3.688	How does the family support loved ones choice of treatment if episodic events continue to occur? Support groups are nowhere to be found (except online) for family or patients. How can my family support me with mental illness?	3.625	Where can you go to get support for substance abuse, bipolar, schizophrenia, therapy, housing? Sometimes it feels like there is no one to help.	4.000
Where/how to find an excellent counselor?	3.625	Where/how to find an excellent counselor?	3.125	How does the family support loved ones choice of treatment if episodic events continue to occur? Support groups are nowhere to be found (except online) for family or patients. How can my family support me with mental illness?	3.750
Why can't my family be more involved with my treatment?	3.313	Why can't my family be more involved with my treatment?	3.000	Why can't my family be more involved with my treatment?	3.625

Supplementary Table 9: Rating of questions related to the “Health care system navigation” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
How do I find the right doctor? Where do I go to find the best doctor? Who's is the right doctor or specialist in L.A. I can trust? How to find a doctor that really knows bipolar? Where should I go to get good therapy once I'm on meds?	3.750	How do I find the right doctor? Where do I go to find the best doctor? Who's is the right doctor or specialist in L.A. I can trust? How to find a doctor that really knows bipolar? Where should I go to get good therapy once I'm on meds?	3.250	How do I find the right doctor? Where do I go to find the best doctor? Who's is the right doctor or specialist in L.A. I can trust? How to find a doctor that really knows bipolar? Where should I go to get good therapy once I'm on meds?	4.250
How often should bipolar patients talk to their psychiatrist?	3.500	Should I go inpatient in the hospital to change meds?	3.000	How often should bipolar patients talk to their psychiatrist?	4.250
Should I go inpatient in the hospital to change meds?	3.438	How often should bipolar patients talk to their psychiatrist?	2.750	Should I go inpatient in the hospital to change meds?	3.875
I would have had a physician follow my child's physical health	2.875	I would have had a physician follow my child's physical health	2.125	I would have had a physician follow my child's physical health	3.625

Supplementary Table 10: Rating of questions related to the “Diagnosis” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
Diagnosed earlier.	4.000	Diagnosed earlier.	4.125	How do you know I'm [this] diagnosis?	4.000
How do you know I'm [this] diagnosis?	3.813	How do you know I'm [this] diagnosis?	3.625	Diagnosed earlier.	3.875
Why is BD considered as possible diagnosis, after diagnosis of depression? (antidepressants trigger manic behavior)	3.750	Why is BD considered as possible diagnosis, after diagnosis of depression? (antidepressants trigger manic behavior)	3.625	Why is BD considered as possible diagnosis, AFTER diagnosis of depression? (antidepressants trigger manic behavior)	3.875
What is the difference in bipolar patient evaluation over the phone vs. in person?	3.063	What is the difference in bipolar patient evaluation over the phone vs. in person?	2.750	Is a diagnosis from a psychopharmacologist better than a psychiatrist?	3.500
Is a diagnosis from a psychopharmacologist better than a psychiatrist?	3.063	Is a diagnosis from a psychopharmacologist better than a psychiatrist?	2.625	What is the difference in bipolar patient evaluation over the phone vs. in person?	3.375

Supplementary Table 11: Rating of questions related to the “BD coping/management” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
How should I manage the manic episode?	4.500	How should I manage the manic episode?	4.250	How should I manage the manic episode?	4.750
How do you control your mood episode?	4.313	How to stop bad thoughts and dreams?	4.250	How do you control your mood episode?	4.500
How to stop bad thoughts and dreams?	4.250	How do you control your mood episode?	4.125	How to handle everyday delusions and/or paranoia?	4.500
How to handle everyday delusions and/or paranoia?	4.188	How to handle everyday delusions and/or paranoia?	3.875	How to stop bad thoughts and dreams?	4.250
When is hospitalization necessary?	3.938	When is hospitalization necessary?	3.750	If I am not currently stable, how can I take meds, eat right, sleep better and feel OK if I'm dealing with multiple issues for a long time?	4.125
If I am not currently stable, how can I take meds, eat right, sleep better and feel OK if I'm dealing with multiple issues for a long time?	3.750	If I am not currently stable, how can I take meds, eat right, sleep better and feel OK if I'm dealing with multiple issues for a long time?	3.375	When is hospitalization necessary?	4.125
What are the advantages of mania in surviving hellish situations?	3.313	What are the advantages of mania in surviving hellish situations?	2.875	When first being diagnosed how to handle sex drive?	3.750
When first being diagnosed how to handle sex drive?	3.188	When first being diagnosed how to handle sex drive?	2.625	What are the advantages of mania in surviving hellish situations?	3.750

Supplementary Table 12: Rating of questions related to the “Social bias and stigma” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
Education of significant others at start of treatment. I would have asked for more education for all family members including siblings (under 18).	3.688	Education of significant others at start of treatment. I would have asked for more education for all family members including siblings (under 18).	3.125	Education of significant others at start of treatment. I would have asked for more education for all family members including siblings (under 18).	4.250
How will this illness effect my professional life?	3.241	How will this illness effect my professional life?	2.625	How will this illness effect my professional life?	3.857
Why do poor people get labeled as deviants while rich people get diagnosed?	2.938	Why do poor people get labeled as deviants while rich people get diagnosed?	2.500	Why do poor people get labeled as deviants while rich people get diagnosed?	3.375

Supplementary Table 13: Rating of questions related to the “Big ideas and children” theme.

Researcher and patient stakeholders		Researcher stakeholders		Patient stakeholders	
Question	Average score	Question	Average score	Question	Average score
Side effects different for young children? I want to know how puberty affects medication efficacy.	4.500	Side effects different for young children? I want to know how puberty affects medication efficacy.	4.375	I would have asked about alternative treatments for children.	4.625
What are the early warning signs for bipolar for teenager?	4.438	What are the early warning signs for bipolar for teenager?	4.250	Side effects different for young children? I want to know how puberty affects medication efficacy.	4.625
What effects will my child have on this medication? Shaking/staring, frozen movements, etc.	4.250	What effects will my child have on this medication? Shaking/staring, frozen movements, etc.	4.000	What are the early warning signs for bipolar for teenager?	4.625
I would have asked about alternative treatments for children.	4.188	How are young children being given diagnosis of BD? What are obstacles to childhood diagnosis?	4.000	What effects will my child have on this medication? Shaking/staring, frozen movements, etc.	4.500
How are young children being given diagnosis of BD? What are obstacles to childhood diagnosis?	4.188	I would have asked about alternative treatments for children.	3.750	There are cultural barriers that exist. We didn't talk about mental illness. Opening the dialog. Impact of race and culture on diagnosis. What medications work for what ethnicity?	4.375
There are cultural barriers that exist. We didn't talk about mental illness. Opening the dialog. Impact of race and culture on diagnosis. What medications work for what ethnicity?	3.938	There are cultural barriers that exist. We didn't talk about mental illness. Opening the dialog. Impact of race and culture on diagnosis. What medications work for what ethnicity?	3.500	How are young children being given diagnosis of BD? What are obstacles to childhood diagnosis?	4.375

Focus Groups Script

Longitudinal Comparative Effectiveness of Bipolar Disorder Therapies (IRB# 16-243)

Welcome

Thank you for agreeing to be part of the focus group. We appreciate your willingness to participate.

Introduction

[The facilitators introduce themselves.]

We were fortunate enough to receive funding from the Patient Centered Outcomes Research Institute, known as PCORI, to address a long-standing patient-centered need about effectiveness of bipolar disorder therapies for people with bipolar disorder. Approximately 5.7 million people are affected with bipolar disorder in the US alone, but how to best meet the needs of the individual patient and which treatment works best for each patient is not well known. Some medications, such as lithium, have been around for a long time, but concerns about side effects have limited their use, despite good evidence for their effectiveness. Other medications, such as second-generation antipsychotics, have more recently been added as treatment options, but limited data are available in specific groups, such as the elderly or young people. Many people with bipolar disorder report that the same treatment has different outcomes for different people. More evidence about the best treatment for a specific individual with bipolar disorder will help doctors and those seeking treatment to select the best treatment(s) for the best disease outcomes.

The goal of our study is to assess the short- and long-term effects of commonly used treatment options for bipolar disorder, including non-treatment. Rather than going out and collecting data, we are going to answer specific research questions about treatment effectiveness by examining a large health insurance claims database of over 1 million people with bipolar disorder. We would like your input on what those specific research questions should be. That is, we want to hear from people who have bipolar disorder and family members of those with bipolar disorder about what would be helpful for them to know about the treatment of bipolar disorder, including side effects and other outcomes. More specifically, we want you to think about what you wish you had known in advance or over the course of treatment for bipolar disorder.

Participant Consent

Before we ask your written consent to participate in the study, we will be going over some details. Please feel free to stop us to ask any clarifying questions. We are handing out consent forms for you to read and review.

[Hand out consent forms.]

Our study can only include adults who are able to consent, who have bipolar disorder, or have a first-degree relative with bipolar disorder, and can communicate in English. We will ask you to acknowledge that you are eligible in the consent form, and show proof of age.

You were selected as a possible participant in this study because you have responded to our call for participation, which has been distributed through the local chapters of NAMI, and you have expressed interest in helping us to answer the question, “what do you wish you had known in the past that could have helped you in managing your disease or the disease of your loved one(s)”.

Your participation in the focus group is voluntary.

If you volunteer to participate in the focus group, you will be asked to do the following:

You will be asked to participate in this patient focus group, to capture patient-centered outcomes of interest that will hopefully drive the research. Our focus groups will each be made up of 8-12 people who live with bipolar disorder as a patient, or who have experienced bipolar disorder in a family member.

In the focus group, you will be asked in hindsight, what you wish you had known in advance over the course of bipolar disorder treatment.

You may refuse to answer any questions that you do not want to answer and still remain in the study.

Potential risks

Every effort will be made to protect the information you give us, but there may risk of loss of confidentiality. A research assistant will be in the room taking notes from the discussion but names will

not be included in the notes so that statements will not be linked to any one individual. No identifying information is being collected. The qualitative data resulting from the focus groups will be maintained on a password protected secure server. Files will be available only to authorized members of the research team, for the duration of the study. Information resulting from this study will be used for research purposes and may be published; however, you will not be identified by name in any publications and data from all participants will be combined and presented for the group overall.

Information from your participation in this study may be reviewed by federal and state regulatory agencies, and by the UNM Human Research Review Committee (HRRC) which provides regulatory and ethical oversight of human research.

All participants will be asked to keep what is said during the group discussion between the participants only. However, complete confidentiality cannot be guaranteed.

There may be some discomfort associated with sharing or hearing about negative experiences of adverse impacts of bipolar disorder on patient and patient family member lives, but a mental health professional will be on-hand to facilitate should any difficulties arise.

Potential benefits

There may or may not be direct benefit to you from being in this study. You may experience a sense of satisfaction from contributing as a subject matter expert to identify high value patient-centered questions of importance to bipolar disorder patients and their families.

The results of the research may provide supporting evidence for a question that is a main concern of every patient with bipolar disorder: "Which treatment works best for a patient like me." Our approach also has the potential to identify patient groups that do not respond well with currently available medications. Such patients could then be the focus of further research into the pathophysiology of their disorder subtype, and which therapeutic options work best. Information about unintended medication effects in specific patient populations gained from this study could also result in enhanced treatment safety. In the long-term, such results have the potential to increase patient/doctor/provider trust and improve long-term therapeutic relationships, an important parameter for improved outcomes.

This study could help in prevention of unintended treatment effects, and assessment of treatment options for patients with bipolar disorder. We will address important evidence gaps on bipolar disorder treatment outcomes for specific subgroups of patients, and in so doing, aim to improve healthcare by

supporting informed decision making. Through communication and dissemination of our results, we will support shared decision making between patients and providers.

Logistics

Participation in the focus group will take approximately 3 hours.

You will receive \$450 for your full participation in the focus group in the form of a visa gift card. The payment will be received after completion of the focus group. This compensation requires full participation in the focus group.

You can choose whether or not you want to be in this study, and you may withdraw your consent and discontinue participation at any time. Whatever decision you make, there will be no penalty to you.

You may refuse to answer any questions that you do not want to answer and still remain in the focus group.

If you have any questions, comments or concerns about the research, you can talk to the one of the researchers or contact the numbers listed on the consent form in front of you.

You will be given a copy of the consent form for your records.

[Ask if there are any questions and be sure to get signed consent forms from all those who agree to participate in the focus group. Verify age by asking to see a driver's license or passport.]

Ground Rules

Now that consent is complete, we would like to set some ground rules for the duration of our focus group:

1. WE WANT YOU TO DO THE TALKING.

We would like everyone to participate.

I may call on you if I haven't heard from you in a while.

2. ENCOURAGE EVERYONE TO CONTRIBUTE

Minimize interruptions.

Try to keep your thoughts to the point, so everyone gets a chance to talk.

3. THERE ARE NO RIGHT OR WRONG ANSWERS

Every person's experiences and opinions are important.

Speak up whether you agree or disagree.

We want to hear a wide range of opinions.

4. WHAT IS SAID IN THIS ROOM STAYS HERE

We want folks to feel comfortable sharing when sensitive issues come up.

5. WE WILL BE TAKING NOTES DURING THE FOCUS GROUP.

We want to capture everything you have to say.

We don't identify anyone by name in our notes. You will remain anonymous.

Are there any other rules that we should add to this list?

Can we all agree to abide by these ground rules?

[Get agreement from each person]

Consented Participant Introductions

Before we commence with our focus group discussions, to break the ice, we'd like to invite each of you to each spend about a minute to talk a bit about yourself. You do not have to disclose your name. We will not be writing down any names within our notes.

[Patients introduce themselves.]

What the project is about

In this research project we would like to identify treatment outcomes that matter to patients over their lifetime and then we will compare the outcomes for common treatments for bipolar disorder, including non-treatment. In large health insurance claims data sets, we would like to study differences in treatment effects in different patient groups. We expect that the outcomes for the same treatment will vary by bipolar disorder subtype, age, gender, and other medical conditions or treatments of a patient.

What the database includes

We will use de-identified health insurance claims records from over 1 million patients with bipolar disorder collected over several years to investigate treatment effects and long-term outcomes overall and also in specific groups of patients, such as the elderly or young adults. These records come from all over the United States but it is important to remember that no one individual can be identified in this dataset.

You might think of the data as a timeline of most of the medical activity of a patient as they engage with healthcare providers. This includes inpatient, outpatient and emergency room visits, diagnoses, drug prescriptions filled, procedures performed, and even payment information. We do not have medical notes or the results of lab tests, but we have basic demographic information on patients, including age, sex, and state of residence. Since the data have been collected in real life settings, such as doctors' offices, emergency rooms, hospitals and other health care settings, the data reflect the diversity of patients with bipolar disorder, and the entire range of medical conditions that could be associated with bipolar disorder.

Because we have such a rich data set, we hope to be able to answer questions, such as:

- What do you wish you had known in the past that could have helped you in managing your disease or the disease of your loved one(s)?
- Which drug is best for controlling mood episodes?
- What drug is best for children for reducing suicidal behavior?
- What would have been helpful for your family to know about your illness?
- What are some of the positive benefits or negative side effects of treatment for bipolar disorder that surprised you?
- What are some of the things that bother you the most about having bipolar disorder and the medical treatment of bipolar disorder?
- Have you ever ended up back in the doctor's office or in another treatment environment after starting medication, changing medication dosages or types, or ceasing medications? If so, what symptoms made that follow-on doctor's visit necessary?

Affinity mapping exercise

Step 1

In order to gather the most perspectives, we ask each of you to take the next 15 minutes to write down, one idea per post-it note, the questions that you would like answered in this study about bipolar treatments, outcomes and side effects.

Please do not write your name on your questions. After you have written down your questions, please stick them up on the wall in random, but reachable, locations -- we will organize them later in a group exercise.

Does anyone have any questions before we begin?

Step 2

We now are going to try to cluster these questions into similar categories. We are going to ask everyone stand up, and silently move up and down the wall, moving the post-it notes with similar themes into clusters of post-it notes, separated by space on the wall. It is easiest to start by pairing up very similar ideas, and looking for others that are close. You are free to recategorize the post-it notes that are already in groups, as well as create entirely new categories. It is okay to silently disagree with people who have a different viewpoint. If an idea is a "loner" that does not seem to fit in any group, it is okay for it to stand alone. Once you feel you have contributed all you can to organize the content, you may sit down.

Does anyone have any questions before we begin?

Step 3

We are now going to try to create a descriptive title for each of these groups. I'm going to read off the content of each group, and then ask for a suggested title. We may discover a relationship between two groups and arrange them in columns under a superheader.

[Facilitator tries to gain general agreement on a label for each major category.]

Step 4

Now that we have identified the major themes, we would like to have you help prioritize them to guide our ongoing research efforts. Would you please write the number 1 on one post-it note, 2 on a second, and 3 on a third post-it note. Now, please go up to the wall and place the number 3 above your top priority group, number 2 above your second priority, and number 1 above your third most important. Remember, bigger numbers mean it is more important.

Step 5

[Invite participants to take a 15-minute break and get a snack while we tally up the results and prepare for discussion. The facilitators calculate the sums for each category and write them on a sticky note in bright marker. Participants are invited to eat at the table during the discussion.]

We will now write down the list of topics from highest to lowest total points on a flip-chart.

How do you feel about this categorization?

[Discussion (encourage all to share in turn).]

Will this categorization do the most good for the most patients?

[Discussion (encourage all to share in turn).]

Closing of the focus group

What we are going to do going forwards is take a deep look at our data to see how feasible it is to tackle these topics, and prioritize our research as best we can according to the information you shared with us today. We intend to disseminate our findings through NAMI in the coming months and years, so please stay tuned.

Thank you all so much for your participation. Before you leave, we will distribute the honorarium for your participation.

[The moderator thanks each participant as he/she distributes the honorarium (incentive).]

[Immediately after all participants leave, the moderator and assistant moderator debrief and label all notes with the date, time and location of the focus group.]