The Children's Hospital of Philadelphia

MEDICAL ADHERENCE MEASURE (MAM)

Name/ID#: _____ **Date:** _____

Directions: Patients who have a medical condition have to follow a complicated schedule that includes coming to clinic, getting labs, taking medications, and sometimes having to change the way they eat or how they exercise. As you know, this takes quite a bit of time and can be difficult to keep track of. Since not all patients follow the same schedule, we would like to understand how *you* manage your illness. Your answers will help us learn which parts are easy for you and which parts are more difficult. Please be honest because your answers can help us improve our program.

Office Use

Transplant type:	(a) kidney (d) heart	(b) liver (e) lung	(c) kidney/liver (f) heart/lung
Referral type:	(a) pre-transplant evaluation (c) initial adherence consult	(b) post-transplant follow-up (e) treatment outcome	
Completed for:	(a) clinical use	(b) research use	
Completed by:	(a) psychologist (d) nurse/physician	(b) research assistant (f) parent report	(c) social worker (g) patient report
Completed where:	(a) in person interview	(b) phone interview	

Comments/Behavioral Observations

_____

_____

_____

I. MEDICATION MODULE

Interviewer should fill in the medication regimen (name and dosages) from the patient's medical record prior to the interview.

Directions: First, tell me all the medications that your doctor has prescribed. (Interviewer should check off the medications patient has *recalled*. Then ask patient if recognizes the rest of the medications on your list and check *prompted*). Now, I'm going to ask specific questions about *each* medication. Think about the last week when answering these questions so that would be since last _____ (count back 7 days). Do your best to answer these questions and if you're not sure we'll ask your mother (or any adult present) for help.

Was this a typical week for you? (a) yes (b) no Comments: _____

Before asking about each medication remind the patient, "In the past 7 days…."

	Medication Regimen *(record from patient's medical chart)*	**What kind of medicine is this?** *(circle one type per medicine)*	**How many times each day did you take this medication?**	**How much of this medication did you take each time?**	**What time of day did you take this medication?** *(circle all that apply)*	**How many times during this week did you miss taking this medication?**	**How many times during this week did you take this medication late?**
1	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart _____ other _____	Liquids ml/cc _____ OR # of pills _____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? _____
2	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart _____ other _____	Liquids ml/cc _____ OR # of pills _____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? _____
3	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart _____ other _____	Liquids ml/cc _____ OR # of pills _____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? _____
4	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Injections	0 1 2 3 4 5 w/ meals spaced apart _____ other _____	Liquids ml/cc _____ OR # of pills _____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? _____

Before asking about each medication remind the patient, "In the past 7 days…."

	Medication Regimen. *(record from patient's medical chart)*	**What kind of medicine is this?** *(circle one type per medicine)*	**How many times each day did you take this medication?**	**How much of this medication did you take each time?**	**What time of day did you take this medication?** *(circle all that apply)*	**How many times during this week did you miss taking this medication?**	**How many times during this week did you take this medication late?**
5	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart ____ other _____	Liquids ml/cc ____ **OR** # of pills ____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? ____
6	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart ____ other _____	Liquids ml/cc ____ **OR** # of pills ____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? ____
7	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart ____ other _____	Liquids ml/cc ____ **OR** # of pills ____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? ____
8	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart ____ other _____	Liquids ml/cc ____ **OR** # of pills ____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? ____
9	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart ____ other _____	Liquids ml/cc ____ **OR** # of pills ____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? ____
10	Name: _____ Dose: _____ Free Recall Patient only Prompted Parent help	Blood Pressure Immunosuppresants Anti-infectives Vitamins GI Other	0 1 2 3 4 5 w/ meals spaced apart ____ other _____	Liquids ml/cc ____ **OR** # of pills ____	Breakfast Lunch After school Dinner Bedtime	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 N/A How late? ____

I. MEDICATION MODULE (CONTINUED)

1. Before this past week, when was the last time you missed any medications?
   (a) don't miss/NA (b) 2 weeks ago (c) last month (d) 3 months ago
   (e) 6 months ago (f) 1 year ago (g) >1year ago

2. What are some reasons you miss taking your medications? **(circle all that apply)**
   (a) don't miss/NA (b) interferes with activity (c) hard to swallow pills (d) hate the taste
   (e) just forget (f) not feeling well (g) don't like the side effects (h) wasn't home
   (i) ran out/didn't fill (j) refuse to/defiant (k) can't afford (l) don't think necessary
   (m) other _____

3. When do you tend to miss taking your medications most often? **(circle all that apply)**
   (a) don't miss/NA (b) morning (c) school/lunch (d) afternoon (e) dinner (f) bedtime

4. Who is in charge of making sure you have enough your medications and ordering more of them? **(circle all that apply)**
   (a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle

5. Where do you keep your medications organized? **(circle all that apply)**
   (a) no system (b) pill box (c) special shelf/cabinet (d) refrigerator (e) plastic bag (f) in my room

6. Who takes the primary responsibility over making sure that you take your medications? **(choose one)**
   (a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle

7. On a scale of 0 (hardly ever take my medications; usually miss) to 10 (always take my medications; rarely miss), how would you rate how well you take your medications, on average? **(enter a response for each one)**
   (a) patient ____ (b) mother ____ (c) father ____

II. CLINIC ATTENDANCE MODULE

1. How often are you supposed to come to clinic?
   (a) once/year (b) every 6 months (c) every 2-3 months (d) once/month (e) twice/month
   (f) once/week (g) twice/week (h) seen on dialysis, no regular clinic visits scheduled

2. Has there been a change as to how often you come to clinic?
   (a) no change, it's been this way for a while (b) yes, more frequent now (c) yes, less frequent now

3. How often do you miss your clinic appointments without calling or rescheduling?
   (a) never/NA (b) once/year (c) every 3 months (d) once/month (e) twice/month (f) once/week

4. In the past year, how many times have you rescheduled your appointment? _____

5. What are some reasons you miss your appointment? **(circle all that apply)**
   (a) always come/NA (b) just forget (c) can't take off work/school (d) interferes with sport/activity
   (e) not necessary to come that often (f) transportation problems (g) wasn't feeling well other _____

6. Who schedules/keeps track of your clinic appointments? **(circle all that apply)**
   (a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle

7. Who comes with you to your clinic appointment? **(circle all that apply)**
   (a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle

8. On a scale of 0 (hardly ever come to clinic; usually miss) to 10 (always come to clinic; never miss), how would you rate your attendance at scheduled clinic visits? **(enter a response for each one)**
   (a) patient ____ (b) mother ____ (c) father ____

III. NUTRITION MODULE

1. Have you been asked to change the way you eat or drink?
(a) no/regular diet (b) yes/special instructions By whom? _____

Interviewer should speak to the nutritionist or look up the dietary recommendations in the patient's medical record and circle the ones that apply before starting the interview. Directions: First, tell me all the special diets that your nutritionist/doctor has prescribed. (Interviewer should check off the diets patient has *recalled*. Then ask patient if recognizes the rest of the diets circled on your list and check *prompted*. Now, I'm going to ask specific questions about *each* diet you're on. Think about the last week when answering these questions, that would be since last _____ (count back 7 days). Do your best to answer these questions and if you're not sure we'll ask your mother (or any adult present) for help.

Was this a typical week for you? (a) no (b) yes Comments: _____

Before asking about each diet remind the patient, "In the past 7 days…."

ND= Not on dialysis
PD= Peritoneal Dialysis
HD= Hemo Dialysis

	Dietary Regimen *(Record from patient medical chart)*	**What special diets were you asked to follow?**	**What foods are high in this?** *(write down what patient reports)*	**How much of those high-content foods can you have?** *(portion size or frequency)*	**How many times during this week did you have these high-content foods?**	**How often do you "cheat" on your diet?**	**What makes it difficult to stick to this diet?**
1	**Low Sodium** ND: 1000- 3000mg PD: 2000 to 4000 mg HD: 1000 to 3000 mg	Free Recall Prompted Patient Only Parent help			0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 never 1 rarely 2 occasionally 3 moderately 4 frequently	Nothing/NA Not sure what I can't eat I just like these foods I just forget about it My friends eat them I eat out/not home
2	**Low Phosphorous** ND: 10 mg/kg/ day PD: <= 17 mg/kg/day HD: <= 17 mg/kg/day	Free Recall Prompted Patient Only Parent help			0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 never 1 rarely 2 occasionally 3 moderately 4 frequently	Nothing/NA Not sure what I can't eat I just like these foods I just forget about it My friends eat them I eat out/not home
3	**Low Potassium** ND: 40 - 70 mEq PD: 75 to 100 mEq HD: 40 to 70 mEq	Free Recall Prompted Patient Only Parent help			0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 never 1 rarely 2 occasionally 3 moderately 4 frequently	Nothing/NA Not sure what I can't eat I just like these foods I just forget about it My friends eat them I eat out/not home

	Dietary Regimen *(Record from patient' medical chart)*	What special diets were you asked to follow?	What foods are high in this? *(write down what patient reports)*	How much of those high-content foods can you have? *(portion size or frequency)*	How many times during this week did you have these high-content foods?	How often do you "cheat" on your diet?	What makes it difficult to stick to this diet?
4	**Low/High Protein** (age dependent) ND: 0.8-2.2 g/kg PD: 1.3 to 3.0 g/kg HD: 1.2 to 2.6 g/kg	Free Recall Prompted Patient Only Parent help			0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 never 1 rarely 2 occasionally 3 moderately 4 frequently	Nothing/NA Not sure what I can't eat I just like these foods I just forget about it My friends eat them I eat out/not home
5	**Low Cholesterol** Any patient on low cholesterol diet: < 300 mg	Free Recall Prompted Patient Only Parent help			0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28	0 never 1 rarely 2 occasionally 3 moderately 4 frequently	Nothing/NA Not sure what I can't eat I just like these foods I just forget about it My friends eat them I eat out/not home

2. Who does the food shopping at home? **(circle all that apply)**
   (a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle

3. Who prepares and cooks your meals at home? **(circle all that apply)**
   (a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle

4. Where do you usually eat breakfast?
   (a) don't eat breakfast (b) eat breakfast at school (c) eat breakfast at home

5. Where do you usually eat lunch?
   (a) don't eat lunch (b) buy lunch at school (c) bring lunch from home (d) go home for lunch

6. Where do you usually eat dinner?
   (a) don't eat dinner (b) eat out with my friends (c) eat out with my family (d) eat at home

7. On a scale of 0 (hardly ever follow my diet; cheat a lot) to 10 (always follow my diet; never cheat), how would you rate your how well you stick to your prescribed diet(s), on average across all the prescribed diets **(enter for each one)**
   (a) patient ____ (b) mother ____ (c) father _____

8. Have you met with the nutritionist to help understand your dietary recommendations and the types of foods you can?
   (a) No Would you like to? No Yes
   (b) Yes How long ago? _____ Would it be helpful to meet with her again? No Yes

V. WEIGHT MANAGEMENT AND EXERCISE MODULE

(Optional module, if patient is asked to lose weight or needs to restrict activity for medical reasons.)

1. Has your doctor/nutritionist asked you to lose any weight?
   (a) no (b) yes How much were you asked to lose?_____

2. Have you been able to lose weight?
   (a) no (b) yes How much did you lose/gain? _____

3. What methods have you tried for losing weight? _____
   What was helpful or what works best for you?_____

4. What makes it difficult to manage your weight? **(circle all that apply)**
   (a) nothing/I was able to do it (b) I just like to eat (c) don't have any healthy snacks at home
   (d) eat out a lot (e) hard when I'm with my friends (f) don't like to exercise
   (g) I'm not sure what the low calorie foods are (h) other_____

5. Has your doctor/nutritionist ask you to change your activity level?
   (a) no (b) yes

6. What changes did your doctor/nutritionist ask you to make in your activity level?
   (a) no changes/NA (b) become more active (c) become less active

7. Have you been able to change your activity the way they asked?
   (a) no (b) yes What have you changed? _____

8. What makes it difficult to change your activity the way they asked? **(circle all that apply)**
   (a) nothing/I have changed (b) don't like sports (c) prefer to stay inside/watch TV (d) have no time
   (e) not allowed outside (f) too cold/hot (g) too dark/late after school (h) don't like to exercise alone
   (i) not sure what to change (j) other _____

9. On a scale of 0 (hardly follow diet/exercise recommendation) to 10 (always follow the diet/exercise recommendation), how would you rate your ability to lose weight/change your activity? **(enter for each one)**
   (a) patient ____ (b) mother ____ (c) father _____

10. Do you play any sports or participate in any physical activity after school?
    (a) no (b) yes What specifically do you play? _____

11. How many times a week do you participate in activities after school?
    (a) I don't/NA (b) 1-2x/month (c) 1x/week (d) 2-3x/ week (e) 4-5x/ week (f) 6-7x/ week

12. How long do you play for each time?
    (a) I don't/NA (b) 10-20 min (c) 20-30 min (d) 30-40 min (e) 40-60 min (f) >60 min

13. Do you participate in PE/gym at school?
    (a) no (b) yes What specifically do you play? _____

14. How many times a week do you participate in PE/gym?
    (a) I don't have PE /NA (b) 1-2x/month (c) 1x/week (d) 2-3x/ week (e) 4-5x/ week

15. How long do you exercise for in PE?
    (a) I don't have PE/NA (b) 10-20 min (c) 20-30 min (d) 30-40 min (e) 40-60 min (f) >60 min

16. Would it be helpful to speak with someone about strategies to lose weight or exercise?
    (a) No Why not? _____
    (b) Yes

VII. CYSTIC FIBROSIS

(Optional module, for lung transplant patients who have cystic fibrosis.)

Chest PT

1. Has your doctor asked you to get Chest PT?
   (a) no (b) yes

2. How often should you get Chest PT?
   (a) I don't have to/NA (b) once a day (c) twice a day (d) three times a day (e) 4 times a day
   (f) other _____

3. How often do you get Chest PT?
   (a) I don't have to/NA (b) once a day (c) twice a day (d) three times a day (e) 4 times a day
   (f) other _____

4. What are some reasons you might miss Chest Pt or do it late? **(circle all that apply)**
   (a) always do it/NA (b) interferes with sport/activity (c) it's painful/uncomfortable (d) just forget
   (e) just don't feel like it sometimes (f) don't think it's necessary to do that often (g) other _____

5. On a scale of 0 (hardly ever get a Chest PT; usually miss) to 10 (always get a Chest PT; never miss), how would you rate your adherence with Chest PT recommendations? **(enter a response for each one)**
   (a) patient ____ (b) mother ____ (c) father ____

6. Who takes the primary responsibility over making sure that you use your chest PT? **(choose one)**
   (a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle

Vest/Flutter

7. Has your doctor asked you to use a vest/flutter?
   (a) no (b) yes

8. How often should you use your vest/flutter?
   (a) I don't have to/NA (b) once a day (c) twice a day (d) three times a day (e) 4 times a day
   (f) other _____

9. How often do you use your vest/flutter?
   (a) I don't have to/NA (b) once a day (c) twice a day (d) three times a day (e) 4 times a day
   (f) other _____

10. What are some reasons you might miss using your vest/flutter or do it late?
    (a) always do it/NA (b) interferes with sport/activity (c) it's painful/uncomfortable (d) just forget
    (e) just don't feel like it sometimes (f) don't think it's necessary to do that often (g) other _____

11. On a scale of 0 (hardly ever use vest; usually miss) to 10 (always use vest; never miss), how would you rate your adherence with the vest/flutter treatment? **(enter a response for each one)**
    (a) patient ____ (b) mother ____ (c) father ____

12. Who takes the primary responsibility over making sure that you use your vest/flutter? **(choose one)**
    (a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle

Supplemental Feedings

13. Do you have a G-tube or use an NG-tube
    (a) no (b) yes

14. Has your doctor asked you to do supplemental feedings?
    (a) no (b) yes

15. How much supplemental feeding has your doctor recommended that you should do?
(a) I don't have to/NA (b) once a day (c) twice a day (d) three times a day (e) four times a day
(f) ____ cans overnight (f) other _____

16. How often do you do supplemental feedings?
(a) I don't have to/NA (b) once a day (c) twice a day (d) three times a day (e) four times a day
(f) every night (g) ___ times a week (g) ___ times a month (h) never (i) other _____

17. What are some reasons you might miss your supplemental feedings? **(circle all that apply)**
(a) always do it/NA (b) interferes with sport/activity (c) just don't feel like it sometimes
(d) just forget (e) it's uncomfortable/painful/feel too full/makes me feel sick
(f) don't think it's necessary to do that often (g) other _____

18. On a scale of 0 (hardly ever take extra feeds; usually miss) to 10 (always take extra feeds; never miss), how would you rate your adherence with vest/flutter? **(enter a response for each one)**
(a) patient ____ (b) mother ____ (c) father ____

19. Who takes the primary responsibility over making sure that you take supplemental feedings? **(choose one)**
(a) myself (b) mother (c) father (d) brother/sister (e) grandmother/grandfather (f) aunt/uncle