HEALTHCARE PREFERENCES

QUESTIONNAIRE©

MASSACHUSETTS DEPARTMENT OF MENTAL HEALTH
METRO SUBURBAN AREA

SUBJECT ID#: ____________________________

DATE OF INTERVIEW: ____________________

INTERVIEWER: __________________________

LENGTH OF INTERVIEW: __________________

CLINICIAN/CASE MANAGER: ________________

LOCATION: ______________________________

Confidential: No information shall be presented or published in any way that would permit identification of any individual.
INSTRUCTIONS---READ TO ALL RESPONDENTS

Before we start the interview, I want to review with you some of the important information that we talked about earlier.

You have been asked to participate in this study because you are a client of the Department of Mental Health.

The decision to participate in the study is completely up to you, and you may withdraw from the study at any time you choose.

The purpose of this interview is to learn about the healthcare preferences of people with mental illness. We would like to hear your opinion.

♦ All of your answers will be kept strictly confidential within the research staff. Your answers will not be shared with other caregivers, doctors, insurance companies, or anyone else without your written permission.

Keep in mind that if there is any question you do not wish to answer, you can tell me and I will skip ahead to the next question. We can take a break whenever you would like one and, of course, we can stop at anytime if you decide you do not want to go on with the interview.
A. HEALTH STATUS

First, I’d like to ask you a few questions about your overall state of health

←SF – 12 HEALTH SURVEY→

These questions ask for your views about your health. They ask about how you feel and how well you are able to do your usual activities.

Please answer every question by choosing the answer that best describes how you feel. If you are unsure about how to answer, please give the best answer you can.

A1 In general, would you say your health is:

- [ ] Excellent
- [ ] Very Good
- [ ] Good
- [ ] Fair
- [ ] Poor

The following are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

A2 Moderate activities such as moving a table, pushing a vacuum cleaner, bowling, or playing golf

- [ ] Yes, Limited A Lot
- [ ] Yes, Limited A Little
- [ ] No, Not Limited At All

A3 Climbing several flights of stairs

- [ ] Yes, Limited A Lot
- [ ] Yes, Limited A Little
- [ ] No, Not Limited At All

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

- [ ] YES
- [ ] NO

A4 Accomplished less than you would like

- [ ] Yes
- [ ] No

A5 Were limited in the kind of work or other activities

- [ ] Yes
- [ ] No
HEALTHCARE PREFERENCE QUESTIONNAIRE

Subject Initials ______  Subject ID#_________________  Date ________________

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

YES NO

A6 Accomplished less that you would like?  □ 1 □ 2

A7 Didn’t do work or other activities as carefully as usual  □ 1 □ 2

A8 During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all A little bit Moderately Quite a bit Extremely

□ 1 □ 2 □ 3 □ 4 □ 5

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks?

All of the Time Most of the Time A Good Bit of the Time Some of the Time A Little of the Time None of the Time

A9 Have you felt calm and peaceful? □ 1 □ 2 □ 3 □ 4 □ 5 □ 6

A10 Did you have a lot of energy? □ 1 □ 2 □ 3 □ 4 □ 5 □ 6

A11 Have you felt down-hearted and blue? □ 1 □ 2 □ 3 □ 4 □ 5 □ 6

A12 During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time Most of the time Some of the time A Little of the time None of the time

□ 1 □ 2 □ 3 □ 4 □ 5

←End of SF-12→
A13 What is the name of your psychiatric condition? __________________________

A14 Are you taking medications for this psychiatric condition?

☐ 1 Yes
☐ 2 No

A15 Do you have a physical health condition or problem?

☐ 1 Yes
☐ 2 No  *(Skip to section B)*

A16 Can you tell me what kind of physical health condition or problem this is? *(Do not prompt—interviewer code as appropriate)*

☐ 1 Lung Disease
☐ 2 Heart Disease/ High Blood Pressure
☐ 3 Diabetes or thyroid
☐ 4 Cancer
☐ 5 HIV/AIDS
☐ 6 Other (Specify) __________________________
☐ 7 Don’t know

*For any of the above responses, write down subject’s own words:*

__________________________________________________________________
__________________________________________________________________

A17 How long have you had it?

Years __________ Months __________

A18 How serious is your physical health problem at the present time?

☐ 1 Not at all serious
☐ 2 Not very serious
☐ 3 Somewhat serious
☐ 4 Very serious
☐ 5 Extremely serious
A19 How life threatening is your physical health problem at the present time?

- 1 Not at all life threatening
- 2 Not very life threatening
- 3 Somewhat life threatening
- 4 Very life threatening
- 5 Extremely life threatening

A20 Who helps you the most with what you need to take care of your physical condition? (Do not prompt—interviewer code as appropriate)

- 1 Family Member
- 2 Friend
- 3 Roommate
- 4 Staff member (i.e. residential staff, home health aide, visiting nurse)
- 5 Volunteer
- 6 Other (Specify below ↓)

A21 Do you trust this person?

- 1 Yes
- 2 No

B. HEALTH CARE PROXY: WHEN YOU CANNOT SPEAK FOR YOURSELF

B1 Next, I want to ask you about how your medical doctor works with you. Is there one main doctor you see for your physical healthcare?

- 1 Yes
- 2 No → (Prompt): Then, think about the doctor who has seen you the longest when you answer the next question.

B2 About how long in months or years have you known this particular doctor?

_________________________(Months / Years)
B3  In addition to providing your medical treatment, how caring is your doctor?
   □ 1  Not caring at all
   □ 2  Not very caring
   □ 3  Somewhat caring
   □ 4  Very caring
   □ 5  Extremely caring

B4  Do you trust your doctor?
   □ 1  Yes
   □ 2  No

B5  Do you have specific wishes or have you made plans about the types of medical treatment you want or don’t want if you become very ill in the future?
   □ 1  Yes
   □ 2  No

B6  Have you talked with your doctor about these wishes?
   □ 1  Yes
   □ 2  No

B7  Have you and your doctor made plans to ensure that your wishes for medical treatment will be followed?
   □ 1  Yes
   □ 2  No

B8  One way that patients and their doctors can work together is by planning ahead for healthcare. Planning for healthcare often includes selecting a person you trust to communicate with your doctor about healthcare decisions if you cannot communicate for yourself. This person is called a healthcare proxy. Do you have a person whom you have selected to be your healthcare proxy? (check one)
   □ 1  Yes→ (Skip to B11)
   □ 2  No
   □ 3  Not sure what healthcare proxy is
   □ 4  Don’t know
B9 Have you ever picked someone to make decisions for you in case you become too sick to make medical decisions for yourself?

☐ 1 Yes → (**Skip to B11**)

☐ 2 No

☐ 3 Don’t know

B10 If you were going to pick a person to make medical decisions for you in a situation like that, whom might you choose? (**Do not prompt--interviewer code as appropriate**)

(AFTER SUBJECT RESPONSE SKIP TO B15)

☐ 1 Spouse  ☐ 2 Child  ☐ 3 Sibling

☐ 4 Parent  ☐ 5 Friend  ☐ 6 Physician

☐ 7 Priest, minister, rabbi  ☐ 8 OTHER (**Specify below ↓**)

B11 Who is this person? (**Do not prompt--interviewer code as appropriate**)

☐ 1 Spouse

☐ 2 Child

☐ 3 Sibling

☐ 4 Parent

☐ 5 Friend

☐ 6 Physician

☐ 7 Priest, minister, rabbi

☐ 7 OTHER (**Specify**)

B12 Did you select this person using a written form?

☐ 1 Yes

☐ 2 No

☐ 3 Don’t know
B13 Have you talked in detail with your (describe as above) _________ about what medical treatments, such as breathing machines or feeding tubes, you would want if you were not able to make medical decisions for yourself?

☐ 1 Yes
☐ 2 No→ (Ask): Why not? ________________________________
☐ 3 Don’t know

B14 Is there anything written down describing what medical treatments, such as breathing machines or feeding tubes, you would want if you were not able to make the decision yourself?

☐ 1 Yes→ (Ask): Where - or with whom - are those written instructions kept?
☐ a Family member ☐ b Health Care Proxy ☐ c Case Manager
☐ d Friend ☐ e Hospital ☐ r Doctor
☐ g Lawyer ☐ h Other ________________________________

☐ 2 No→ (Ask): Why not? ________________________________
☐ 3 Don’t know

B15 Have you thought about what medical treatments you would want if you were ill in the future and became too sick to make your own medical decisions?

☐ 1 Yes (Prompt): Please tell me what health care decisions you would be the most concerned about others making for you if you were unable to make your own choices during a serious illness or at the end of your life.

☐ 2 No (Prompt): Would you please think about this for a moment now, and tell me what health care decisions you would be the most concerned about others making for you if you were unable to make your own choices during a serious illness or at the end of your life.

continued on next page
B16 If you were unable to make or communicate your health care decisions at some time in the future, then ______________ (subject’s proxy; if none, say: “someone else”) would make those decisions for you. Tell me how you think that person should make those decisions. (read choices, using name of subject’s proxy if applicable, or say: “that person”)

Should {proxy name or “that person”} …
☐ 1 … do what your doctor thinks is best?
☐ 2 … do what he/she thinks is best?
☐ 3 … do what he/she thinks you would want?
☐ 4 … have a list of what kind of medical treatments you want, and choose from that list only?

Section C - VIGNETTE 1

I will now read an imaginary situation and I would like your reaction. I will read it slowly. Please let me know if you need to hear it a second time.

C1 A patient develops cancer that spreads into the brain and bones. Imagine the person to be in terrible pain without hope of a cure. Pain medications like morphine do not completely control the pain. In this case, should the dose of pain medication be increased even if that causes the patient to become confused or unable to communicate?
☐ 1 Yes
☐ 2 No

C2 What if this happened to you? Would you want the pain medication increased to control the pain even if it caused you to become confused or unable to communicate?
☐ 1 Yes
☐ 2 No

C3 If you were receiving strong medication to control pain in a situation like this, would you worry about becoming addicted to the pain medication?
☐ 1 Yes
☐ 2 No
C4 Imagine that this patient asks the doctor to give him enough medicine to die by taking an overdose. In this situation, do you think the doctor should purposely give him that much medicine?

☐ 1 Yes
☐ 2 No

C5 What if this happened to you? Imagine that you have asked your doctor to give you enough medication to die by taking an overdose. Would you want him to give you that much medication?

☐ 1 Yes
☐ 2 No

**Section D - VIGNETTE 2**

Now I will read another imaginary situation and I would like your reaction. Again, I will read it slowly. Please let me know if you need to hear it a second time.

D1 Imagine that a person has been in a very serious accident. The person is left permanently paralyzed with serious brain damage and is not expected to recover. Keeping this person alive requires mechanical support like a breathing machine and feeding tubes. The medical staff and family members must make a decision about what to do. They have several possible choices. I will read you a list of these choices, and I would like you to tell me which one you think would be best.

☐ 1 Turn off the machines now
☐ 2 Wait 7 days and if there is no change, then turn off the machines
☐ 3 Wait 30 days and if there is no change, then turn off the machines
☐ 4 Continue to keep the person alive indefinitely

☐ 5 Other (Specify) ____________________________________________

D2 Could you tell me the reason that you decided *(repeat subject’s answer above)* was the best choice?

________________________________________________________________________
________________________________________________________________________
HEALTHCARE PREFERENCE QUESTIONNAIRE

Subject Initials ______ Subject ID#_________________ Date ________________

D3 If this happened to you, what do you think you would want for yourself?

☐ 1 Turn off the machines right away
☐ 2 Wait 7 days and if there were no change, then turn off the machines
☐ 3 Wait 30 days and if there were no change, then turn off the machines
☐ 4 Continue to keep me alive indefinitely
☐ 5 Other (Specify):

__________________________________________________________________

D4 Could you tell me the reason that you decided (repeat subject’s answer above) was the best choice in this case?

__________________________________________________________________
__________________________________________________________________

SECTION E - VIGNETTE 3

I am going to read one last imaginary situation. Please tell me if you would like me to read it a second time.

Imagine that a person with a serious mental illness becomes frightened of others, upset, and confused. Over a few weeks things get worse and the person is placed in a hospital. He believes that other people want to hurt him, and that the food is poisoned. He refuses to take any medications. At this point, he is so sick that he is unable to make good decisions.

E1 If medication would help this person get better is it OK to give it to him against his will?

☐ 1 Yes
☐ 2 No

E2 If this were you, would you want medication to be given to you against your will?

☐ 1 Yes
☐ 2 No
E3 If you had a person who was your Health Care Proxy, would you want your Proxy to approve medication for you, even if you were refusing it?

☐ 1 Yes
☐ 2 No

Now, returning to the hospitalized patient we have been talking about, let’s say he suddenly assaults a hospital employee because he is afraid the employee wants to hurt him, even though that employee was trying to help.

E4 In this situation, should the doctors use an emergency treatment such as putting the person in a locked quiet room, or limiting the person’s movements by tying him down to his bed with restraints?

☐ 1 Yes
☐ 2 No

E5 If this were you, would you want either of these emergency treatments?

☐ 1 Yes→ (Ask): Which treatment would be your first choice?

☐ a locked quiet room
☐ b restraints

☐ 2 No

I would like to return to the imaginary patient again. This patient is very mentally ill and has been refusing to take medications that could improve his thinking. Now he is so confused and fearful that he is attacking others.

E6 In this situation, should the doctor order an injection of a medication that would calm the patient and might help treat his mental illness?

☐ 1 Yes
☐ 2 No

E7 If this were you, would you want to receive medication by injection?

☐ 1 Yes
☐ 2 No

E8 Are there any medications used to treat mental illness that have such severe side effects you would not want the medication under any circumstances—even if you were having a psychiatric emergency like the one I’ve described?  (next page)
HEALTHCARE PREFERENCE QUESTIONNAIRE

Subject Initials ______ Subject ID#______________ Date ________________

☐ 1  Yes→ (Ask): Please list those medications:

a
____________________________________________________________________________

b
____________________________________________________________________________
c
____________________________________________________________________________
da
____________________________________________________________________________
b
____________________________________________________________________________
c
____________________________________________________________________________

☐ 2  No

E9  Do you have a preference about the best medications to treat your mental illness?

☐ 1  Yes→ (Ask): Please list those medications:

a
____________________________________________________________________________

b
____________________________________________________________________________
c
____________________________________________________________________________
da
____________________________________________________________________________
b
____________________________________________________________________________
c
____________________________________________________________________________

☐ 2  No

E10 If you had a Health Care Proxy, and a judge decided that you were not competent to make decisions about medication due to increased symptoms of your mental illness, would you want your Health Care Proxy to tell the judge about what medication(s) you want and what medication(s) you don’t want?

☐ 1  Yes

☐ 2  No

E11 If you had a Health Care Proxy, would you want the Proxy to tell your doctor about what medication(s) you want and what medication(s) you don’t want?

☐ 1  Yes

☐ 2  No

E12 Now let’s imagine that this person’s mental illness symptoms might be quickly and effectively treated with ECT (electroconvulsive therapy, or “electric shock therapy”) treatments. In this situation, he is refusing ECT. If a judge says that the person is not able to decide for himself at this time because of his illness, is it OK to give these treatments?

☐ 1  Yes

☐ 2  No
E13 If you were in this situation, and a judge ruled that you were unable to decide for yourself at that time, would you want ECT (electric shock treatments)?

☐ 1  Yes
☐ 2  No

E14 If you had a Health Care Proxy, would you want the Proxy to tell the judge your wishes about electric shock treatments?

☐ 1  Yes
☐ 2  No

E15 If you had a Health Care Proxy, would you want the Proxy to tell your doctor your wishes about electric shock treatments?

☐ 1  Yes
☐ 2  No

In the situation we have been discussing, the patient’s severe mental illness has caused him to be hospitalized, and a judge has ruled that he is not able to make decisions for himself. I have presented a few different treatments that might be used to improve the symptoms. I have asked you whether it would be OK to use these treatments to improve the patient’s thinking or control his dangerous actions, even if the patient is refusing the treatment. Now I have one final question about that.

E16 If this patient’s situation worsened so that *his life was in danger* due to his mental illness (for example, he is in danger of dying from starvation or self-injury because he was hearing voices), and other treatments were not helping, do you think electric shock treatments should be ordered, even if he were refusing them at the time?

☐ 1  Yes
☐ 2  No

E17 If you were in a situation where *your life was in danger* due to your mental illness (for example, you were in danger of dying from starvation or self-injury because you were hearing voices,), and other treatments were not helping, would you want electric shock treatments to be ordered for you, even if you were refusing them at the time?

☐ 1  Yes
☐ 2  No
F. Belief System

F1 If a person is too sick to make decisions about (use subject’s gender) his/her care, and has not given written instructions for his/her care in advance, should someone else make medical care decisions for him/her?

☐ 1 Yes
☐ 2 No (Skip to F3)
☐ 7 Don’t know (Skip to F3)

F2 Who should make decisions for them? In your opinion, who is the best person to make these decisions? (Do not prompt—interviewer code as appropriate)

☐ 1 Family member
☐ 2 Close friend
☐ 3 Medical doctor
☐ 4 Psychiatrist
☐ 5 Lawyer
☐ 6 Minister/rabbi/priest
☐ 7 Other (Specify)______________

F3 Is there any reason why someone else should NOT make decisions for patients in situations like the ones we have discussed?

☐ 1 YES
☐ 2 NO→ (Skip to F5)

F4 Why shouldn’t someone else make decisions for them? (Do not prompt—interviewer code as appropriate)

☐ 1 Only the patient should make that decision
☐ 2 Fate, (God, chance, other force) will decide when the person should die
☐ 3 Life should be preserved at all costs
☐ 4 No one should be asked to make those decisions for another person
☐ 5 Other (Specify below ↓)

F5 Do you have spiritual or religious beliefs that would influence your decisions if you found yourself in either of the imaginary situations I have read to you?

☐ 1 Yes
☐ 2 No
HEALTHCARE PREFERENCE QUESTIONNAIRE

Subject Initials ______ Subject ID#_________________ Date ________________

F6 What is your religion? (Do not prompt—interviewer code as appropriate)

☐ 1 Protestant
☐ 2 Catholic
☐ 3 Jewish
☐ 4 Muslim
☐ 5 Hindu
☐ 6 Christian
☐ 7 Other (Specify)__________________________
☐ 8 None

F7 Do you consider yourself to be extremely religious, very religious, somewhat religious, not very religious, or not religious at all?

☐ 1 Not religious at all
☐ 2 Not very religious
☐ 3 Somewhat religious
☐ 4 Very religious
☐ 5 Extremely religious

F8 Take a moment to imagine that you are very ill, and likely to die from your illness. As you think about this possibility, what might be your three greatest concerns? (Do not give cues or prompt. Interviewer check appropriate box(es) below when the response includes any of the following cues. Mark all that apply.)

☐ 1 A painful death
☐ 2 Financial burden for your family or loved ones
☐ 3 Physical disability
☐ 4 Being dependent on others to care for you
☐ 5 Loss of control
☐ 6 Not knowing what lies ahead
☐ 7 Being alone
☐ 8 Emotional burden on your loved ones
☐ 9 Doesn’t Know / No Answer
☐ 10 Other (Specify below ↓)
HEALTHCARE PREFERENCE QUESTIONNAIRE

Subject Initials ______ Subject ID#_________________ Date ________________

F8 Which of the concerns you mentioned is your single greatest concern? Can you
tell me more about that? *(If not addressed, probe: “Can you tell me how you
decided that __________ would be a great concern for you?”)*

Greatest concern: ___________________________________________________

Explanation:_______________________________________________________

__________________________________________________________________

__________________________________________________________________

__________________________________________________________________

G. CLOSURE

We are reaching the end of the interview and I have just four closing questions.

G1 I would like to know how comfortable you have been with this interview and with
talking about the end of life. Would you say that you were:

- [ ] 1 Extremely uncomfortable
- [ ] 2 Somewhat uncomfortable
- [ ] 3 Neither comfortable nor uncomfortable
- [ ] 4 Somewhat comfortable
- [ ] 5 Extremely comfortable

G2 Now I would like to know if this interview caused you to feel any stress. On a
scale of 1 to 5 with 1 meaning no stress at all and 5 meaning a great amount of
stress, how much stress would you say this interview caused you?

1  2  3  4  5
No Stress A Great Amount of Stress

final March 2000
G3 Earlier we talked about selecting a healthcare proxy. Do you want more information about selecting a healthcare proxy?
☐ 1 YES → (Give information sheet)
☐ 2 NO

G4 Would you be willing to have someone working on this study contact you in about three or four weeks to ask you a few follow up questions about this interview and your feelings about it?
☐ 1 YES
☐ 2 NO

We have talked about some very complicated topics. I want to thank you for your opinions and your patience. I especially want to thank you for taking the time to participate in this project. Before we stop I want to be sure that you understand that the situations we talked about were not real but just imaginary. You might want to take some time to think about the things we discussed. Sometimes people have questions after the interview. If there is anything at all that you would like to discuss concerning this study, the principal investigator is available to you. [His/Her] name is [Name] at [Name of Institution] and you can reach [him/her] at [phone number].

INTERVIEW END TIME: ____ : ____ AM/PM

Hour : Minutes    Circle one