



Early Treatment Program

Date:

Site ID:

Subject ID:

Child

Parent

Rater ID:

Pathways to Care for Psychosis Interview Protocol (PCP-Q)

PART I. Basic Social Media Usage

[During the consent process, the interviewer and interviewee will exchange names and establish a basic rapport. Interviewees will be trained to focus on helping the interviewee to be motivated and somewhat relaxed before the interview begins.]

Interviewer: “Now I am going to ask you some questions about your life—both online and in the real world. Are you ready to begin?”

- 1) Have you ever used social media? Yes/no [If no, skip to question #8] [may need to define or give examples]

- 2) Do you currently use social media? Yes/no - If no, when did you stop? [if no, skip to question # 5]

- 3) How often do you currently check your social media sites (either to post, comment or explore)?
 - a) If you check daily: ____ times per day

 - b) If you check weekly: ____ times per week

c) If you check monthly: _____times per month

d) I do not use social media:_____

4) How much time do you currently spend on/using social media per day?

_____Hours

_____Minutes

_____Check if not a daily user

5) For how many months/years have (had) you been using social media?

Months: _____

Years: _____

6) What sites do you currently use? Please rank the top 5 used sites (1=most used, 5=least used). [skip if no longer using social media]

a) Facebook

b) Twitter

c) Tumblr

d) Instagram

e) Pinterest

f) Four Square

g) Google+

h) Myspace

i) 4Chan

j) Personal blog

k) Youtube

l) Reddit

m) Other (which) _____

7) What sites have you used in the past (but no longer use)? Please rank the top 5 sites used in the past but no longer use (1=most used, 5=least used).

- n) Facebook
- o) Twitter
- p) Tumblr
- q) Instagram
- r) Pinterest
- s) Four Square
- t) Google+
- u) Myspace
- v) 4Chan
- w) Personal blog
- x) Youtube
- y) Reddit
- z) Other (which) _____

8) What do you currently use social media for /what have you used social media for in the past?
[If the person has never used social media: What are some reasons why you don't use social media?]

9) If you no longer use social media or have deleted one or more of your accounts, what led you to make that decision? [skip if never used social media]

10) Do you play any video games (on a console or on your phones)? Yes/no [skip 11-13 if no]

11) What video games do you play?

12) Which one of these video games do you play the most?

13) How much time do you currently spend on playing video games per day?

_____Hours

_____Minutes

_____Check if not a daily user

Turn off audio recorder for Part II.

Part II. Duration of Untreated Psychosis (not audio recorded)

Interviewer: “This part of the interview is not tape recorded, and is meant to try and pinpoint the dates on which you first started to have the kind of experiences that eventually brought you to mental health care and how long it took you to reach that care. This information may help many young people in the future who have similar experiences. Are you ready to begin?”

[Note: This portion is adapted in part from items on the *Topography of Psychotic Episode (TOPE)* developed at the Prevention and Early Intervention for Psychoses Program (PEPP) at London Health Sciences Center, London, Ontario, Canada. We will make sure that our research team is appropriately trained to administer this portion of the interview. For this portion of the interview, we will turn off the tape recorder, and all notes will be taken by hand. For this reason, some of the questions here are repeated in the audio recorded section.]

How old were you when you first saw a professional for any emotional or psychiatric reason?

Have you ever been hospitalized for emotional or psychiatric reasons? If so how many times?

At what age were you first prescribed medicines for any emotional or psychiatric reasons?

ONSET OF PSYCHOTIC SYMPTOMS – DUI – Patient Report

NOTES:

[First ever signs of psychotic illness:]

When were you last your usual self?

When did you first notice a change in your sense of self?

When did you first notice that something was or had gone wrong?

What was the first change that you noticed?

When did you first feel:

A) Confused about whether something was real or imaginary?

B) That you weren't in control of your own ideas or thoughts (e.g. thoughts broadcast to others, mind-reading or thoughts inserted by others)?

C) Suspicious of others?

D) Heard, saw or felt something that other people didn't?

E) That you were getting preoccupied by the experiences that brought you into (insert NAPLS clinic name here)?

[Distinguish the prodrome for this episode from earlier illness:]

Were the difficulties you just described present continuously, or did they come and go?

YES NO

If “no”, sort out prior illness from prodrome.

Date onset of the prodrome, i.e., meaning that psychiatric symptoms were present for a period of time leading up to the onset of psychosis (first appearance of prodromal symptoms of the illness contiguous (i.e., without clearly discernible periods of wellness intervening) with subsequent onset of psychosis; Keshavan et al., *Schizophr Bull*, 2003).

Date of Onset of Prodrome: ____ / ____ / ____ (dateduip)

ONSET OF PSYCHOSIS – DUP – Patient Report

Date of the initial onset of psychosis (hallucinations or delusions ≥ 3 on PANSS, see below)

Date of Onset of Psychosis: ____/____/____ (datedupp)

Describe the evidence of onset:

PANSS 3. Hallucinatory Behavior – Verbal report or behavior indicating perceptions which are not generated by external stimuli. These may occur in the auditory, visual, olfactory, or somatic realms. Basis for rating: verbal report and physical manifestations during the course of interview as well as reports of behavior by primary care workers or family.

3 = Mild - One or two clearly formed but infrequent hallucinations, or else a number of vague, abnormal perceptions which do not result in distortions of thinking or behavior.

PANSS 1. Delusions – Beliefs which are unfounded, unrealistic, and idiosyncratic. Basis for rating: thought content expressed in the interview and its influence on social relations and behavior.

3 = Mild - Presence of one or two delusions which are vague, uncrystallized, and not tenaciously held. Delusions do not interfere with thinking, social relations, or behavior.

DUP-HALLUCINATIONS – Patient Report

N/A.

Date of initial onset of hallucinations (PANSS ≥ 3): ____/____/____ (datehap)

Unable to obtain.

NOTES:

DUP-DELUSIONS – Patient Report

N/A.

Date of initial onset of delusions (PANSS ≥ 3): ____/____/____ (datedep)

Unable to obtain.

NOTES:

MODE OF ONSET OF PSYCHOSIS – WHO-IPSS – Patient Report Jablensky et al. Chapter 2.

Sociodemographic, clinical and diagnostic description of study population. *Psycholog Med* (Monograph Supplement) 1992;20:18-42.

(variable name = modep)

ONSET = the beginning of the first psychotic episode, manifested by hallucinations, delusions, or disorganization

- Acute. A florid psychotic state developing within days (up to a week)

Mild ('suggestive', non-psychotic) prodromal signs or symptoms may have been:

- absent (sudden onset), (1), or
- present (precipitous onset) (2)

- Subacute. Symptoms appearing and developing into a clear-cut psychotic state over a period of exceeding one week and up to one month. (3)

- Gradual. Slow, incremental development of psychotic symptoms over a period exceeding one month; prodromal signs or symptoms (if any) cannot be clearly distinguished from overt psychotic symptoms as regards their timing because of a gradual transition from one to the other. (4)

- Insidious. No clear demarcation can be made between premorbid personality and mental illness, and onset as such cannot be rated. (5)

Part III. Early Experiences of Psychosis (audio recorded)

Interviewer: “Now we are going to turn the tape recorder back on. I would like to ask you about your thoughts and feelings during the time before you came here. Let’s start with how you decided to reach out for help. My apologies if I seem to be repeating myself at times, but we want to make sure we have a thorough account of your recent experiences so that we can do our best to provide good care to people in the future.

Are you ready to begin?”

1) When was the first time someone else suggested to you that something was different or not quite right with you? That you had changed? That you were not your usual self?

Year:

Month:

2) Who was this person?

- a. Friend
- b. Relative
- c. Neighbor
- d. Teacher
- e. Coach
- f. Religious counselor
- g. Health professional (non-mental health)
- h. Health professional (mental health)
- i. Police officer
- j. Other (Specify: _____)
- k. No one

3) What changes did they refer to/were they concerned about the most?

4) How did you respond? [Let them respond openly, then offer prompts]

- a) Did nothing

- b) Got upset
- c) Followed their advice
- d) Anything else?

5) Were there any ways in which you agreed with them? Were there ways in which you disagreed?

6) But now we know that you were experiencing some changes. Which changes did **you** first notice? [After they are done listing, ask them to please rank the 5 that were the biggest problem of those listed. More than ten are welcome.]

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.
- 7.
- 8.
- 9.
- 10.

7) What did you think was causing or contributing to these changes? [If no answer, offer the following as possibilities and see what they say after each one, but first let them speak openly.]

- a) Stress
- b) Relationship problems
- c) A traumatic event (please specify:)
- d) Mental illness
- e) Physical illness
- f) Drugs/alcohol
- g) Other (specify):
- h) I don't know

- 8) Did you think the changes would go away on their own? Yes/No
- 9) If yes, what led you to think the changes might go away? If no, what led you to think they might not go away?
- 10) Did you think the changes would get worse? Yes/No
- 11) If yes, what led you to think that the changes might get worse? If no, what led you to think that the changes would not get worse?
- 12) If yes, how did you think the changes would get worse? What did you think might happen?
- 13) What seemed to make the problems better? Check all that apply.
- a) Alcohol/drugs (specify:)
 - b) Video/computer games (specify:)
 - c) Movies
 - d) Music
 - e) Family
 - f) Friends
 - g) Exercise
 - h) Being with people
 - i) Avoiding people
 - j) Other (Specify :)

14) Did you try to make the changes go away on your own? What did you do?

Part IV. Pathway to Formal Mental Health Care

15) Where did you go to find answers about the changes you were experiencing? [If no response, offer these prompts, but let them answer openly first.]

- a) Books (specify which ones:_____)
- b) Internet (specify which sites, what specific search terms_____)
- c) Magazines (specify:_____)
- d) Friends (specify:_____)
- e) Family (specify:_____)
- f) Medical health care professional (Specify:_____)
- g) Clergy or community leader
- h) Other professional helpers (specify:_____)
- i) Other (specify:_____)

16) Which of these sources was the most helpful? How so?

17) Which of these was the least helpful? How so?

18) During the time between when you first noticed a change (specify date) and when you first received any help, did your social media habits change?

YES NO

19) If your social media habits changed, when did you first notice that they changed?

Year:

Month:

20) If your social media habits changed, in what way(s) did they first change? [Prompts below if needed, but let them speak openly.]

- a. I spent more time using social media (how much more:_____)
- b. I spent less time using social media (how much less:_____)
- c. I used different social media sites (specify:_____)
- d. I used social media in a different way (specify:_____)

21) During the time between when you first noticed a change (specify date) and when you first received any help, did you ever talk about your concerns/changes on social media, such as on a personal blog or Facebook? Yes/no

22) How long did you wait between first noticing these concerns/changes and talking about them *online*?

_____ days

_____ weeks

_____ months

_____ years

23) What led you to reach out to people online instead of seeking help from someone in person?

[Let them answer first, but then also check these reasons if they are not mentioned.]

- a) The problem did not seem serious enough
- b) I thought it would go away
- c) I didn't know where to go for help
- d) I didn't know who to ask for help
- e) I was worried about what other people would say/think if they found out
- f) I was worried about what would happen to me
- g) Other (Specify: _____)

24) If you ever talked about your concerns/changes on social media, how often did you do this?

25) If you ever talked about your concerns/changes on social media, which sites did you go to/use?

26) If you ever talked about your concerns/changes on social media, what concerns/experiences did you share?

27) Did you ever receive any advice for these concerns/experiences on social media? Yes/no

28) If you ever received any advice for these concerns/experiences on social media, what was it?

29) Was this advice helpful?

- 30) If yes, how so? If not, how so?
- 31) Can you tell me about what information or help you wanted the most when you first noticed the changes we've been discussing?
- 32) During the time between when you first noticed a change (specify date) and when you first received any help, did anyone tell you that your social media activity (posts/comments/photos) had changed or were concerning?
- 33) Did social media activity in any way have any impact on you receiving care? (for example, did a friend or parent notice social media activity that worried them?)
- 34) During the time between when you first noticed a change (specify date) and when you first received any help, did you reach out to anyone in *person*?
- a) Friend
 - b) Relative
 - c) Neighbor
 - d) Teacher
 - e) Coach
 - f) Religious counselor or community leader
 - g) Health professional (non-mental health)
 - h) Health professional (mental health)
 - i) Other (specify):
 - j) No one
- 35) How long did you wait between first noticing these concerns/changes and talking about them in *person*? Please indicate your answer on one line.
- _____ days
- _____ weeks
- _____ months
- _____ years
- 36) What led you to decide to go ahead and reach out in person?
- 37) Can you tell me what you said to this person? What did you talk about? What did you ask for?

- 38) What did he/she recommend? [Let them answer first, then offer these prompts.]
- a) Get professional psychiatric/mental health help
 - b) Go see the Primary Care
 - c) Don't go out with peers
 - d) Restrict Alcohol/ Drug use
 - e) Take over-the-counter medication (Specify:_____)
 - f) Improve your sleep
 - g) Change your diet
 - h) Other (Specify:_____)
- 39) If you had your choice about how to get **information** about the changes you were experiencing, what would you have preferred back then? (Prompts: Internet, Facebook; friends, family, etc.)?
- 40) If you had your choice about how to get **help** for the changes you were experiencing, what would you have preferred back then?
- 41) Was it your choice to seek out help from a mental health professional for these experiences?
- 42) If it was not your choice initially, who made that choice for you? How did they get you to agree to see a mental health professional?
- 43) Were the police involved? If so how?
- 44) How would you have felt at the time if we at the Early Treatment Program (or insert name of clinic) used the internet or social media to reach out to you directly to initiate a conversation about your experiences before you ever came in for treatment? Keep in mind that we did not know you.
- 45) How would you feel if a professional offered you *help/advice/suggestions* via the internet or social media?

46) Would you feel comfortable sharing what you have written online on social media in the past with us? Yes/No

47) Who referred you to your first mental health **evaluation or treatment**? [Prompts if no answer.]

- a) Friend
- b) Relative
- c) Neighbor
- d) Teacher
- e) Coach
- f) Religious counselor
- g) Health professional (non-mental health)
- h) Health professional (mental health)
- i) Self
- j) Other (Specify: _____)
- k) No one

V. Professional Mental Health Treatment

48) Who provided this first treatment for these changes?

- a. Counselor at school or work
- b. Primary care doctor
- c. Social worker
- d. Psychologist
- e. Psychiatrist
- f. Counselor at a religious institution
- g. Other (Specify: _____)

49) What diagnosis or other information did the professional give you to explain the changes you had been experiencing?

50) How did this make you feel?

51) Did you agree with them?

52) What was the first treatment approach offered by professionals for this problem?

- a) Education
- b) Stress management
- c) Attending self-help groups
- d) Counseling (what type:_____)
- e) Medication (which one(s):_____)
- f) Therapy
- g) Other (Specify:_____)

53) How many different contacts with a health care provider did you have for the changes before the first therapy or counseling was started? _____

54) How many different contacts with a health care provider did you have for the changes before the first medication treatment was started? _____; or No Medication_____

Interviewer: “Now we are going to talk about pharmacologic (“prescription medication”) treatments for your changes.” Then we will talk about other kinds of treatment.

55) Was the first medication-based treatment stopped? Yes/no

56) What specifically was this prescribed treatment? [If possible, the exact name of the medication and dosage would be good to know.]

57) If you continued with the prescribed treatment, what motivated this decision?

58) If the first treatment was stopped, for how long did you continue with this first treatment before it was stopped?

- _____ days
- _____ weeks
- _____ months
- _____ years

59) If the first medication treatment was stopped, who made the decision to stop this first treatment? [Listen and then use these prompts if needed.

- a. You
- b. Parent
- c. Other family member
- d. Treatment provider
- e. Friend
- f. Other (Specify: _____)

60) If the first “prescription medication” treatment was stopped, why was it stopped? [Listen and then use prompts if needed].

- a. It did not work
- b. I did not think it was necessary
- c. It had side effects
- d. It was too expensive
- e. I had transportation issues
- f. I had no time
- g. Others advised me against the treatment (specify)

Interviewer: “Now let’s talk about non-pharmacological treatments, such as counseling.”

61) Was the first counseling/therapy treatment stopped? Yes/no

62) If you continued with the counseling/therapy, what motivated this decision?

63) If the first counseling/therapy treatment was stopped, for how long did you continue with this first treatment before it was stopped?

- _____ days
- _____ weeks
- _____ months
- _____ years

64) If the first counseling/therapy treatment was stopped, who made the decision to stop this first treatment? [Listen and then use these prompts if needed.

- a. You
- b. Parent
- c. Other family member
- d. Treatment provider
- e. Friend
- f. Other (Specify: _____)

65) If the first counseling/therapy treatment was stopped, why was the first treatment stopped? [Listen and then use prompts if needed].

- a. It did not work
- b. I did not think it was necessary
- c. It had side effects
- d. It was too expensive
- e. I had transportation issues
- f. I had no time
- g. Others advised me against the treatment (specify)

66) Is there anything you would like to add about your experiences before you received any care at this clinic?

67) If you could suggest two or three things that would have helped you most in this entire process, what would they have been?

68) If you could give any advice to yourself back at the beginning of this process based on what you have learned since, what would that advice be?

Interviewer: “Thank you for your time! This information, we hope, will go a long way to help young people in the future have a positive experience despite these confusing kinds of experiences.”