PhenX Toolkit

Data Collection Worksheet

GO FIGS Pedigree Drawing Instructions

v. 3.21.12

Begin with the FIGS General Screening Questions (p. 1), Step 1:

Let's go over your family tree.

Have the pedigree form ready. Place in front of participant, and once constructed, keep it in front of participant throughout interview.

Pedigree Drawing.

1. In the middle of the page, draw a symbol for the participant (circle for female, square for males). **This is you.** (Write participant's name under the symbol.)

2. If participant:

   a. Is only child: **You told me that you have no brothers and sisters, is that correct?** (If yes, above the participant's symbol, draw a square for dad on the left, a circle for mom on the right, connect with line, and draw another line directly down to participant's symbol. Proceed with instruction #3 below.)

   b. Has siblings. **You told me that you had (insert number) siblings: (insert number) brothers and (insert number) sisters. Is that correct?** (If yes, proceed; if not, correct.) Do they all have the same mother and father as you?

      i. *YES* (same biological parents): Determine where in birth order participant falls (First, second, third and so on). Above the participant's symbol, draw a square for dad on the left, a circle for mom on the right, connect with line, and draw another line downward. From left to right, add symbols for the other full siblings from oldest (firstborn) to youngest around the proband. Write each sibling's name underneath his/her symbol.

      ii. *NO:* **"For this family tree, I am going to ask you only about full biological**

siblings: your brothers/sisters who have the same mom AND dad as you." For FULL sibs only, determine where in birth order participant falls (First, second, third and so on). From left to right, add symbols for the other full siblings from oldest (firstborn) to youngest around the proband. Write each sibling's name underneath his/her symbol.

3. **Do you have any children?**

   a. *YES:* Draw a horizontal line from the participant to a partner, and drop down a line (or set of lines) to depict children. Write each child's name underneath his/her symbol. Go to FIGS screener.

   b. *NO:* Go to FIGS screener.

Proband's Initials: _____

ID: _____

FAMID: _____

Age: _____

Assessor: _____

Date: _____

Start time: _____

End time: _____

v. 11/19/09

FIGS: Proband Pedigree

FIGS: GENERAL SCREENING QUESTIONS

Interview date: ☐ ☐ ☐ - ☐ ☐ - ☐ ☐ ☐ ☐

	Month	Day	Year

Family last name: [   ]   Family ID number: [ ][ ][ ][ ]

Informant name: _____ _____ _____

　　　　　　　　　　　First　　　　　　　　　MI　　　　　　　　Last

Informant ID: [ ][ ][ ][ ]

INTERVIEWER: Before you begin, you need to generate or obtain a pedigree on which to record all of the responses to the following General Screening Questions. (See FIGS Manual for details.)

Step 1: *Let's go over your family tree.* (Include first-degree relatives only: offspring, parents, siblings.)

Step 2: *Now I am asking you to keep in mind all those in your family tree as I go through this list of questions.* (Note all positive responses on the pedigree.)

　　[ ] Was anyone adopted?

　　[ ] Was anyone mentally retarded?

Did anyone:

　　[ ] Have problems with their nerves or emotions? Take medicine or see a doctor for it? Take lithium?

　　[ ] Feel very low for a couple of weeks or more, or have a diagnosis of depression?

　　[ ] Attempt or complete suicide?

　　[ ] Seem overexcited (or manic) day and night, or have a diagnosis of mania?

　　[ ] **Have visions, hear voices, or have beliefs that seem strange or unreal?

　　[ ] **Have unusual or bizarre behavior, or have a diagnosis of schizophrenia?

　　[ ] Have trouble with the police, with completing school, or with keeping a job?

　　[ ] Have alcohol or drug use that caused problems (with health, family, job, or police)? Go to AA or NA, or have treatment for this?

　　[ ] (Was anyone) hospitalized for psychiatric problems, or for drug or alcohol problems?

[ ] Have inherited medical diseases such as Huntington's disease or seizure disorder or any other disorders of the brain or nervous system?

[ ] **(Did anyone) have few friends, or seem to be a loner?

[ ] **(Did anyone) seem odd or eccentric in behavior or appearance?

[ ] **(Was anyone) extremely jealous, or suspicious, or believe in magic, or see special meanings in things that no one else saw?

Step 3: Complete a Face Sheet for each of the informant's first-degree relatives.

FIGS: FACE SHEET

Interview date: [ ][ ][ ] - [ ][ ] - [ ][ ][ ][ ]

| Month | Day | Year |

Family last name: [   ]   Family ID number: [ ][ ][ ][ ]

Informant name: _____ _____ _____

First   MI   Last

Informant ID: [ ][ ][ ][ ][ ]

Person being described name: _____ _____ _____

First   MI   Last

Person being described ID: [ ][ ][ ][ ][ ]

Relationship to informant: _____

Birthdate of person described, if known: [ ][ ][ ] - [ ][ ] - [ ][ ][ ]

Is person described living?

    0 [ ] No

    1 [ ] Yes

    9 [ ] Unknown

Age and Year when last seen or known about, or died:

| | | in | | | |

        Age   year

If deceased, cause of death::

_____

Suicide?

    0 [ ] No

    1 [ ] Yes

    9 [ ] Unknown

INTERVIEWER: Refer to General Screening Questions if necessary.

| 1. Write narrative: | If any General Screening Questions endorsed about this relative, code 1 and transcribe details here. Complete psychosis checklist if any *starred* items endorsed. | 0 1 9 |

FIGS: PSYCHOSIS CHECKLIST

Interview date: | | | | - | | | - | | | |

        Month   Day   Year

Family last name: [   ]   Family ID number: | | | | |

Informant name:

First	MI	Last

Informant ID: ☐☐☐☐☐

Person being
described name:

First	MI	Last

PSYCHOSIS

Code for a single episode (best recalled, worst episode if possible).

1. *What were his/her unusual beliefs or experiences?*

Specify:

_____

____

Did he/she ever…	No	Yes	Unk
1.a) *…believe people were following him/her, or that someone was trying to hurt or poison him/her?*	0	1	9
1.b) *…believe someone was reading his/her mind?*	0	1	9
1.c) *…believe he/she was under the control of some outside person or power or force?*	0	1	9
1.d) *…believe his/her thoughts were broadcast, or that an outside force took away his/her thoughts or put thoughts into his/her head?*	0	1	9
1.e) *…have any other strange or unusual beliefs?*	0	1	9

If yes: Describe:

_____

1.f)   ...*see things that were not really there?*   0   1   9

1.g) ...*hear voices or other sounds that were not real?*   0   1   9

If yes: Describe:

_____

If 1.g = 0, then skip to question 1.h

1.g.1) (Code **YES** if: voice with content having no relation to   0   1   9
depression or elation, or voice keeping up running
commentary on subject's behavior or thoughts, or two or
more voices conversing.)

1.h)   ...*speak in a way that was difficult to make sense of?*   0   1   9

If yes: Describe:

_____

1.i)   ...*seem to be physically stuck in one position, or move*   0   1   9
        around excitedly without purpose?

1.j)   ...*appear to have no emotions, or inappropriate emotions?* 0   1   9

2. *How long did the <u>longest</u> of these experiences last?*

Weeks

INTERVIEWER: If less than 1 week (unless successfully treated), STOP HERE. Otherwise continue, if informant is knowledgeable about this person.

Code Response

6. Code and describe professional treatment (Code and   0   1   2   3   4   9
   describe all that apply):

   0 [ ] None

1 [ ] Inpatient: _____

2 [ ] Outpatient: _____

3 [ ] ECT: _____

4 [ ] Medication: _____

9 [ ] Unknown

Describe details and/or other treatment:

Age

7. Age of onset:

☐☐

Episodes

8. Number of episodes (Code **001** if chronic symptoms and/or treatment since onset):

☐☐☐

Weeks   Years

9. Total illness duration (all episodes, includes active and prodromal and/or residual symptoms and/or treatment):

☐☐ OR ☐☐

Code Response

10. Rate and code impairment or incapacitation:

0 [ ] None

1 [ ] Impaired

2 [ ] Incapacitated

9 [ ] Unknown

11. Interviewer judgment on reliability of this information:

1 [ ] Good

2 [ ] Fair

3 [ ] Poor

FIGS: PSYCHOSIS CHECKLIST

Interview date: [ ][ ][ ] - [ ][ ] - [ ][ ][ ][ ]

                  Month   Day   Year

Family last name: [_____]   Family ID number: [ ][ ][ ][ ]

Informant name: _____ _____ _____

                  First   MI   Last

Informant ID: [ ][ ][ ][ ][ ]

Person being described name: _____ _____ _____

                  First   MI   Last

Person being described ID: [ ][ ][ ][ ][ ]

PSYCHOSIS

Code for a single episode (best recalled, worst episode if possible).

1. *What were his/her unusual beliefs or experiences?*

Specify:

_____

_____

Did he/she ever…

1.a) *…believe people were following him/her, or that someone was trying to hurt or poison him/her?*

    0 [ ] No

1 [ ] Yes

9 [ ] Unknown

1.b) *...believe someone was reading his/her mind?*

　　0 [ ] No

　　1 [ ] Yes

　　9 [ ] Unknown

1.c) *...believe he/she was under the control of some outside person or power or force?*

　　0 [ ] No

　　1 [ ] Yes

　　9 [ ] Unknown

1.d) *...believe his/her thoughts were broadcast, or that an outside force took away his/her thoughts or put thoughts into his/her head?*

　　0 [ ] No

　　1 [ ] Yes

　　9 [ ] Unknown

1.e) *...have any other strange or unusual beliefs?*

　　0 [ ] No

　　1 [ ] Yes

　　9 [ ] Unknown

If yes: Describe:

_____

_____

1.f) *...see things that were not really there?*

　　0 [ ] No

　　1 [ ] Yes

　　9 [ ] Unknown

1.g) *...hear voices or other sounds that were not real?*

0 [ ] No

1 [ ] Yes

9 [ ] Unknown

If yes: Describe:

_____

_____

If no: Skip to Question 1.h.

1.g.1) (Code **YES** if: Voice with content having no relation to depression or elation, or voice keeping up running commentary on subject's behavior or thoughts, or two or more voices conversing.)

0 [ ] No

1 [ ] Yes

9 [ ] Unknown

1.h) ...*speak in a way that was difficult to make sense of?*

0 [ ] No

1 [ ] Yes

9 [ ] Unknown

If yes: Describe:

_____

_____

1.i) ...*seem to be physically stuck in one position, or move around excitedly without any purpose*?

0 [ ] No

1 [ ] Yes

9 [ ] Unknown

1.j) ...*appear to have no emotions, or inappropriate emotions?*

0 [ ] No

1 [ ] Yes

9 [ ] Unknown

2. *How long did the <u>longest of these experiences last?</u>*

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Weeks

INTERVIEWER: If less than one week, unless successfully treated, STOP HERE. Otherwise continue, if informant is knowledgeable about this person.

3. Code and describe professional treatment (Code and describe all that apply):

   0 [ ] None

   1 [ ] Inpatient: _____

   2 [ ] Outpatient: _____

   3 [ ] ECT: _____

   4 [ ] Medication: _____

   9 [ ] Unknown

Describe details and/or other treatment:

_____

_____

4.) Age of onset:

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Age

5. Number of episodes (Code **001** if chronic symptoms and/or treatment since onset):

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Episodes

6. <u>Total</u> illness duration (<u>all</u> episodes, includes active and prodromal and/or residual symptoms and/or treatment).

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OR

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Weeks   Years

7. Rate and code impairment or incapacitation:

   0 [ ] None

   1 [ ] Impaired

2 [ ] Incapacitated

9 [ ] Unknown

8. Interviewer judgement on reliability of this information:

1 [ ] Good

2 [ ] Fair

3 [ ] Poor

Protocol source: https://www.phenxtoolkit.org/protocols/view/660702