



Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid integration of a PhenX protocol into a study. The PhenX DCW is not designed to be a data collection instrument. Investigators will need to decide the best way to collect data for the PhenX protocol in their study. Variables captured in the DCW, along with variable names and unique PhenX variable identifiers, are included in the PhenX Data Dictionary (DD) files.

FAMILY INTERVIEW FOR GENETIC STUDIES

FIGS: FACE SHEET

(FIGS)

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:

			-			-				
--	--	--	---	--	--	---	--	--	--	--

Month

Day

Year

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. (**Probe:** has he/she had any psychiatric or personality problems like those we mentioned earlier?)

0 [] No

1 [] Yes

9 [] Unknown

Write Narrative:

FIGS: OTHER DISORDERS

1. Indicate any disorder not in the checklists and complete questions 1.a-f for the disorder.

Specify: _____

1.a) Code and describe professional treatment:

0 [] None

1 [] Inpatient: _____

2 [] Outpatient: _____

3 [] ECT: _____

4 [] Medication: _____

9 [] Unknown

1.b) Age of onset:

--	--

Age

1.c) Number of episodes:

--	--	--

Episodes

1.d) Duration of longest episode in weeks:

--	--	--

Weeks

1.e) Rate and code impairment or incapacitation:

Family last name: Family ID number:

Informant name: _____

Informant ID:

		First		
--	--	-------	--	--

		MI		
--	--	----	--	--

		Last		
--	--	------	--	--

Person being described name: _____

Person being described ID:

		First		
--	--	-------	--	--

		MI		
--	--	----	--	--

		Last		
--	--	------	--	--

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

1. *During depression...*

1.a) *...was he/she depressed most of the day, nearly every day, for as long as a week or more?*

- 0 [] No
- 1 [] Yes
- 9 [] Unknown

1.b) *...did he/she lose interest in things or become unable to enjoy most things, for as long as a week?*

- 0 [] No
- 1 [] Yes
- 9 [] Unknown

1.c) *...did he/she have a change in appetite or weight without trying to?*

- 0 [] No
- 1 [] Yes
- 9 [] Unknown

1.d) ...*did he/she have a change in sleep patterns (either too much or too little)?*

0 [] No

1 [] Yes

9 [] Unknown

1.e) ...*did he/she become unable to work, go to school, or take care of household responsibilities?*

0 [] No

1 [] Yes

9 [] Unknown

If Yes: Describe: _____

If No: Discontinue this checklist.

1.f) ...*did he/she move or speak more slowly than usual?*

0 [] No

1 [] Yes

9 [] Unknown

1.g) ...*did he/she pace or wring his/her hands?*

0 [] No

1 [] Yes

9 [] Unknown

1.h) ...*did he/she have less energy or feel tired out?*

0 [] No

1 [] Yes

9 [] Unknown

1.i) ...*did he/she feel guilty, worthless or blame himself/herself?*

0 [] No

1 [] Yes

9 [] Unknown

1.j) ...*did he/she have trouble concentrating or making decisions?*

0 [] No

1 [] Yes

9 [] Unknown

1.k) ...*did he/she talk of death or suicide? Or try suicide?*

0 [] No

1 [] Yes

9 [] Unknown

1.l) ...*did he/she have visions, or hear voices, or have beliefs or behavior that seem strange or unusual, at the same time as (symptoms above)? (If YES, complete a Psychosis Checklist after this one.)*

0 [] No

1 [] Yes

9 [] Unknown

2. Code and describe professional treatment:

0 [] None

1 [] Inpatient: _____

2 [] Outpatient: _____

3 [] ECT: _____

4 [] Medication: _____

9 [] Unknown

3.) Age of onset:

--	--

Age

4.) Number of episodes:

--	--	--

Episodes

5.) Duration of longest episode in weeks:

--	--	--

Weeks

6. Rate and code impairment or incapacitation:

- 0 [] None
- 1 [] Modified RDC Impairment
- 2 [] Modified RDC Incapacitation
- 3 [] RDC Minor Role Dysfunction
- 4 [] Change from previous functioning
- 9 [] Unknown

7. Interviewer judgement on reliability of this information:

- 1 [] Good
- 2 [] Fair
- 3 [] Poor

FIGS: MANIA CHECKLIST

Interview date:

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 -

--	--	--	--

Month

Day

Year

Family last name:

--

 Family ID number:

--	--	--	--

Informant name: _____

Informant ID:

--	--	--	--	--

First MI Last

Person being described name:

Person being described ID:

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First MI Last

1. *For most of the time day and night over several days, did he/she (more than usual)...*

1.a) *...seem too happy/high/excited?*

- 0 [] No
- 1 [] Yes
- 9 [] Unknown

1.b) *...become so excited or agitated it was impossible to converse with him/her?*

- 0 [] No
- 1 [] Yes
- 9 [] Unknown

1.c) *...act very irritable or angry?*

- 0 [] No
- 1 [] Yes
- 9 [] Unknown

1.d) *...need less sleep without feeling tired?*

- 0 [] No
- 1 [] Yes
- 9 [] Unknown

1.e) *...show poor judgement (e.g., spending sprees, sexual indiscretions?)*

0 [] No

1 [] Yes

9 [] Unknown

If Yes: Describe: _____

If No: Discontinue this checklist.

1.f) *...behave in such a way as to cause difficulty for those around him/her (obnoxious/manipulative)?*

0 [] No

1 [] Yes

9 [] Unknown

1.g) *...feel that he/she had special gifts or powers?*

0 [] No

1 [] Yes

9 [] Unknown

1.h) *...become more talkative than usual?*

0 [] No

1 [] Yes

9 [] Unknown

1.i) *...jump from one idea to another?*

0 [] No

1 [] Yes

9 [] Unknown

1.j) *...become easily distracted?*

0 [] No

1 [] Yes

9 [] Unknown

1.k) *...get involved in too many activities at work or school?*

0 [] No

1 [] Yes

9 [] Unknown

1.l) *...have visions? hear voices? have beliefs or behavior that seem strange or unusual? at the same time as (above symptoms)? (If YES, complete a Psychosis Checklist after this one.)*

0 [] No

1 [] Yes

9 [] Unknown

2. Code and describe professional treatment:

0 [] None

1 [] Inpatient: _____

2 [] Outpatient: _____

3 [] ECT: _____

4 [] Medication: _____

9 [] Unknown

3.) Age of onset:

--	--

Age

4.) Number of episodes:

--	--	--

Episodes

5.) Duration of longest episode in weeks:

--	--	--

Weeks

ALCOHOLISM

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

1. *Because of drinking, did he/she ever have problems such as...*

1.a) *...being unable to stop or cut down on drinking?*

0 [] No

1 [] Yes

9 [] Unknown

1.b) *...spending a lot of time drinking or being hung over?*

0 [] No

1 [] Yes

9 [] Unknown

1.c) *...being unable to work, go to school, or take care of household responsibilities?*

0 [] No

1 [] Yes

9 [] Unknown

1.d) *...being high from drinking when he/she could get hurt?*

0 [] No

1 [] Yes

9 [] Unknown

1.e) *...accidental injuries?*

0 [] No

1 [] Yes

9 [] Unknown

1.f) *...reducing or giving up important activities?*

0 [] No

1 [] Yes

9 [] Unknown

1.g) *...objections from the family or friends, at work or school?*

0 [] No

1 [] Yes

9 [] Unknown

1.h) *...legal problems more than once (DWIs, arrests)?*

0 [] No

1 [] Yes

9 [] Unknown

1.i) *...blackouts more than once?*

0 [] No

1 [] Yes

9 [] Unknown

1.j) *...binges or benders more than once?*

0 [] No

1 [] Yes

9 [] Unknown

1.k) *...physical health problems (liver disease, pancreatitis)?*

0 [] No

1 [] Yes

9 [] Unknown

1.l) *...emotional or psychological problems (uninterested, depressed, suspicious/paranoid, having strange ideas)?*

0 [] No

1 [] Yes

9 [] Unknown

1.m) ...*withdrawal symptoms (shakes, seizures/convulsions, DTs)?*

0 [] No

1 [] Yes

9 [] Unknown

2. *Did he/she go to AA or have any kind of treatment? (Code and describe all that apply)*

0 [] None

1 [] Inpatient: _____

2 [] Outpatient: _____

3 [] AA or other self-help: _____

4 [] Medication: _____

9 [] Unknown

Describe details and/or other treatment: _____

3. *Does he/she currently have a problem with alcohol?*

0 [] No

1 [] Yes

9 [] Unknown

4. Record age he/she began to have alcohol-related problems.

--	--

Ons Age

5. Record age he/she stopped drinking heavily.

--	--

Rec Age

DRUG ABUSE/DEPENDENCE

6. *Which drugs did he/she have trouble with?*

Specify:

7. *Because of his/her drug use, did he/she have...*

7.a) ... *physical health problems (hepatitis, overdose, withdrawal symptoms, accidental injuries)?*

0 [] No

1 [] Yes

9 [] Unknown

7.b) ... *emotional or psychological problems (uninterested, depressed, suspicious/paranoid, having strange ideas)?*

0 [] No

1 [] Yes

9 [] Unknown

7.c) ... *legal problems (arrests for possessing, selling, or stealing drugs)?*

0 [] No

1 [] Yes

9 [] Unknown

7.d) ... *problems with family or friends?*

0 [] No

1 [] Yes

9 [] Unknown

7.e) ... *troubles at work or school?*

0 [] No

1 [] Yes

9 [] Unknown

8. *Did he/she go to NA or have any kind of treatment? (Code and describe all that apply)*

0 [] None

1 [] Inpatient: _____

2 [] Outpatient: _____

3 [] NA or other self-help: _____

4 [] Medication: _____

9 [] Unknown

Describe details and/or other treatment: _____

9. *Does he/she currently have a problem with drugs?*

0 [] No

1 [] Yes

9 [] Unknown

10. Record age he/she began to have drug-related problems.

--	--

Ons Age

11. Record age he/she stopped using drugs heavily.

--	--

Rec Age

12. Interviewer judgement 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: _____

Informant ID:

--	--	--	--	--

--	--	--	--

--	--	--	--

Person being described name: _____

Person being described ID:

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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 longest of these experiences last?

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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.

INTERVIEWER: If subject did NOT have any episode of Major Depression or

Mania (by FIGS checklists from this informant), skip to Question 6.

3. *When any (SX above) happened, did he/she also have the mood disturbance we discussed before, at the same time?*

0 [] No

1 [] Yes

9 [] Unknown

If no: Skip to Question 6.

INTERVIEWER: For the rest of this checklist, "illness duration" refers to total time of illness, including active and prodromal and/or residual symptoms and/or treatment (include time on medication).

4. (Probe and code **YES** if mania and/or depression lasted at least 30% of total duration of illness described above, or medication for it.)

0 [] No

1 [] Yes

9 [] Unknown

5. (Probe and code **YES** if illness described above, or medication for it, was ever present for as long as one week, without depression and/or mania.)

0 [] No

1 [] Yes

9 [] Unknown

If no: Skip to Question 6.

5.a) (Code **YES** if the above was true for as long as two weeks.)

0 [] No

1 [] Yes

9 [] Unknown

6. 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:

7.) Age of onset:

--	--

Age

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

--	--	--

Episodes

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

--	--

OR

--	--

Weeks

Years

10. Rate and code impairment or incapacitation:

0 [] None

1 [] Impaired

2 [] Incapacitated

9 [] Unknown

11. Interviewer judgement on reliability of this information:

1 [] Good

2 [] Fair

3 [] Poor

INTERVIEWER: If informant apparently does not know subject well enough to give information on Prodromal/Residual symptoms, STOP HERE.

If duration criterion for DSM III-R Schizophrenia, Chronic Type, already met, (Question 9, total illness duration > 2 years), STOP HERE

INTERVIEWER: Use this page only if Schizo-affective is ruled out (by Questions 3 to 5 above), or if the psychosis symptoms lasted at least one week (or shorter duration if successfully treated).

Establishing the Prodromal Period:

16. *Now I would like to ask you about the year before his/her (psychotic symptoms) started. During that time did he/she...*

16.a) *...stay away from family and friends, become socially isolated?*

0 [] No

1 [] Yes

9 [] Unknown

16.b) *...have trouble doing his/her job, going to school, or doing work at home?*

0 [] No

1 [] Yes

9 [] Unknown

16.c) *...do something peculiar like talking to self in public?*

0 [] No

1 [] Yes

9 [] Unknown

16.d) *...neglect hygiene and grooming?*

0 [] No

1 [] Yes

9 [] Unknown

16.e) *...appear to have no emotions or inappropriate emotions?*

0 [] No

1 Yes

9 Unknown

16.f) *...speak in a way that was hard to understand, or was he/she at a loss for words?*

0 No

1 Yes

9 Unknown

16.g) *...have unusual beliefs or ideas?*

0 No

1 Yes

9 Unknown

16.h) *...have unusual perceptions, like sensing the presence of a person not actually present?*

0 No

1 Yes

9 Unknown

16.i) *...have no interests, no energy?*

0 No

1 Yes

9 Unknown

16.j) *...find special meaning in TV, radio, or newspaper articles?*

0 No

1 Yes

9 Unknown

16.k) *...feel nervous with other people?*

0 No

1 Yes

9 [] Unknown

16.l) *...worry that people were out to get him/her?*

0 [] No

1 [] Yes

9 [] Unknown

(Ask after completing question 16.a-n for the Prodromal period:)

Establishing the Residual Period:

16. *Now I would like to ask you about the year after his/her (psychotic symptoms) stopped. During that time did he/she...*

16.a) *...stay away from family and friends, become socially isolated?*

0 [] No

1 [] Yes

9 [] Unknown

16.b) *...have trouble doing his/her job, going to school, or doing work at home?*

0 [] No

1 [] Yes

9 [] Unknown

16.c) *...do something peculiar like talking to self in public?*

0 [] No

1 [] Yes

9 [] Unknown

16.d) *...neglect hygiene and grooming?*

0 [] No

1 [] Yes

9 [] Unknown

16.e) *...appear to have no emotions or inappropriate emotions?*

0 [] No

1 [] Yes

9 [] Unknown

16.f) *...speak in a way that was hard to understand, or was he/she at a loss for words?*

0 [] No

1 [] Yes

9 [] Unknown

16.g) *...have unusual beliefs or ideas?*

0 [] No

1 [] Yes

9 [] Unknown

16.h) *...have unusual perceptions, like sensing the presence of a person not actually present?*

0 [] No

1 [] Yes

9 [] Unknown

16.i) *...have no interests, no energy?*

0 [] No

1 [] Yes

9 [] Unknown

16.j) *...find special meaning in TV, radio, or newspaper articles?*

0 [] No

1 [] Yes

9 [] Unknown

16.k) *...feel nervous with other people?*

0 [] No

1 [] Yes

9 [] Unknown

16.l) ...worry that people were out to get him/her?

0 [] No

1 [] Yes

9 [] Unknown

17.a). How long did he/she have these experiences?

--	--	--

Weeks

17.b). How long did he/she have these experiences after his/her (Active psychotic features) stopped?

--	--	--

Weeks

18. Was he/she always this way?

0 [] No

1 [] Yes

9 [] Unknown

FIGS: PARANOID/SCHIZOID/SCHIZOTYPAL PERSONALITY CHECKLIST

SITE OPTIONAL

Interview date:

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--	--	--	--

Month Day Year

Family last name:

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 Family ID number:

--	--	--	--

Informant name: _____

1.d) *...take a long time to forgive someone if they have insulted or hurt him/her?*
Bears grudges or unforgiving of insults/slights.

0 [] No

1 [] Yes

9 [] Unknown

1.e) *...seem to believe it is best not to let other people know much about him/her?*

Reluctant to confide in others because of unwarranted fear that information will be used against him/her.

0 [] No

1 [] Yes

9 [] Unknown

1.f) *...often get angry about being insulted or slighted?*

Easily slighted, quick to react with anger or counterattack.

0 [] No

1 [] Yes

9 [] Unknown

1.g) *...seem to be a jealous person?*

Ever suspected that his/her spouse/partner was unfaithful? Questions, without justification, fidelity of spouse or sexual partner.

0 [] No

1 [] Yes

9 [] Unknown

SCHIZOID PERSONALITY

2. *Does he/she...*

2.a) *...seem not to want or enjoy close relationships, like with family or friends?*

Neither desires nor enjoys close relationships, including family.

0 [] No

1 [] Yes

9 [] Unknown

2.b) *...prefer to do things alone rather than with other people?*

Almost always chooses solitary activities.

0 [] No

1 [] Yes

9 [] Unknown

2.c) *...hardly ever seem to have strong feelings, like being very angry or very happy?*

Rarely, if ever, claims or appears to experience strong emotions, anger/joy.

0 [] No

1 [] Yes

9 [] Unknown

2.d) *...seem uninterested in being sexually involved with another person?*

Little if any desire to have sexual experiences with another person (age taken into account).

0 [] No

1 [] Yes

9 [] Unknown

2.e) *...seem not to care if people praise or criticize him/her?*

Indifferent to praise and criticism from others.

0 [] No

1 [] Yes

9 [] Unknown

2.f) *...have no one to be really close to or confide in, or just one person, outside of the immediate family?*

No close friends or confidants, or only one, other than first-degree relatives.

0 [] No

1 [] Yes

9 [] Unknown

2.g) *...act cold or distant, hardly ever smile or nod back at people?*

Constricted affect, aloof, cold, rarely reciprocates gestures or expressions.

0 [] No

1 [] Yes

9 [] Unknown

SCHIZOTYPAL PERSONALITY

3. *Does he/she...*

3.a) *...wonder if people talking to each other are talking about him/her? Say that a common event or object is a special sign for him/her?*

Ideas of reference (not delusions of reference).

0 [] No

1 [] Yes

9 [] Unknown

3.b) *...often act nervous in a group of unfamiliar people?*

Excessive social anxiety.

0 [] No

1 [] Yes

9 [] Unknown

3.c) *...reports experiences with the supernatural? Believe in astrology, seeing the future, UFOs, ESP or a "sixth sense"?*

Odd beliefs or magical thinking, influencing behavior and inconsistent with subcultural norms.

0 [] No

1 [] Yes

9 [] Unknown

3.d) *...mistake objects or shadows for people, or noises for voices? Have a sense that some invisible person or force is around? See faces change before his/her eyes?*

Unusual perceptual experiences.

0 [] No

1 [] Yes

9 [] Unknown

3.e) *...behave in odd or eccentric ways? Look peculiar or untidy, have unusual mannerisms, talk to him/herself?*

Odd, eccentric, peculiar behavior or appearance.

0 [] No

1 [] Yes

9 [] Unknown

3.f) *...sometimes make it hard to follow what he/she is saying? Ramble off the subject, talk in vague or abstract terms?*

Odd speech (without loosened associations or incoherence).

0 [] No

1 [] Yes

9 [] Unknown

3.g) *...sometimes act silly, not in keeping with the situation? Or tend not to show any feelings in response to people?*

Inappropriate or constricted affect (e.g., silly or aloof).

0 [] No

1 [] Yes

9 [] Unknown

INTERVIEWER: If any **YES** to any Personality Disorders, ask the following questions (to be used for research, not diagnosis).

IMPAIRMENT DISTRESS

4. *Does he/she have problems because of this behavior or thinking or feeling-either with the family or socially, or at work or school?*

Significant social or occupational impairment.

0 No

1 Yes

9 Unknown

5. *Does this behavior or thinking or feeling cause the person unhappiness?*

Significant subjective distress.

0 No

1 Yes

9 Unknown

6. Interviewer judgement on reliability of this information:

1 Good

2 Fair

3 Poor

Protocol source: <https://www.phenxtoolkit.org/protocols/view/660701>