PhenX Toolkit

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.

Social Networks – Important Matters

1. From time to time, most people discuss IMPORTANT MATTERS with other people, and we need people we can depend on for help. These can be family, friends, people who have been really helpful to you—what we are interested in are the ones that you are most likely to talk to about **really** important matters in your life, whether they live near you or far away.

Who are the people in your life with whom you discuss important matters? Who are the people you can really count on?

► RECORD NAMES ON NETWORK FORM

2. Is there anyone who always wants to talk to you about your important matters in your life whether you want them to or not?

► RECORD NAMES ON NETWORK FORM

3. Are there people who are, in general, a burden to you, because they want to discuss matters important to them, even if you dont?

► RECORD NAMES ON NETWORK FORM

4. Have there been any important changes in this recently? In other words, were there people whom you used to discuss important matters with that you would not or no longer talk to about such things? These could be people whom you no longer feel close to, who might have moved or died.

Who are they?

► RECORD NAMES ON NETWORK FORM

Social Networks – Health

5. Im interested in the people in your life that you talk to about health problems when they come up. Who are the people that you discuss your health with or you

can really count on when you have physical or emotional problems?

6. Who are the people, whether or not you have mentioned them before, who are always talking about <u>your</u> mental and physical health and trying to get you to do things about them?

7. Are there people who are, in general, a burden to you because of <u>their</u> emotional or physical health problems and always want to talk to you about their problems, whether you want them to or not?

8. Have there been any important changes in any of these lists? In other words, were there people whom you used to discuss health issues with or that you would rely on for help that you would not or no longer talk to about such things? These could be people whom you no longer feel close to, who might have moved or died.

Network Recording Form

2) From which name generator was this person mentioned?

CODES: I = Important Matters H = Health B = Both

3) Which name generator section? ► **Circle all that apply**

CODES: 1 2 3 4 5 6 7 8

6) How are you connected to this person? ► **USE CARD A; RECORD ALL THAT APPLY**

7) How close are you to this person?

CODES: 1 = Very close 2 = Sort of close 3 = Not very close

8) How often do you see or talk to the person?

CODES: 1 = Often 2 = Occasionally 3 = Hardly ever

9) Do they trust doctors to take care of peoples problems?

CODES: 1 = A lot 2 = Most of the time 3 = Not very much 8 = Dont know/unsure

10) Has this person done any of the following for you or helped you out?

► HAND FUNCTION CARD B; RECORD ALL THAT APPLY…. PROBE: WHAT ELSE?

11) Does this person hassle you, cause you problems, or make your life difficult?

CODES: 1 = A lot 2 = Sometimes 3 = No/Not really

1) Full Name, Initials, Other Identifiers	2) Name Generator	3) Section – Name Generator	4) M F	5) Age	6) Connection	7) How Close	8) Contact	9) Trust Docs?	10) Function	11) Cause Problems
#1	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#2	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#3	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#4	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#5	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#6	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#7	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#8	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#9	I H B	1 2 3 4 5 6	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3

		7 8								
#10	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#11	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#12	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#13	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#14	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#15	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#16	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#17	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#18	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#19	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3
#20	I H B	1 2 3 4 5 6 7 8	M F			1 2 3	1 2 3	1 2 3	1 2 3 4 5	1 2 3

Density Matrix

Please think about the relations between these people you told me about earlier.

Some of them may be total strangers in the sense that they wouldnt recognize one another if they bumped into each other on the street.

Others may know each other a bit, or they may be especially close.

First, think about (1) and (2).

How close are they to one another:

> 1 = Very close
> 2 = Sort of close
> 3 = Not very close
> 4 = Dont know each other
> 8 = I dont know

	2	3	4	5	6	7	8	9	10
1	___	___	___	___	___	___	___	___	___
2		___	___	___	___	___	___	___	___
3			___	___	___	___	___	___	___
4				___	___	___	___	___	___
5					___	___	___	___	___
6						___	___	___	___

7						___	___	___
8							___	___
9								___

CARD
A

1	=	Spouse/partner
2	=	Parent
3	=	Brother/sister (including stepbrothers and sisters)
4	=	Child
5	=	Grandparent
6	=	Grandchild
7	=	Aunt or uncle
8	=	In-law
9	=	Other relative
10	=	Coworker or colleague
11	=	Neighbor

12   **=**   **Friend**

13   **=**   **Boss, employer, teacher**

14   **=**   **Employee**

15   **=**   **Fellow student (goes/went to school together)**

16   **=**   **Lawyer**

17   **=**   **Doctor**

18   **=**   **Other medical person**

19   **=**   **Counselor or mental health therapist**

20   **=**   **Priest, minister, rabbi**

21   **=**   **Fellow church member**

22   **=**   **Belongs to same club or social group**

23   **=**   **Do leisure activities with**

CARD B

What does/did this person do for you?

1. **Listen to you when you were feeling down or upset?**
2. **Tell you they care about what happens to you?**
3. **Give you suggestions when you have a problem about what you could do, where you could go, or whom you could talk to?**
4. **Try to help you with daily chores, like shopping for food, cooking,**

fixing things, cleaning your apartment/house, or taking you places that you need to go?

5. **Help out when you are short of money by giving or loaning you money?**

Scoring Instructions

Size of Social Network: Add up the number of individuals mentioned in Important Matters (IM) (Item A1) alone, Health Networks (HN) (Item B5) alone, or combined for Overall Network (ON). Recent research (Perry & Pescosolido, 2010) suggests that influence may be specific (e.g., health matters affect health outcomes).

Density = number of cells in density matrix scored 1–3 divided by the total number of filled-in cells in the density matrix. This measure provides a measure of the tightness or interconnectedness of the respondents network. This can be computed for the total network or separately for the IM and HN.

Composition of Social Network: typical computed variables include percentage kin, percentage female, percentage similar age, percentage coworkers, percentage neighbor. Each of these can be constructed on the basis of IM or HN alone or the combined ON. Similar variables can be constructed for Functionality (column 1) and Problem (column 11) on the Network Recording Form.

To get a sense of the "tightness of the network," four measures can be computed:

1) Density

2) Averaged Closeness – Information from column 7 is added and divided by the number of ties (reverse code before averaging for variables to indicate greater closeness).

3) Frequency of Contact – Constructed variables include percentage seen often on the average frequency, constructed and recoded as indicated for Average Closeness.

4) Interactive Terms – Both social network theory and research (Pescosolido, Brooks-Gardner, & Lubell, 1998; Pescosolido, Wright, Alegria, & Vera, 1998) suggest that structural network variables may have interactive effects on outcomes (e.g., size x closeness). However, caution must be exercised in the construction and interpretation of these variables (see cites above for more information and sample coding).