

## 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.

### Global Functioning: Social Scale (GF: Social)

Current _____	Lowest Past Year _____	Highest Past Year _____
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Check here if this is a retrospective rating.

#### Superior social/interpersonal functioning

- 10 Superior functioning in a wide range of social and interpersonal activities. Frequently seeks out others and has multiple satisfying interpersonal relationships, including multiple close and casual friends. Is sought out by others because of his or her many positive qualities. Age-appropriate involvement in intimate relationships.

#### Above average social/interpersonal functioning

- 9 Good functioning in all social areas, and interpersonally effective. Interested and involved in a wide range of social and interpersonal activities, including both close and casual friends. Age-appropriate involvement in intimate relationships. No more than everyday interpersonal problems or concerns (e.g., an occasional argument with spouse, girlfriend/boyfriend, friends, coworkers, or classmates). Able to resolve such conflicts appropriately.

#### Good social/interpersonal functioning

- 8 Some transient mild impairment in social functioning.

Mild social impairment is present, but transient and expectable reactions to psychosocial stressors (e.g., after minor arguments with spouse, girlfriend/boyfriend, friends, coworkers, or classmates). Has some meaningful interpersonal relationships with peers (casual and close friends), and/or age-appropriate intimate relationships. Infrequent interpersonal conflict with peers.

Mild problems in social/interpersonal functioning

- 7 Some persistent mild difficulty in social functioning.

Mild impairment present that is NOT just expectable reaction to psychosocial stressors (e.g., mild conflicts with peers, coworkers or classmates; difficulty resolving conflicts appropriately). Has some meaningful interpersonal relationships with peers (casual and/or close friends). Some difficulty developing or maintaining age-appropriate intimate relationships (e.g., multiple short-term relationships).

Moderate impairment in social/interpersonal functioning

- 6 Moderate impairment in social functioning.

Moderate impairment present (e.g., few close friends; significant but intermittent conflicts with peers, coworkers, or classmates). Moderate difficulty developing age-appropriate intimate relationships (e.g., infrequent dating). Occasionally seeks out others but will respond if invited by others to participate in an activity.

Serious impairment in social/interpersonal functioning

- 5 Serious impairment in social functioning.

No close friends or intimate partner but has some casual social contacts (e.g., acquaintances, school/work friends only). Rarely seeks out others. Occasional combative or verbally argumentative behavior with peers. Beginning to withdraw from family members (e.g., does not initiate conversation with family, but will respond if addressed).

## Major impairment in social and interpersonal functioning

### 4 Major impairment in social functioning.

Serious impairment in relationships with friends or peers (e.g., very few or no friends, frequent conflicts with friends, or frequently avoids friends). Frequent combative or verbally argumentative behavior with peers. Infrequent contact with family members (e.g., sometimes does not respond to family or avoids family members).

## Marginal ability to function socially

### 3 Marginal ability to function socially or maintain interpersonal relationships.

Frequently alone and socially isolated. Serious impairment in relationships with all peers, including acquaintances. Few interactions with family members (e.g., often alone in room). Serious impairment in communication with others (e.g., avoids participating in most social activities).

## Inability to function socially

### 2 Unable to function socially or to maintain any interpersonal relationships.

Typically alone and socially isolated. Rarely leaves home. Rarely answers the phone or the door. Rarely participates in interactions with others at home or in other settings (e.g., work, school).

## Extreme social isolation

### 1 Extreme social isolation.

No social or family member contact at all. Does not leave home. Refuses to answer the phone or door.

Please rate the patient's most impaired level of social functioning for the specified time period by selecting the "lowest" level which describes his/her functioning within that time frame. For "current," rate most impaired level of functioning in the "past month." Rate actual functioning regardless of etiology of social

problems.

Note: The emphasis is on social contact/interactions with people other than family members, unless these are the only interpersonal contacts a person has (e.g., the lower end of the scale). Also note that ratings of intimate relationships are secondary to the rating of primary friendships and should take into account the age of the individual. For example, older individuals may be expected to have intimate relationships involving steady dating, cohabitation, or marriage, whereas younger individuals may be expected to have only romantic interests (i.e., flirtations or crushes) or close friendships.

### **Global Functioning: Social Scale Prompts**

Specific questions to aid in rating the GF: Social scale are provided below. Be sure to assess for changes in social functioning over the previous year (to rate highest and lowest) as well as current functioning in the past month.

1. Tell me about your social life. Do you have friends?
2. Are they casual or close friends? If only casual-are they school or work friends only? If close-how long have you been close friends?
3. How often do you see friends? Do you see them outside of work/school? When was the “last time” you saw one of your friends outside of work/school? (Attempt to determine “actual” amount of social contact vs. perceived amount of social contact.)
4. Do you usually initiate contact or activities with friends or do they typically call or invite you? Do you ever avoid contact with friends?
5. Do you ever have problems/falling outs with friends? Arguments or fights?
6. Are you dating or interested in dating? (Alter as needed to assess age-appropriate intimate relationships.)
7. Do you spend time with family members (at home)? How often do you communicate with them? Do you ever avoid contact with family members?

### **Global Functioning: Role Scale (GF: Role)**

Current _____	Lowest Past Year _____	Highest Past Year _____
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Check here if this is a retrospective rating.

### Superior role functioning

- 10 Independently maintains superior functioning in demanding roles. Obtains only superior performance evaluations at competitive work placement. Obtains all A's in mainstream school. Generates, organizes, and completes all homemaking tasks with ease.

### Above-average role functioning

- 9 Independently maintains very good functioning in demanding roles. Rarely absent or unable to perform. Obtains good-to-superior performance evaluations at competitive work placement. Obtains grades in A and B range in all courses in mainstream school. Generates, organizes, and completes all homemaking tasks.

### Good role functioning

- 8 Independently maintains good role functioning in demanding roles. Occasionally falls behind on tasks but always catches up; obtains satisfactory performance evaluations at competitive work placement; obtains grades of C and above in mainstream school; occasional difficulty generating or organizing homemaking tasks; or maintains above-average performance with minimal support (e.g., tutoring, reduced academic course load at 4-year university, attends community college, may receive additional guidance at work less than 1-2 times a week). Receives A's and B's, good work/school evaluations, and completes all tasks with this level of support.

### Mild impairment in role functioning

- 7 Mildly impaired functioning in demanding roles independently. Frequently behind on tasks or unable to perform; frequently obtains poor performance evaluations at competitive work placement or grades of D's or better in mainstream school; frequent difficulty generating or organizing homemaking tasks; or maintains good performance with minimal support (e.g., minimal accommodations in general education classroom, receives additional guidance/support at work 1-2 times a week). Receives C's or higher, satisfactory work/school evaluations, and completes most

homemaking tasks with this level of support.

#### Moderate impairment in role functioning

- 6 Moderate impairment independently. May receive occasional F in mainstream courses, persistently poor performance evaluations at competitive work placement; may change jobs because of poor performance, persistent difficulty generating, or organizing homemaking tasks; or requires partial support (some resource or special education courses, receives guidance/support at work 2 times per week). May require less demanding or part-time jobs and/or some supervision in home environment but functions well or adequately given these supports (may fall behind but eventually completes assigned tasks, obtains satisfactory evaluations at work or passing grades in school).

#### Serious Impairment in Role Functioning

- 5 Serious impairment independently. Failing multiple courses in mainstream school, may lose job, or unable to complete most homemaking tasks independently; or in entirely special education classes, requires less demanding job/daily support or guidance, may require vocational rehabilitation, and/or some supervision in home environment but maintains “above average” performance-receives A’s and B’s, good evaluations at work/school, completes all tasks.

#### Major impairment in social and interpersonal functioning

- 4 Very serious impairment independently. All F’s in mainstream school or failing out of school; cannot obtain or hold independent job or unable to complete virtually any homemaking tasks independently; or adequate to good functioning with major support. Requires assisted work environment, entirely special education classes, nonpublic or psychiatric school, home schooling for the purpose of a supportive school environment, and/or supported home environment but functions adequately given these supports (may fall behind but completes assigned tasks, obtains satisfactory performance evaluations at work or passing grades).

#### Marginal ability to function

- 3 Impaired functioning with major support. Requires supported work environment, entirely special education classes, nonpublic or psychiatric school, home schooling for the purpose of a supportive school environment, and/or supported home environment but functions poorly despite these supports (persistently behind on tasks, frequently unable to perform, obtains poor performance evaluations at work or fails courses at school).

#### Inability to function

- 2 Disabled but participates in structured activities. On disability or equivalent nonindependent status. Not working for pay, attending classes for grades, or living independently. Spends 5 or more hours a week in structured role-related activities (e.g., residential treatment, volunteering, tutoring, sheltered work programs).

#### Extreme role dysfunction

- 1 Severely disabled. On disability or equivalent nonindependent status. Not working for pay, attending classes for grades, or living independently. Spends fewer than 5 hours a week in structured role-related activities.

Please rate the patient's "lowest" level of functioning in occupational, educational, and/or homemaker roles, as appropriate, within specified time frame. For "current," rate most impaired level of functioning for the "past month." Rate actual functioning regardless of etiology of occupational/educational problems.

Note: This scale emphasizes the level of support provided within the individual's environment and the individual's performance given such support. The term "independently" as used throughout this instrument implies that an individual is functioning at an "age appropriate level" without the assistance of external supports or accommodations. Examples of independent functioning include (1) age-appropriate functioning in a mainstream school without requiring extra help, special

classes, or special accommodations for testing; (2) competitive full-time employment without additional guidance, support, job coaching, or other forms of special assistance; and (3) full-time homemaker responsible for generating, organizing, and pacing of household tasks and activities for a family without additional guidance, support, or supervision.

## Global Functioning: Role Scale Prompts

Be sure to assess for changes in role functioning over the previous year (to rate highest and lowest) as well as current functioning within the past month. Determine and rate functioning for “primary role” setting (work, school, or home) based upon questions below. However, if the subject is engaged in multiple roles, consider total amount of time spent in role-related activities (i.e., part-time school plus part-time work equals full-time role status).

1. How do you spend your time during the day?
2. If currently working:
  - a. Where do you work? What are your job responsibilities?
  - b. How many hours a week do you work?
  - c. How long have you been in your current job? Have you had any recent changes in your job status (e.g., lost job, stopped working, changed position, or workload)?
  - d. Do you usually need assistance or regular supervision at work? How often do you need extra help? Are there any tasks that you are not able to do alone?
  - e. Do you ever have trouble keeping up? Are you able to catch up if you fall behind?
  - f. Have you received any comments (positive or negative) or formal reviews regarding your performance? Have others pointed out things that you have done well or poorly?
3. If currently attending school:
  - a. What type of school do you attend? (general education, nonpublic school, residential/hospital)
  - b. Have you ever been in special education classes or other non-general education classes?
  - c. How long have you been at this school? Have you had any recent changes in your school placement?
  - d. Do you receive any extra help or accommodations in your classes? Do you receive tutoring or extra help in school or after school? Do you receive extra time to take tests or are you able to leave the classroom to take tests in a quiet place?
  - e. Do you have trouble keeping up with your coursework? Are you able to catch up if you fall behind?
  - f. How are your grades? Are you failing any classes?
4. If a homemaker:
  - a. What are your responsibilities around the house or for the family?
  - b. How long have you been in charge of the home?
  - c. How many hours per week do you spend working on household tasks?
  - d. Are you able to keep up with the demands of your household? Do you



- ever fall behind? If so, are you able to catch up or do you need others' help? Are you avoiding any tasks? Do you need regular assistance or supervision for any tasks within the home?
- e. Have you received any comments (positive or negative) regarding your performance? Have others pointed out things that you have done well or poorly?

Protocol source: <https://www.phenxtoolkit.org/protocols/view/661201>