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.

S T E P

1 Obtain accurate measurements When weighing and measuring children, follow procedures that yield accurate measurements and use equipment that is well maintained. For weight and height measurements, refer to the PhenX Height and Weight Measures. (Note: for consistency, this sentence has been modified to reference PhenX measures, instead of the reference in the original protocol)

2 Select the appropriate growth chart Select the growth chart to use based on the age and sex of the child being weighed and measured.

Enter the child's name and the record number, if appropriate.

Use the charts listed below when measuring weight and length of children from **birth up to 2 years of age:**		Use the charts listed below when measuring weight and stature in children and teens aged **2 through 19 years:**
• WHO Weight-for-age		• CDC Weight-for-age
• WHO Length-for-age		• CDC Stature-for-age
• WHO Weight-for-length		• CDC BMI-for-age

3 Record data After selecting the appropriate chart and entering the patient's name and record number, if appropriate, complete the data entry table.

First, record information about factors obtained at the initial visit that influence growth.

• *Enter mother's and father's stature as reported.*

• *Enter the gestational age in weeks. (Omit this step when using the CDC growth charts for children and teens aged 2 to 20 years.)*

The next line is reserved for recording the child's birth data. (Omit this step when using the CDC growth charts for children and teens aged 2 to 20 years.)

• *Enter the date of birth.*

• *Enter birth weight and length.*

• *Add notable comments (e.g., breastfeeding).*

Record information obtained during the current visit.

• *Enter today's date.*

Determine age to the nearest month for infants and children up to 2 years and to the nearest 1/4-year for children aged 2 to 20 years.

• *Enter the child's age.*

• *Enter weight, and length or stature, immediately after taking the measurement.*

• *Add any notable comments (e.g., was not cooperative).*

Example of how to calculate the child's age: To calculate Sam's age, subtract his birth date from the date of the visit or measurement. To subtract, it will be necessary to convert months to days and years to months if either the month or day in the birth data is larger than in the date of measurements. When converting one month to days, subtract 1 from the number of months in the date of measurement, then add 28, 30, or 31, as appropriate, to the number of days. When converting one year to months, subtract 1 from the number of years in the date of measurement, then add 12 to the number of months.

Days à Months		**Months à Year**	
0-15	0	0-1	40
16-31	1	2-4	1/4

Using the guide above, 3 years, 6 months, and 19 days is rounded to 3 years and 7 months. Because age for children over 2 is rounded to the nearest ¼ year, Sam's age is rounded to 3 ½ years	5-7	1/2
	8-10	3/4
	11-12	1

	Year	**Month**	**Day**
Date of Measurement	1998	4	4
Convert one month to days	1998	(-1) 3	(+30) 34
Convert one year to months	(-1) **1997**	(+12) **15**	**34**
Birth Date	1994	9	15
Child's Age	3	6	19

Sam is aged 3 years, 6 months, and 19 days.

4 Calculate BMI when a child is aged 2 to 20 years BMI is calculated using weight and stature measurements, then used to compare a child's weight relative to stature with other children of the same age and sex in the reference population.

• *Using a calculator, hand-held device or software, determine BMI using the calculation below. The Rare Genetic Conditions WG slightly revised the below calculation and added the example.*

BMI = [Weight (kg) ÷ (Stature (cm) x Stature (cm))] x 10,000

Or

BMI = [Weight (lb) ÷ (Stature (in) x Stature (in))] x 703

For example: If an individual's weight is 70kg and their stature is 180cm, then their BMI would be calculated as follows:

BMI = [Weight (kg) ÷ (Stature (cm) x Stature (cm))] x 10,000

BMI = [70 kg ÷ (180 cm x 180 cm)] x 10,000 = [70 ÷ 32,400] x 10,000 = 0.002160 x 10,000 = 21.60

It is necessary to convert the weight and stature measurements to the appropriate decimal value shown in Table 1.

Example: 37 lbs. 4 oz. = 37.25 lbs., 41-1/2 inches = 41.5 in.

Table 1. Decimal Conversions

Fraction	Ounces	Decimal
1/8	2	.125
1/4	4	.25
3/8	6	.375
1/2	8	.5
5/8	10	.625
3/4	12	.75
7/8	14	.875

• *Enter BMI to one place after the decimal point (Example: 15.204 = 15.2).*

For more information and additional resources on calculating BMI, see U*sing the CDC BMI-for-age Growth Charts for Children and Teens Aged 2 to 20 Years* at www.cdc.gov/nccdphp/dnpa/growthcharts/training/modules/module1/text/page1a.htm

5 Plot measurements On the appropriate WHO or CDC growth chart, plot the measurements recorded in the data entry table for the current visit.

• *Find the child's age on the horizontal axis. When plotting weight-for-length, find the length on the horizontal axis. Use a straight edge or right-angle ruler to draw a vertical line up from that point.*

• *Find the appropriate measurement (weight, length, stature, or BMI) on the vertical axis. Use a straight edge or right-angle ruler to draw a horizontal line across from that point until it intersects the vertical line.*

• *Make a small dot where the two lines intersect.*

6 Interpret the plotted measurements The curved lines on the growth chart show selected percentiles that indicate the rank of the child's measurement. For example, when the dot is plotted on the 95th percentile line on the CDC BMI-for-age growth chart, it means that 5 of 100 children (5%) of the same age and sex in the reference population have a higher BMI-for-age.

The WHO growth standard charts use the 2nd and the 98th percentiles as the outer most percentile cutoff values indicating abnormal growth.

The CDC growth reference charts use the 5th and the 95th percentiles as the outermost percentile cutoff values indicating abnormal growth.

Interpret the plotted measurements based on the percentile ranking on the WHO or the CDC growth charts and the percentile cutoff value corresponding to the nutrition indicator shown in the table below. If the percentile rank indicates a nutrition-related health concern, additional monitoring and assessment are recommended.

• *Determine the percentile rank.*

• *Determine if the percentile rank suggests that the anthropometric index is indicative of nutritional risk based on the percentile cutoff value.*

• *Compare today's percentile rank with the rank from previous visits to identify any major shifts in the child's growth pattern and the need for further assessment.*

When transitioning from the WHO growth charts to the CDC growth charts at aged 2 years, a change in growth classification may occur. During this transition, caution should be used in interpreting any changes in classification.

Anthropometric Index	**Percentile Cut-off Values**	**Nutritional Status Indicato**

WHO Growth Charts 2nd and 98th percentiles		
Length-for age	< 2nd	Short stature
Weight-for-length	< 2nd	Low weight-for-length
Weight-for-length	> 98th	High weight-for-length
CDC Growth Charts 5th and 95th percentiles		
BMI-for-age	≥ 95th	Obesity
BMI-for-age	≥ 85th and < 95th	Overweight
BMI-for-age	< 5th	Underweight
Stature-for-age	< 5th	Short stature

Cerebral palsy:

Growth charts are available for indivduals with cerebral palsy at the Life Expectancy Project's website: www.lifeexpectancy.org/articles/NewGrowthCharts.shtml This site contains weight-for-age, height-for-age, and BMI-for-age growth charts, for individuals age 2 to 20 years old. The charts are strafied by gender and the Gross Motor Function Classification System (GMFCS). Additionally, there are separate charts for individuals with a level 5 GMFCS who require a feeding tube and those who do not require a feeding tube.

Note: the proper use of growth charts require an accurate height and weight of the individual. The Rare Genetic Conditions Working Group recommends investigators use the height and weight measures in the PhenX Toolkit, if they do not have an individual's height/weight.

Achondroplasia:

Growth charts are available for individuals with achondroplasia at the Little People

of America's (LPA) Medical Resource Center website. The charts are separated by gender and the age range is 0-18 years (depending upon the feature which is being plotted). There are charts to plot height for age, head circumference, segmental growth, and other measurements. See the "Specific Instructions" section for the Rare Genetic Conditions Working Group's suggestions regarding other measurements.

The growth charts listed below are specific to individuals with achondroplasia. These charts are available via the links below and also on the LPA Medical Resource Center website.

A. [alink[A_Growth_Charts_Achondroplasia_Height_for_Age_Males.pdf|Growth Charts: Achondroplasia Height for Age: Male]]
B. [alink[B_Growth_Charts_Achondroplasia_Height_for_Age_Females.pdf|Growth Charts: Achondroplasia Height for Age: Female]]
C. [alink[C_Growth_Charts_Achondroplasia_Head_Circumference_Males.pdf|Growth Charts: Achondroplasia Head Circumference: Male]]
D. [alink[D_Growth_Charts_Achondroplasia_Head_Circumference_Females.pdf|Growth Charts: Achondroplasia Head Circumference: Female]]
E. [alink[E_Growth_Charts_Achondroplasia_Foramen_Magnum_Size.pdf|Growth Charts: Achondroplasia Foramen Magnum Size]]

Turner Syndrome:

A growth chart for height for age is available from the Abbott Nutrition Health Institute:

images.abbottnutrition.com/ANHI2010/MEDIA/BC%20Decker%20Appendix%20Fig%2047-50%20Turner%20Syndrome.pdf

This chart is for girls with Turner syndrome who are 2-19 years old and have not been receiving hormone therapy.

Duchenne Muscular Dystrophy:

Dr. Nancy West and colleagues have developed growth charts for males with Duchenne muscular dystrophy (DMD). These charts are for weight for age, height for age, and BMI for age and apply to males with DMD who are age 2-12 years, ambulatory, and steroid-naïve. These charts are available in the publication titled: "Patterns of Growth in Ambulatory Males with Duchenne Muscular Dystrophy." Publication details are listed in the "Source" section.