



## 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.

**Adam's forward bend test:** This is a screening test to determine if an individual has scoliosis or signs of scoliosis. While bending forward the individual has their feet together, knees straight, and their arms dangling by their sides. If signs of scoliosis are observed, an x-ray with Cobb technique is recommended. Signs of scoliosis include imbalances in the rib cage (i.e., one side is higher than the other), and other deformities along the back.

Please note: The Adam's forward bend test can also be used to differentiate postural scoliosis from structural scoliosis, since the curvature will disappear on forward bending in postural scoliosis. Additional information on the Adam's forward bend test is available at: U.S. National Library of Medicine, National Institutes of Health MedlinePlus:

<http://www.nlm.nih.gov/medlineplus/ency/imagepages/19465.htm>

### X-ray:

Full-length standing posteroanterior and lateral radiographs of the spine are required in order to assess the degree of curvature (i.e., deformity). These are taken with the patient in a standing position in order to assess the effect of gravity on the deformity. Patients are instructed to remove their shoes, and any lower limb discrepancy is compensated with a shoe lift before the radiograph is taken.

Radiographs are taken with the patient looking straight ahead, legs apart for stability and with their hands on clavicles.

A straight spine has a curve of  $0^{\circ}$ , any curve greater than  $10^{\circ}$  is considered scoliosis. Between  $0^{\circ}$  and  $10^{\circ}$  is considered a curvature which is not true scoliosis.

### Cobb Technique:

Identify the superior and the inferior end vertebrae-the vertebrae with the greatest tilt at the proximal and distal ends of the curve. The angle between them is measured by drawing a line from the top of the superior end vertebra parallel to the upper endplate, and another line from the bottom of the inferior end vertebra

parallel to the lower endplate. Perpendicular lines are then constructed at right angles to the lines along the endplates. The angle formed by the intersection of the perpendicular lines defines the Cobb angle. This angle is then compared to a standard scale in order to determine whether or not the curvature is potentially harmful. Individuals with a straight spine have zero degree curve. Individuals with a curve between 0° and 10° degrees are considered to have a curvature. Individuals with a spine that has a curve of greater than 10° degrees are considered to have scoliosis. Typically surgery is recommended in adolescents with a curve of a Cobb angle of more than 45° to 50° degrees.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/221601>