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.

Acute Chest Syndrome During Pregnancy With Sickle Cell Disease

Past Medical History			
1. Acute chest syndrome		[ ] Yes	[ ] No
1a. If yes: Hospitalization		[ ] Yes	[ ] No
1b. If yes: ICU admission		[ ] Yes	[ ] No
Previous Pregnancy			
2. ACS requiring hospitalization		[ ] Yes	[ ] No
2a. If yes: simple transfusion		[ ] Yes	[ ] No
2b. If yes: exchange transfusion		[ ] Yes	[ ] No
Current Pregnancy			
3. Hyperhemolysis		[ ] Yes	[ ] No
4. Pneumonia (choose only in absence of ACS; if features of ACS, choose ACS) instead		[ ] Yes	[ ] No
5. Acute chest syndrome		[ ] Yes	[ ] No
5a. If yes: # of distinct ACS episodes during current study pregnancy		_____ number	
5b. If yes: GA at 1st event Gestational age in weeks with days as decimal point 12 1/7 = 12.1 12 2/7 = 12.3 12 3/7 = 12.4 12 4/7 = 12.6 12 5/7 = 12.7 12 6/7 = 12.9		_____ week.days	
5c. If yes: ICU admission		[ ] Yes	[ ] No
5d. If yes: ACS during current study pregnancy requiring hospitalization (but **not** ICU care)		[ ] Yes	[ ] No
What clinical features of ACS were present?	Present	Absent	Unknown
5e. Chest Pain	[ ]	[ ]	[ ]
5f. Positive Auscultatory Chest signs	[ ]	[ ]	[ ]
5g. Fever (Temp > 38oC)	[ ]	[ ]	[ ]

5h. Signs of respiratory distress (RR > 20 per minute)	[ ]	[ ]	[ ]
5i . Increase in oxygen requirement/demand	[ ]	[ ]	[ ]
5j. SpO2: < 94% OR drop by 3% below baseline	[ ]	[ ]	[ ]
5k. New radiodensity on chest x-ray (CXR)	[ ]	[ ]	[ ]
Acute Chest Syndrome Diagnosis - The below section should be filled out for all hospitalizations			
6. Was the criteria for diagnosis of acute chest syndrome fulfilled? Criteria for Acute Chest Syndrome: Abnormal finding on lung examination [grunting, flaring, retractions (intercostal, subcostal), audible wheezing without auscultation with stethoscope, difficulty breathing based on visually inspection, pulmonary auscultatory findings] typically evaluated without oxygen supplementation, if possible, with thepresence of at least two of the following criteria: Temperature greater than or equal to 38ºC. Increased respiratory rate greater than the 90th percentile for age. Positive chest pain or pulmonary auscultatory findings increased oxygen requirement (saturation of peripheral oxygen drop by > 3% from a documented steady-state value on room air). New radiodensity on chest roentgenogram.			[ ] Yes [ ] No
7. Did the inpatient care team diagnose acute chest syndrome during hospitalization?			[ ] Yes [ ] No

Protocol source: https://www.phenxtoolkit.org/protocols/view/890601