



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.

1. Have any of your biological mother, sisters, half-sisters, or female first cousins ever had any of the following pregnancy complications?

a. Delivery of a child more than 3 weeks before the expected due date

01 [] Yes

02 [] No

-8 [] Don't know

b. Delivery of a child weighing less than 5 lb 8 oz (or 2500 grams)

01 [] Yes

02 [] No

-8 [] Don't know

c. Spontaneous preterm delivery (<37 weeks)

01 [] Yes

02 [] No

-8 [] Don't know

d. Early or preterm rupture of the membranes

01 [] Yes

02 [] No

-8 [] Don't know

e. Preeclampsia, eclampsia, toxemia, or pregnancy-induced hypertension

01 [] Yes

02 [] No

-8 [] Don't know

f. Induction of labor due to low amniotic fluid or poor fetal growth

01 [] Yes

02 [] No

-8 [] Don't know

g. Stillbirth

01 [] Yes

02 [] No

-8 [] Don't know

h. Delivery of an infant with a birth defect

01 [] Yes

02 [] No

-8 [] Don't know

i. Other pregnancy complication, specify

01 [] Yes

02 [] No

-8 [] Don't know

1. Specify _____

IF YES TO ANY OF THE ABOVE [COMPLETE #2]

IF NO OR DON'T KNOW TO ALL OF THE ABOVE [END]

2. For each family member, tell me the relation and the pregnancy complications.
(Use codes in lists below)

Code Family Relation and up to five pregnancy complications for any family member

a. Family relation code _____

Pregnancy complication 1 _____

Pregnancy complication 2 _____

Pregnancy complication 3 _____

Pregnancy complication 4 _____

Pregnancy complication 5 _____

Other specify pregnancy complication 1 _____

Other specify pregnancy complication 2 _____

b. Family relation code _____

Pregnancy complication 1 _____

Pregnancy complication 2 _____

Pregnancy complication 3 _____

Pregnancy complication 4 _____

Pregnancy complication 5 _____

Other specify pregnancy complication 1 _____

Other specify pregnancy complication 2 _____

c. Family relation code _____

Pregnancy complication 1 _____

Pregnancy complication 2 _____

Pregnancy complication 3 _____

Pregnancy complication 4 _____

Pregnancy complication 5 _____

Other specify pregnancy complication 1 _____

Other specify pregnancy complication 2 _____

d. Family relation code _____

Pregnancy complication 1 _____

Pregnancy complication 2 _____

Pregnancy complication 3 _____

Pregnancy complication 4 _____

Pregnancy complication 5 _____

Other specify pregnancy complication 1 _____

Other specify pregnancy complication 2 _____

e. Family relation code _____

Pregnancy complication 1 _____

Pregnancy complication 2 _____

Pregnancy complication 3 _____

Pregnancy complication 4 _____

Pregnancy complication 5 _____

Other specify pregnancy complication 1 _____

Other specify pregnancy complication 2 _____

Codes for Question #2

Codes for Family Relation to Participant

01 = Participant's mother

02 = Participant's sister/half-sister

03 = Participant's female first cousin, maternal

04 = Participant's female first cousin, paternal

Codes for Pregnancy Complication

01 = Delivery of a child more than 3 weeks before the expected due date

02 = Delivery of a child weighing less than 5 lb 8 oz (or 2500 grams)

03 = Spontaneous preterm delivery (<37 weeks)

04 = Early or preterm rupture of the membranes

05 = Preeclampsia, eclampsia, toxemia or pregnancy induced hypertension

06 = Induction of labor due to low amniotic fluid or poor fetal growth

07 = Stillbirth

08 = Delivery of an infant with a birth defect

09 = Other pregnancy complication (SPECIFY)

Protocol source: <https://www.phenxtoolkit.org/protocols/view/240801>