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.

For each of the following conditions, indicate whether you have ever had the condition or if a doctor has told you that you have the condition. Mark only one response for each. If the condition is still present, mark **P (Present).** If it has been a problem but is no longer a problem, mark **Y (Yes).** Otherwise, mark **N (Never).**

Condition	P	Y	N
Prominent rash on cheeks for more than 1 month	[ ]	[ ]	[ ]
Skin breaks out in the sun (not sunburn)	[ ]	[ ]	[ ]
Sores in mouth for more than 2 weeks	[ ]	[ ]	[ ]
Arthritis or rheumatism for more than 3 months	[ ]	[ ]	[ ]
Pain for more than a few days when taking deep breath (pleurisy)	[ ]	[ ]	[ ]
Protein in urine	[ ]	[ ]	[ ]
Low blood counts (anemia, low white blood cell count, or low platelet count)	[ ]	[ ]	[ ]
If yes or still present Anemia	[ ]	[ ]	[ ]

Hemolytic anemia Low white blood cell count Low platelet count	[ ] [ ] [ ]	[ ] [ ] [ ]	[ ] [ ] [ ]
Idiopathic thrombocytopenia purpura (ITP)	[ ]	[ ]	[ ]
Bruise easily	[ ]	[ ]	[ ]
Positive skin test for tuberculosis (tuberculin, PPD, or TINE test)	[ ]	[ ]	[ ]
Positive blood test for syphilis (VDRL or RPR)	[ ]	[ ]	[ ]
Seizure, convulsion, or fit	[ ]	[ ]	[ ]
Mental illness (requiring hospital admission) or psychosis or hallucinations	[ ]	[ ]	[ ]
Rapid hair loss NOT due to chemotherapy	[ ]	[ ]	[ ]
Mononucleosis (mono)	[ ]	[ ]	[ ]
If yes or still present, age you first had mono			
0 [ ]-[ ] 12 13-[ ] 19 20+			

Condition	P	Y	N
Chronic fatigue	[ ]	[ ]	[ ]
Psoriasis	[ ]	[ ]	[ ]

Scleroderma	[ ]	[ ]	[ ]
Vitiligo	[ ]	[ ]	[ ]
Fever blisters on lips	[ ]	[ ]	[ ]
Poison ivy	[ ]	[ ]	[ ]
Athletes foot	[ ]	[ ]	[ ]
Fibromyalgia	[ ]	[ ]	[ ]
Arthritis	[ ]	[ ]	[ ]
Osteoarthritis	[ ]	[ ]	[ ]
Bunions	[ ]	[ ]	[ ]
Myasthenia gravis	[ ]	[ ]	[ ]
Slow heart beat (less than 50 beats per minute)	[ ]	[ ]	[ ]
Recurrent chest pain	[ ]	[ ]	[ ]
Heart attack	[ ]	[ ]	[ ]
Asthma	[ ]	[ ]	[ ]
Recurrent heart burn	[ ]	[ ]	[ ]

Ulcer (stomach or duodenal)	[ ]	[ ]	[ ]
Recurrent diarrhea	[ ]	[ ]	[ ]
Hemorrhoids (piles)	[ ]	[ ]	[ ]
Jaundice	[ ]	[ ]	[ ]
Appendicitis	[ ]	[ ]	[ ]
Cancer	[ ]	[ ]	[ ]
Kidney stones	[ ]	[ ]	[ ]
Recurrent urinary tract infections	[ ]	[ ]	[ ]

Condition	**P**	**Y**	**N**
Recurrent vaginitis	[ ]	[ ]	[ ]
Depression	[ ]	[ ]	[ ]
Chronic headaches	[ ]	[ ]	[ ]
Anxiety or panic disorder	[ ]	[ ]	[ ]
Carpal tunnel syndrome	[ ]	[ ]	[ ]
Anemia	[ ]	[ ]	[ ]

Pernicious anemia	[ ]	[ ]	[ ]
Diabetes	[ ]	[ ]	[ ]
Thyroid problems	[ ]	[ ]	[ ]
Infertility	[ ]	[ ]	[ ]
Multiple miscarriages	[ ]	[ ]	[ ]
High blood pressure	[ ]	[ ]	[ ]
Phlebitis	[ ]	[ ]	[ ]
Pulmonary embolus	[ ]	[ ]	[ ]
Stroke	[ ]	[ ]	[ ]
Blood clot	[ ]	[ ]	[ ]
Sjögrens syndrome	[ ]	[ ]	[ ]
Dry eyes	[ ]	[ ]	[ ]
Dry mouth	[ ]	[ ]	[ ]
False teeth	[ ]	[ ]	[ ]
Seasonal allergies (or hay fever)	[ ]	[ ]	[ ]

Sinus problems	[ ]	[ ]	[ ]
Graying of all or nearly all hair before 35	[ ]	[ ]	[ ]
Baldness	[ ]	[ ]	[ ]
Varicose veins	[ ]	[ ]	[ ]
Breast implants	[ ]	[ ]	[ ]
Spleen removed	[ ]	[ ]	[ ]

List your familys history of the following diseases. For example, the first row would indicate that you have a history of rheumatoid arthritis. The second row would indicate that Jane Doe, your grandmother on your fathers side, has a history of type 2 diabetes. Use the back of this page if you need more space.

Diseases	
1	Systemic lupus erythematosus (SLE)
2	Rheumatoid arthritis
3	Sjögrens syndrome
4	Discoid lupus
5	Autoimmune thyroid disease (AITD)
6	Type 1 diabetes (Juvenile onset)

7	Type 2 diabetes (Adult onset)
8	Myasthenia gravis
9	Scleroderma
10	Addisons disease
11	Idiopathic thrombocytopenia (ITP)
12	Antiphospholipid syndrome
13	Graying of all hair before age 35
14	Other autoimmune disorder

Relationships	
1	Self
2	Full sibling
3	Half sibling
4	Child
5	Grandchild
Mothers Side	**Fathers Side**

6	Mother	**7**	Mother
8	Aunt	**9**	Aunt
10	Uncle	**11**	Uncle
12	Cousin	**13**	Cousin
14	Grandmother	**15**	Grandmother
16	Grandfather	**17**	Grandfather
18	Other	**19**	Other

Disease	**Relationship**	**Name of Relative** (if not self)
2	1	
7	15	JANE DOE
___ ___	___ ___	
___ ___	___ ___	
___ ___	___ ___	
___ ___	___ ___	
___ ___	___ ___	

____ ____	____ ____	
____ ____	____ ____	
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Protocol source: https://www.phenxtoolkit.org/protocols/view/161401