



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.

How to complete the KPS

1. Nurses, physicians, and patients may complete the KPS scale. Please note that patients ratings are more accurate than clinician ratings.
2. Review KPS scale form.
3. Review medical record to assess presence and extent of specific disease, signs and symptoms.
4. During assessment, observe the patient's subtle dependencies and interactions within the existing support networks.
5. Interview patient and/or family to obtain functional assessment information using questions

The following questions can begin to serve as guidelines and aid in the standardization for increased consistency for determining the performance status of an individual patient.

Evidence of Disease

1. Has there been any weight loss or weight gain?
2. Has there been any reduction in energy or increase in fatigue?

Self-Care

1. Has there been any difficulty grooming or bathing?

Daily Activities

1. Has there been any difficulty in walking or moving around?
2. Has there been any difficulty driving?

Work Difficulty

1. Has there been any difficulty working full or part time?

The information obtained from these questions, the assessment and other medical data should be used to determine a KPS score.

Following the admission assessment, when possible, the same health care provider should administer the scale on subsequent evaluations.

Condition	Performance status %	Comments
Able to carry on normal activity and to work. No special care needed.	100 []	Normal. No complaints. No evidence of disease.
	90 []	Able to carry on normal activity. Minor signs or symptoms of disease.
	80 []	Normal activity with effort. Some signs or symptoms of disease.
Unable to work. Able to live at home and care for most personal needs. A varying degree of assistance is needed.	70 []	Cares for self. Unable to carry on normal activity or to do active work.
	60 []	Requires occasional assistance, but is able to care for most of personal needs.
	50 []	Requires considerable assistance and frequent medical care.
Unable to care for self. Requires equivalent of institutional or	40 []	Disabled. Requires special care and assistance.

hospital care. Disease may be progressing rapidly.	30 []	Severely disabled. Hospital admission is indicated although death is not imminent.
	20 []	Hospitalization necessary. Very sick, active supportive treatment necessary.
	10 []	Moribund; fatal processes progressing rapidly.
	0 []	Dead.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/320601>