



GENERAL INSTRUCTIONS

All patients enrolled in the PALF Cohort study meeting age and language requirements will be assessed for health related quality of life (HRQOL) at 6 months and 12 months after enrollment. A parent/guardian of every patient enrolled in the PALF Cohort study meeting age and language requirements will also complete surveys regarding their child’s quality of life. If the 6 or 12 month visit occurs while a patient is hospitalized, the HRQOL surveys should not be completed at that visit.

Patients and parents/guardians completing the HRQOL surveys must be comfortable speaking either English or Spanish. If a parent/guardian or patient is not comfortable speaking either language, the HRQOL surveys should not be completed. The language version (English or Spanish) with which the child or parent/guardian is most comfortable should be used. The same language does not need to be used to patient and parent/guardian.

The coordinator will administer the appropriate PedsQL™ or PedsQL™ Infant Scales and the PedsQL™ Multidimensional Fatigue scale forms, based on age and language, to the parent and child at both timepoints.

If it is not possible to administer HRQOL assessments to both the patient and the parent/guardian at the follow-up visit, surveys should still be administered to whoever can complete them. The reason for not completing either the patient or parent/guardian surveys should be recorded in the Missed Visit Utility in the Data Management System.

All self-report PedsQL™ surveys should be completed by patients without help from the parent/guardian. Coordinators can read the questions for children who are unable to read.

It is important to note that an individual completing the PedsQL during the summer months may ask how they should complete the questions regarding school function. If they ask, the study coordinator/site psychologist needs to state that if the child has not been in school for the past month, the items should be left blank. However, this should only be stated if the individual inquires.

All questionnaires should be reviewed for completeness at the time the child and parent/guardian complete them. The administration of the HRQOL surveys will take approximately 30 minutes.

Every effort will be made to have patients complete the required assessments at both timepoints, but patients can still complete the 12 month assessment even if the 6 month assessment was not completed.

Refer to the PedsQL™ Administration GuidelinesSM for additional instructions. If there are questions about the PedsQL™, contact Katie Neighbors at Chicago.

HRQOL Testing Surveys with time intervals (age at time of study visit):

For both 6 and 12 Month follow-up visits:

DOMAIN	<2 years	2 years to <5 years	5 years to ≤18 years	
	Parent	Parent	Parent	Child
HRQOL	PedsQL™ Infant Scales (10 min)	PedsQL™ (10 min)	PedsQL™ (10 min)	PedsQL™ (10 min)
HRQOL-Fatigue	--	PedsQL™ Multidimensional Fatigue Scale (5 min)	PedsQL™ Multidimensional Fatigue Scale (5 min)	PedsQL™ Multidimensional Fatigue Scale (5 min)