

## PediHome: A Family-Reported Measure of Pediatric Home Healthcare Quality

# **USER GUIDE**

# **OVERVIEW**

PediHome is a content-valid, family reported survey measure of home healthcare quality for children with medical complexity. PediHome can be used for care delivery evaluation, research, quality improvement, and identifying deficits in care to improve training.

The survey was developed with input from a national multidisciplinary expert panel that included patient-families, pediatricians and other physician specialists, nurses, home healthcare agency staff, and state administrators. The questions were validated with a diverse sample of English-and Spanish-speaking family caregivers (parents) of children with medical complexity.<sup>1</sup>

PediHome's questions are designed to gather a family caregiver's perspective on whether and to what degree their child is receiving accessible, high-quality home healthcare. The questions are framed by the National Academy of Medicine's (NAM) (previously the Institute of Medicine's) 6 quality dimensions: effectiveness, safety, patient-centeredness, timeliness, equity, and efficiency.<sup>2</sup> PediHome was designed to evaluate long-term home healthcare services and does not assess visiting nursing or other intermittent home healthcare.

PediHome is structured with an initial screener question to determine what types of home healthcare a child receives, followed by question-blocks that are based on 2 broad levels of clinical care:

- 1) Private duty nursing (home nursing) care provided by registered nurse (RN) or licensed practical nurse (LPN) who can administer complex medication regimens and manage medical devices and,
- Certified nursing assistant (CNA) and home health aides/personal care aides which, at minimum, can perform support for activities of daily living and simple monitoring.

<sup>&</sup>lt;sup>1</sup> Foster C et al. Acad Pediatr, 2022

<sup>&</sup>lt;sup>2</sup> Institute of Medicine, Crossing the Quality Chasm, 2001

The survey is phrased to ask about the last month (30 days of care), so it can be used as a onetime cross-sectional measurement or repeated longitudinally over time to assess for improvements in how a particular child is experience care or how a program or agency is improving care.

# DEFINITIONS

#### Children with medical complexity

Children with medical complexity were defined by the Cohen et al framework, as children with one more complex chronic condition(s) who often have functional impairment and medical technology use.<sup>3</sup>

#### Certified nursing assistant (CNA)

A certified nursing assistant (CNA) is a non-family member paid to help your child on a routine basis at your home and possibly at school and other community locations, for ongoing chronic illnesses. A CNA cannot do the same level of care as a RN or LPN, but can still help with getting dressed, changing bandages, and measuring vital signs.

#### Home health aide

A home health aide - also called a home attendant, personal care aide, or caregiver assistant - is a non-family member paid to help your child with activities of daily living such as getting dressed, bathing, or similar activities, at home and possibly at school and other community locations.

#### Home healthcare

Home healthcare is a range of services and supplies delivered in the home for individuals with disabilities, chronic conditions, and functional impairments to support living outside of healthcare facilities (i.e., community-based settings).<sup>4</sup>

#### Home nurse

A "home nurse" or "shift nurse" or "private duty nurse" is either a registered nurse (RN) or licensed practical nurse (LPN) who provides medical care on a routine basis at your home and possibly at school and other community locations, for ongoing chronic illnesses. Examples of tasks a home nurse might do include giving medications and administering feedings. Home nurses care for your child at home, not at a facility.

<sup>&</sup>lt;sup>3</sup> E Cohen, et al. Pediatrics, 2011

<sup>&</sup>lt;sup>4</sup> CC Foster, et al. Home Healthc, 2020

# **COPYRIGHT INFORMATION**

PediHome is publicly available in English and Spanish. The survey items are free to download on <u>fosterhealthlab.com</u> after completion of a brief survey to ensure understanding of copyright information. Future survey revisions may occur and will be updated on the website as further validation is assessed.

PediHome survey language is covered by an open access publication [Creative Commons Attribution-NonCommercial-NoDerivs (CC BY-NC-ND)] and can be used for non-commercial purposes only and must credit the author(s): Foster C, Kaat AJ, Shaunfield S, et al. PediHome: Development of a Family-Reported Measure of Pediatric Home Healthcare Quality. *Acad Pediatr.* Apr 16 2022;doi:10.1016/j.acap.2022.04.004. PMID: 35439604

More information regarding copyright can be found on the publisher's website.

## **INSTRUCTIONS ON USE**

The items can be administered via paper, REDCap (Research Electronic Data Capture), or Qualtrics survey tools

Based on the family caregiver's responses to the screener questions about which type of home healthcare providers care for their child, they are prompted to answer questions about access to and quality of care based on the relevant provide types.

If the survey will be used in a scenario where it is already known what type of home healthcare provider(s) the child has used, it is acceptable to remove the screener questions to reduce the survey length. However, we caution that this may impact the electronic survey skip logic, and that the question blocks do not provide definitions for the families for what is meant by a home nurse, CNA, or home health/aide. We would recommend the survey definitions be included somewhere in the survey administration to ensure the respondents understand what type of provider they are responding about given the terminology varies nationally.

Please also be aware that the electronic versions of the survey have logic embedded in them to ensure certain responses. For example, a parent cannot report a child received care more than 168 hours in a week (24/7). However, none of the surveys can check that a child's hours of care *received* is less than or equal to hours *approved*. As a result, we recommend you review the hour-based data for accuracy. If there are alternative means to obtain hours of care received versus approved (e.g., claims/orders), we recommend those for additional validation.

The electronic versions also have different defaults for requiring responses (i.e., "forced response") which can be altered based on your survey needs.

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#### Paper

Visit fosterhealthlab.com to download PediHome in English and Spanish, including:

- PediHome Survey Screener Questions to determine the provider type used by the child
- PediHome Home Nurse Questions to be administered if child had home nursing care
- PediHome CNA Questions to be administered if a child had a CNA and/or home health aide/personal care aide.

### REDCap

English and Spanish versions of PediHome can be imported into REDCap.

- 1. Go to <u>fosterhealthlab.com</u>
- 2. Download the REDCap ZIP file
- 3. Open your REDCap program and create a new project.
- 4. Go to Online Designer.
- 5. Under Data Collection Instruments click Upload:

| Data Collection Instruments  |
|--|
| + Create a new instrument from scratch   |
| a new instrument from the official <u>REDCap Instrument Library</u> 2              |
| LUpload instrument ZIP file from another project/user or <u>external libraries</u> |

- 6. Open the downloaded ZIP file.
- 7. The PediHome Survey is now ready for use in both English and Spanish.

Note: The English version of the PediHome survey also can be found in the REDCap shared library. To import the survey into your project please follow the steps below.

- 1. Open your REDCap program and create a new project.
- 2. Go to Online Designer.
- 3. Under Data Collection Instruments click Import:

#### **Data Collection Instruments**

Create a new instrument from scratch
Import a new instrument from the official <u>REDCap Instrument Library</u>
Upload instrument ZIP file from another project/user or <u>external libraries</u>

- 4. Search "PediHome Survey English".
- 5. Select "Import into my REDCap Project."
- 6. Accept the Terms and Conditions, and PediHome Survey English is now ready for use.

#### **Qualtrics**

Import English or Spanish versions of PediHome into your Qualtrics account:

- 1. Go to Foster Health Lab Website
- 2. Download the QSF file for the English or Spanish version.
- 3. Open your Qualtrics program and click on "Create a New Project."
- 4. Select "Survey" and then select "Get Started."
- 5. Name your survey and then select "Import a QSF file."
- 6. Open the downloaded QSF file.
- 7. The PediHome Survey is now ready for use.

| Create a new project                   |   |
|--|---|
| Survey                                 |   |
|  |   |
| Name                                   |   |
| Untitled project                       |   |
| How do you want to start your survey?  |   |
| Create a blank survey project          | ^ |
| Create a blank survey project          |   |
| Import a QSF file                      |   |
| Copy a survey from an existing project |   |
|  |   |

Use a survey from your library

## **CONTACT INFORMATION**

If you have any questions or identify logic problems or errors in the survey materials, please reach out to the primary investigator, Dr. Carolyn Foster: <u>ccfoster@luriechildrens.org</u>.

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