## Manual Cough Assist (“Heimlich” style maneuver)

Frequency of Use:

Daily

Weekly

As needed

Other, specify:

* + 1. If Daily, times per day (on average):

< 1 time/day

1-2 times/day

3 or more times

Settings: Time per session (min):

## Respiratory Support/Assisted Ventilation Devices

1. Device brand, specify:
2. Device model, specify:

Non-invasive, positive pressure (check all that apply)

Nasal mask

Nasal cannula/pillows

Oral interface

Oronasal interface

Other, specify:

Date of Initiation of non-invasive, positive pressure (yyyy-mm-dd):

Age at initiation (Years [Derived variable, use Date of Birth from Demographics form]):

Non-invasive, negative pressure (specify below)

Cuirass

Porta-Lung

Rocking Bed

Pneumobelt

Other, specify:

Date of Initiation of non-invasive, negative pressure (yyyy-mm-dd):

Age at initiation (Years [Derived variable, use Date of Birth from Demographics form]):

Invasive with Tracheostomy tube

Date of Tracheostomy (yyyy-mm-dd):

Brand/Style:

Size mm ID:

Length mm:

Cuffed?

Yes

No

If Yes, Inflation/Deflation Timing:

Inflated 24 hour/ day

Deflated 24 hour/ day

Inflated during night, deflated during the day

Other, specify:

Other, specify:

1. Ventilation mode:

Bilevel positive pressure

Spontaneous breathing with Timed backup (ST)

Average Volume Assured Pressure support (AVAPS)

Spontaneous (S)

Timed (T)

Automatic Servo Ventilation (Auto SV)

Assist Control

Pressure Control

Volume Control

SIMV with Pressure Support

Pressure Control

Volume Control

Negative Pressure:

Other, specify:

1. Ventilation Measurements

Table 1 Ventilation Measurements

| Settings | Respiratory Rate  (breaths per minute) | IPAP/PIP (cm H20) | PEEP/EPAP (cm H20) | Tidal Volume (mL) | Pressure Support (change above PEEP) (cm H20) | Supplemental Oxygen (L per minute) |
| --- | --- | --- | --- | --- | --- | --- |
| Asleep  Awake  (record only if different from asleep settings) | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site |
| Asleep  Awake  (record only if different from asleep settings) | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site | Data to be entered by site |

1. Frequency of Use:

Daily

As needed

1. Schedule of Use:

Hours per day:

Night (during sleep)

Intermittent Day time and continuous at night

Continuous

Intermittent with acute illnesses

## Oxygen

1. Method of Administration:

Trach collar

Nasal Cannula

Trans tracheal O2

Bipap or Ventilator

Face mask

Other, specify:

1. Flow Rate (L/minute):
2. Frequency of Use:

Daily (continuously or intermittent)

As needed

Schedule of Use:

Intermittent

Continuous

Hours per day:

1. Other relevant therapies for respiratory system (e.g. physical therapy related to respiration, aquatic therapy):

## General Instructions

This CRF contains data that would be collected when a pulmonary study is performed studying gas exchange.

Important note: None of the data elements included on this CRF Module are classified as Core (i.e., required for neuromuscular disease clinical studies to collect.) All data elements are classified as Supplemental (i.e., non-Core) and should only be collected if the research team considers them appropriate for their study. Please see the Data Dictionary for element classifications.

## Specific Instructions

Please see the Data Dictionary for definitions for each of the data elements included in this CRF Module.