## 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.