Sustain Follow-up Data Collection Form
(Revised 2/4/2014)
(both pediatric and adult elements)

Patient Information

Visit Date ▼ ▼ ▼ (Please select) ▼
Patient Birth Date ▼ ▼ ▼ (Please select) ▼
Gender ▼ (please select) ▼

What is the nature of this follow-up?
(check all that apply)
- □ Routine or uncomplicated outpatient visit
  (including telephone contact, update, or other demographic updates)
- □ Outpatient visit with morbidity
- □ Patient hospitalized
- □ Patient expired
- □ Patient discontinued therapy not due to morbidity or mortality

Discontinuation of Home PN

Was Home PN Discontinued for this patient since last recorded visit? □ Yes □ No

Date PN Discontinued ▼ ▼ ▼ (Please select) ▼
Reason PN Discontinued □ Patient transitioned to oral diet
□ Patient transitioned to enteral nutrition
□ Patient had small bowel transplant
□ Patient had surgery to restore intestinal continuity
□ Patient converted to IV fluids
□ Patient completed PN therapy course
□ Patient placed on hospice care
□ Patient wishes to discontinue
□ Loss of vascular access
□ Patient Expired
□ Patient hospitalized
Lost to followup
☐  Other

**Restart Home PN**

Was Home PN Restarted for this patient since last recorded visit?  ☐  Yes  ☐  No

Restart Home PN Date  

**Morbidity**

In what setting was the patient treated? (check all that apply)

☐  Treated as outpatient
☐  Treated in Emergency department or short stay unit
☐  Hospitalized

Date of Admission to Hospital  

Has patient been discharged on Home PN?  ☐  Yes  ☐  No

Date of discharge on Home PN  

What was the main cause of morbidity? (check one primary reason)

☐  **HPN Related Issue** (check all that apply)

☐  Catheter related

☐  Central Line Bloodstream Infection

Was catheter removed?  ☐  Yes  ☐  No

Was patient given antibiotics for this infection?  ☐  Yes  ☐  No

Type of organism  (please select)

Did patient have skin or pocket infection?  ☐  Yes  ☐  No

☐  Thrombosis/Occlusion

Was catheter removed?  ☐  Yes  ☐  No

Anticoagulation regimen?  ☐  Yes  ☐  No  Please describe:

Other treatment for occlusion?  ☐  Yes  ☐  No - Please describe:

☐  Incorrect position (ex. Outgrown)

☐  Damage (leak, crack, broken)

☐  Other

If catheter was removed, was another central line placed for PN?  ☐  Yes  ☐  No
Type of catheter placed:
- PICC
- Port
- Tunneled
- Other

Lumen:
- Single Lumen
- Double Lumen
- Triple Lumen

Date new catheter placed: [ ] [ ] (Please select)

Metabolic Issues (check all that apply)
- Dehydration
- Electrolyte imbalance
- Hyperglycemia
- Liver failure
- CHF
- Renal insufficiency
- Other

Non-HPN Related but Related to Indication for HPN (check 1 primary reason)
- Bowel Rest
- Enteritis/Colitis
- Chemotherapy
- Infectious
  - C. diff
  - Diverticulitis, non-obstructing
  - Giardia
  - Viral
  - Other - Please specify: [ ]
- Inflammatory
  - Crohns
  - Graft vs. Host
  - Ischemia bowel/Intestinal angina
  - Necrotizing Enterocolitis (NEC)
  - Non-specific enteritis/colitis
- Celiac disease
- Congenital Malabsorption
- Cystic fibrosis
- Idiopathic
- Pancreatic insufficiency
- Scleroderma
- Other Please specify:

Obstruction

- Malignant
  - GYN
  - GI
  - Other Please specify:

- Benign
  - Adhesive
  - Stricture
    - Crohn's disease
    - Radiation
    - Diverticulitis
    - Other

Short Bowel Syndrome - Non fistulous in origin

- Bowel resection
- Crohn's disease
- Radiation
- Other: Please specify:

Small bowel stoma

- Yes
- No

Where is stoma?

- Jejunum
- Ileum
- Duodenum
- Don't know

Colonic stoma

- Yes
- No

Large bowel in continuity with small bowel

- Yes
- No

Ileo-cecal valve present

- Yes
- No

Length of remaining small bowel in continuity cm (current or last known measurement)

Measurement date 2003
Length of remaining large bowel in continuity
- Less than 50%
- Greater than 50%

Bowel measurement technique (before any lengthening procedure):
- At time of surgery
- Radiographically
- Estimated

History of bowel lengthening surgical procedure
- Yes
- No

Operative procedure used:
- STEP
- Non-STEP lengthening procedure
- Don’t know

Length prior to lengthening surgery: cm
Length after lengthening surgery: cm

Enteral Nutrition Failure
- Inability to place EN tube
- Refusal of EN tube
- Inability to tolerate EN

Post-operative Surgical Complications
- Chyle Leak
- Anastomotic Leak
- Bowel perforation
- Abdominal abscess

Not Related to HPN or Indication for HPN

Mortality

- Check here if patient expired

Is date of death known?
- Yes
- No

Date of Death: (Please select)
Approximate Date of Death: (Please select)

Approximate Date of Death is 6/15/YYYY if only the year is known.

Source of Mortality Information
- Family/caregiver
- Clinician/Healthcare Professional
- Public Records

Primary Cause of Death (select primary reason)
HPN Related

Cause of death HPN related?  
- Yes  
- No

(check all that apply)

- Vascular access (check below all that apply)
  - sepsis
  - thrombosis
  - other

- Metabolic (check below all that apply)
  - fluids and electrolytes
  - hyperglycemia
  - hypoglycemia
  - other

- Organ Failure (check below all that apply)
  - liver
  - renal
  - heart
  - pulmonary
  - other

- Other:

Related to Indication for HPN

Death related to underlying diagnosis?  
- Yes  
- No

(check all that apply)

- post operative bleeding, explain:
- bleeding
- sepsis
- other

Not Related to HPN or HPN Indications

(check all that apply)

- Myocardial Infarction
- Congestive Heart Failure
- Cerebral Vascular Accident
- Pulmonary Embolus
- Other Cancer
- New Trauma (i.e., accident, fall, gsw, etc.)
Follow-up Demographics

Patient Number (As designated by study) [________] Enrolled in registry [______]
Attending Physician's Name [______________________]
Discharging Institution Name [______________________]
PN Home Infusion Care Provider Name [______________________]

1. Gestational age at birth [_______] weeks gestation
2. All age children: Birthweight: [_______] grams

Date began Home PN [________]

Mobility status: [ ] Ambulatory [ ] Bedrest
Who does patient live with? [ ] Alone
[ ] Someone else (check all that apply)
[ ] Parent
[ ] Spouse
[ ] Significant Other
[ ] Child
[ ] Hired professional assistance
[ ] Other: Please specify: [______________________]

Insurance Coverage (check all that apply) [ ] Private Insurance
[ ] Medicare
[ ] Medicaid
[ ] Personal Payment
[ ] Medicare Supplement
[ ] Unknown
[ ] Other: Please specify: [______________________]
Current Height/Length [cm]
Current Weight [Kg]

**Pediatric Elements**

Weight for Height/Length: [ ] % (percentile)
BMI: [ ] % (percentile)
Head Circumference (for children under 3 years of age) [ ] cm

**Labs at Follow-up**

(complete as many as you have)
Date Labs Collected [ ] [ ] [ ] (Please select) [ ]
(Please select) (date closest to most labs drawn)

Serum Albumin [ ] g/dL
Platelet Count [ ] /uL (per microliter)
Total Bilirubin [ ] mg/dL
Direct Bilirubin [ ] mg/dL
AST [ ] U/L
ALT [ ] U/L
BUN [ ] mg/dL
Creatinine [ ] mg/dL

**Primary Indication for Home PN**

(Please be as specific as possible)

- [ ] Bowel Rest
- [ ] Enteritis/Colitis
  - [ ] Chemotherapy
- [ ] Infectious
  - [ ] C. diff
  - [ ] Diverticulitis, non-obstructing
- [ ] Giardia
- [ ] Viral
- [ ] Other: Please specify: [ ]
- [ ] Inflammatory
  - [ ] Crohns
Graft vs. Host
Ischemia bowel/Intestinal angina
Necrotizing Enterocolitis (NEC)
Non-specific enteritis/colitis
Radiation
Ulcerative Colitis
Eosinophilic esophagitis
Other: Please specify:

Idiopathic

Pancreatitis

Acute

Chronic

Dysmotility

Hirschsprung's pediatric
Hirschsprung's adult
Ileus, prolonged

Autonomic (i.e. 2o to Diabetes)

Idiopathic

Post-op

Scleroderma

Intestinal pseudoobstruction

Other: Please specify:

Failure to Thrive/Malnutrition

Pediatric

Feeding intolerance

Socio-economic

Neglect/Munchausen

Other: Please specify:

Adult

Cancer Cachexia

Cardiac Cachexia

Hepatic failure

Pulmonary Cachexia

Renal Cachexia

General Malnutrition
Pre-op nutrition support

**GI Fistula**
- Benign
- Malignant

**Malabsorption**
- Celiac disease
- Congenital Malabsorption
- Cystic fibrosis
- Idiopathic
- Pancreatic insufficiency
- Scleroderma
- Other: Please specify:

**Obstruction**
- Malignant
  - GYN
  - GI
  - Other: Please specify:
- Benign
  - Adhesive
  - Stricture
    - Crohn’s disease
    - Radiation
  - Diverticulitis
  - Other: Please specify:

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□ Anastomotic Leak

□ Bowel perforation

□ Abdominal abscess

Significant Comorbid Conditions

(check all that apply)

□ Alcohol or drug addiction (past or current)

□ Active Oncologic Process

□ Active non-PN related infection

□ Cirrhosis

□ Chronic Kidney Disease

□ Congestive Heart Failure

□ COPD
Goals of PN therapy

**Weight related goals** (check all that apply):
- Weight gain for adults
- Growth for children
- Weight maintenance
- Weight loss (ex. obesity)

**Non-weight related goals** (check all that apply):
- Future surgery and re-establishment of GI anatomy
- Indefinite (permanent) HPN
- Resolution of GI issue and stopping HPN

**Current PN Formula**

- **PN Infusion**
  - (please select) days per week
  - Total volume in ml per day or mL/kg/day
  - Total Dextrose in g per day or g/kg/day
  - Total Protein as Amino Acids in g per day or g/kg/day
  - Cycled over (please select) hrs

- **IV Fat Emulsion**
  - (please select) days per week
  - IV fat emulsion dose g per day or g/kg/day of fat infusion

**Type of Fat Emulsion: select all that apply**
- Soybean/Safflower
- Soybean only
- Emulsion containing Omega-3 fatty acids
- Other:

**Medications**

(Check all that apply)
Food and Diet

(Check all that apply)

- NPO
- On concurrent enteral nutrition or breast milk via tube

What % calories come from enteral or breast milk via tube: [ ]
What type of enteral formula is the patient on?
Name of product:
- Breast Milk
- Calcilol
- Complete Pediatric
- Elecare
- Fibersource
- Neocate
- Neocate Infant
- Vivonex RTF
- Pediasure
- Pregestimil
- Pulmocare
- Other
- Liquids or oral rehydration only
- Breast fed
- Food and/or beverages for comfort only
- Restricted/therapeutic diet
- Unrestricted diet/Ad lib
- Unknown

If on oral nutrition or breast feeding, what % calories come from oral?: [ ]

Current Catheter
Type of Central Venous Catheter
- PICC
- Port
- Tunneled
- Other: Please specify: 

Lumen
- Single Lumen
- Double Lumen
- Triple Lumen

Date of Insertion [ ] [ ] [ ] (Please select)

Type of Catheter Flush or Lock (check all that apply)
- Heparin
- Ethanol
- Antibiotic
- Saline only
- Taurolidine

Catheter Used for Blood Draw
- Never
- Occasionally
- Often or Always
- Don’t Know

Signature: 