

SBS Management Survey 1.0

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Welcome to the Real World Management of Short Bowel Syndrome Survey.

Intestinal failure (IF) is rare condition defined as “the reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that parental/intravenous supplementation (Parental Support, PS) is required to maintain health and/or growth” (Pironi et al. Clin Nutrition 2016, 2018, 2020).

IF can be classified as Type I acute intestinal failure (AIF) Type II prolonged AIF and Type III chronic intestinal failure (CIF) and it may be due to one or more of five major pathophysiological mechanisms. Evidence Based Guidelines and management concepts for IF in adults, have been outlined endorsed by experts in the European Society for Clinical Nutrition and Metabolism (ESPEN) (Pironi et al 2018).

Short bowel syndrome (SBS) is the most frequent pathophysiological mechanism of CIF seen in about two thirds of patients. In these patients, the main objective of SBS CIF treatment is to optimize gastrointestinal function using an integrated approach to medical and nutritional management and to provide optimal parenteral support. The Evidence-based guidelines (EBG) have facilitated a standard approach across the world. However, despite the advent of EBG’s there is a variable approach in practice to IF and a lack of specific guidance from experts who have real world experience in managing the high stool output associated with SBS IF.

The aim of this survey is to identify and illuminate real-world practice in expert IF management centers. The goal is to develop specific guidance to improve management in SBS CIF in adult patients. In addition to questions about your IF program, questions addressing management of stool output are grouped into 4 areas: Diet, Fluids, Medications, GLP-2 Therapy,

As a site investigator for EASE trials, your IF/HPN team has been identified as a center of excellence for the management of SBS IF. Your input into this work is anticipated to have implications for both acute and chronic IF management and the adult patients who live with this condition.

Thank you for participating in our survey. Your feedback is important.

Please enter as multi-disciplinary team. One questionnaire per team per site.

Program characteristics

* 1. What are the disciplines in your team?

- Dietitian
- Nurse
- Nurse Practitioner
- Pharmacist
- Gastroenterologist
- Endocrinologist
- Surgeon
- Pediatrician
- Internist (Internal medicine)
- Physician assistant
- Psychologist
- Social worker
- Financial Counselor
- Research Coordinator
- Other (please specify)

* 2. In what country is your medical center?

Country

* 3. Do you have dedicated IF beds supported by specialized knowledgeable team in your hospital?

- Yes
- No
- Other (please specify)

* 4. What is the full-time equivalent (FTE) of each discipline that makes up your team?

Please provide numbers of each discipline, e.g. 1.0 FTE works full time , 0.5 FTE works half time in a discipline, 2 nurses at 1.0 FTE would = 2.0 FTE

Dietitians

Nurses

Nurse Practioner

Pharmacists

Gastroenterologists

Endocrinologists

Surgeons

Pediatricians

Internist (Internal medicine)

Physician assistant

Psychologists

Social workers

Financial Counselor

Research Coordinator

Others

* 5. How many CIF patients [see definition on page 1] in total are in your program?

Enter a number

* 6. What is the estimated number of patients whose main diagnosis is in the following pathophysiological classifications of IF? (per ESPEN guidelines)

Specify the proportion to the closest tenth percent

	None 0 %	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	All 100 %
Short bowel	<input type="radio"/>										
Intestinal fistula	<input type="radio"/>										
Intestinal dysmotility	<input type="radio"/>										
Mechanical obstruction	<input type="radio"/>										
Extensive small bowel mucosal disease	<input type="radio"/>										
Other	<input type="radio"/>										

Other causes (please specify, one line per cause)

* 7. What is the estimated proportion of patients in each pathophysiological classification of SBS IF?

Specify the proportion to the closest tenth percent

	None 0 %	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	All 100 %
Mesenteric ischemia	<input type="radio"/>										
Inflammatory bowel diseases	<input type="radio"/>										
Radiation enteritis	<input type="radio"/>										
Surgical complication	<input type="radio"/>										
Volvulus and hernia	<input type="radio"/>										
Cancer	<input type="radio"/>										
Other	<input type="radio"/>										

Other causes (please specify, one line per cause)

* 8. What proportion of your patients are anticipated to be shorter term (HPN < 1 year) versus lifelong?

Specify to the closest tenth percentage

	Never 0 %	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	Always 100 %
Shorter term patients (HPN < 1 year)	<input type="radio"/>										

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Better Management of high stool output: Diet

* 9. How often do you recommend the following diets to patients with colon in-continuity with high stool output?

Specify the proportion to the closest tenth percent

	Never 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	Always 100%
Low simple sugar diet	<input type="radio"/>										
Low fat diet	<input type="radio"/>										
Addition of soluble fiber	<input type="radio"/>										
Separation fluid and solid food	<input type="radio"/>										
High Sodium diet	<input type="radio"/>										
Reduce oxalate	<input type="radio"/>										
Oral nutritional Supplements	<input type="radio"/>										
Other diets	<input type="radio"/>										

Other diets (please specify)

* 10. How often do you recommend the following diets to patients without colon in-continuity with high stool output?

Specify the proportion to the closest tenth percent

	Never 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	Always 100%
Low simple sugar diet	<input type="radio"/>										
Low fat diet	<input type="radio"/>										
Addition of soluble fiber	<input type="radio"/>										
Separation fluid and solid food	<input type="radio"/>										
High Sodium diet	<input type="radio"/>										
Reduce oxalate	<input type="radio"/>										
Oral nutritional Supplements	<input type="radio"/>										
Other diets	<input type="radio"/>										

Other diets (please specify)

Better Management of high stool output: Fluids

* 11. Do you recommend to **restrict** the following types of oral fluid in patients with high stool output?

Select all that apply

- Water
- Tea
- Coffee (regular)
- Coffee (decaf)
- Fruit juice
- Sweetened Beverages (lemonade, sweat tea, fruit punch, soft-drinks/Coke/Pepsi/Sprite/Ginger Ale)
- Alcohol
- Other oral fluids (please specify)
- No, we provide general guidance on fluid management (e.g. osmolarity and solute load)

* 12. Do you recommend the following types of ORS (oral rehydration solution)?

Select all that apply

- Homemade ORS
- Commercial products (e.g. WHO ORS, Pedialyte)
- Sport drinks (e.g. G2)
- Other ORS (please specify)

* 13. What proportion of patients experience the following as barriers to use ORS as listed in Question 10?

Select all that apply

	None 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	All 100%
Taste fatigue	<input type="radio"/>										
Cost	<input type="radio"/>										
Accessibility	<input type="radio"/>										
Gastrointestinal symptoms (i.e. nausea, vomiting, abdominal pain)	<input type="radio"/>										
Inadequate tools and/or education for ORS	<input type="radio"/>										
Other	<input type="radio"/>										

Other (please specify)

* 14. What proportion of patients experience the following as enablers to use ORS as listed in Question 10?

Specify to closest percent

	None 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	All 100%
Good taste	<input type="radio"/>										
Affordable price	<input type="radio"/>										
Reimbursement	<input type="radio"/>										
Availability	<input type="radio"/>										
Treatment of gastrointestinal symptoms (nausea, vomiting, abdominal pain)	<input type="radio"/>										
Decreased stool output	<input type="radio"/>										
Improved sense of hydration	<input type="radio"/>										
Other	<input type="radio"/>										

Other (please specify)

* 15. Which IV solutions do you use for simple rehydration of SBS IF patients

Specify the proportion to the closest tenth percent

	Never 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	Always 100%
Normal saline	<input type="radio"/>										
½ Normal saline	<input type="radio"/>										
Dextrose water	<input type="radio"/>										
Dextrose / glucose 5%	<input type="radio"/>										
Ringer lactate solution	<input type="radio"/>										
Compounded solution	<input type="radio"/>										
Other IV hydration	<input type="radio"/>										

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Better Management of high stool output: Medications

* 16. Which of the following guides your choice of anti-diarrhoeal medication?

Specify the proportion to the closest tenth percent

	None 0 %	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	All 100 %
Remnant anatomy	<input type="radio"/>										
Type of ostomy	<input type="radio"/>										
Stool volume	<input type="radio"/>										
Urine output	<input type="radio"/>										
Presence of ileo-caecal valve	<input type="radio"/>										
Underlying disease	<input type="radio"/>										
Other	<input type="radio"/>										

Other drug (please specify)

* 17. Do you within your practice use the following antimotility drugs?

Specify the proportion to the closest tenth percent

	None 0 %	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	All 100 %
Loperamide	<input type="radio"/>										
Diphenoxylate and atropine (lomotil)	<input type="radio"/>										
Codeine	<input type="radio"/>										
Tincture opium	<input type="radio"/>										
Other	<input type="radio"/>										

Other drug (please specify)

* 18. What daily dose do you usually start with for each antimotility medication?

Enter total daily dose for each medication

Loperamide

Total daily dose (mg)

Diphenoxylate

and atropine (1 Lomotil =
2.5mg diphenoxylate and
0.025 mg atropine
sulphate)

Total daily dose
of diphenoxylate (mg)

Codeine

Total daily dose (mg)

Tincture opium

Total daily dose (mg)

Other medication

Medication name
and Total daily dose

* 19. In your practice, what is the indication to increase the dose of antimotility medications?

Select all that apply

Increased stool output

Thirst and dehydration

Increased stool frequency

Increased BUN/Cr
(blood urea nitrogen / creatinine ratio)

Loosening stool

Insufficient effect of current dose

Other (please specify)

* 20. What is the highest daily dose and frequency you usually use for each antimotility medication?

Enter a highest dose and frequency per day for each medication

Loperamide

Total daily dose (mg)

Diphenoxylate

and atropine (1 Lomotil =
2.5 mg diphenoxylate and
0.025 mg atropine
sulphate)

Total daily dose of
diphenoxylate (mg)

Codeine

Total daily dose (mg)

Tincture opium

Total daily dose (mg)

Other medication

Medication name and
Total daily dose

* 21. What are the first, second and third choice of antimotility medications for the average SBS IF patient?

	Loperamide	Diphenoxylate and atropine (lomotil)	Codeine	Tincture opium	Other medication
1st choice antimotility medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2nd choice antimotility medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3rd choice antimotility medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 22. Do you change your strategy for patients above 75 years?

Yes

No

* 23. For an average patient older than 75 years of age, what are the first, second and third choice antimotility medications?

	Loperamide	Diphenoxylate and atropine (lomotil)	Codeine	Tincture opium	Other medication
1st choice antimotility medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2nd choice antimotility medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3rd choice antimotility medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 24. What proportion of patients receive more than one antimotility drug?

Specify to the closest tenth percentage

	Never 0 %	10 %	20 %	30 %	40 %	50 %	60 %	70 %	80 %	90 %	Always 100 %
SBS IF patients receiving >1 antimotility medication	<input type="radio"/>										

* 25. Is your choice of antimotility drugs influenced by residual intestinal anatomy?

No

Yes

If Yes, how?

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Better Management of high stool output: Medications

* 26. How within your practice do you use the following antisecretory drugs?

Specify to the closest tenth percent

	Never 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	Always 100%
Proton Pump Inhibitor (capsule, tablet)	<input type="radio"/>										
Proton Pump Inhibitor (Multiple-Unit Pellet System (MUPS) given as tablets, dissolves into subunits across stomach and small intestine)	<input type="radio"/>										
H2 Receptor Antagonist (oral)	<input type="radio"/>										
H2 Receptor Antagonist (add to PN)	<input type="radio"/>										
Somatostatin analogue (e.g. Octreotide)	<input type="radio"/>										
Other antisecretory drug	<input type="radio"/>										

* 27. What are the first, second and third line antisecretory medications?

	Proton Pump Inhibitor (capsule, tablet)	Proton Pump Inhibitor (MUPS)	H2 Receptor Antagonist (oral)	H2 Receptor Antagonist (add to PN)	Somatostatin analogue	Other medication
1st line antisecretory medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2nd line antisecretory medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3rd line antisecretory medication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 28. What total daily dose do you usually start with for each antisecretory medication?

Enter a generic name and start total daily dose for each antisecretory medication

PPI

which PPI?

Total daily dose (mg)

H2 Receptor Antagonist

(Oral)

Which H2RA?

Total daily dose (mg)

H2 Receptor Antagonist

(add to PS)

Which H2RA?

Total daily dose (mg)

Somatostatin analogue

Total Daily dose (mg)

* 29. What highest daily dose do you prescribe for each antisecretory medication?

Enter a generic name and highest total daily dose for each antisecretory medication

PPI

which PPI?

Highest total daily dose
(mg)

H2 Receptor Antagonist

(Oral)

Which H2RA?

Highest total daily dose
(mg)

H2 Receptor Antagonist

(add to PS)

Which H2RA?

Highest total daily dose
(mg)

Somatostatin analogue

Highest total Daily dose
(mg)

* 30. Do you stop PPI after SBS IF diagnosis?

Select one answer

- After 6 months
- Never stop
- Other (please specify)

31. Do you stop Oral H2RA after SBS IF diagnosis?

Select one answer

- After 6 months
- Never stop
- Other (please specify)

* 32. Do you stop PS H2RA after SBS IF diagnosis?

Select one answer

- After 6 months
- Never stop
- Other (please specify)

* 33. How often in your practice do you trial the following medicines or supplements in SBS IF with colon in-continuity (CiC)?

Specify to the closest tenth percent

	Never 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	Always 100%
Fiber, e.g. psyllium fiber supplement	<input type="radio"/>										
Bile acid binders, e.g. questran	<input type="radio"/>										
Probiotics	<input type="radio"/>										
Pancreatic enzymes	<input type="radio"/>										

* 34. Within your practice, how often do you trial the following medicines or supplements in SBS IF without colon in-continuity?

Specify to the closest tenth percent

	Never 0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	Always 100%
Fiber e.g. metamucil	<input type="radio"/>										
Bile acid binders e.g. questran	<input type="radio"/>										
Probiotics	<input type="radio"/>										
Pancreatic enzymes	<input type="radio"/>										