

Supplementary data

Table S1 Outline of the concept elicitation guide.

Phase I (concept elicitation)	
Themes to be explored	Examples of questions
1. History of EPI	Time since diagnosis of EPI? What led to diagnosis? Type of physician diagnosing?
2. EPI symptoms	Participants were probed on their symptom experience; the endorsed symptoms were probed on: • Time since symptom onset? • Time from symptom onset to EPI diagnosis? Description: • Please describe you experience of <<symptom>> • Location (if applicable)? • Frequency? • Severity?

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- Timing (time of day, proximity to ingestion)?
 - Related to ingestion of ...?
 - Consistency (continuous, variable)?

Variation:

- How does your experience of <<symptom>> vary or change?

3. Treatments for EPI

- What treatments have you tried?
- How many EPI treatments have you tried?

4. Impact of EPI symptoms on participant's life

EPI symptom impact/impact on functioning on participant's life:

- How is your life affected by EPI?

Daily activities:

- How is your everyday activity affected by EPI?

Social activities:

- How are your social activities affected by EPI?

Relationships:

- How are your relationships affected by EPI?
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Work/school:

- How is work or school affected by EPI?

Other activities:

- How are your other activities affected by EPI?
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Phase II (Cognitive Interviews)

Topics

Examples of questions

Feedback on the EPI-SQ

Overall:

- What were your first impressions of the questionnaire?
- Does it cover the areas important to your experiences?

Understanding of the instructions:

- In your own words, please tell me what the instructions were asking you to do.
 - Please describe any confusion or difficulty you had in understanding the instructions.
 - Please tell me about any words or phrases you would change to improve the instructions.
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Understanding of the items and testing of alternate item wording:

- What does <<item>> mean to you?
- How does <<item>> relate to your experience with EPI?
- Rate your <<item>> during the past 7 days

Alternate wording:

During the past 7 days, how bad was your <<item>>?

Understanding of the response scales:

- What did you think of the response options overall?
- Were you able to select a response for each item?
- What caused you to choose <<response>>?
- Please tell me about a time when you might have chosen
<<response above / response below>>

Understanding of the recall period:

- When you answered the questions, what period of time did you think about (e.g., today, yesterday, last week, “the past 7 days”)?
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EPI, Exocrine pancreatic insufficiency; EPI-SQ: Exocrine Pancreatic Insufficiency Symptom Questionnaire.

Table S2 Saturation grid of symptom concepts.

Symptom concepts*	Group 1 [†] (n = 5)	Group 2 [‡] (n = 3)	Group 3 [†] (n = 4)	Group 4 [‡] (n = 4)	Group 5 [‡] (n = 5)	Total (%)
Abdominal pain	X (5)	X (2)	X (4)	X (3)	X (5)	19 (90)
Nausea or vomiting	X (4)	X (2)	X (4)	X (4)	X (3)	16 (76)
Abdominal bloating	X (4)	X (2)	X (3)	X (3)	X (3)	15 (71)
Constipation	X (5)	X (1)	X (3)	X (2)	X (3)	15 (71)
Appetite changes	X (5)	–	X (2)	X (3)	X (4)	14 (67)
Change in energy	X (5)	–	X (3)	X (2)	X (4)	13 (62)
Gas or flatulence	X (3)	X (2)	X (4)	X (3)	X (1)	13 (62)
Eating and Digestion or bowel movements	X (3)	X (3)	X (3)	X (3)	X (1)	13 (62)
Weight loss	X (4)	–	X (4)	X (3)	X (2)	13 (62)
Indigestion	X (2)	X (2)	X (4)	X (2)	X (2)	12 (57)
Cramping	X (3)	–	X (4)	X (4)	X (1)	12 (57)
Urgent bowel movements	X (1)	X (1)	X (3)	X (3)	X (2)	10 (48)

Foul smelling stools	X (3)	–	X (4)	X (2)	X (1)	9 (43)
Change in stool consistency	X (2)	X (3)	X (1)	X (3)	X (1)	9 (43)
Diarrhea	X (1)	X (3)	X (2)	X (2)	X (1)	9 (43)
Greasy or fatty or floating stools	X (1)	–	X (3)	X (2)	X (3)	9 (43)
Difficulty flushing toilet	X (1)	–	X (1)		X (1)	3 (14)
Muscle loss	X (1)	–	–	X (1)	X (1)	3 (14)
Distention	–	–	–	X (3)	–	3 (14)
Heartburn	–	X (2)	–	–	–	2 (10)
Frequent bowel movements	–	X (1)	X (1)	–	–	2 (10)
Difficulty swallowing	–	–	X (1)	–	X (1)	2 (10)

*Other symptom concepts endorsed by participants (n = 1 each) included: bloody stool, bruises, chest pain, difficulty digesting food, dizziness, dry cough, headache, numbness and salty tongue, rusty urine, shortness of breath, spasms, sweating, and uncomfortable.

[†]Themes were identified from one-on-one interviews.

[‡]Themes were identified from focus group discussions.