21ST ANNUAL

PSC PARTNERS SEEKING A CURE CONFERENCE

PSC Partners' Symptom Assessment Project (SAP): Using PRO measures to communicate patient experiences with fatigue, brain fog & liver pain

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UNC SCHOOL OF MEDICINE

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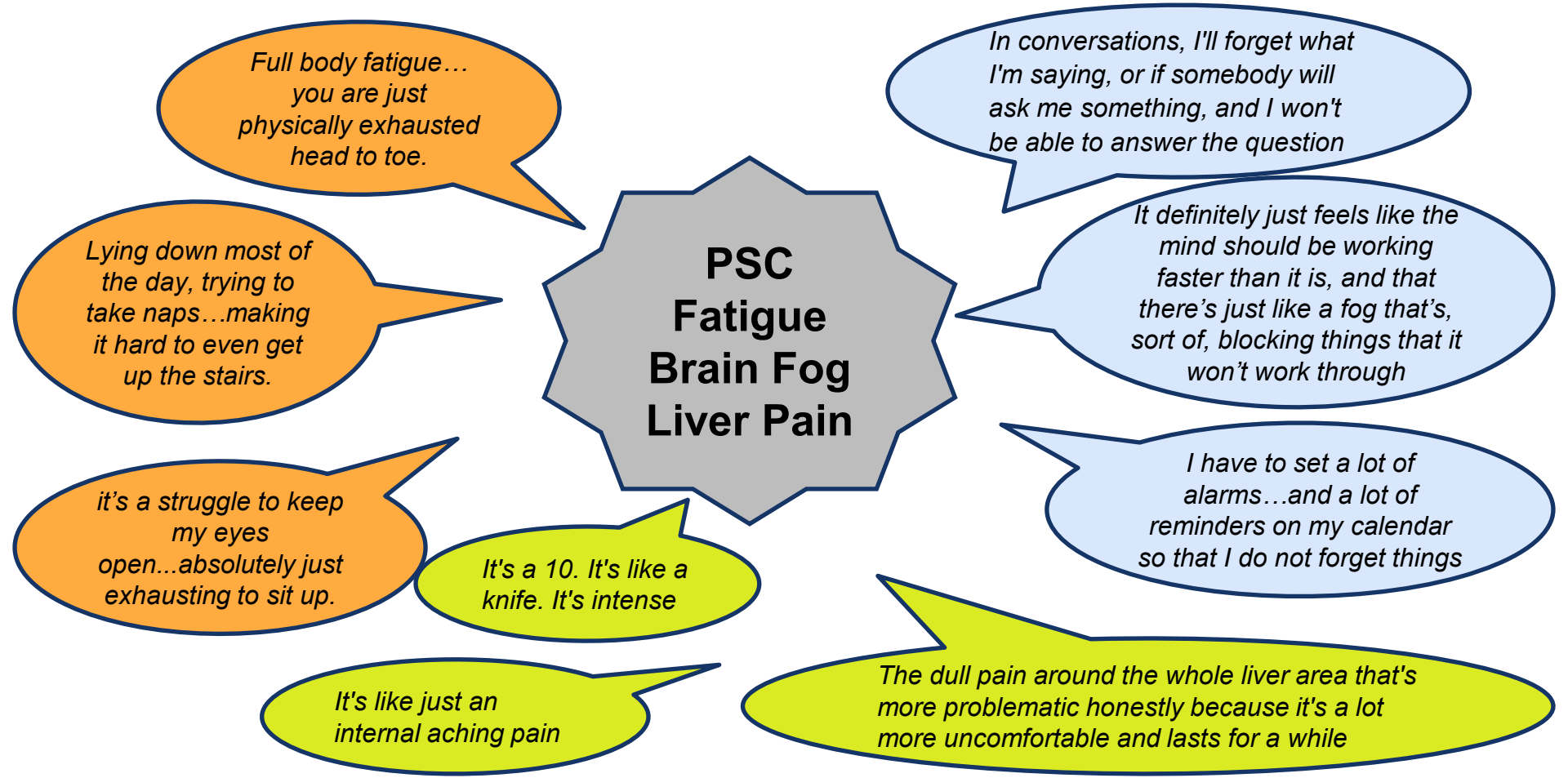
MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

PSC Fatigue, Brain Fog, and Liver Pain



Conflict of Interest

Dr. Evon has no conflicts of interest to disclose related to this project.

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Discussion Points

- The value of patient-reported outcome (PRO) measures to patients
- Development of 3 symptom measures for PSC (PSC-SAP)
- Patients' descriptions of fatigue, brain fog and liver pain
- Evaluating 3 symptom measures in PSC-P Patient Registry
- Discordance between patient – doctor symptom reporting
- Using PRO measures to communicate symptoms to your doctors

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Why have patient-reported outcome (PRO) measures become so important?

How you feel and function matter

Normal labs ≠ Better Qualify of Life

Symptoms are subjective experiences to be captured directly from the patient

Poor correlation between clinician-grading and patient-reported symptoms and side effects of treatment

Courtesy of B. Reeve

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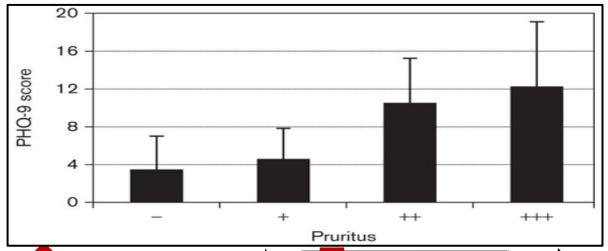
Utilize PRO measures in the treatment and management of PSC

PRO Symptom Measure

Survey Research studies



Itch → QOL → Depression

Gotthardt et al. Eur J Gastroenterol Hepatol. 2014; Bowlus et al., Hep Comm. 2023 PMID: 37184523; https://healthcaredelivery.cancer.gov/pro-ctcae/.

Utilize PRO measures in the treatment and management of PSC

PRO Symptom Measure

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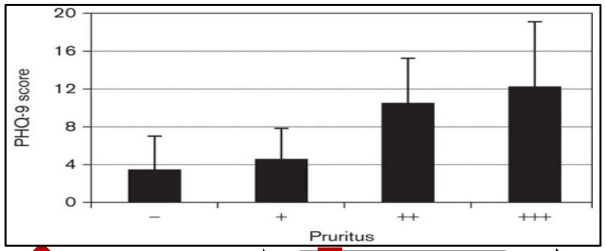
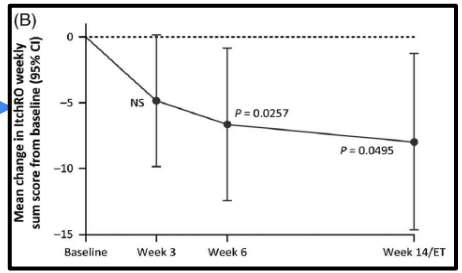


Itch → QOL → Depression

PSC drug trials Treatment Benefits & Harms



Treatment Benefits

PRO-CTCAE

Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events

Treatment Harms

Gotthardt et al. Eur J Gastroenterol Hepatol. 2014; Bowlus et al., Hep Comm. 2023 PMID: 37184523; https://healthcaredelivery.cancer.gov/pro-ctcae/.

Utilize PRO measures in the treatment and management of PSC

PRO Symptom Measure

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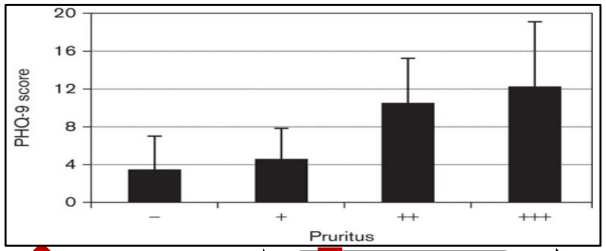

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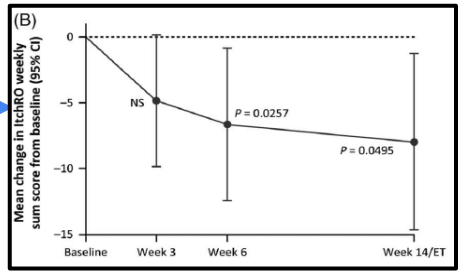

Treatment Benefits

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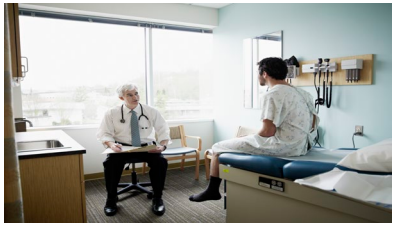
Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events

Treatment Harms

Healthcare



Gotthardt et al. Eur J Gastroenterol Hepatol. 2014; Bowlus et al., Hep Comm. 2023 PMID: 37184523; https://healthcaredelivery.cancer.gov/pro-ctcae/.

Goal of the Symptom Assessment Project *(PSC-SAP)*

Design patient-reported outcome (PRO) measures that assess symptoms that are most important to adults with PSC that are appropriate for use in research and clinical trials to evaluate treatment benefits.

Patient-driven with extensive patient involvement

"Nothing about us, without us"

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SAP Study Aims

Aim 1: Conduct in-depth interviews to characterize key symptoms and life impacts associated with PSC

Aim 2: Decide to select, modify, or develop self-report measures to assess three key symptoms associated with PSC

Aim 3: Conduct cognitive testing for three symptom measures to evaluate the relevance of content and clarity of the questions

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Screening symptomatic patients helped identify key symptoms

Symptoms N=126	Present in Last Month N (%)
Fatigue	105 (83%)
Daytime Drowsiness	92 (73%)
Anxiety	80 (63%)
Liver Pain	80 (63%)
Brain Fog	79 (63%)
Pruritus	78 (62%)
Difficulty Sleeping	77 (62%)
Sadness	59 (47%)
Nausea	57 (45%)
Night Sweats	42 (33%)
Other Belly Pain	38 (30%)
Vomiting	15 (12%)
Jaundice	12 (10%)

Evon et al., Symptom burden profiles identified among symptomatic adults with PSC (under review)

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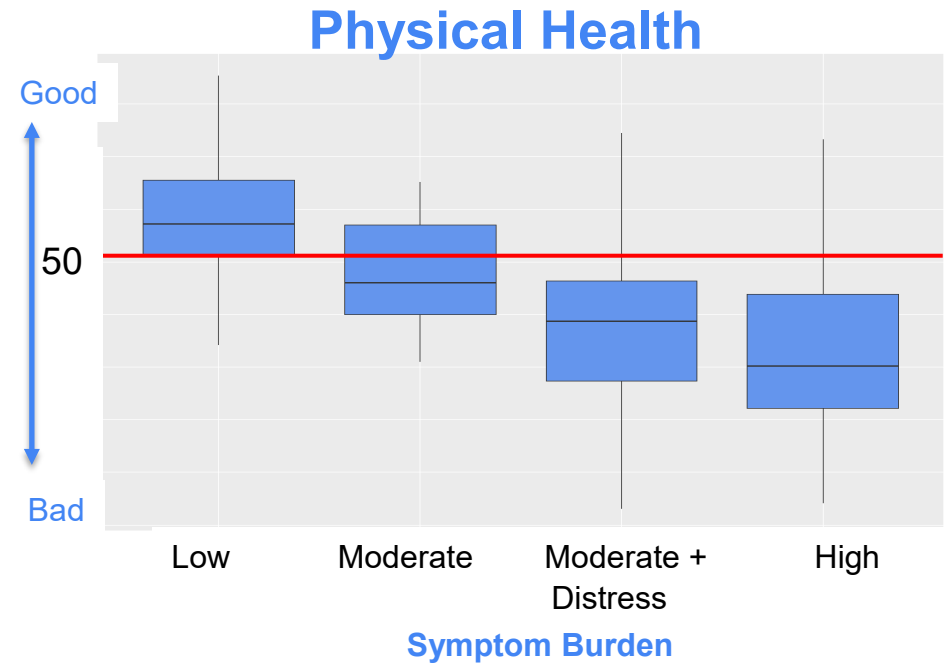
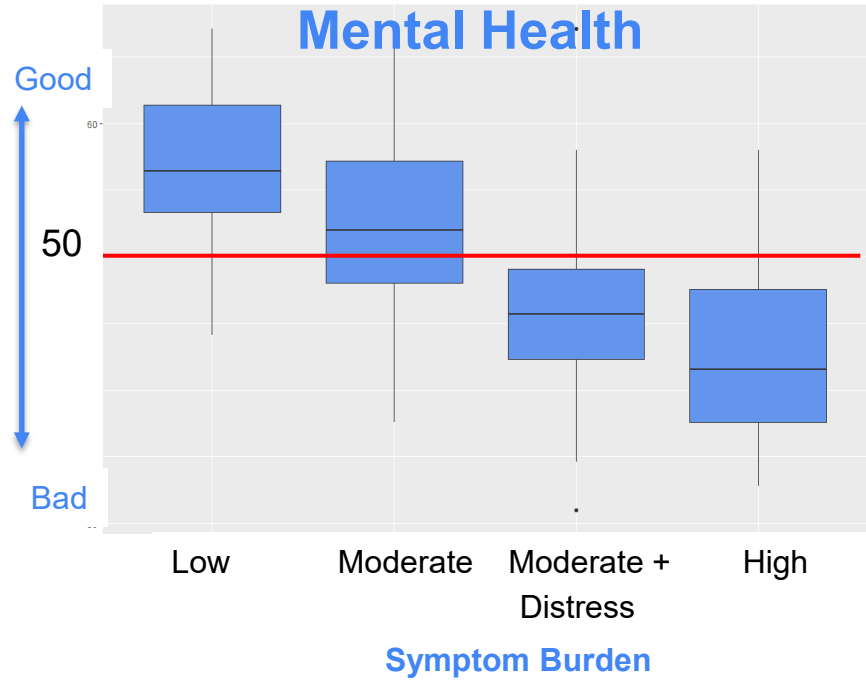
High Symptom Burden ⇨ Worse Physical & Mental Health





Note: Score of 50 = US General Population Norms

Evon et al., Symptom burden profiles identified among symptomatic adults with PSC (under review)

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Symptom Selection with PSC Partners & Community Advisors

(1) How important, (2) does a symptom tool exist, (3) likelihood of being future study endpoint

Top Priorities

- **Fatigue**
- **Brain Fog**
- **Liver Pain**

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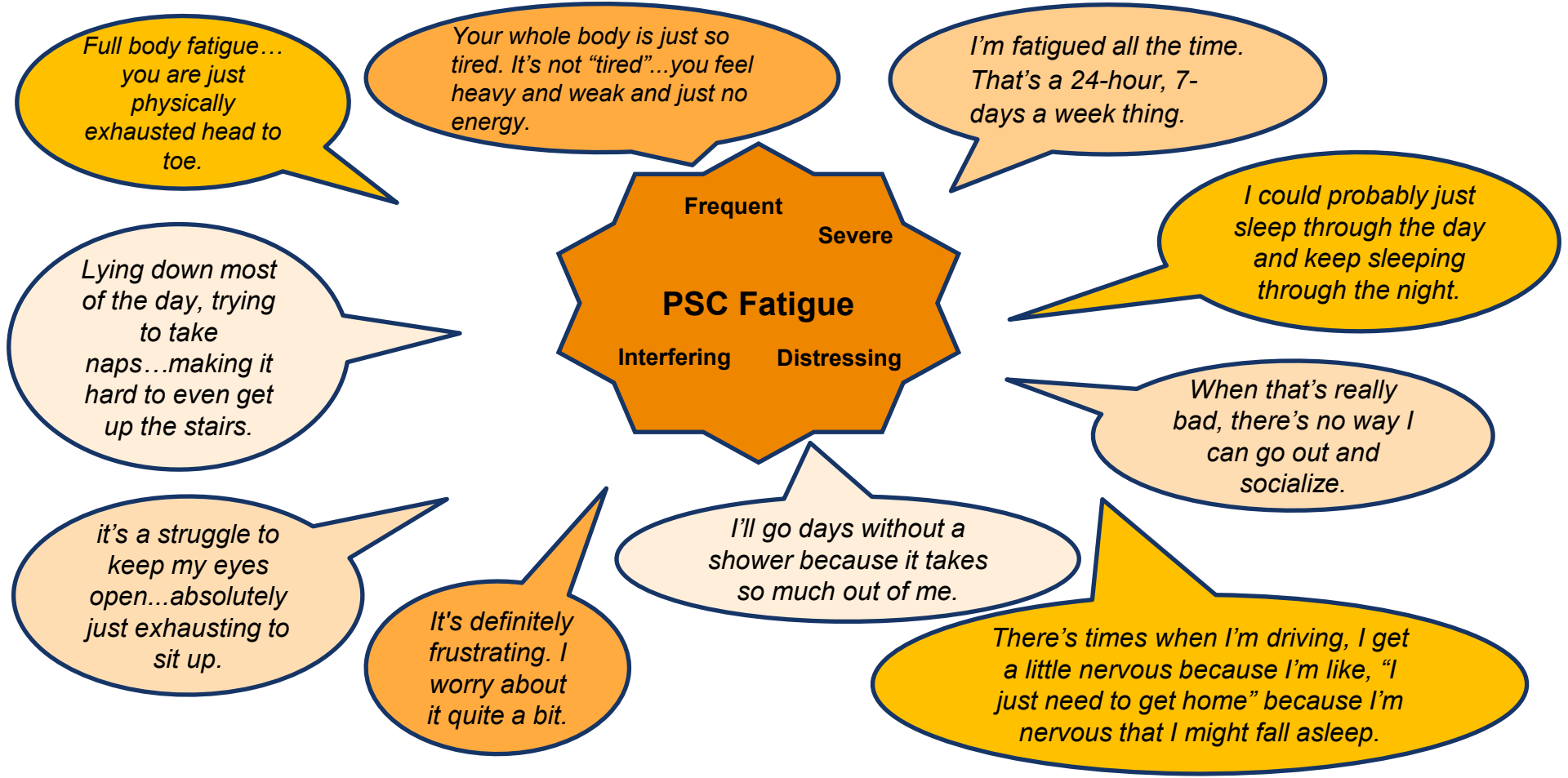
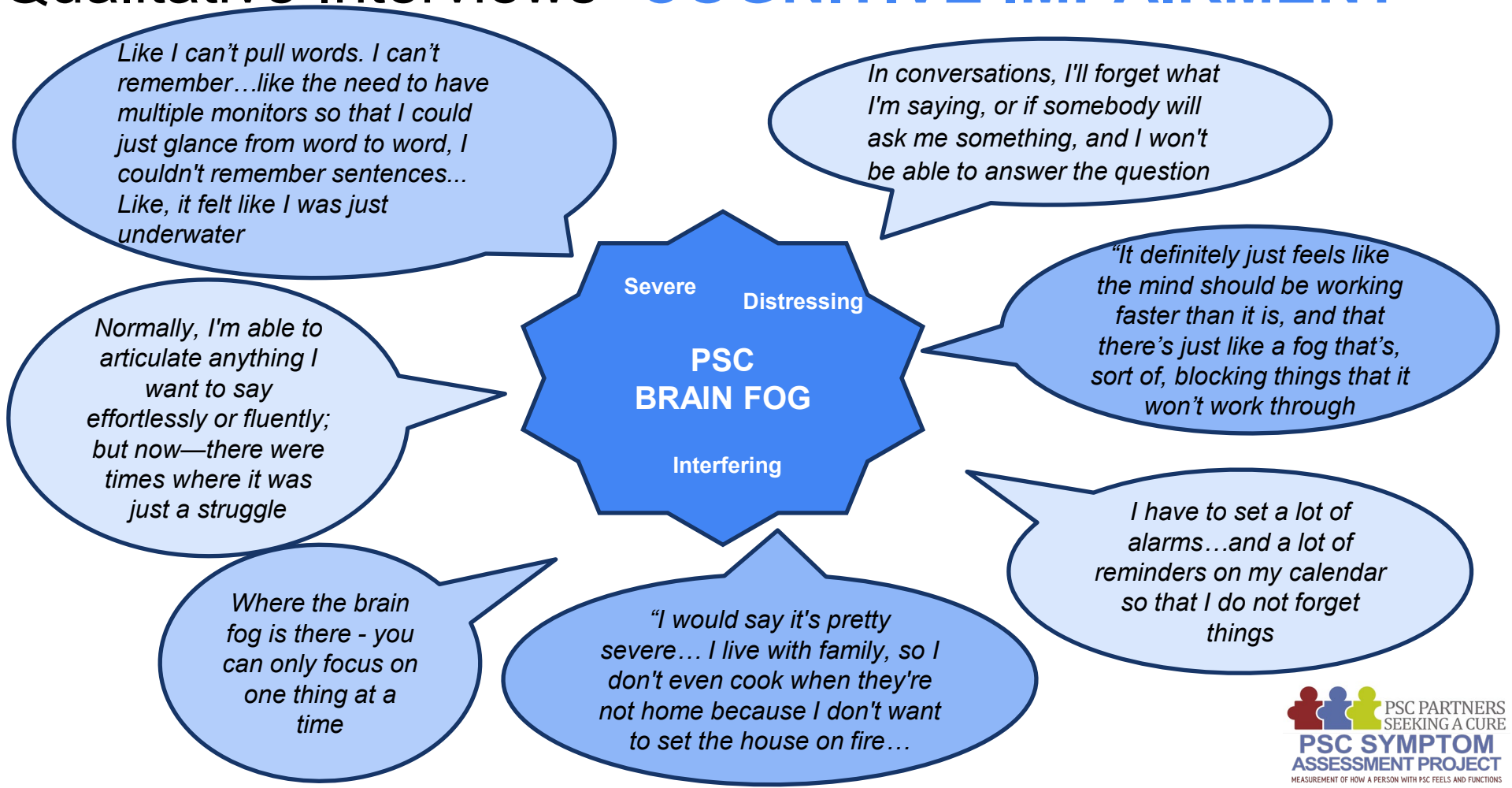
PSC SYMPTOM ASSESSMENT PROJECT

Qualitative Interviews- FATIGUE



Qualitative Interviews- COGNITIVE IMPAIRMENT



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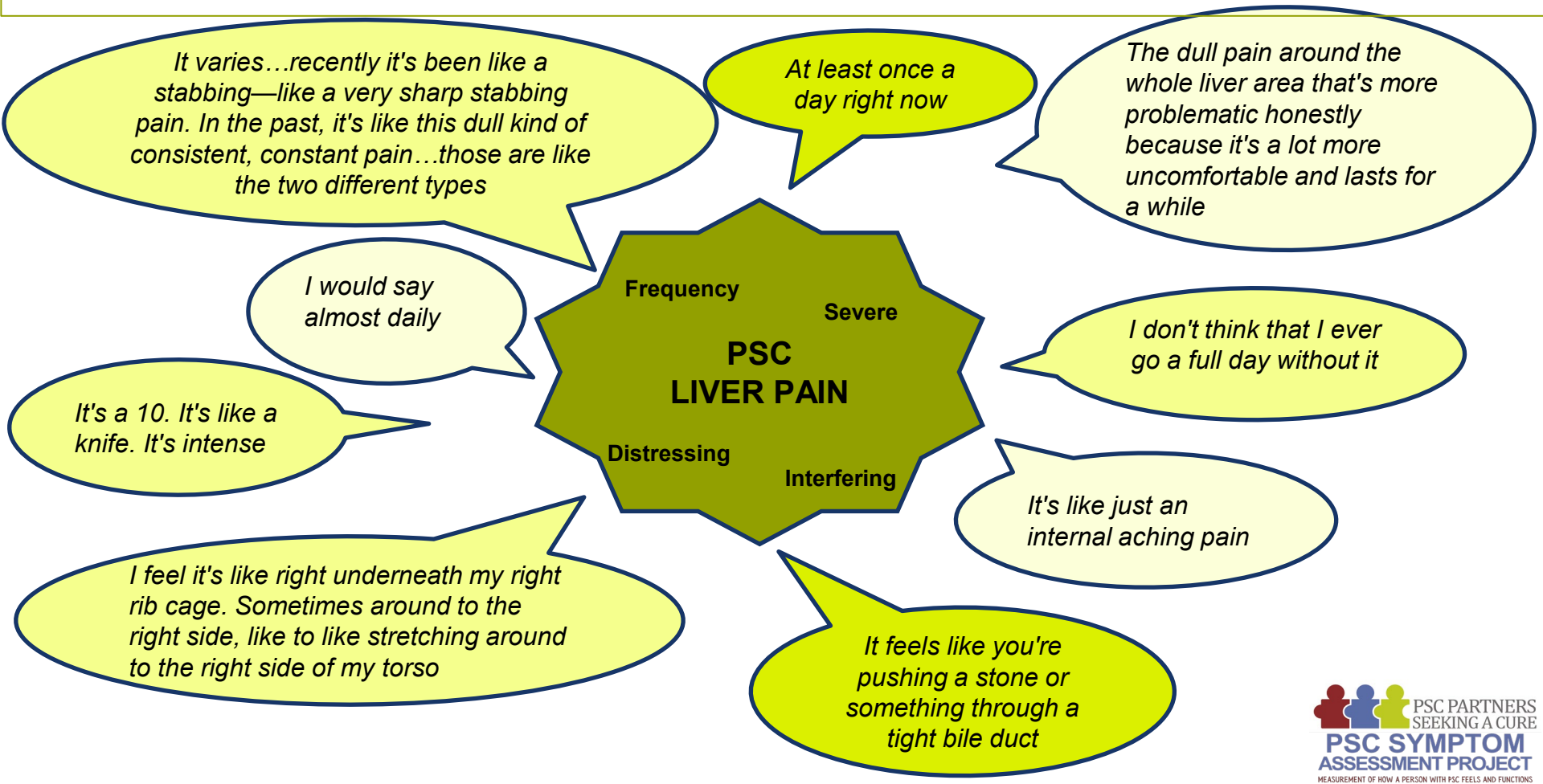
Qualitative Interviews- LIVER PAIN



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Interview data led to measurement decisions

1. Customize a **Fatigue** measure for PSC using PROMIS® fatigue item bank

2. Customize a **Cognitive Function** measure for PSC using PROMIS® cognitive function item bank

3. Develop **new Liver Pain** measure for PSC

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MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

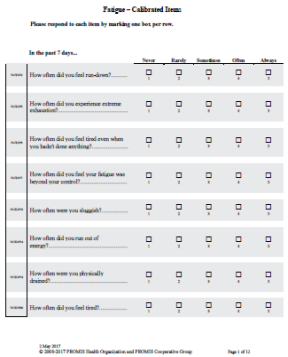
Rationale to modify PROMIS® measures for PSC

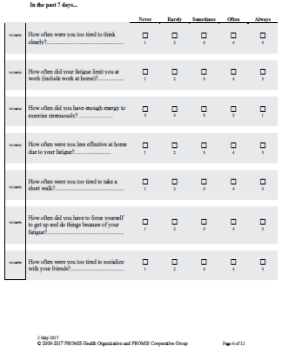
NIH- funded Patient-Reported Outcomes Measurement Information System

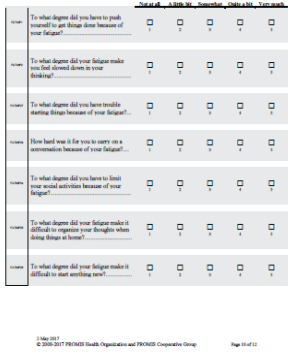
- Designed following best practices in survey development
- Robust reliability and validity data
- Trust and transparency in the process
- Allowed to customize symptom measures
- Free, accessible, translated >30 languages
- Used internationally

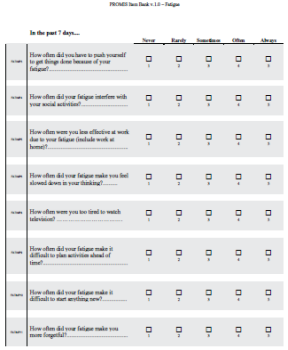
https://www.healthmeasures.net/explore-measurement-systems/promis
https://pubmed.ncbi.nlm.nih.gov/17443114/
https://pubmed.ncbi.nlm.nih.gov/17443115/
https://pubmed.ncbi.nlm.nih.gov/20685078/

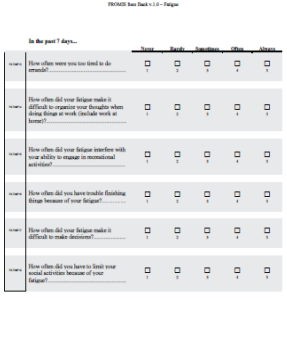
Example of Item Bank for Symptoms (PROMIS Fatigue Item Bank - 95 items)

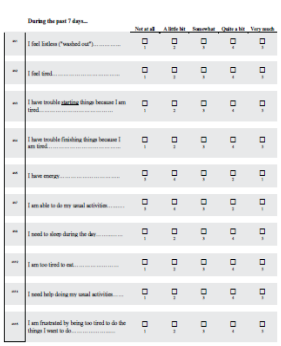


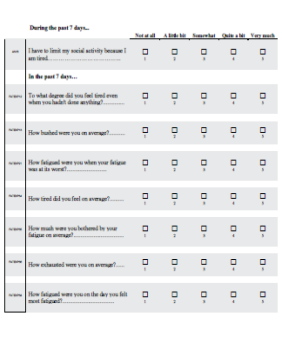


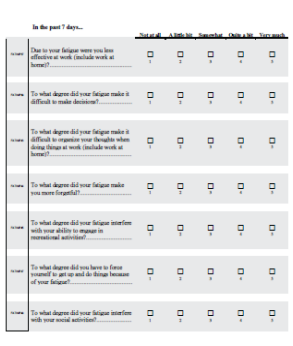


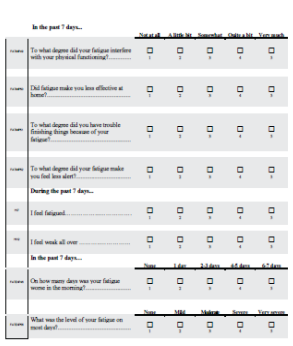












Customizing a PROMIS® Fatigue Measure for PSC

		In the past 7 days…	Not at all	A little bit	Somewhat	Quite a bit	Very much
General fatigue →	1	I feel fatigued.					
Weakness →	2	I feel weak all over.					
Sleep →	3	I need to sleep during the day.					
Frustration, emotional impact →	4	I am frustrated by being too tired to do the things I want to do.					
Interference with social activity →	5	I have to limit my social activity because I am tired					
Exhaustion →	6	How exhausted were you on average?					
Interference with work →	7	Due to your fatigue were you less effective at work (include work at home)?					
Impact on cognitive function →	8	To what degree did your fatigue make you feel slowed down in your thinking?					
Overall interference →	9	To what degree, did you feel tired even when you hadn't done anything?					
Impact on initiation / motivation →	10	To what degree, did you have to force yourself to get up and do things because of your fatigue?					
Impact on finishing tasks →	11	To what degree did you have trouble finishing things because of your fatigue?					
Feelings of heaviness →	12	My body and limbs feel heavy.					
Full body experience →	13	My fatigue is a full body experience.					

		In the past 7 days…	Not at all	A little bit	Somewhat	Quite a bit	Very much
Energy →	14	I have energy.					

Customizing a PROMIS® Cognitive Function Measure for PSC

		In the past 7 days…	Never	Rarely (once)	Sometimes (two or three times)	Often (about once a day)	Very Often (several times a day)
Attention & Concentration →	1	I have had trouble concentrating.					
Attention: Sustained Vigilance →	2	I have had to work really hard to pay attention or I would make a mistake.					
Attn&Con, Exec Function, Working Memory →	3	I have had trouble shifting back and forth between different activities that require thinking.					
Processing Speed →	4	My thinking has been foggy.					
Lang/Verbal skills: Naming and Fluency →	5	I have had to work harder than usual to express myself clearly.					
Lang/Verbal skills: Naming →	6	I have had trouble recalling the name of an object while talking to someone.					
Processing Speed →	7	My thinking has been slow.					
Working Memory →	8	I have walked into a room and forgotten what I meant to get or do there.					
Working Memory / Numeracy →	9	I have had trouble adding and subtracting numbers in my head.					
Work Interference →	10	My problems with memory, concentration, or making mental mistakes have interfered with my ability to work.					
Quality of Life Interference →	11	My problems with memory, concentration, or making mental mistakes have interfered with the quality of my life.					

Developing a new Liver Pain Measure for PSC

If you selected dull or achy pain, please answer questions #2 to question #8.

2. In the past 7 days, how often did you have dull or achy pain in the area around your liver?
   - Never
   - 1 to 2 days
   - 3 to 4 days
   - 5 to 6 days
   - All 7 days

3. In the past 7 days, how many times per day did you usually have dull or achy pain in the area around your liver?
   - None
   - Once a day
   - 2-3 times a day
   - 4-5 times a day
   - 6 or more times, or constant pain during the day

4. In the past 7 days, how would you rate the dull or achy pain in the area around your liver at its worst?
   - No pain
   - Mild
   - Moderate
   - Severe
   - Very severe

5. In the past 7 days, how much did the dull or achy pain in the area around your liver interfere with your daily activities?
   - Not at all
   - A little bit
   - Somewhat
   - Quite a bit
   - Very much

- **Ask about dull vs sharp pain separately**
- **Use skip logic to reduce # of items**

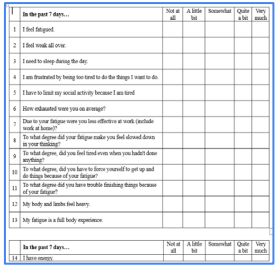
6. In the past 7 days, how much did the dull or achy pain in the area around your liver interfere with your sleep?
   - Not at all
   - A little bit
   - Somewhat
   - Quite a bit
   - Very much

7. In the past 7 days, how much did the dull or achy pain in the area around your liver cause you distress?
   - Not at all
   - A little bit
   - Somewhat
   - Quite a bit
   - Very much

8. In the past 7 days, how much did the dull or achy pain in the area around your liver interfere with your quality of life?
   - Not at all
   - A little bit
   - Somewhat
   - Quite a bit
   - Very much

Cognitive Testing Ensured Relevance and Clarity

Fatigue



	In the past 7 days…	Not at all	A little bit	Somewhat	Quite a bit	Very much
1	I feel fatigued.					
2	I feel weak all over.					
3	I need to sleep during the day.					
4	I am frustrated by being too tired to do the things I want to do.					
5	I have to limit my social activity because I am tired					
6	How exhausted were you on average?					
7	Due to your fatigue were you less effective at work (include work at home)?					
8	To what degree did your fatigue make you feel slowed down in your thinking?					
9	To what degree, did you feel tired even when you hadn't done anything?					
10	To what degree, did you have to force yourself to get up and do things because of your fatigue?					
11	To what degree did you have trouble finishing things because of your fatigue?					
12	My body and limbs feel heavy.					
13	My fatigue is a full body experience.					

	In the past 7 days…	Not at all	A little bit	Somewhat	Quite a bit	Very much
14	I have energy.					

Round 1

Interviews
8 patients

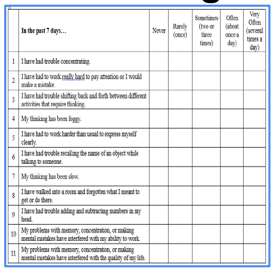
Revised

Round 2

Interviews
6 patients

Finalized

Brain Fog



	In the past 7 days…	Never	Rarely (once)	Sometimes (two or three times)	Often (about once a day)	Very Often (several times a day)
1	I have had trouble concentrating.					
2	I have had to work really hard to pay attention or I would make a mistake					
3	I have had trouble shifting back and forth between different activities that require thinking					
4	My thinking has been foggy.					
5	I have had to work harder than usual to express myself clearly					
6	I have had trouble recalling the name of an object while talking to someone.					
7	My thinking has been slow.					
8	I have walked into a room and forgotten what I meant to get or do there.					
9	I have had trouble adding and subtracting numbers in my head.					
10	My problems with memory, concentration, or making mental mistakes have interfered with my ability to work.					
11	My problems with memory, concentration, or making mental mistakes have interfered with the quality of my life.					

Interviews
8 patients

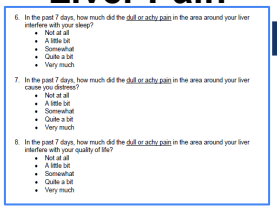
Revised

Round 2

Interviews
6 patients

Finalized

Liver Pain



6. In the past 7 days, how much did the dull or achy pain in the area around your liver interfere with your sleep?
   - Not at all
   - A little bit
   - Somewhat
   - Quite a bit
   - Very much
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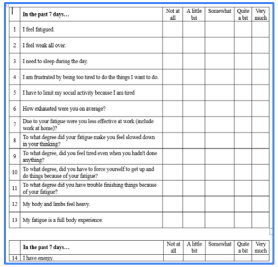
Cognitive Testing Ensured Relevance and Clarity

Fatigue



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7	Due to your fatigue were you less effective at work (include work at home)?					
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9	To what degree, did you feel tired even when you hadn't done anything?					
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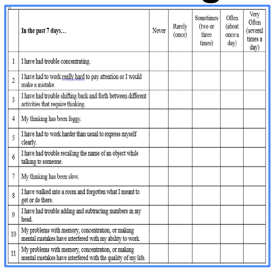
Brain Fog



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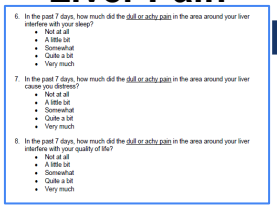
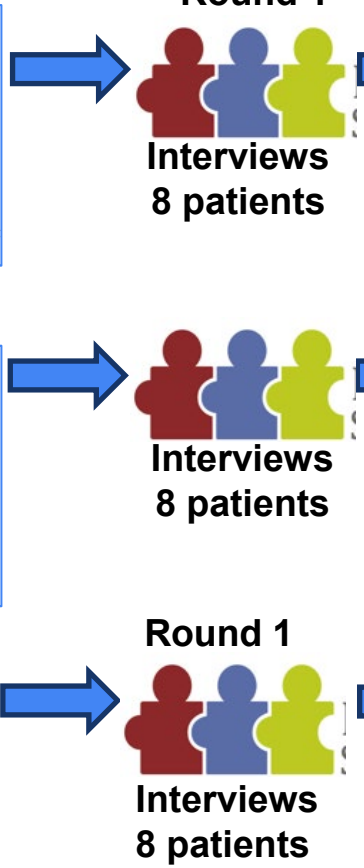
Liver Pain



6. In the past 7 days, how much did the dull or achy pain in the area around your liver interfere with your sleep?
   - Not at all
   - A little bit
   - Somewhat
   - Quite a bit
   - Very much
7. In the past 7 days, how much did the dull or achy pain in the area around your liver cause you distress?
   - Not at all
   - A little bit
   - Somewhat
   - Quite a bit
   - Very much
8. In the past 7 days, how much did the dull or achy pain in the area around your liver interfere with your quality of life?
   - Not at all
   - A little bit
   - Somewhat
   - Quite a bit
   - Very much



Next Steps

Evaluate how the measures perform

- Patient Registry
- WIND
- Industry

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PSC SYMPTOM ASSESSMENT PROJECT
MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

Evaluate measures performance via PSC Partners Patient Registry

PSC PARTNERS PATIENT REGISTRY

Online global registry of PSC patients: 2700 participants from 54 countries

Building real world evidence at large scale:

1. What is the distribution of responses?
2. Is increased symptom burden associated with disease history?
3. How do responses compare when retaken 7 days later?

Launched 8/19: Currently available for Registry participants experiencing symptoms

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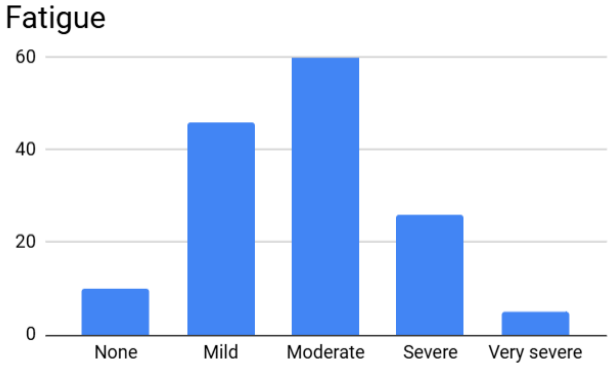
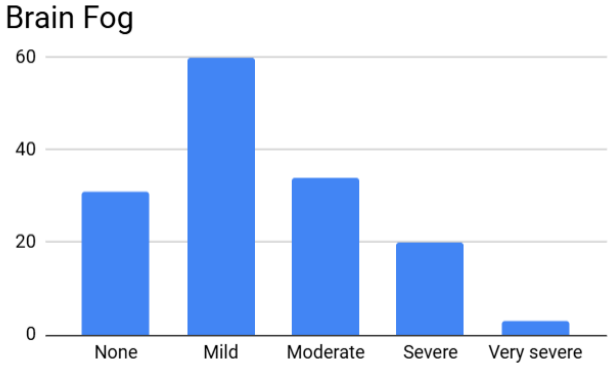
MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

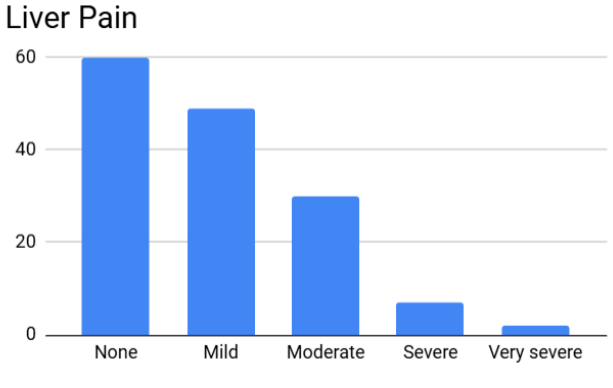
Evaluate measures performance via PSC Partners Patient Registry

PSC PARTNERS PATIENT REGISTRY

Patients' overall ratings of symptoms







Preliminary data as of 9/2

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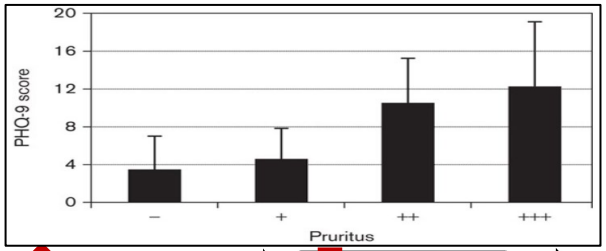
MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

Utilize PRO measures in the treatment and management of PSC

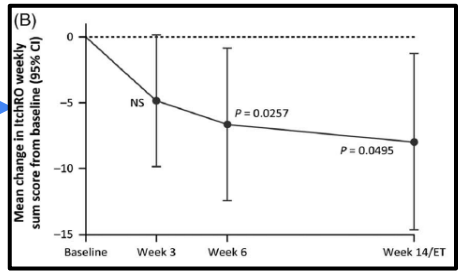
PRO Symptom Measure

Survey Research studies



Itch → QOL → Depression

PSC drug trials Treatment Benefits & Harms



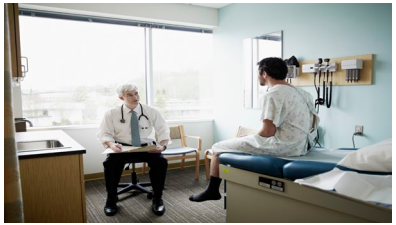
Treatment Benefits

PRO-CTCAE

Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events

Treatment Harms

Healthcare



Gotthardt et al. Eur J Gastroenterol Hepatol. 2014; Bowlus et al., Hep Comm. 2023 PMID: 37184523; https://healthcaredelivery.cancer.gov/pro-ctcae/.

Discordance between patient – doctor symptom reporting

Doctor symptom monitoring does not adequately capture patient symptoms

Generally, clinicians report:

- Fewer symptoms
- Lower severity
- Across different diseases
- In clinical trials
- In clinical care

Agreement is modest:
Correlations: 0.30 to 0.50
(0=no overlap to 1.0 = perfect overlap)

PMID:20220181;PMC3243678; PMID:40256972; PMID:36377818; PMID:27059693; PMC9113216; https://doi.org/10.1371/journal.pone.0230317; PMID:28950896; https://doi.org/10.1155/2022/2673911

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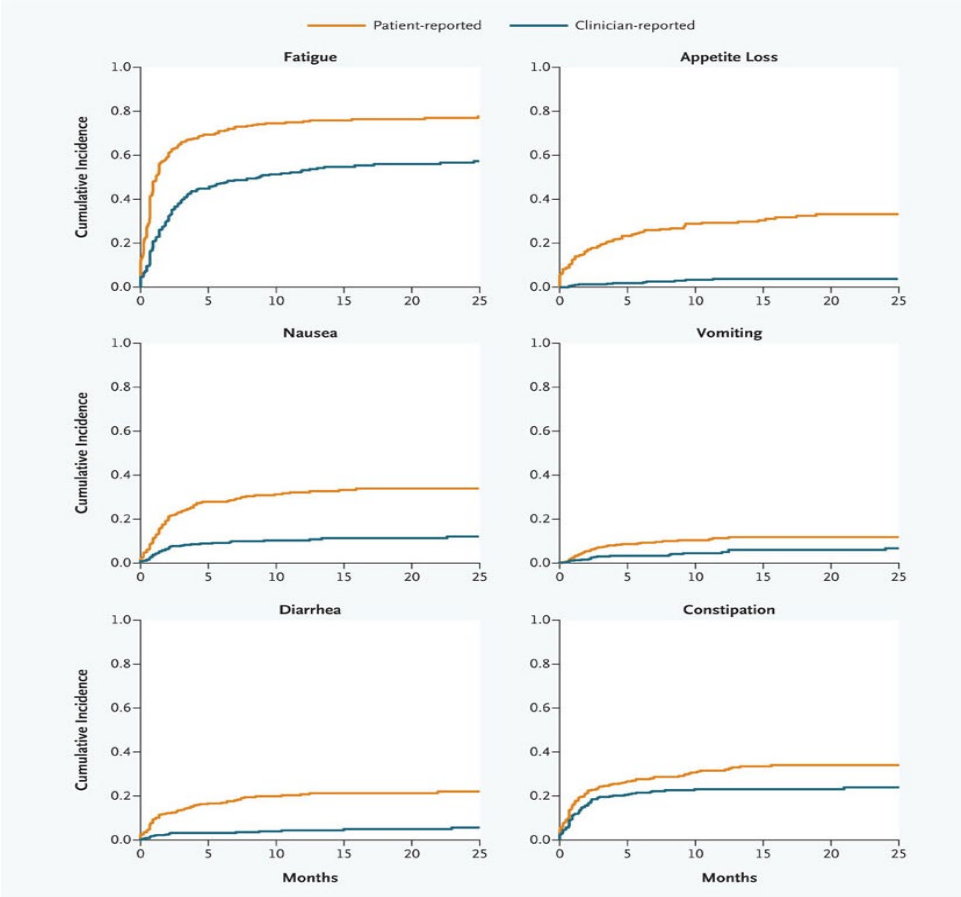
Discordance between patient – doctor symptom reporting

Patient-reported

Clinician-reported



Basch E. The missing voice of patients in drug-safety reporting. N Engl J Med. 2010 PMC3031980.

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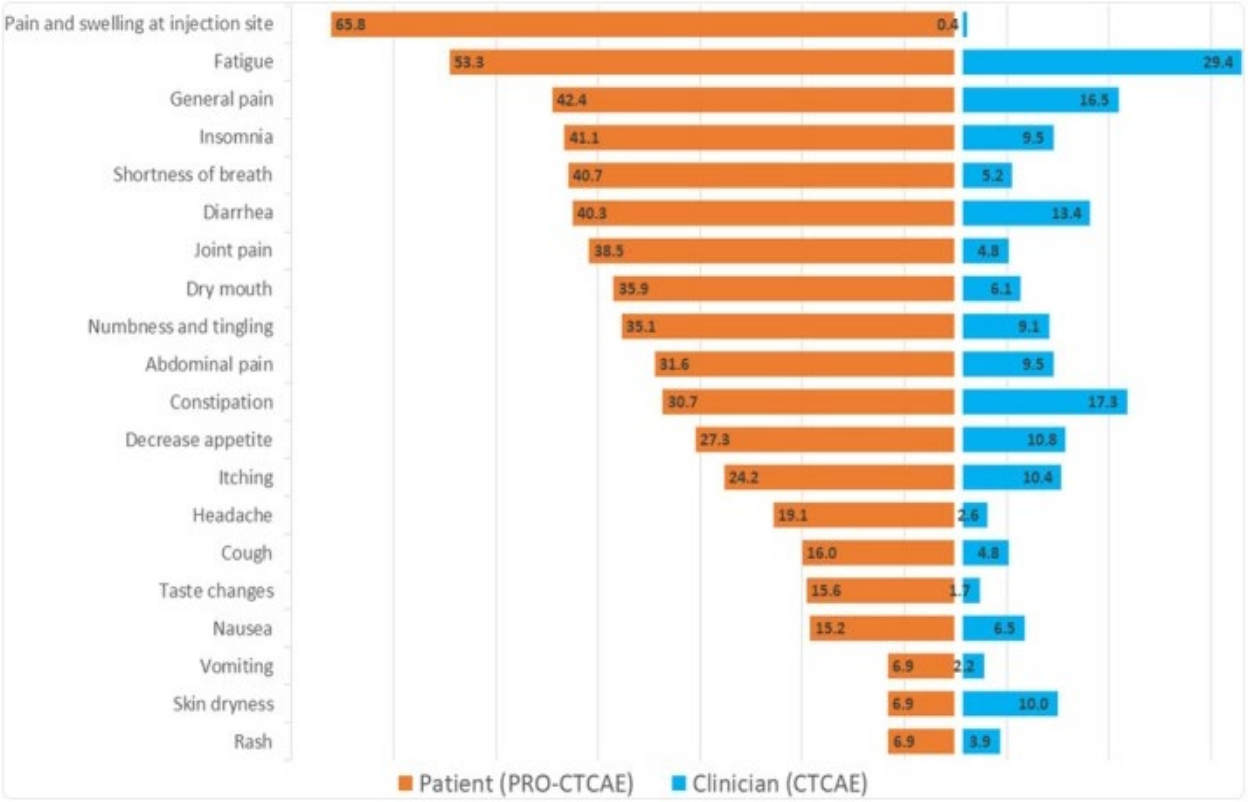
Discordance between patient – doctor symptom reporting



Annakib et al. Patient Vs Clinician Reported Symptoms Agreement in Advanced Metastatic Bladder Cancer Patients. Cancer Med. 2025 PMC12010202.

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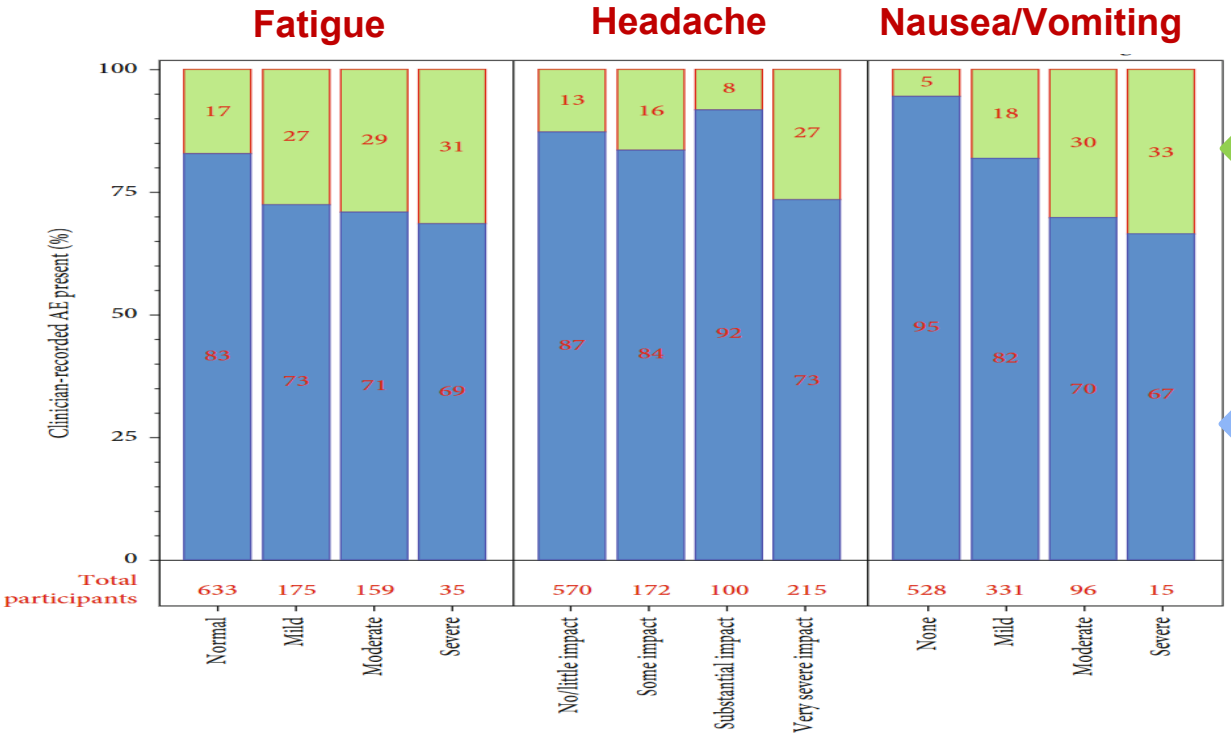
MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

Discordance between patient – doctor symptom reporting



Clinician **DID** record symptom/adverse event in chart

Clinician did **NOT** record symptom/adverse event in chart

Reeve, BB et al., Concordance between Patients and Clinicians for Reporting Symptoms Associated with Treatment for Chronic Hepatitis C during a Pragmatic Clinical Trial, *GastroHep*, 2022. https://doi.org/10.1155/2022/2673911

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MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

Why does discordance happen?

- Symptoms are subjective and non-observable
- Symptoms do not correlate with disease activity
- Overlap with other issues (e.g., depression) or other condition
- Clinicians are busy/overworked
- Inadequate time to communicate

What can be done?

- Use PRO surveys to communicate
- Electronic PROs in medical record
- Shared patient-clinician symptom review helps
- Real time ePRO measures helps

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MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

Use PRO measures to communicate your symptoms to your doctors

PSC Fatigue measure

PSC Cognitive Function measure

- Complete before clinic visits
- Upload attachment to EHR
- Communicate attributes:
  - Frequency
  - Duration
  - Severity
  - Distress
  - Interference with life

Instructions: We have listed 24 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how OFTEN you had it, how SEVERE it was usually and how much it DISTRESSED or BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."

DURING THE PAST WEEK Did you have any of the following symptoms?	DID NOT HAVE	IF YES How OFTEN did you have it?				IF YES How SEVERE was it usually				IF YES How much did it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness/tingling in hands/feet		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4

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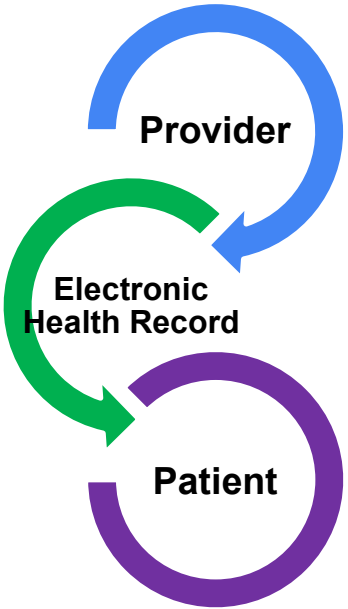
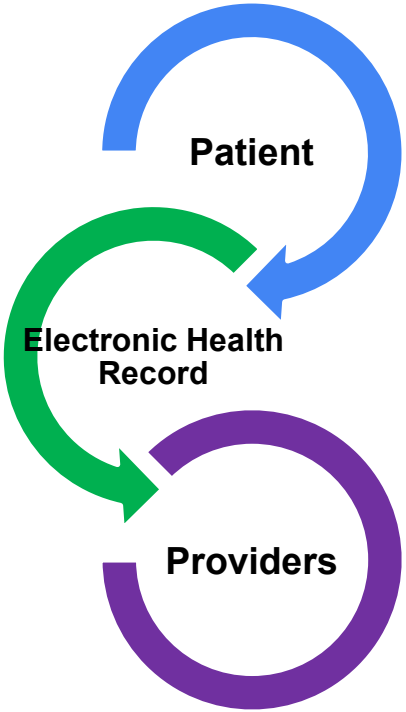
PSC SYMPTOM ASSESSMENT PROJECT
MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

PROs Improve Patient Care and Patient-Provider Communication



- Complete ePROs in Patient Portal
- Checklists identifies patient issues:
  - Medical
  - Psychosocial
  - Informational
  - Nutritional
- Results populate in EHR
- Message is sent to right provider
- SUPPORT is on the way



Wagner LI et al. Bringing PROMIS to practice: brief and precise symptom screening in ambulatory cancer care. Cancer. 2015 PMC4352124.

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MEASUREMENT OF HOW A PERSON WITH PSC FEELS AND FUNCTIONS

Take home points

- Patient reported outcome (PRO) measures are tools to communicate subjective experiences
- PSC-SAP has developed symptom measures for PSC fatigue, brain fog and liver pain
- PROs – research, clinical trials, healthcare
- Use PRO measures to communicate your symptoms

With Gratitude

- Ricky Safer & PSC-Partners for funding the PSC-SAP
- 126 people living with PSC who contacted us to participate in PSC-SAP
- 13-member Community Advisory Board
- Duke: Bryce Reeve, Nicole Lucas, Laura Mkumba, Lauren Wright
- UNC: Kaya Merkler