

A pilot study of patient-reported health-related quality of life among individuals with histiocytic neoplasms

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Outline

1. Introduction

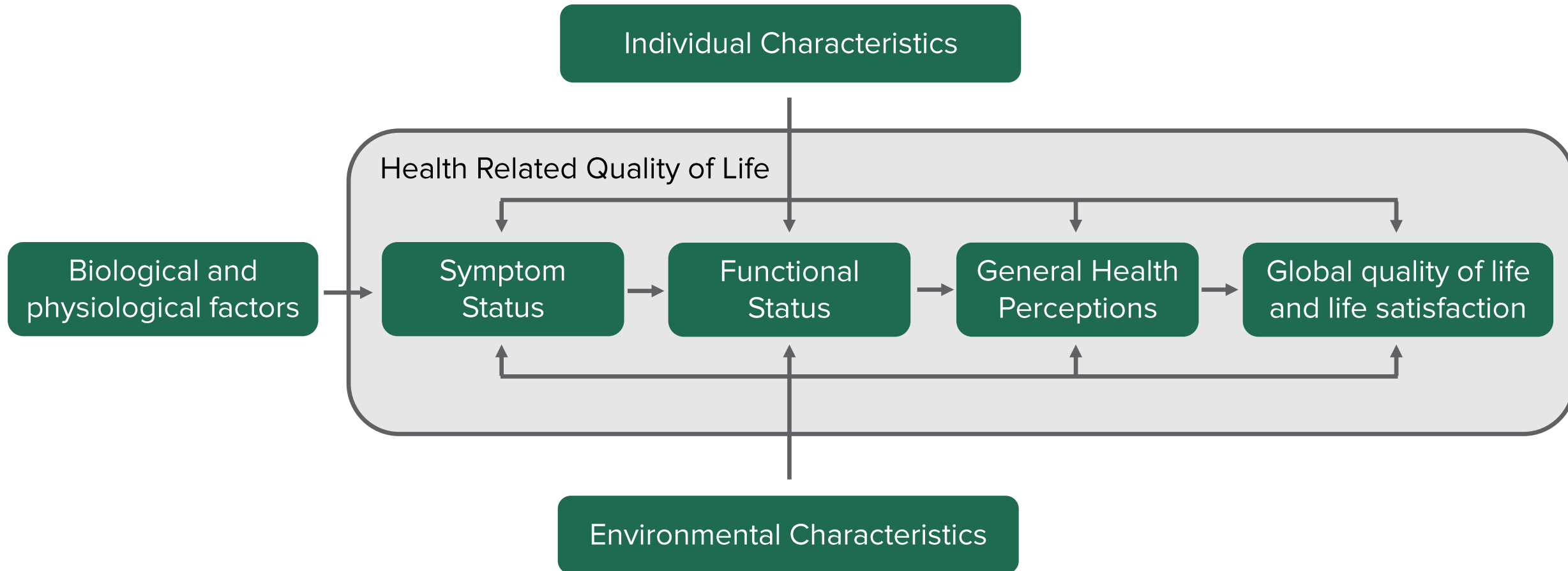
- Health Related Quality of Life
- Patient-Reported Outcomes and measurement tools

2. Methods

3. Results

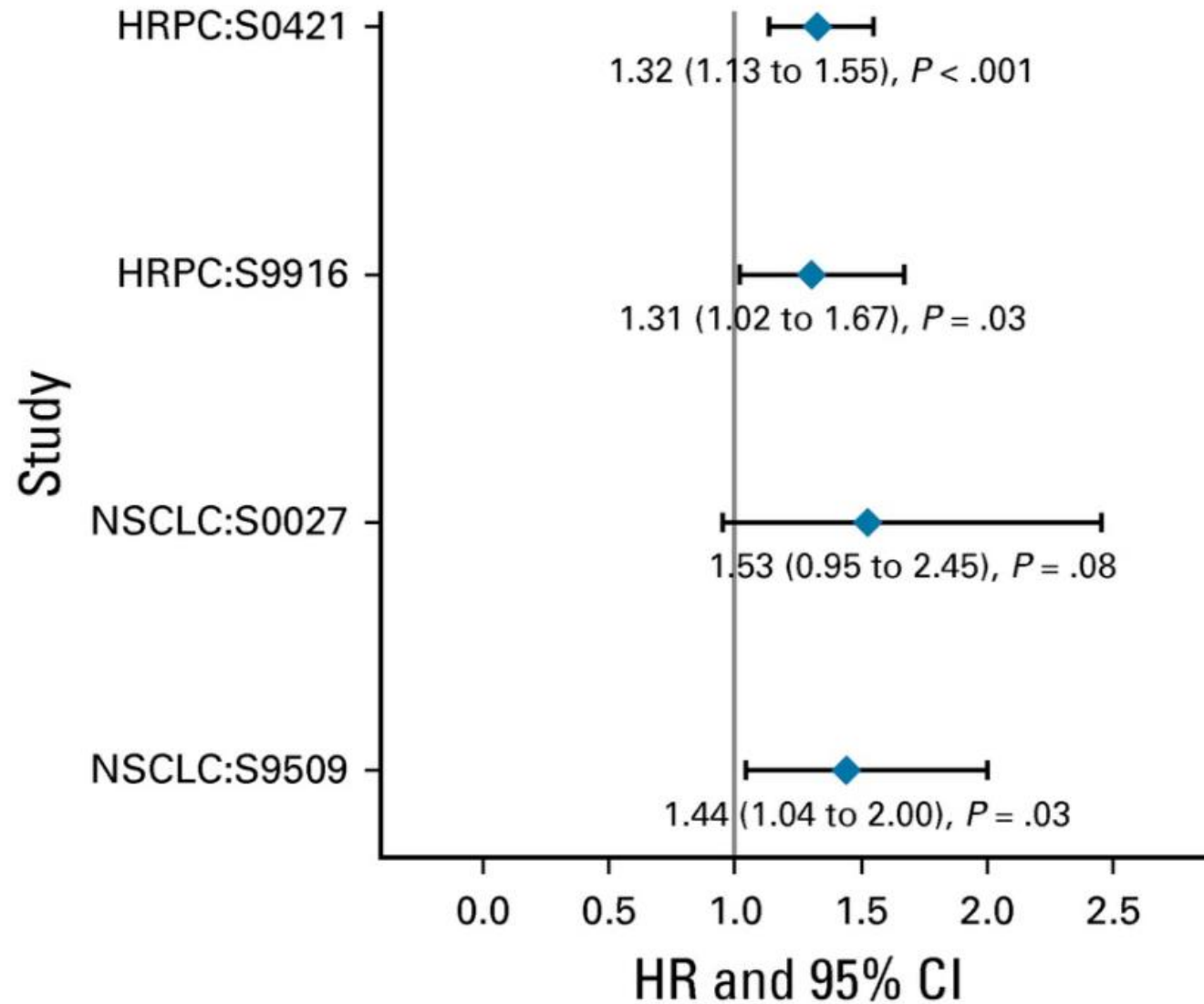
4. Conclusions

Health Related Quality of Life



(Revicki D et al, Dialogues Clin Neurosci., 2014)

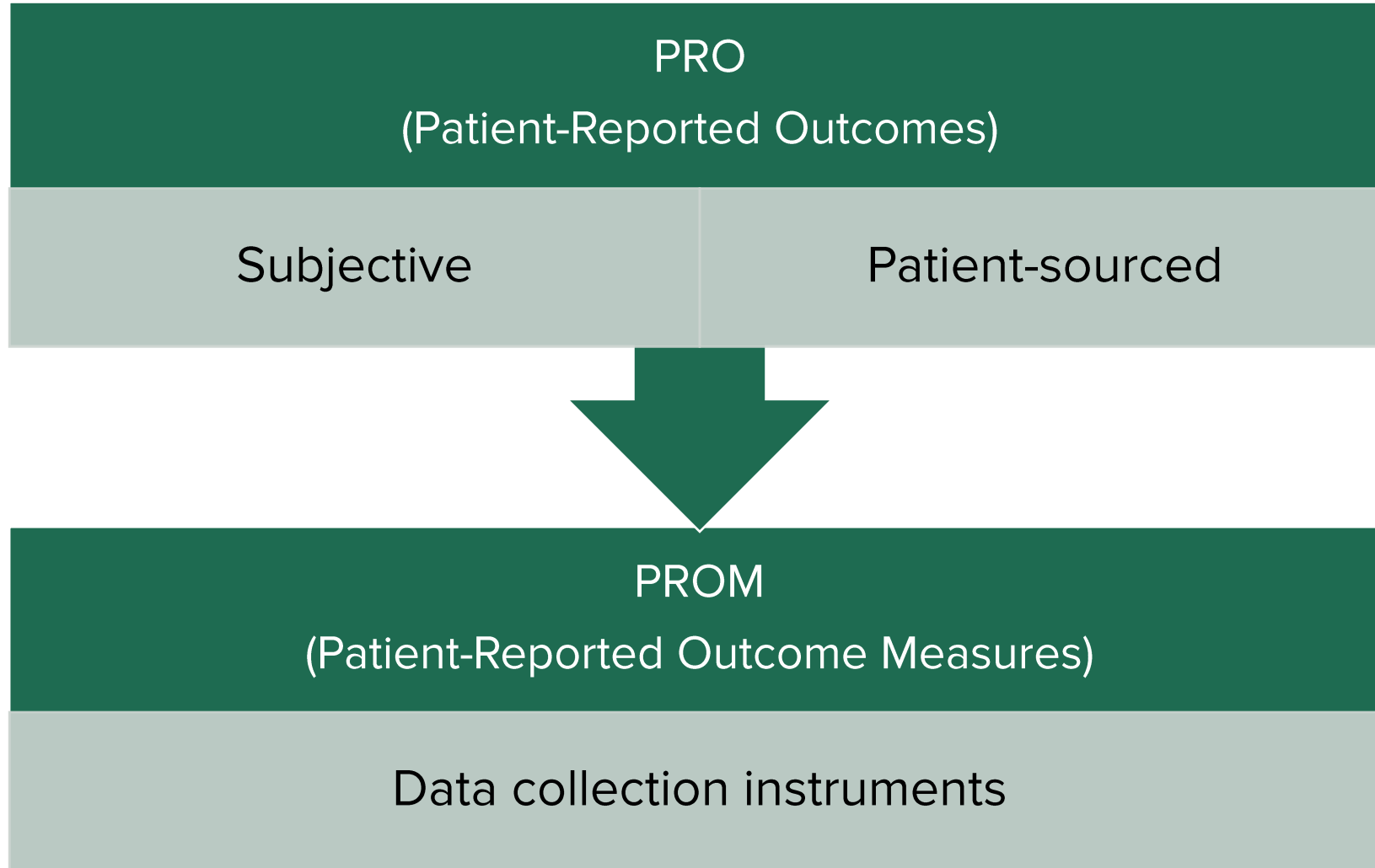
Baseline Fatigue and Overall Survival in other cancers



HR, hazard ratio;
HRPC, hormone-refractory prostate cancer;
NSCLC, non-small-cell lung cancer.

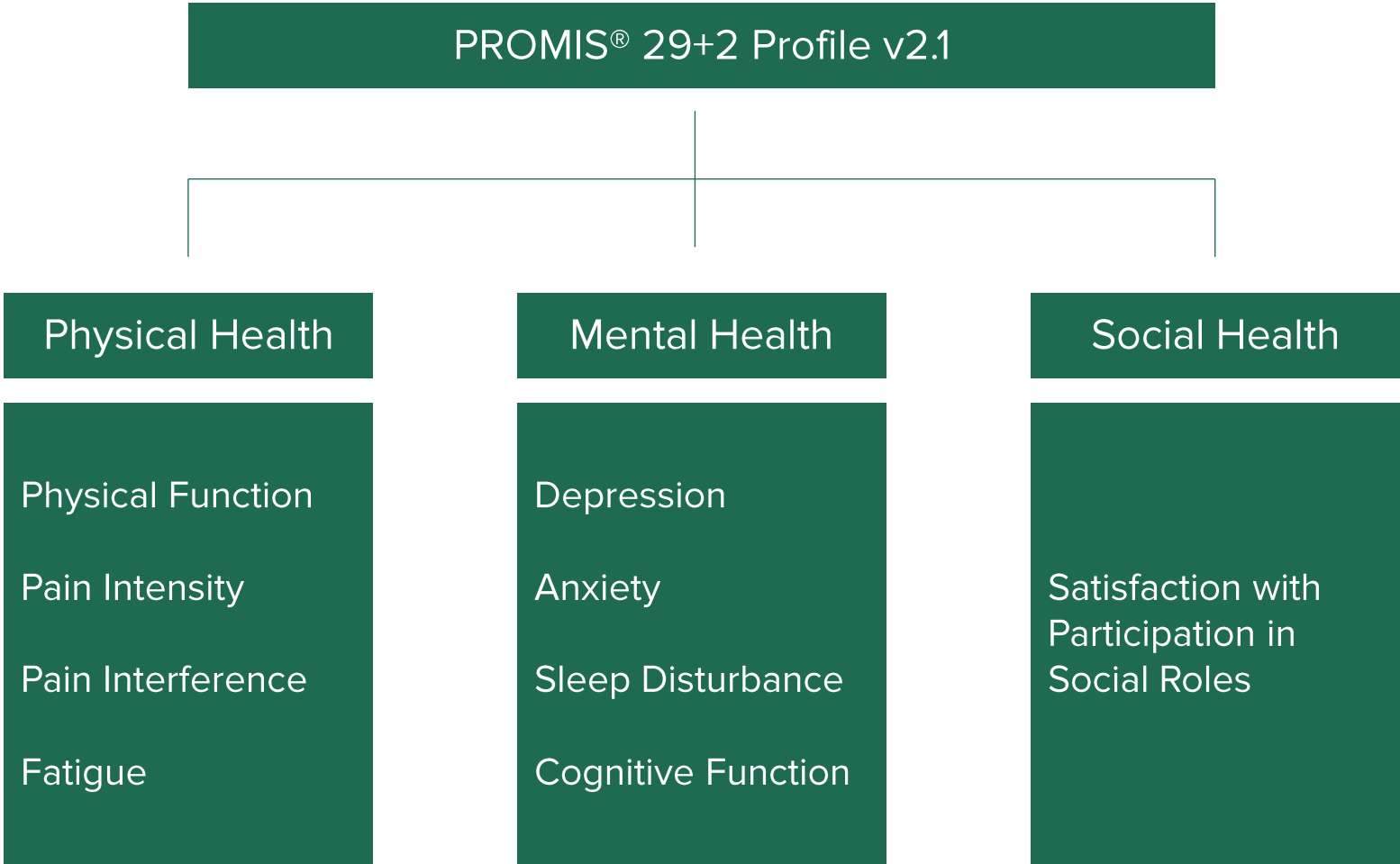
(Mo J et al, JCO Oncol Pract., 2021)

Patient Reported Outcomes



Patient Reported Outcomes Measurement Information System (PROMIS®)

- National institute of Health developed PROM
- Widely applicable
- Efficient
- Reliable



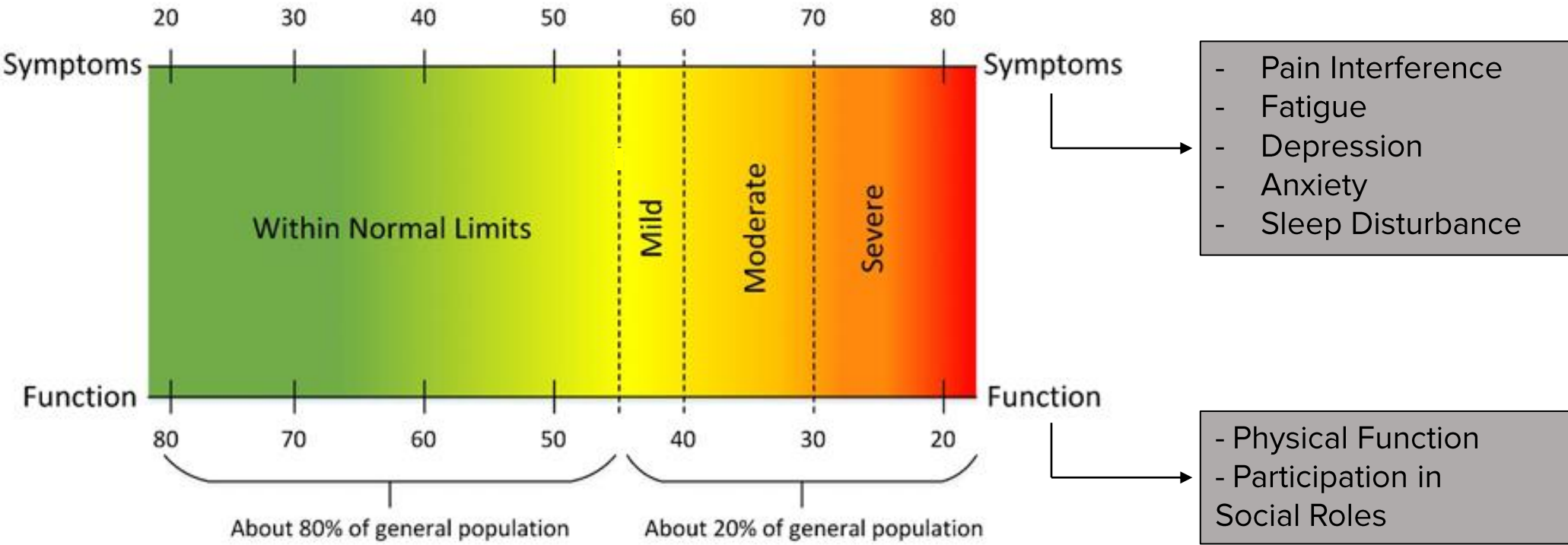
PROMIS® 29+2 Profile v2.1 (PROPr)

Please respond to each question or statement by marking one box per row.

<u>Physical Function</u>		Without any difficulty	With a little difficulty	With some difficulty	With much difficulty	Unable to do
PFA11	Are you able to do chores such as vacuuming or yard work?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA21	Are you able to go up and down stairs at a normal pace?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA23	Are you able to go for a walk of at least 15 minutes?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
PFA53	Are you able to run errands and shop?.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1
<u>Anxiety</u> <u>In the past 7 days...</u>		Never	Rarely	Sometimes	Often	Always
EDANX01	<u>I felt fearful.....</u>	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input checked="" type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX40	I found it hard to focus on anything other than my anxiety	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX41	My worries overwhelmed me.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
EDANX53	I felt uneasy	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

<https://www.healthmeasures.net>

PROMIS® T-Score Interpretation

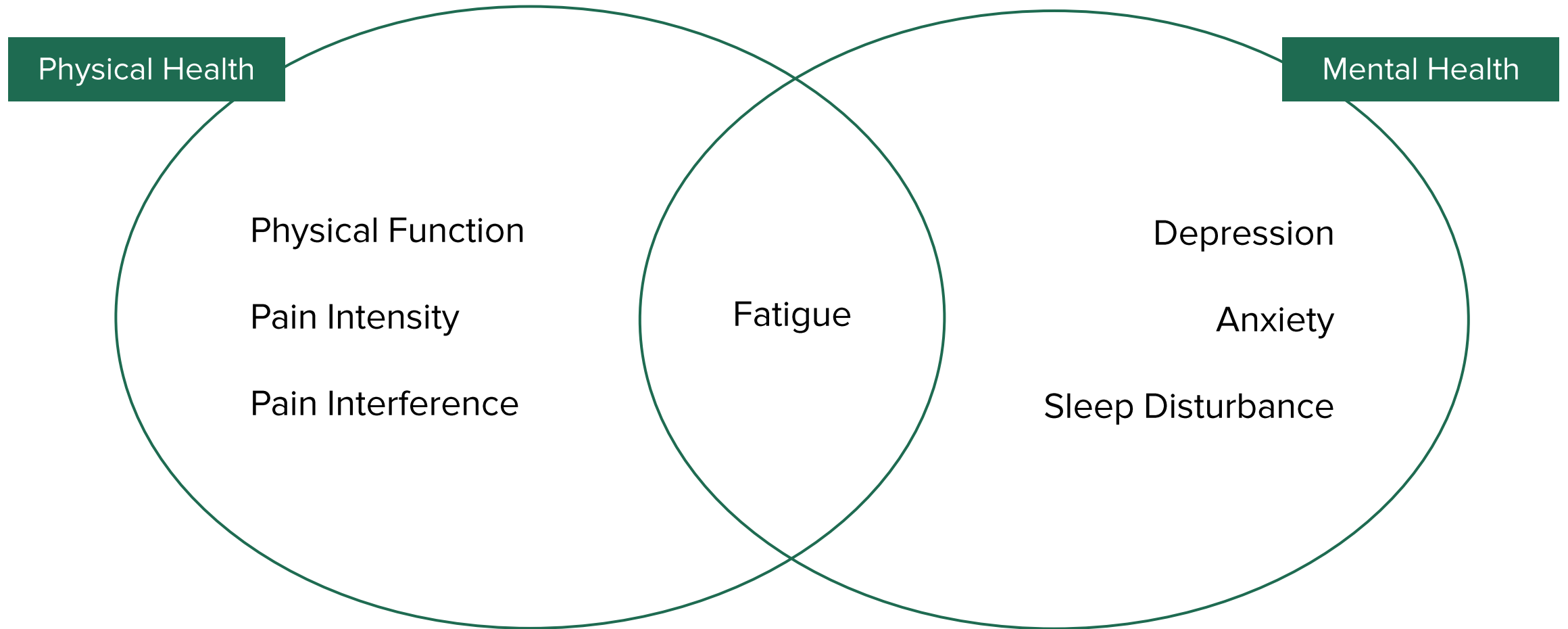


For each domain, mean deviation of ± 3 was considered clinically significant

*These are general guidelines to aid in interpreting PROMIS T-scores. Within a given condition or PROMIS domain, thresholds may differ.

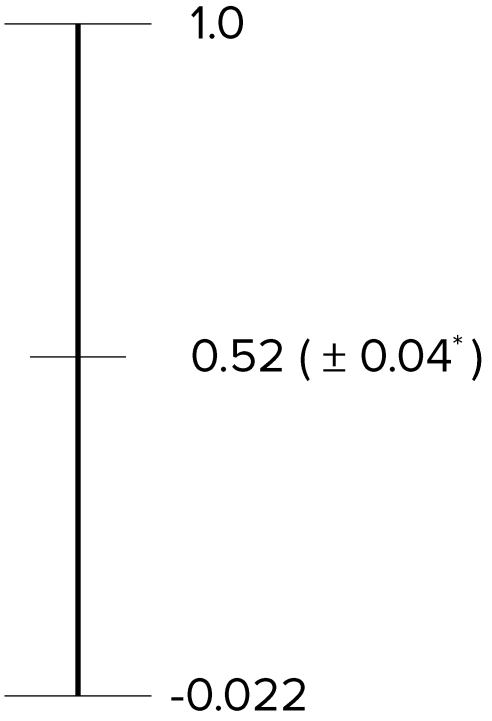
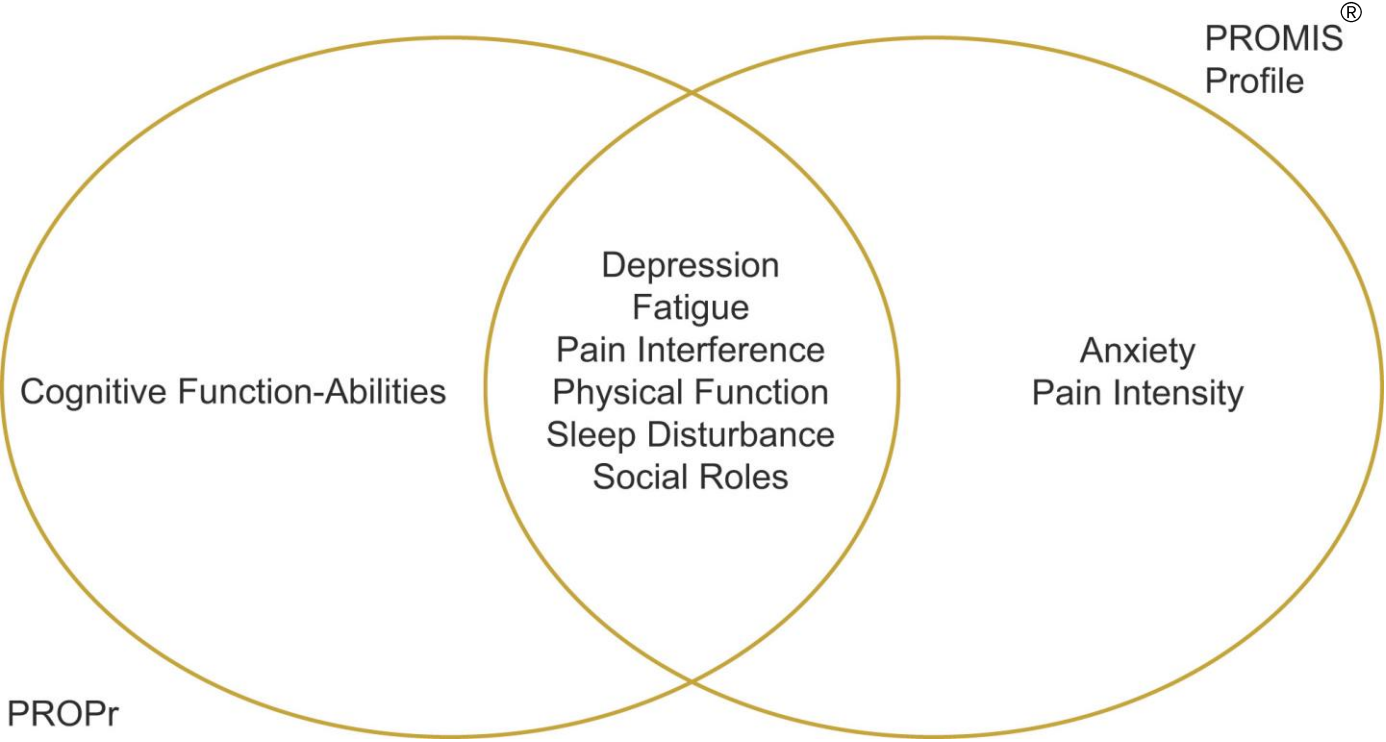
(Sturgill D et al, Kidney Dis (Basel), 2020)
(Jensen R et al, J Clin Oncol., 2017)

Summary Scores



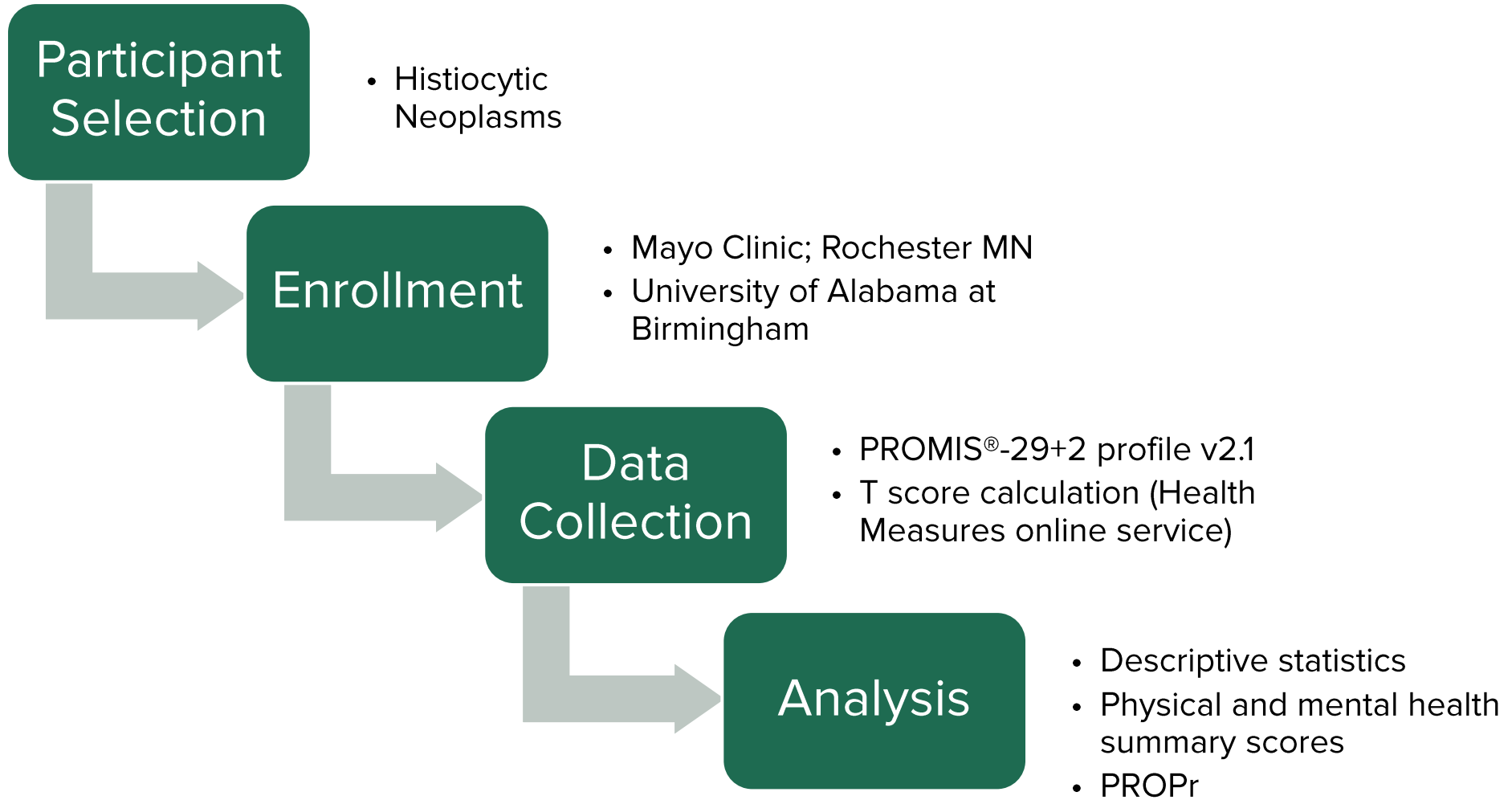
(Hays R et al, Qual Life Res., 2018)

PROMIS-Preference (PROPr)



(Dewitt B et al, Med Decis Making., 2018)

Methods

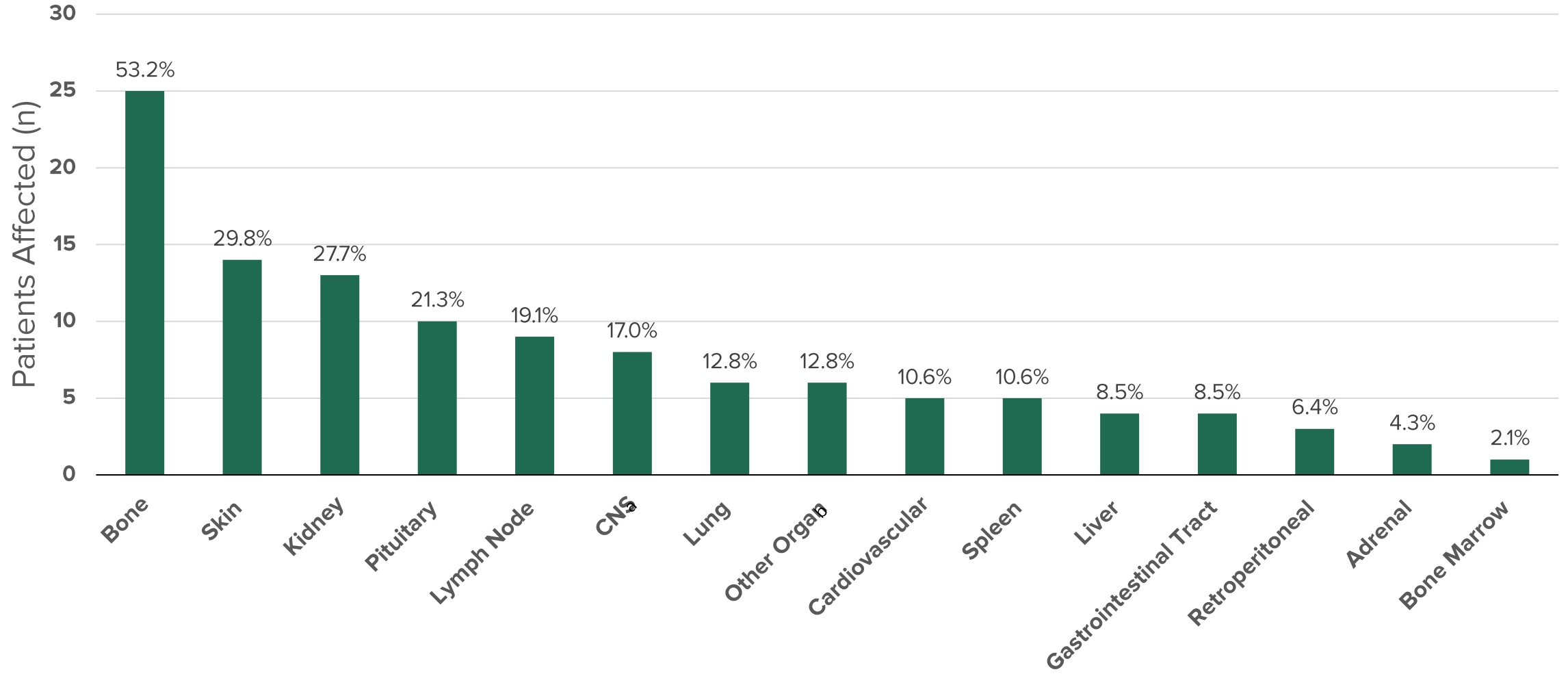


Demographic Characteristics N=47

Variable	Patients, n (%)
Age at diagnosis, median (range)	49 (9-79)
Age at survey completion, median (range)	52 (18-82)
Female Sex	25 (53.2)
Ethnicity	
Non-Hispanic White	29 (61.7)
Black or African American	7 (14.9)
Hispanic	3 (6.4)
Unknown or other	8 (17.0)
Diagnosis	
ECD	13 (27.7)
LCH	18 (38.3)
RDD	15 (31.9)
ECD/LCH Overlap	1 (2.1)
Disease Extent	
Unifocal	9 (19.1)
Single System Multifocal	6 (12.8)
Single System Lung	2 (4.3)
Multisystem	30 (63.8)

ECD = Erdheim-Chester disease; LCH = Langerhans cell histiocytosis ; RDD = Rosai-Dorfman disease

Organ Involvement

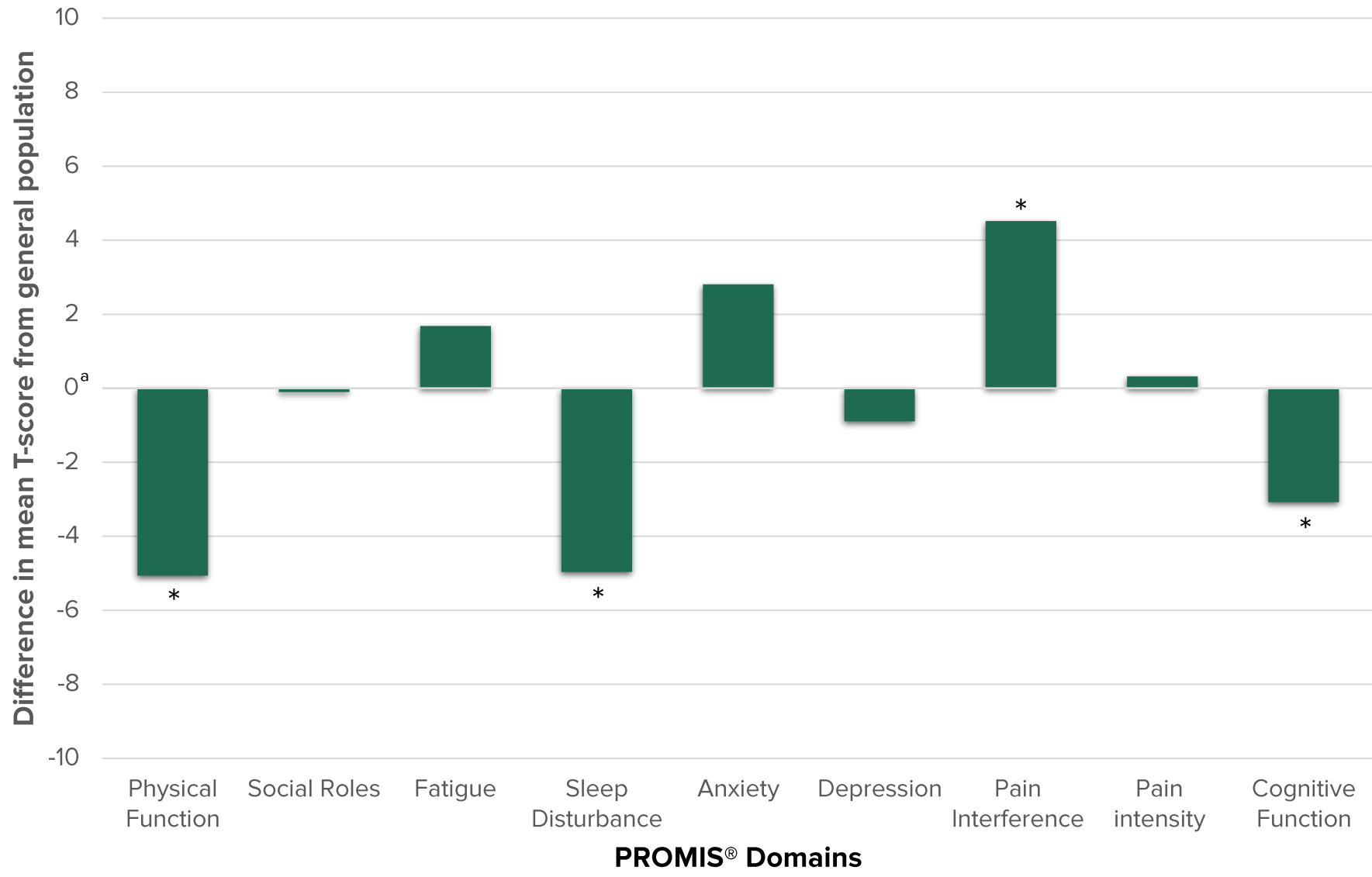


CNS^a = Central Nervous System excluding pituitary

Other organ^b = omentum, sinus and eye

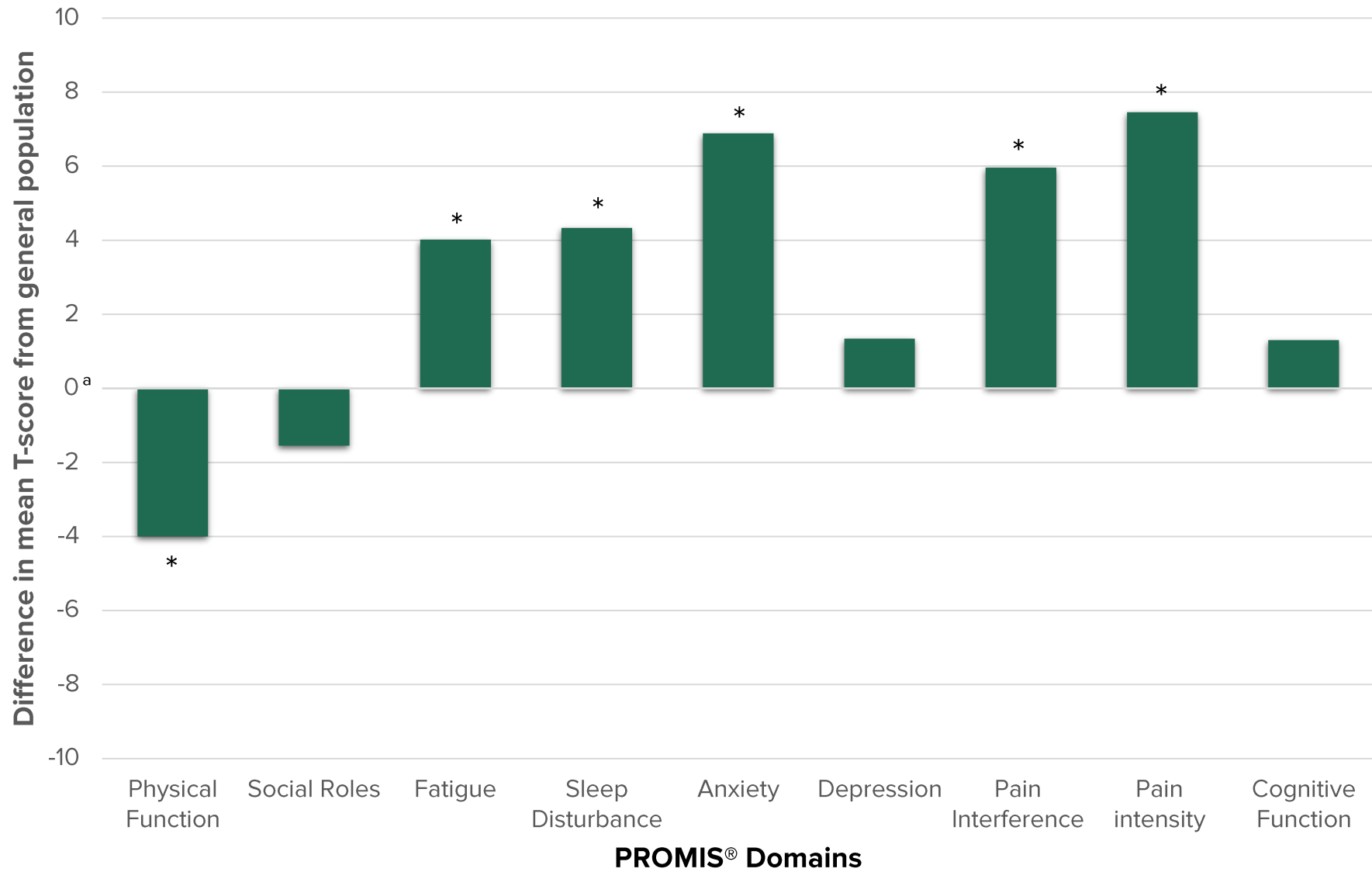
Organ Type

PROMIS® Scores in Erdheim-Chester Disease



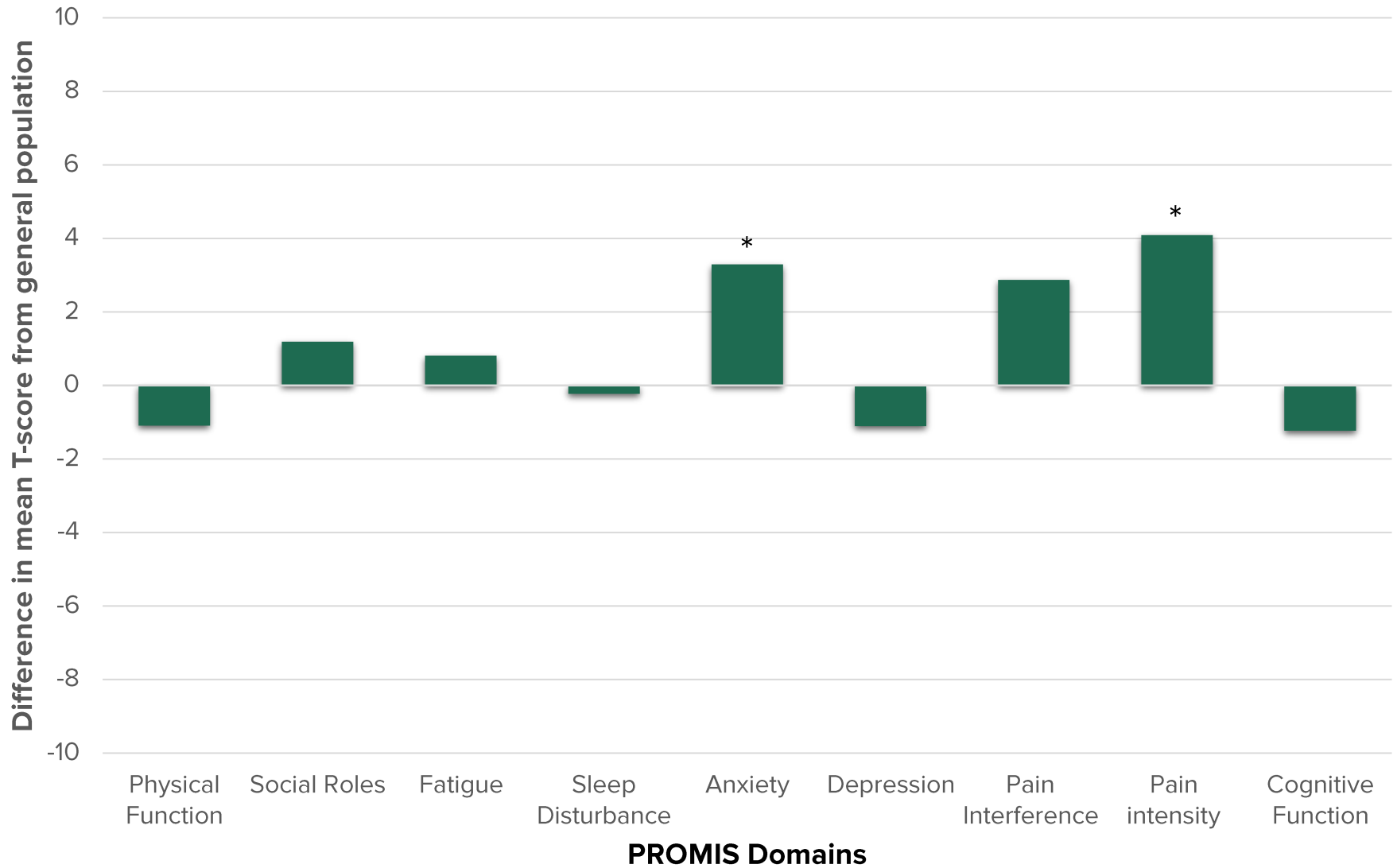
0^a = mean population T-score 50

PROMIS® Scores in Langerhans Cell Histiocytosis



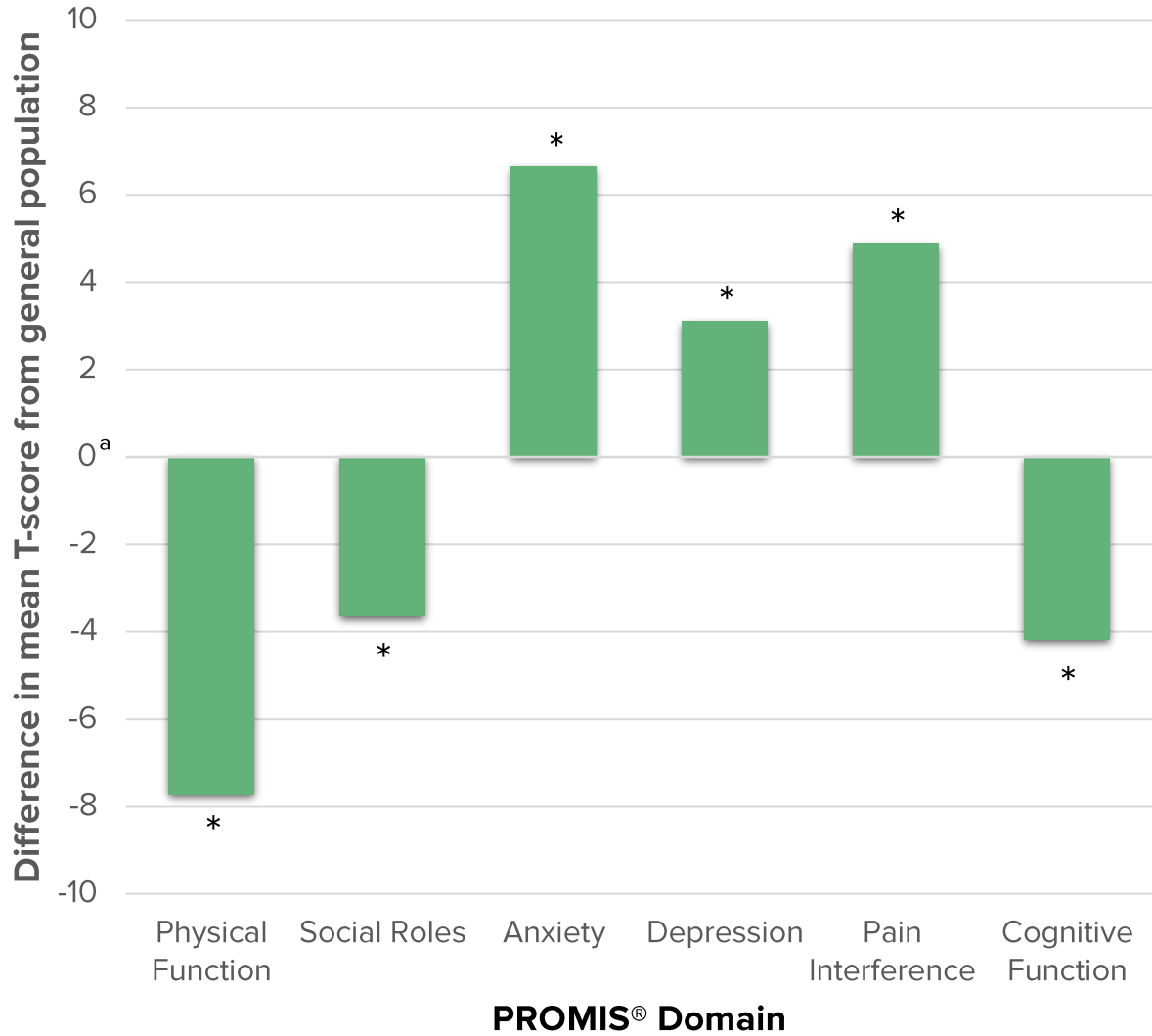
0^a = mean population T-score 50

PROMIS® Scores in Rosai-Dorfman Disease

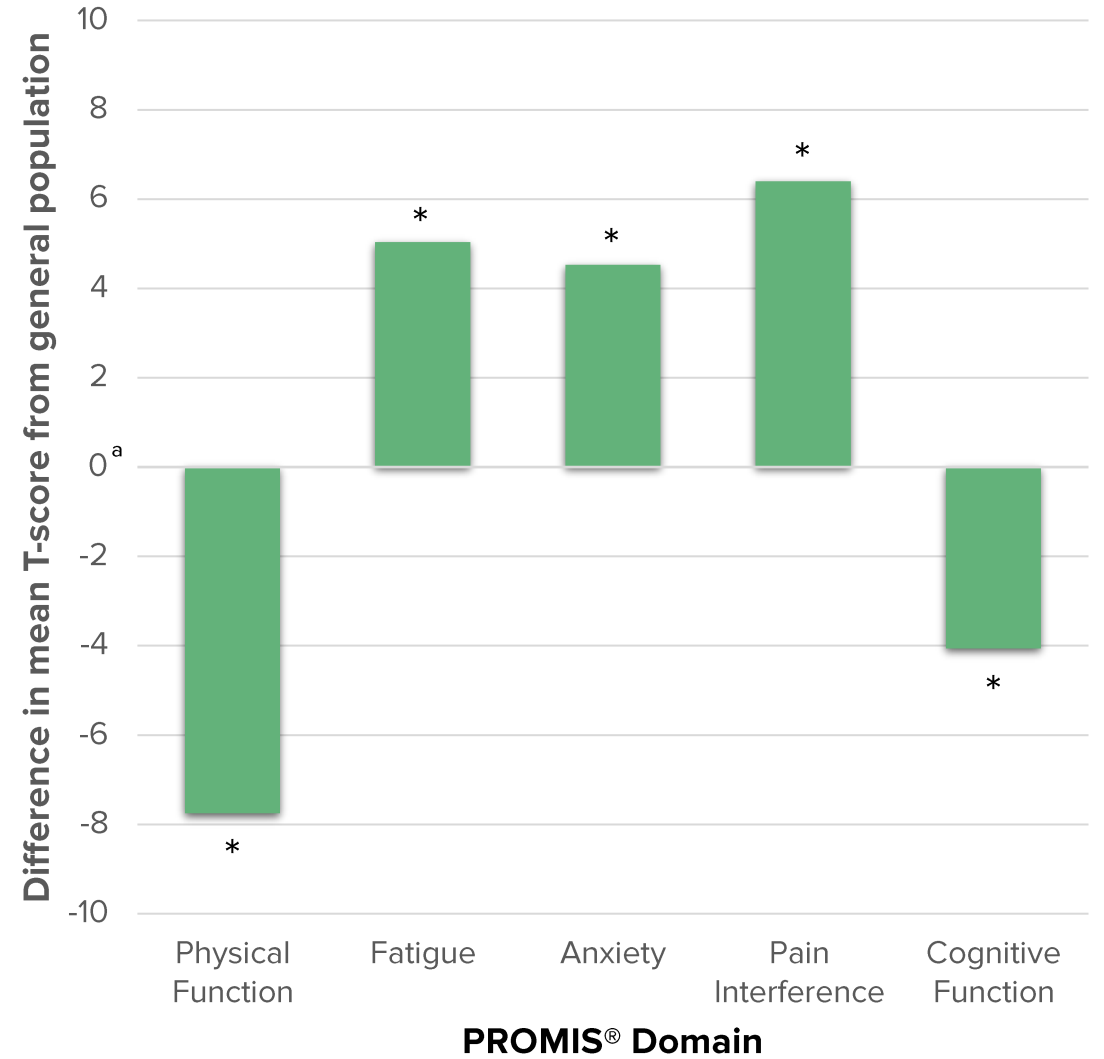


0^a = mean population T-score 50

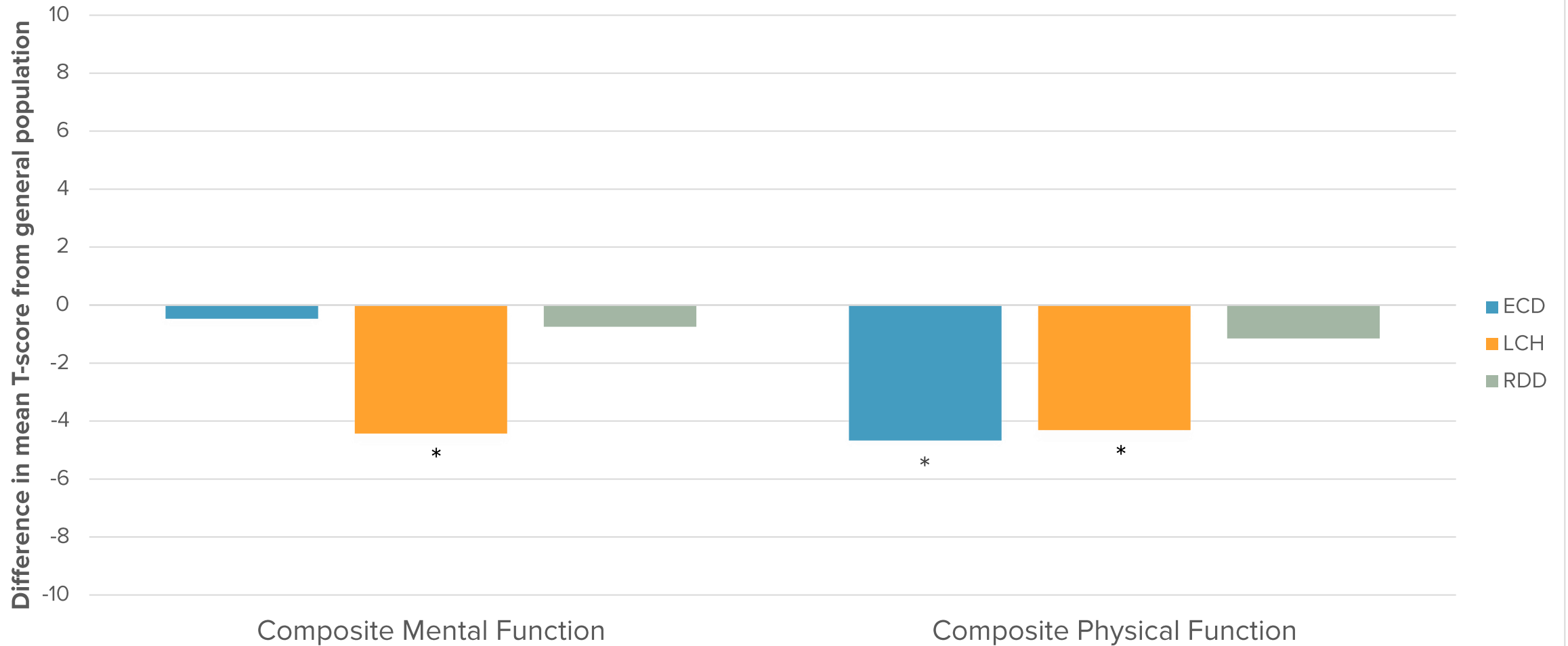
PROMIS® Scores for CNS (non-pituitary)



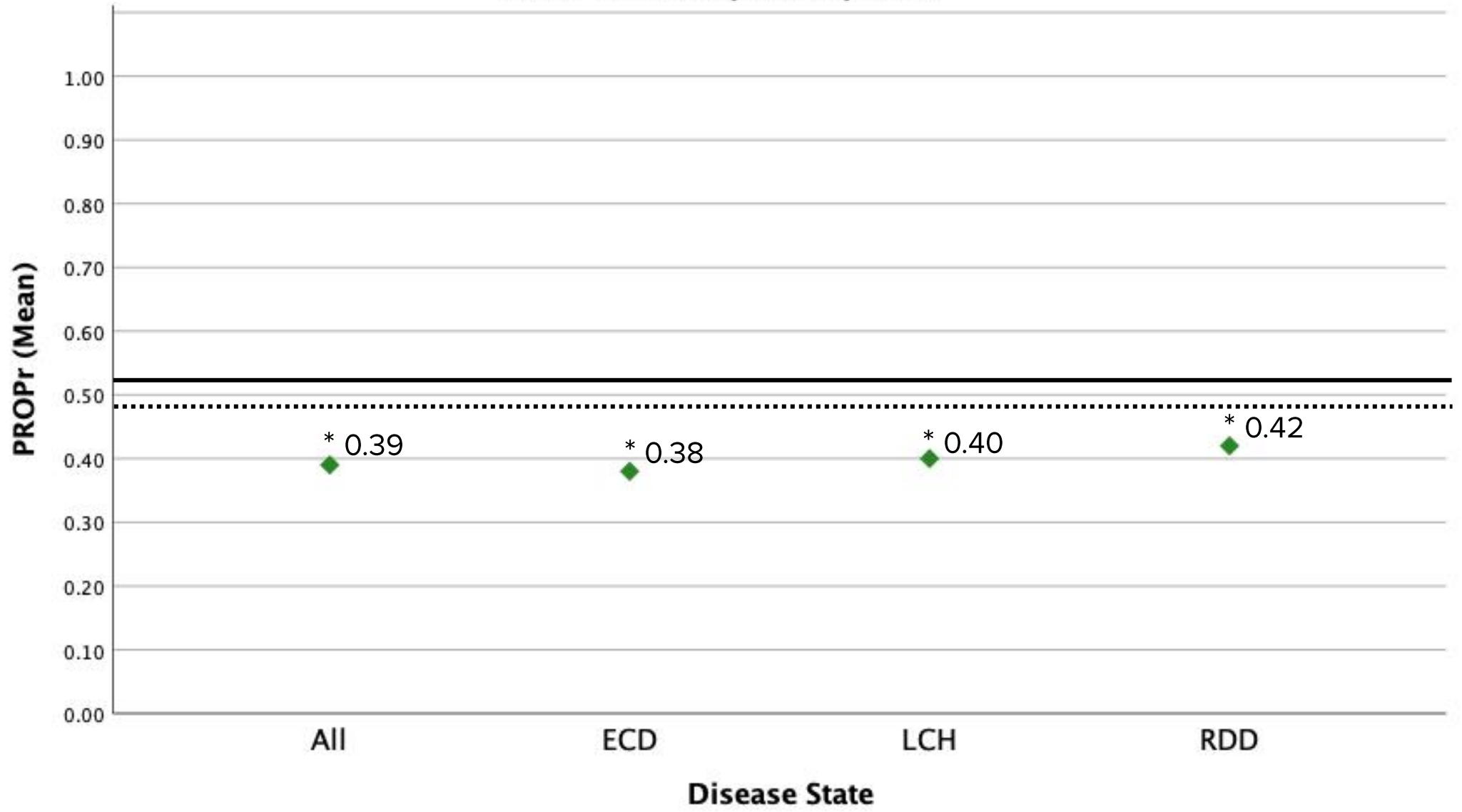
PROMIS® Scores for Pituitary



PROMIS® Summary Scores



PROPr in Histiocytic Neoplasms



Conclusions and Next Steps

- People with histiocytic neoplasms report impaired HRQOL
- PROMIS domains associate with disease subtype and organ involvement
- Expanded study enrollment and longitudinal data is needed
- Future study includes impact of chronic health conditions, disease status, and treatment effects

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Thank you!

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- Figure 2 Wilson and Cleary (1995) model of health-related quality of... ResearchGate. Accessed March 27, 2023. https://www.researchgate.net/figure/Wilson-and-Cleary-1995-model-of-health-related-quality-of-life-Note-Reproduced-with_fig2_362697354
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