Priority Rankings of Patient-Reported Outcomes for Pancreatic Ductal Adenocarcinoma: A Comparison of Patient and Physician Perspectives

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ABSTRACT

Background: Pancreatic ductal adenocarcinoma (PDAC) is associated with high symptom burden. However, treatment decisions currently depend heavily on physician interpretation of clinical parameters and may not consider patients' health preferences. The NIH Patient-Reported Outcomes Measurement Information System (PROMIS) initiative standardized a set of patient-reported outcomes for use in chronic diseases. This study identifies preference rankings among patients with PDAC and physicians for PROMIS domains and compares the priorities of patients and their providers. **Methods:** We condensed the 96 NIH PROMIS adult domains into 31 domains and created a Maximum Difference Scaling questionnaire. Domain preference scores were generated from the responses of patients with PDAC and physicians, which were compared using Maximum Difference Scaling software across demographic and clinical variables. **Results:** Participants included 135 patients with PDAC (53% male; median age, 68 years) and 54 physicians (76% male; median years of experience, 10). Patients selected physical functioning (PF) as their top priority, whereas physicians identified pain as most important. PF, ability to perform activities of daily living, and symptom management were within the top 5 domains for both patients and physicians, and varied only slightly across age, sex, and ethnicity. However, several domains were ranked significantly higher by patients than by physicians, including but not limited to PF; ability to do things for yourself, family, and friends; ability to interact with others to obtain help; and sleep quality. Physicians ranked pain, anxiety, and depression higher than patients did. **Conclusions:** Our findings suggest that patients with PDAC value PF and engaging in daily and social activities the most, whereas physicians prioritize symptoms such as pain. Patient-reported outcomes need to become more integrated into PDAC care and research to better identify unmet patient needs, inform treatment decisions, and develop therapies that address outcomes valued by patients.

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Background

Pancreatic ductal adenocarcinoma (PDAC) is one of the most lethal cancers in the United States, with a 5-year survival rate of approximately 9%.¹ Pancreatic cancer currently represents the third leading cause of cancer mortality in the United States and is expected to become the second leading cause of cancer-related death by 2030.² Because of the often asymptomatic nature of PDAC during early stages, 80% to 90% of patients with PDAC have unresectable tumors at presentation, with therapeutic options that are noncurative and often accompanied by serious toxicities and symptoms.^{3,4} The high disease burden of PDAC notably affects the health-related quality of life (HRQoL) of patients, making it essential for patient preferences and goals to be adequately considered when treatment decisions are made.⁵

Historically, priorities in oncology emphasized clinical outcomes and the evaluation of tumor response based on physician interpretation of parameters such as laboratory values, tumor markers, and imaging. It is increasingly recognized that these clinically oriented metrics used to assess efficacy in clinical trials do not reflect the patient's lived experience of their illness and treatments.^{6–8} Consequently, patient-reported outcomes (PROs) have increased in importance because of their ability to capture outcomes important to patients, such as impact of treatment adverse effects on daily functioning, emotional well-being, health perceptions, and satisfaction with care.^{9,10}

In the 1980s, the still widely used EORTC Quality of Life Questionnaire (QLQ-C30) and the Functional Assessment of Cancer Therapy–General (FACT-G) questionnaire were developed.^{11,12} These questionnaires were developed without formal patient involvement and cover markedly different aspects of HRQoL, with the EORTC QLQ-C30 emphasizing physical domains more than the

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FACT-G questionnaire.^{11–13} Because multiple PRO instruments exist, the comparability of PRO data across patient care and research is suboptimal. To address these shortcomings, the NIH initiated the Patient-Reported Outcomes Measurement Information System (PROMIS) program in 2004 to standardize PRO item banks, resulting in the development of 96 PROMIS adult domains assessing aspects of patient-reported physical, mental, and social health.^{14,15} However, because PROMIS domains were developed for use in any disease or clinical population, the spectrum of health domains included may have varying relevance to patients with PDAC as opposed to other chronic conditions. Furthermore, studies have established that patients with cancer with shorter estimated survival times, such as those with PDAC, report greater limitations in their ability to work, poorer mental health, more fatigue, and overall greater burden than patients with other cancer types.^{16,17} Despite the distinct burdens of patients with PDAC, it is still poorly understood which domains of the PROMIS item banks are prioritized by these patients. After a 2016 study of patients with pancreatic cancer reported differences in the health values of patients and their healthcare providers, it became crucial to identify and address the specific inconsistencies in the health priorities of patients with PDAC and their providers.¹⁸

The purpose of this study was to establish the highest-priority PROMIS domains for patients with PDAC and compare the priorities among patients with PDAC and physician providers. By developing a focused tool for patients with PDAC using previously validated domains from the PROMIS initiative, we contrasted these patients' reports with those of other clinical populations and hoped to increase the consistency and efficiency of PRO use in both clinical care and novel therapy development for PDAC. We also hoped to identify improvement areas for achieving more patient-centered care across this disease population.

Methods

Participants

With Cedars-Sinai Medical Center Institutional Review Board approval, we identified patients with histologically confirmed PDAC receiving care between June 2017 and June 2019 and gained their consent to participate in the survey. Only English-speaking patients aged >18 years were included.

PDAC physician specialists at sites belonging to the Pancreatic Cancer Action Network Precision Promise Clinical Trial Consortium and additional institutions across the United States and Canada were identified and recruited through electronic communication. Medical, radiation, and surgical oncologists and gastroenterologists and palliative care specialists who treated or managed patients with PDAC as part of their clinic in the past or

present were included. A complete list of the 35 contacted academic and medical centers is provided in supplemental eTable 1, available with this article at JNCCN.org.

Patients with PDAC and physicians received identical questionnaires. Surveys were self-administered at a single time point. For each patient, demographic and clinical data, including age, sex, race/ethnicity, and disease status (unresectable or resectable), were recorded from the electronic health records. For physicians, a self-reported section asking for the physician's sex and number of years of physician experience with PDAC was included. Additional information regarding the physician's institution was separately recorded by study staff. Patients completed the survey on a tablet, whereas physicians completed it through an email link.

Survey Development

Each of the 96 adult PRO domains from the PROMIS initiative were considered in the study's "PancPROMIS" survey, informed by the literature and previously established core outcome sets for pancreatic cancer and a consensus-based approach.^{19,20} Using a consensus-based approach, 2 medical oncologists (A.S. and A.E.H.) specializing in the care of patients with PDAC independently screened the 96 PROMIS domains for adults to evaluate relevancy to PDAC (Figure 1).²¹ Overlapping domains were grouped and summarized as displayed in supplemental eTable 2. PRO domains identified as infrequent or overly specific, including substance abuse (alcohol, smoking) and itching, were excluded. Any discrepancies in selection of PROMIS domains were resolved through discussion at weekly meetings, and additional discrepancies were resolved by a third investigator (V.R.P.H.). The final PancPROMIS survey included 31 domains across 4 categories: global health (1 domain), mental health (11 domains), physical health (12 domains), and social health (7 domains) (supplemental eFigure 1). Maximum Difference Scaling (MaxDiff) software (Lighthouse Studio, Sawtooth Software) was used to create the final survey. The 31 PRO domains were displayed in a series of 20 questions generated by the MaxDiff software, with each domain appearing 3 or 4 times as determined by the software algorithm. For each question, participants were given a list of 5 PROMIS domains and asked, "Please choose the most important aspect/domain and the least important aspect/domain of HRQoL when assessing someone with pancreatic cancer" (supplemental eFigure 2).

Statistical Analysis

Descriptive analyses were reported to characterize the patient and physician populations. Demographic and clinical factors were expressed appropriately as continuous (means and standard errors [SEs]) or categorical variables (frequencies and percentages). Preference scores for each

Figure 1. Flowchart of study procedures.

Abbreviations: MaxDiff, Maximum Difference Scaling; PanCAN, Pancreatic Cancer Action Network; PDAC, pancreatic ductal adenocarcinoma; PRO, patient-reported outcome; PROMIS, Patient-Reported Outcomes Measurement Information System.

of the 31 PRO items were generated and ranked separately for physicians and patients using the MaxDiff software.

Preference scores were analyzed using MaxDiff, a type of conjoint analysis, via Lighthouse Studio software.¹⁸ MaxDiff analysis is a standard method used to rank patient preferences based on an individual's responses to a series of questions that involve selecting a single preference from among a list of options. The survey consisted of 31 items and 5 items per set, with a total of 20 sets.

Logit modeling was used to generate individual-level preference scores for each of the 31 PRO domains for patients and physicians, based on their cumulative responses. MaxDiff analysis was run for patients grouped based on age, sex, disease status, and race/ethnicity. Physicians were grouped together based on sex, specialty, years of experience treating patients with PDAC, institution type, and institution region. Preferences were reported separately for patients and physicians and by each of the previously listed variables. Rescaled scores using 0 to 100 scoring were computed to allow comparison of preferences. For example,

an item with a score of 10 is twice as important/preferred as an item with a score of 5. Raw scores and SEs were also exported from the Lighthouse Studio software, and differences in means were calculated using *t* tests for 2 independent samples and simple linear regression.

Results

Of 328 patients screened, a total of 135 eligible patients with PDAC who were treated at Cedars-Sinai Medical Center completed this research survey between June 2017 and April 2019 (Figure 1). Participant characteristics of patients and physicians are shown in Table 1. Participants included 71 male (52.6%) and 64 female (47.4%) patients (mean and median, 68 years; range, 37–95 years). Of the 98 physicians contacted, 54 (55.1%) completed the online survey, including 41 male and 13 female physicians from 25 institutions (Table 1 and supplemental eTable 1).

Preference scores for patients and physicians for each domain are presented in Table 2 and Figure 2. The top-ranked domain for patients was “ability to be

Table 1. PancPROMIS Survey Patient and Physician Demographics and Clinical Data

Characteristic	n (%)
Patients with PDAC (n=135)	
Sex	
Female	64 (47.4)
Male	71 (52.6)
Age, y	
<60	29 (21.5)
60–69	46 (34.1)
70–79	44 (32.6)
≥80	16 (11.8)
Race/Ethnicity	
Non-Hispanic white	95 (70.4)
Asian	17 (12.6)
Hispanic	12 (8.9)
Black	8 (5.9)
Other	3 (2.2)
Disease status	
Resectable	44 (32.6)
Unresectable	91 (67.4)
PDAC physicians (n=54)	
Sex	
Male	41 (75.9)
Female	13 (24.1)
Physician specialty	
Medical oncology	34 (63)
Radiation oncology	2 (3.7)
Surgical oncology	9 (16.7)
Gastroenterology	7 (12.9)
Palliative care	2 (3.7)
Years treating patients with PDAC	
1–5	11 (2.4)
6–10	18 (33.3)
11–15	9 (16.7)
≥16	14 (2.6)
NR	1 (1.9)
Institution type	
Academic	52 (96)
Nonacademic	2 (4)
Institution region	
West Coast, United States	30 (55.6)
East Coast, United States	10 (18.5)
Midwest, United States	2 (3.7)
South, United States	6 (11.1)
Canada	6 (11.1)

Abbreviations: NR, not reported (missing response from one participant); PDAC, pancreatic ductal adenocarcinoma.

physically functional” (physical functioning [PF] domain), with a mean preference score of 0.48 (SE, 0.12) and rescaled value of 7.49, whereas the lowest-ranked domain was “anger,” with a mean preference score -2.81 (SE, 0.13) and rescaled value of 0.57. PF was thus ranked 15 times as important as anger among patients. Among physicians, “pain and its effect on life” was ranked highest (mean, 0.70; SE, 0.20) with a rescaled value of 8.32, and “sexual satisfaction and functioning” was ranked lowest (mean, -3.58 ; SE, 0.22) with a rescale score of 0.32 (Table 2).

Pain ($P<.001$), anxiety/fear ($P=.001$), and depression/sadness ($P<.001$) were ranked significantly higher in importance by physicians than by patients. PF ($P<.05$); ability to do things for yourself, family, and friends ($P<.049$); ability to interact with others to obtain help ($P=.006$); and sleep quality ($P<.001$) were among some of the domains ranked significantly higher by patients than by physicians. Among the domains ranked similarly by physicians and patients are fatigue and its impact on functioning ($P=.442$), ability to manage recommended medications and treatments ($P=.412$), and diarrhea ($P=.279$), which are domains important for patients in their HRQoL through day-to-day activities and for providers as a means of assessing clinical improvement or response to various interventions. Additional comparisons in mean priority scores between patients and physicians are displayed in Figure 3.

Overall, PF was ranked highest by patients across most subgroups, including sex and age and among non-Hispanic white patients (supplemental eTable 3). The social and mental aspects of health, including the ability to perform daily activities, participate in work and social activities, do things for oneself, and ability to manage symptoms, were among the top 5 ranked preferences of all patients ($n=135$) and in adults aged <65 years, women, men, and white patients. General well-being was among the top 5 ranked items by men, Hispanic patients, and Asian patients, whereas sleep quality appeared in the top 5 ranked items only for Asian patients. Physicians rated pain and its effect on life to be most important, followed by the ability to perform daily activities (mental), ability to manage symptoms (mental), ability to be physically functional (physical), and general well-being (general) (supplemental eTable 3).

Discussion

To our knowledge, this is the first study reporting PDAC-specific patient and physician rankings of the priorities of the NIH’s PRO domains as determined for 135 patients with PDAC and 54 PDAC physician specialists. This study compares the variations in the health priorities of patients with PDAC and their providers, specifically the importance patients placed on PF and autonomy to perform daily and social activities, as opposed to PDAC physicians’ current emphasis on pain. These findings can inform

Table 2. Preference Scores and Rankings by Patients With PDAC and Physicians

PRO Domain	Dimension	Patient Score (Rank)	Physician Score (Rank)	P Value ^{a,b}
Ability to be physically functional	Physical	7.49 (1)	6.35 (4)	.047
Ability to perform daily activities	Mental	6.75 (2)	7.45 (2)	.268
Ability to participate in work and interactions with family/friends	Social	6.73 (3)	5.74 (6)	.059
Ability to do things for yourself, family, and friends	Social	6.63 (4)	5.59 (7)	.049
Ability to manage symptoms	Social	5.83 (5)	7.20 (3)	.082
General well-being	General	5.81 (6)	6.11 (5)	.050
Pain and its effect on life	Physical	5.53 (7)	8.32 (1)	<.001
Fatigue and its impact on functioning	Physical	4.56 (8)	4.81 (8)	.442
Ability to interact with other people to get medical help or information that I need	Mental	3.91 (9)	2.68 (16)	.006
Belly pain	Physical	3.24 (10)	4.63 (9)	.062
Sleep quality	Physical	3.22 (11)	1.00 (25)	<.001
Positive impact of cancer on sense of self and life	Mental	3.16 (12)	1.65 (21)	<.001
Access to someone for advice or information when needed	Social	3.16 (13)	2.00 (20)	.003
Ability to manage recommended medications and treatments	Mental	3.15 (14)	3.34 (13)	.412
Negative impact of cancer on sense of self and life	Mental	2.70 (15)	2.99 (14)	.485
Nausea and vomiting	Physical	2.68 (16)	3.57 (12)	.166
Difficulty with cognition	Mental	2.62 (17)	1.53 (23)	.001
Shortness of breath and its impact on functioning	Physical	2.48 (18)	1.61 (22)	.005
Access to someone to help with tasks if needed	Social	2.46 (19)	2.61 (17)	.392
Ability to handle negative emotions and feelings	Mental	2.11 (20)	2.90 (15)	.160
Gastrointestinal reflux symptoms	Physical	2.01 (21)	0.36 (30)	<.001
Access to someone who meets emotional needs	Social	1.89 (22)	2.53 (18)	.200
Isolation/Connectedness to others	Social	1.69 (23)	2.48 (19)	.110
Constipation	Physical	1.65 (24)	0.51 (29)	<.001
Anxiety or fear	Mental	1.63 (25)	3.90 (11)	.001
Depression or sadness	Mental	1.51 (26)	4.13 (10)	<.001
Gas and bloating	Physical	1.46 (27)	0.63 (28)	<.001
Difficulty with swallowing	Physical	1.43 (28)	0.70 (27)	<.001
Diarrhea	Physical	1.35 (29)	1.36 (24)	.279
Sexual satisfaction and functioning	Physical	0.61 (30)	0.32 (31)	<.001
Anger	Mental	0.57 (31)	0.95 (26)	.061

Abbreviations: PDAC, pancreatic ductal adenocarcinoma; PRO, patient-reported outcome.

^at test was used to calculate differences in rescaled raw scores.

^bBold indicates statistically significant *P* values.

PDAC providers regarding ways to achieve more patient-centered care, and facilitate the design of PDAC trials that address outcomes identified as important by patients.

In the past few decades, there has been increased emphasis on the use of PROs to improve shared

decision-making between patients and physicians. However, there is limited research on the relevancies of the numerous available PROs to patients with PDAC and whether these align with what their physicians believe are patient priorities. In a 2016 study that observed

Figure 2. Preference rankings of PRO items among (A) patients with PDAC (n=135), and (B) PDAC physicians (n=54). Abbreviations: PDAC, pancreatic ductal adenocarcinoma; PRO, patient-reported outcome.

Figure 3. Differences in mean preference scores between patients with pancreatic ductal adenocarcinoma and physicians, grouped by domain. SMD=0, no difference in preferences between physicians and patients; SMD>0, physicians scored higher than patients; SMD<0, patients scored higher than physicians. The dotted red line indicates overall SMDs in priority scores between patients and physicians. Abbreviations: PROMIS, Patient-Reported Outcomes Measurement Information System; SMD, standardized mean difference.

patients with pancreatic cancer during their care, contradictions were revealed between medical staff preconceptions of patient experiences and what patients reported, including assumptions that long-term survival outcomes are most important for these patients.¹⁸ This study illustrated that discrepancies in health values between patients with PDAC and their providers exist, which we further examined through individual-level guidance from patients and physicians.

In our study, we found that patients placed significantly higher value than physicians on their ability to engage in social interactions and independently do things for themselves and for others. The top 5 patient health priorities included statements beginning with “ability to,” emphasizing patient desires for preserving autonomy and minimizing disease-related disruptions in their lives. Unfortunately, these social health and role function domains are currently understudied and

underused in PDAC.²² In 2013, one of the first pancreatic cancer PRO tools was developed: the Pancreatic Cancer Disease Impact score, which is calculated from 8 health domains of pain, fatigue, anxiety, bowel problems, loss of appetite, dry mouth, itchiness, and nausea.²³ Notably, these items are predominantly disease-related physical symptoms, which have been shown to be lower-priority concerns for patients with PDAC in our study and more recent PRO studies.²⁴ Similarly, the PROMIS questionnaire contains a larger percentage of questions relating to physical health than those concerning mental or social health (supplemental eFigure 1). Furthermore, the 26-question EORTC QLQ-PAN26 assessment tool that was designed to be used in conjunction with the 30-question EORTC QLQ-C30 contains an overwhelming number of questions with emphasis on highly specific physical symptoms that are not of top-priority interest to patients with PDAC.²⁴

Our study also noted that physicians ranked pain, anxiety, and depression of greater importance than patients did, which is consistent with the results of the 2017 Core Set of Patient-Reported Outcomes in Pancreatic Cancer study, which used a Likert scale design to survey patients with pancreatic cancer and providers.²⁰ In our study, pain and its impact on life was ranked highest by physicians, whereas patients ranked it as the sixth most important. Interestingly, pain, anxiety, and depression represent some of the most commonly cited symptoms reported in advanced cancers.²⁵ The benefits of palliative care integration into oncology care, as recommended in the 2016 ASCO clinical practice guideline update, are also becoming more recognized and may also contribute to this increased focus on symptoms such as pain.²⁶ To demonstrate this point, palliative care programs in American hospitals have tripled since 2000.²⁷

Although palliative care often focuses on addressing immediate physical, psychologic, and social distress concerns related to HRQoL, the solutions offered are frequently short term and centered on the management of complex or refractory symptoms.²⁸ Conversely, rehabilitation services focus more on long-term solutions for restoration and optimal function at home, at work, and in the community through interventions addressing the physical, psychologic, and vocation-related impairments that patients with cancer may encounter.^{29,30} Our study showed that PF was ranked as the top priority for patients and a top 5 priority for physicians, revealing a consensus understanding of patients' desires to resume daily activities and self-sufficient lifestyles. Unfortunately, cancer rehabilitation services are still underused, despite numerous studies documenting improvements in general well-being, symptom severity, physical performance status, and HRQoL in patients with advanced cancer with the incorporation of a rehabilitation program.^{18,30–33}

Routine multidisciplinary consultation with services such as supportive care, nutrition, genetic counseling, and social services should also be used to understand each patient's unique perspectives, questions, and concerns. Support and patient advocacy groups can also aid patient understanding of potential treatment-related ramifications and how they may impact domains of importance to patients. A multidisciplinary focus, in addition to services tailored to improving PF and other disease-related processes affecting PF, is necessary to minimize discord between patients and

providers and move toward a more patient-centered, shared-decision-making approach to care.

It should be noted that this study is limited by its single-institution design, cross-sectional nature, imbalances in provider characteristics, and heterogeneity in patients' treatment and disease courses. Expanding this study into a multicenter longitudinal study over multiple time points to capture potential changes in priorities across patients' disease courses and compare across predefined patient characteristics would enhance the generalizability of our findings and further validate these domains. Currently, however, this study has identified opportunities for patient care HRQoL intervention, especially among patients with unresectable PDAC.

Conclusions

Identifying patients priorities is the first step toward encouraging the medical community to recommend these desired multidisciplinary services to colleagues, patients, and families earlier in the continuum of care. Through integration of additional interdisciplinary services in earlier phases of PDAC care, the severity of treatment-related impairments that later develop may be reduced, which is especially relevant to a high-symptom burden disease such as PDAC. Further research on the feasibility of incorporating PROs in pancreatic cancer care is needed so that awareness of unmet patient needs can increase and advances in patient health, function, HRQoL, and satisfaction in care can occur.

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Supplemental online content for:

Priority Rankings of Patient-Reported Outcomes for Pancreatic Ductal Adenocarcinoma: A Comparison of Patient and Physician Perspectives

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eFigure 1: Percentage of PRO Items by NIH PROMIS Category in PancPROMIS Survey

eFigure 2: Sample PancPROMIS Best/Worst Scaling Survey Questions

eTable 1: List of Participating Academic Centers

eTable 2: Evaluated PROMIS Domains

eTable 3: Top 5 Preferences Among Patients With PDAC and Physicians

eFigure 1. Percentage of PRO items by NIH PROMIS category in PancPROMIS survey.
Abbreviations: PRO, patient-reported outcome; PROMIS, Patient-Reported Outcomes Measurement Information System.

Please choose the **most** important aspect/domain and the **least** important aspect/domain of quality of life when assessing someone with pancreatic cancer
(5 of 20)

Most Important		Least Important
☒	Pain and its effect on life	☐
☐	Access to someone to help with tasks if needed	☐
☐	Anger	☒
☐	Ability to be physically functional	☐
☐	Depression or sadness	☐

Click the forward arrow to continue...

eFigure 2. Sample PancPROMIS best/worst scaling survey questions.

eTable 1. List of Participating Academic Centers

List of Contacted Centers	Number of Physicians Respondents/Number Contacted
Cedars-Sinai Medical Center	15/19
City of Hope National Medical Center	2/7
Dana-Farber Cancer Institute	0/1
Duke University Medical Center	0/1
Fox Chase Cancer Center	1/1
George Washington University	0/1
Johns Hopkins University	2/3
Kaiser Permanente (Southern California)	1/1
Karmanos Cancer Center (Wayne State University)	1/1
Massachusetts General Hospital Cancer Center	0/2
MD Anderson Cancer Center	1/3
Memorial Sloan Kettering Cancer Center	3/3
Moffitt Cancer Center	0/1
Northwestern University	1/1
New York University	2/2
Ohio State University	0/1
Ottawa Hospital	4/5
Stanford University	0/1
University of Washington	2/3
University of California, Davis	1/2
University of California, Irvine	0/1
University of California, Los Angeles	2/5
University of California, San Diego	2/8
University of California, San Francisco	3/3
University of Chicago	0/2
University of Florida	2/2
University of British Columbia	2/3
University of Calgary	0/1
University of Pennsylvania	2/2
University of Utah	0/1
Vanderbilt University	1/1
Verity Health	2/4
Virginia Mason Medical Center	1/1
Washington University in St. Louis	0/2
West Virginia University	1/1

eTable 2. Evaluated PROMIS Domains

Adult Domain Group	Adult Domain	Included	Wording on Survey
Global	Global health	Y	General well-being
	Global mental	Y	
	Global physical	Y	
Mental health	Alcohol – alcohol use	N	NA
	Alcohol – negative consequences	N	
	Alcohol – negative expectancies	N	
	Alcohol – positive consequences	N	
	Alcohol – positive expectancies	N	
	Cognitive function	Y	Difficulty with cognition
	Cognitive function - abilities	Y	
	Emotional distress – anger	Y	Anger
	Emotional distress – anxiety PROMIS-Cancer – Anxiety	Y	Anxiety or fear
	Emotional distress – depression PROMIS-Cancer – Depression	Y	Depression or sadness
	General life satisfaction	Y	Positive impact of cancer on sense of self and life
	Meaning and purpose	Y	
	Positive affect	Y	
	Psychosocial illness impact – positive	Y	Negative impact of cancer on sense of self and life
	Psychosocial illness impact – negative	Y	
	Self-efficacy – general	Y	Ability to perform daily activities
	Self-efficacy for managing chronic conditions – manage daily activities	Y	
	Self-efficacy for managing chronic conditions – manage emotions	Y	Ability to handle negative emotions and feelings
	Self-efficacy for managing chronic conditions – manage medications/treatment	Y	Ability to manage recommended medications and treatments
	Self-efficacy for managing chronic conditions – manage social interactions	Y	Ability to interact with other people to get medical help or information that I need
	Self-efficacy for managing chronic conditions – manage symptoms	Y	Ability to manage symptoms
	Smoking – coping expectancies all smokers; daily smokers; nondaily smokers	N	NA
	Smoking – emotional/sensory expectancies all smokers; daily smokers; nondaily smokers	N	
	Smoking – negative health expectancies all smokers; daily smokers; nondaily smokers	N	
	Smoking – negative psychosocial expectancies all smokers; daily smokers; nondaily smokers	N	
	Smoking – nicotine dependence all smokers; daily smokers; nondaily smokers	N	
	Smoking – social motivations all smokers; daily smokers; nondaily smokers	N	
	Substance use – appeal past 30 days; past 3 months	N	
	Substance use – prescription pain medication misuse	N	
	Substance use – severity past 30 days; past 3 months	N	

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eTable 2. Evaluated PROMIS Domains (cont.)

Adult Domain Group	Adult Domain	Included	Wording on Survey
Physical health	Dyspnea – activity motivation	Y	Shortness of breath and its impact on functioning
	Dyspnea – activity requirements	Y	
	Dyspnea – airborne exposure	Y	
	Dyspnea – assistive devices	Y	
	Dyspnea – characteristics	Y	
	Dyspnea – emotional response	Y	
	Dyspnea – functional limitations	Y	
	Dyspnea – task avoidance	Y	
	Dyspnea – time extension	Y	
	Dyspnea – severity	Y	
	Fatigue PROMIS-Cancer – Fatigue	Y	Fatigue and its impact on functioning
	Gastrointestinal – belly pain	Y	Belly pain
	Gastrointestinal – bowel incontinence	N	NA
	Gastrointestinal – constipation	Y	Constipation
	Gastrointestinal – diarrhea	Y	Diarrhea
	Gastrointestinal – disrupted swallowing	Y	Difficulty with swallowing
	Gastrointestinal – gas and bloating	Y	Gas and bloating
	Gastrointestinal – gastroesophageal reflux	Y	Gastrointestinal reflux symptoms
	Gastrointestinal – nausea and vomiting	Y	Nausea and vomiting
	Itch – activity and clothing	N	NA
	Itch – mood and sleep	N	
	Itch – interference	N	
	Itch – quality	N	
	Itch – scratching behavior	N	
	Itch – severity	N	
	Itch – triggers	N	
	Pain – behavior	Y	Pain and its effect on life
	Pain – interference PROMIS-Cancer – Pain Interference	Y	
	Pain intensity	Y	
	Pain quality – neuropathic pain	Y	
	Pain quality – nociceptive pain	Y	
	Physical function PROMIS-Cancer – Physical Function	Y	Ability to be physically functional
	– Mobility	Y	
	– Upper extremity	Y	
	Physical function for samples with mobility aid users	Y	Sexual satisfaction and functioning
	Sexual function and satisfaction: anal discomfort with sexual activity (for sexually active people)	Y	
	Sexual function and satisfaction: bother regarding sexual function – Female – Male	Y	
	Sexual function and satisfaction: erectile function (for sexually active men)	Y	
	Sexual function and satisfaction: factors interfering with sexual satisfaction	Y	
	Sexual function and satisfaction: interest in sexual activity	Y	

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eTable 2. Evaluated PROMIS Domains (cont.)

Adult Domain Group	Adult Domain	Included	Wording on Survey
	Sexual function and satisfaction: oral discomfort with sexual activity (for sexually active people)	Y	
	Sexual function and satisfaction: oral dryness with sexual activity (for sexually active people)	Y	
	Sexual function and satisfaction: orgasm – ability (for sexually active people)	Y	
	Sexual function and satisfaction: orgasm – pleasure (for sexually active people)	Y	
	Sexual function and satisfaction: satisfaction with sex life	Y	
	Sexual function and satisfaction: screeners	Y	
	Sexual function and satisfaction: sexual activities – Female – Male	Y	
	Sexual function and satisfaction: therapeutic aids for sexual activity – Female – Male	Y	
	Sexual function and satisfaction: vaginal discomfort with sexual activity (for sexually active women)	Y	
	Sexual function and satisfaction: vaginal lubrication for sexual activity (for sexually active women)	Y	
	Sexual function and satisfaction: vulvar discomfort with sexual activity – clitoral (for sexually active women)	Y	
	Sexual function and satisfaction: vulvar discomfort with sexual activity – labial (for sexually active women)	Y	
	Sleep disturbance	Y	
	Sleep-related impairment	Y	
Social health	Ability to participate in social roles and activities	Y	Ability to participate in work, and interactions with family/friends
	Companionship	Y	
	Emotional support	Y	Access to someone who meets emotional needs
	Informational support	Y	Access to someone for advice or information when needed.
	Instrumental support	Y	Access to someone to help with tasks if needed
	Satisfaction with participation in discretionary social activities (v1.0)	Y	Isolation/Connectedness to others
	Social isolation	Y	
	Satisfaction with participation in social roles (v1.0)	Y	Ability to do things for yourself, family and friends
	Satisfaction with social roles and activities (v2.0)	Y	

Abbreviations: NA, not applicable; PROMIS, Patient-Reported Outcomes Measurement Information System.

eTable 3. Top 5 Preferences Among Patients With PDAC and Physicians

Characteristic	Items	Rank	Domain			
			Physical	Mental	Social	General
Patients						
All patients (n=135)	Pain and its effect on life	1	X			
	Ability to perform daily activities	2		X		
	Ability to manage symptoms	3			X	
	Ability to be physically functional	4		X		
	General well-being	5	X			
Sex						
Female (n=64)	Pain and its effect on life	1	X			
	Ability to manage symptoms	2		X		
	Ability to participate in work and interactions with family/friends	3		X		
	Ability to perform daily activities	4		X		
	Fatigue and its impact on functioning	5			X	
Male (n=71)	Ability to be physically functional	1	X			
	Ability to participate in work and interactions with family/friends	2			X	
	Ability to perform daily activities	3	X			
	Ability to do things for yourself, family, and friends	4		X		
	General well-being	5				X
Age						
≤65 y (n=48)	Ability to be physically functional	1	X			
	Ability to do things for yourself, family, and friends	2		X		
	Ability to participate in work and interactions with family/friends	3			X	
	Ability to perform daily activities	4		X		
	Ability to manage symptoms	5		X		
>65 y (n=87)	Ability to be physically functional	1	X			
	Ability to perform daily activities	2		X		
	Pain and its effect on life	3	X			
	General well-being	4				X
	Ability to participate in work and interactions with family/friends	5			X	
Resection status						
Resectable (n=44)	Ability to be physically functional	1	X			
	Ability to perform daily activities	2		X		
	Ability to do things for yourself, family, and friends	3		X		
	Ability to participate in work and interactions with family/friends	4			X	
	General well-being	5				X

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eTable 3. Top 5 Preferences Among Patients With PDAC and Physicians (cont.)

Characteristic	Items	Rank	Domain			
			Physical	Mental	Social	General
Unresectable (n=91)						
	Ability to be physically functional	1	X			
	Ability to participate in work and interactions with family/friends	2		X		
	Ability to perform daily activities	3	X			
	Ability to do things for yourself, family, and friends	4				X
	Ability to manage symptoms	5			X	
Race/Ethnicity						
Non-Hispanic white (n=95)						
	Ability to be physically functional	1	X			
	Ability to participate in work and interactions with family/friends	2			X	
	Ability to do things for yourself, family, and friends	3		X		
	Ability to perform daily activities	4		X		
	Ability to manage symptoms	5		X		
Hispanic (n=12)						
	Ability to participate in work and interactions with family/friends	1			X	
	Ability to be physically functional	2	X			
	Ability to do things for yourself, family, and friends	3		X		
	Pain and its effect on life	4	X			
	General well-being	5				X
Black (n=8)						
	Ability to perform daily activities	1		X		
	Ability to do things for yourself, family, and friends	2		X		
	Ability to be physically functional	3	X			
	Ability to participate in work and interactions with family/friends	4			X	
	Positive impact of cancer on sense of self and life	5		X		
Asian (n=17)						
	Ability to perform daily activities	1		X		
	Ability to manage symptoms	2		X		
	General well-being	3				X
	Ability to be physically functional	4	X			
	Sleep Quality	5	X			
Physicians						
All physicians (n=54)						
	Pain and its effect on life	1	X			
	Ability to perform daily activities	2		X		
	Ability to manage symptoms	3		X		
	Ability to be physically functional	4	X			
	General well-being	5				X

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eTable 3. Top 5 Preferences Among Patients With PDAC and Physicians (cont.)

Characteristic	Items	Rank	Domain			
			Physical	Mental	Social	General
Sex						
Female (n=13)						
	Ability to be physically functional	1	X			
	Ability to do things for yourself, family, and friends	2		X		
	Ability to manage symptoms	3		X		
	Ability to perform daily activities	4		X		
	Ability to participate in work and interactions with family/friends	5			X	
Male (n=41)						
	Pain and its effect on life	1	X			
	Ability to perform daily activities	2		X		
	Ability to manage symptoms	3	X			
	Ability to be physically functional	4		X		
	General well-being	5				X
Specialty						
Medical oncology (n=34)						
	Pain and its effect on life	1	X			
	Ability to perform daily activities	2		X		
	Ability to be physically functional	3	X			
	Ability to manage symptoms	4		X		
	Ability to do things for yourself, family, and friends	5		X		
Other specialty ^a (n=20)						
	Pain and its effect on life	1	X			
	Ability to manage symptoms	2		X		
	Ability to perform daily activities	3		X		
	General well-being	4				X
	Belly Pain	5	X			
Years of experience						
0–5 (n=11)						
	Ability to perform daily activities	1		X		
	Pain and its effect on life	2	X			
	Ability to be physically functional	3	X			
	Ability to manage symptoms	4		X		
	Nausea and vomiting	5	X			
6–10 (n=18)						
	Pain and its effect on life	1	X			
	Ability to manage symptoms	2		X		
	Fatigue and its impact on functioning	3	X			
	Ability to perform daily activities	4		X		
	General well-being	5				X

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eTable 3. Top 5 Preferences Among Patients With PDAC and Physicians (cont.)

Characteristic	Items	Rank	Domain			
			Physical	Mental	Social	General
11–15 (n=10)	Pain and its effect on life	1	X			
	Ability to perform daily activities	2		X		
	Ability to be physically functional	3	X			
	Ability to manage symptoms	4		X		
	Negative impact of cancer on sense of self and life	5		X		
≥16 (n=15)	Pain and its effect on life	1	X			
	Ability to perform daily activities	2		X		
	General well-being	3				X
	Ability to participate in work and interactions with family/friends	4			X	
	Ability to manage symptoms	5		X		

Abbreviation: PDAC, pancreatic ductal adenocarcinoma.

^aSurgery, radiation therapy, palliative care, gastroenterology.