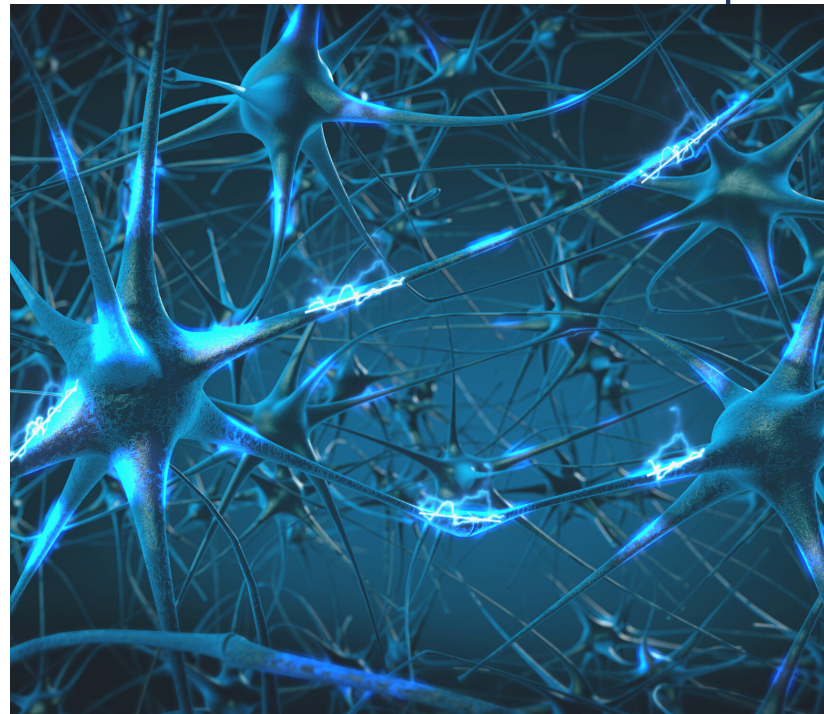


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CHRONIC PAIN ASSESSMENT: PATIENT PERSPECTIVES

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INTRODUCTION

Acute pain is a normal sensation triggered in the nervous system to alert you to possible injury and the need to protect yourself. [1] Acute pain comes on quickly and can last a moment or a few months. Chronic pain is different; chronic pain persists. By definition, chronic pain is pain that remains for more than three months or lasts more than one month beyond the “normal healing” time for the underlying cause of the pain. [2] But that doesn't capture the wide-reaching personal, social and psychological impacts, as well as national economic consequences of chronic pain. Chronic pain affects 50 - 100 million adults in the United States, [3, 4] and the numbers are rising. [5] These estimates do not account for certain populations, including pediatrics, or military and elderly residing in long-term health care facilities; yet they translate to an estimated economic cost from \$560 to \$635 billion for necessary health care and lower worker productivity. [6]

Chronic pain can occur in nearly any part of the body and nearly everyone is susceptible. Chronic pain manifests in different ways [1, 2] and there is an essential difference between pain as a symptom and chronic pain. [7] As a symptom, pain results from an illness or injury; chronic pain refers to a disorder or disease process that results from changes at cellular and molecular levels. [7, 8] Classifications have been used to separate chronic primary pain conditions, which exist independent of another disorder, from chronic secondary pain conditions, where at least initially chronic pain is due to conditions such as cancer or its treatment. [9, 10] But in either case, and regardless of its etiology, chronic pain touches all aspects of patients* lives; negatively affecting their daily activities, physical and mental health, family and social relationships, financial stability and their interactions in the workplace. [11, 12]

Impact of Chronic Pain

A recent Voice of the Patient Report from the Food and Drug Administration (FDA) confirmed that the health effects of chronic pain are pervasive and wide ranging for patients. [2] Individuals who live with daily unrelenting widespread pain experience numerous comorbidities, including increased levels of anxiety, depression, decreased quality of life, sleep disturbances, fear of further pain and disability, and withdrawal from social and pleasurable activities. [2, 13] Data support these sentiments. Studies have shown the correlation between chronic pain and reduced physical activity; [12, 14] and that the intensity, duration, or location of chronic pain influences a patient's physical performance, diminishing their physical activity and even causing disability. [12, 15] Health-related quality of life (HRQoL) assessments further show the consequences of chronic pain on the mental and physical aspects of a patient's life and the detrimental effects to the families of patients. [16, 17] When comparing the HRQoL of acute pain and chronic pain patients with that of pain-free individuals, chronic pain patients achieved worse scores in all the dimensions of HRQoL compared to individuals who suffered from acute pain or had no pain. [12]

"No doctor I have seen for my chronic pain has ever asked me about the profound effect pain has on every other important aspect of my life." – Chronic Pain Patient

Chronic pain interferes with everyday activities, such as family and home responsibilities, recreational activities, work and sleep. [17, 18] Sleep disturbances such as shorter sleep duration or poor sleep quality are common. Sleep complaints present in 67-88% of chronic pain disorders, [19, 20] and at least 50% of individuals with insomnia suffer from chronic pain. [20, 21] Sleep debt can also increase levels of stress and make it difficult for patients to perform simple tasks at home and in the workplace. [12, 22] Decreased productivity, reduced efficiency, and early retirement related to chronic pain present a

burden at least as great as established health care priorities.

Family, social and sexual relationships are also impacted by chronic pain. Patients often experience social isolation and loneliness and report that their condition has prevented them from attending social or family events [12, 23] and to have less frequent contact with family. [17] Decreased contact can result from family members being unable to cope with the impacts of chronic pain on their family unit, which leads to avoidance or abandonment of the patient. Or, with the physical decline patients may experience from their chronic pain and the dependency that can cause, patients may choose to avoid interactions with members of their family or social group to not be a burden. [12, 24] The consequence of chronic pain on sexual relationships is common but often overlooked. Chronic pain may interfere with sexuality because of the pain itself, or other factors associated with chronic pain, including mood, decreased sex drive, medications or stress. [25, 26]

In addition to the physical and personal impacts of chronic pain, patients often face societal stigma and discrimination when reporting pain, particularly when they do not respond readily to treatment. [3] They are judged simply for having a common, complex, health condition with no visible signs – they don't 'seem' sick. Another factor that contributes to the stigma of chronic pain is that nearly everyone at some point experiences some degree of pain, and they equate an acute pain experience with which they are familiar to that of chronic severe pain. [3] Employers, family members, friends and even health care providers question the legitimacy of a patient's chronic pain and treatment needs. [2, 27] The stigma associated with having chronic pain has been made worse by the opioid crisis. [28] The unintended consequences of state and national policies enacted to address opioid abuse and overdose cause patients to feel under attack and perceived as 'drug-seekers' or unable to access appropriate treatments because doctors

fear patients need opioids but are wary of prescribing them. [28]

Complex Nature of Chronic Pain

One factor that influences the physical, personal and societal impacts of chronic pain is that the complexity of the condition is not generally understood by most people. Focus often remains on the original problem that caused the pain, and not on the fact that, for some, the pain itself is the remaining problem. [28] Although primarily considered a disease of the nervous system, often worsening over time, chronic pain is often a multi-system, multi-symptom disease that can involve the musculoskeletal, endocrine, immune, and inflammatory systems. [3, 29] These systems interact and collectively comprise a defensive biological response to injury. [29] Yet, despite the multi-system changes associated with chronic pain, signs and symptoms may be subtle and difficult to interpret. Individuals experience symptoms differently based on their social and physical environment, and the unique interactions of genetic, epigenetic and past experiences that characterize each person. [29] This multi-system context can result in diagnosis by exclusion and necessitates a multidimensional approach to pain assessment and treatment.

"Generalizations are the biggest misconception among my health care providers."
– Chronic Pain Patient

Pain Assessment

Comprehensive pain assessment and re-assessment that evaluates both pain and non-pain symptoms (i.e., sleep, mood, cognition, physical and social function) are essential in all stages of managing chronic pain. [30] The importance of assessment for patients goes beyond diagnosis, it provides information about the severity of the condition, guides treatment decisions and allows clinicians and scientists to monitor the course of disease and to quantify treatment effects. [31] The development of

devices and techniques as objective pain measurement tools is ongoing and holds promise, [32, 33] but standardized self-reported assessment scales and tools remain the standard of care across clinical practice. When utilized appropriately, assessment scales are designed to evaluate a patient's pain intensity, functional abilities, expectations, and emotional distress. [34]

Chronic pain is a subjective experience and when communicated verbally and non-verbally is influenced by factors such as how patients uniquely perceive pain and their ability to communicate, as well as health care provider bias and limitations in knowledge. [3]

Communication barriers exist for patients speaking a different language or being unable to speak due to age or an assisted breathing device. Emotional and cognitive impairments, cultural, and educational differences can also make the pain scales difficult to grasp. [35] Elderly patients with dementia, poor vision or diminished hearing may have trouble understanding pain scales, and under-reporting of pain can also occur due to fear of being stigmatized. [3] Patients are experts on appraising the impact of chronic pain on their lives and selection of pain assessment tools should be informed by the physician's goals, but equally informed by the needs and preference of the patient.

"I would like my HCP to show me a few assessment tools & let me pick the one I feel best reflects my chronic pain experience."
– Chronic Pain Patient

Pain Assessment Tools

As noted in Response Scale Selection in Adult Pain by Safikhani, et. al, in which they examined 42 review articles, consensus guidelines, expert opinion pieces, and primary research articles, "there is an abundance of existing literature on pain measurement." [36] Yet, we have found that the patient perspective has rarely been incorporated into the development of

assessment tools. In 1948 Kenneth Keele, an English physician, developed a simple descriptive scale which categorized pain from 0 (none) to 4 (complete). [37, 38] Around that same time Hewer, working with Keele, showed that by recording categorical responses at regular intervals or by having patients record the pain score on a daily pain chart, a graphic representation of pain over time could be constructed. [38] These pain charts were used to evaluate the effect of analgesic administration on pain at specific intervals after dosing and compared to a placebo for significance. [39] This was the primary driver for the development of standardized pain scales, not as tools for the clinical assessment of pain as an aid to diagnosis, but the need to establish the efficacy of analgesics and other therapies. [38] From here, the number of pain scales multiplied, along with the practice of asking patients to report on pain intensity using verbal rating scales and visual analog scales. [38]

Severity of pain can be measured by categorical scales, numerical rating scales (NRS), visual analog scales (VAS), and verbal descriptor scales (VDS). [31] The Behavioral Pain Scale (BPS), Critical-Care Pain Observation Tool (CPOT), and Nonverbal Pain Scale (NVPS) can be administered to screen pain in critically ill patients who are unable to communicate. [40] Instruments such as the Brief Pain Inventory ask patients to report their worst, least, and average pain intensity over some period of time because measurement of pain at a single point of time may not accurately reflect a patient's overall pain experience. [41] Quality of Life scales assess physical and psychological health, independence and social relationships. [12, 42] Single-item measures are most frequently used to assess pain intensity and pain affect, but multiple-item instruments can provide additional information regarding the sensory and affective qualities of pain. [31]

In rare instances, patient and health care provider input was incorporated into the development of

pain scales. The well recognized Wong-Baker faces scale was developed in the hospital and patient setting by health care providers who saw a need for children to be able to communicate their pain effectively. [43] Panels of students, patients, and doctors were used to identify terms of pain that formed the basis of the McGill Pain Scale. [44] In 2003, after finding no published study in the past several decades that looked at patient preferences for the frequently used verbal rating scale and visual analog scale, Clark et. al studied the patient's preference. [45] And, more recently a study looked at the challenges intensive care unit nurses' encounter in using current pain assessment scales on patients unable to communicate. [40] But, given the limited inclusion of the patients' perspective and driven by a perception within the pain community that the impact of chronic pain on patients' lives is not adequately, consistently, or uniformly measured by available current pain scales, we conducted a patient-focused survey on how chronic pain is currently assessed with the aim to improve chronic pain evaluation for patients and thereby enhance management and outcomes.

US Pain Collaborative

In June of 2017, Grünenthal, a German based pharmaceutical company focused on pain, sponsored a meeting in New York City focused on mapping the patient and caregiver pain experience across four dimensions – diagnosis, treatment, cultural stigma and caregiver roles. It was attended by 35 patients, caregivers and patient organization leaders from 13 disease areas in which pain was a key feature. Participants generated multiple ideas for collaborative projects; evaluating the use of pain scales from the patient perspective surfaced as an important area of inquiry. Participants reported dissatisfaction with currently available tools as well as how they were used in the clinical setting.

With support from the New York based consulting firm VOZ Advisors, and Grünenthal, a survey was developed by the US Pain

Collaborative (USPC): a chronic pain steering committee that included the Chronic Pain Research Alliance, For Grace, Reflex Sympathetic Dystrophy Syndrome Association, and US Pain Foundation. For the analysis and writing of this paper, the USPC was expanded to include two additional organizations – the International Pain Foundation and the Hereditary Neuropathy Foundation. Ultimately, the survey's patient advocacy group leaders hope study findings and recommendations improve the conversations that people living with chronic pain have with their health care providers, and, more importantly, result in better quality of life for people living with chronic pain.

CHRONIC PAIN SURVEY FINDINGS

Survey Goals

The objectives of the survey were, first, to understand patient awareness of and satisfaction with chronic pain assessment instruments currently used by health care providers and researchers; and second, to learn what questions people living with chronic pain want raised by health care providers during pain assessment, and the frequency with which those questions are currently raised during evaluation. The goals of the survey were to establish a patient-informed baseline against which to consider enhanced chronic pain assessment methods and tools, and to surface recommendations for improved chronic pain assessment that would result in more effective pain evaluation and enhanced treatment plans and outcomes.

Survey Logistics

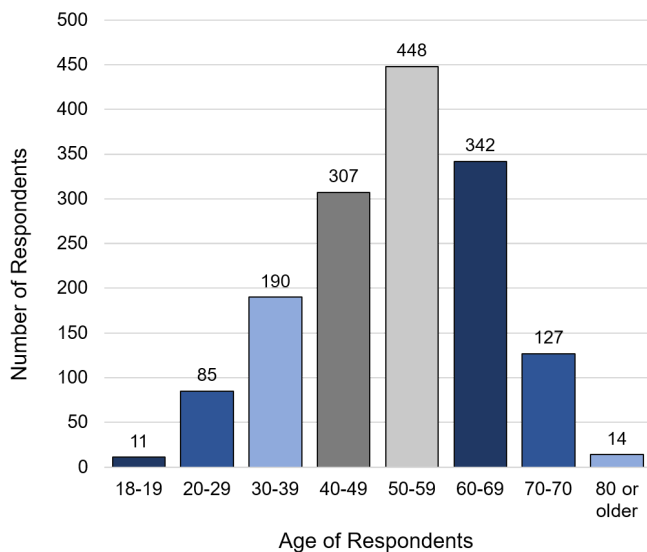
The survey questions were based on a review of the literature and from problem statements identified by chronic pain patient advocacy leaders. USPC members provided insights into the development of survey questions, reviewed

and commented on first and subsequent drafts of the survey, beta tested the final draft, and disseminated the final approved survey to their constituents.

Demographic Data

Chronic pain survey respondents numbered 2,793; some respondents chose not to answer all questions. Of those who responded to a question about gender (1,524), 89% were women, 10% were men; and 1% were transgender or indicated they preferred not to answer. The majority of survey participants who responded to a question about age (1,524) were between the ages of 40 and 69, with the largest percentage being 50 to 59 years of age (Figure 1).

Figure 1: Age distribution of survey respondents (n=1,524)



Length of time living with chronic pain, pain conditions and treatment providers

Survey participants spoke from a depth of experience, nearly two-thirds (61%) of 1,527 respondents reported living with chronic pain for 10 years or longer; half that number (30%) have lived with chronic pain for 20 or more years (Figure 2).

Respondents were being treated for a variety of conditions; response options included six specific conditions: complex regional pain syndrome/reflex sympathetic dystrophy (CRPS/RSD), back pain, arthritis, migraine or other chronic

headache, fibromyalgia, vulvodynia, none of those listed and "other," with the option to provide a write-in response. Survey participants were asked to select more than one response, if they suffered from multiple conditions, or to provide a written response (Figure 3).

Figure 2: Length of time survey respondents have been living with chronic pain (n=1,527)

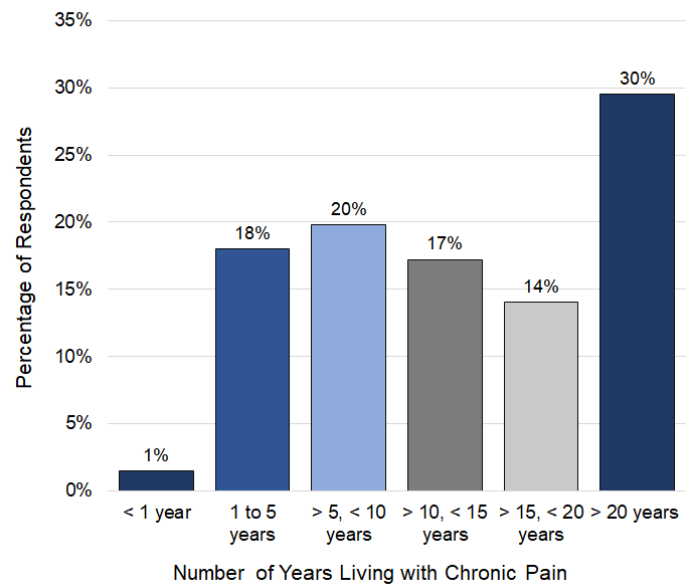
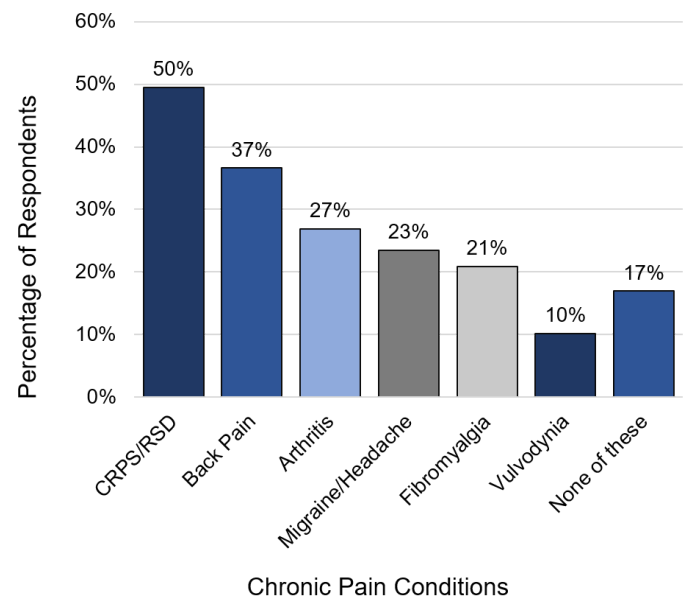


Figure 3: Chronic pain conditions respondents were being treated for. More than one condition could be selected by each respondent (n=1,527).



Half (50%) of 1,527 respondents who answered a question about their conditions reported living with CRPS/RSD, followed by back pain (37%),

arthritis (27%), migraine or other headache (23%), fibromyalgia (21%), and vulvodynia (10%). Write-in responses, which accounted for 17% of the responses, covered a wide range of conditions, most frequently interstitial cystitis. The high percentage of write-in responses is attributed to the USPC members sharing the survey with constituents of their organizations, who have been underrepresented in previous surveys.

Of the 1,527 respondents who answered a question about the number of health care providers (HCPs) consulted for chronic pain, more than 30% reported seeing three providers or more. Survey participants were subsequently asked what kinds of medical specialties they consult for pain treatment (Figure 4) with the option to select from as many of six referenced specialties, or "none of the above." Survey participants were asked to select more than one response if they routinely consulted more than one HCP, or to provide a written response. Close to 60% of the 1,527 respondents regularly visit primary care or family practice HCPs, and half (50%) routinely consult pain medicine practitioners. Specialties not included in the survey question but referenced frequently in write-in responses included chiropractic, orthopedic, psychology/psychiatry, urology, and urogynecology.

"I can't sleep or work or drive. There's no comfortable position for me that doesn't feel like I'm on fire." – Chronic Pain Patient

Pain evaluation by health care professionals

One of the survey objectives was to understand what questions health care providers typically raise of patients during office visits about the impact of chronic pain on a variety of psycho-social-physical aspects of life. During routine evaluations of chronic pain in the HCPs office, just under half (47%) of 1,527 survey respondents reported being asked not at all or only to some degree about the severity of their chronic pain; with just over half (53%) being asked to a large degree or completely.

The survey explored 18 specific life aspects. Respondents were asked about which aspects HCPs routinely inquire, and which they would like their HCPs to inquire. With the exception of questions about severity/intensity of pain on a numeric scale, which HCPs raise slightly more often than patients wish, HCPs explore chronic pain's impact on functionality, quality of life, and treatment issues significantly less often than patients wish, summarized in Figure 5, next page (highest to lowest differential, n = 1,527).

Figure 4: Medical specialists routinely consulted for chronic pain. More than one specialist could be selected by each respondent (n=1,527).

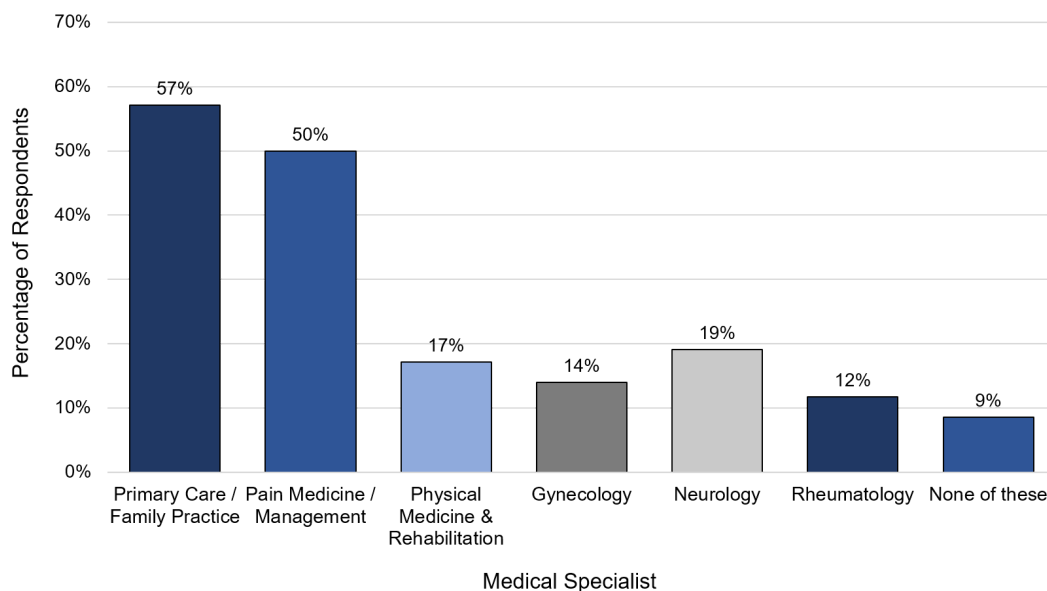
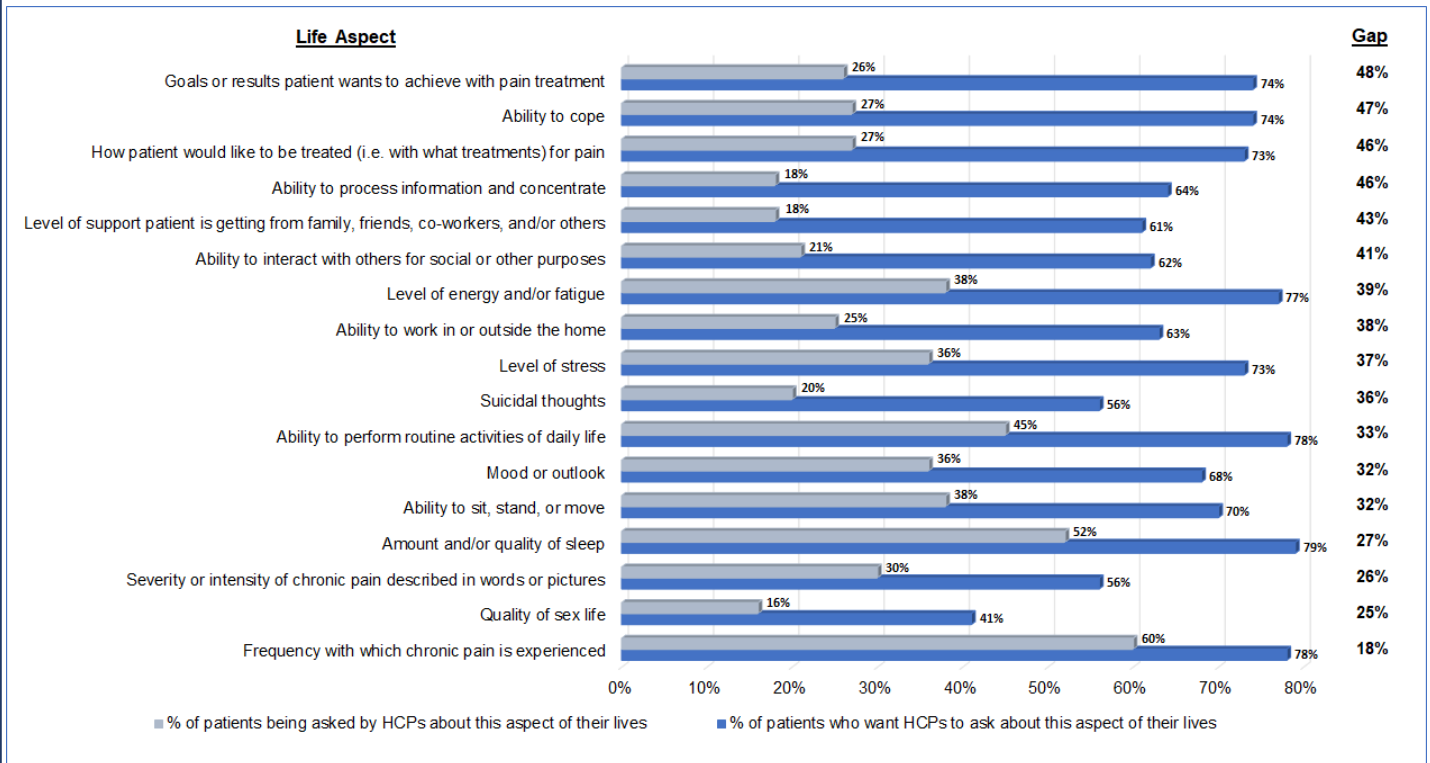


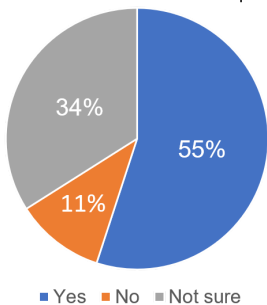
Figure 5: Life aspects health care providers routinely ask chronic pain patients, compared to the frequency with which patients would like to be asked (highest to lowest differential, n = 1,527).



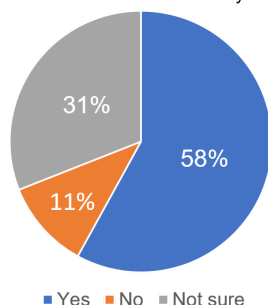
The survey also explored the value of pain diaries and trackers to chronic pain patients. Somewhat over half of 1,527 respondents believe daily or weekly record-keeping with a pain diary or tacker between appointments helps HCPs better understand and treat chronic pain and should be a routine component of chronic pain evaluation, while the balance of respondents are more likely to be unsure rather than to disagree that these are useful tools (Figure 6). The length of time a respondent had been living with chronic pain did not significantly influence their response.

Figure 6: Utility of pain diaries and trackers to chronic pain patients. n = 1,527).

Does sharing information from a pain tracker or diary help HCPs better understand and treat chronic pain?



Should reporting from a pain tracker or diary be part of routine chronic pain assessments conducted by HCPs?



Pain scale familiarity, use, utility

Survey participants were asked about their familiarity with eight established pain evaluation assessments; the extent to which they considered each assessment useful, whether or not they felt each assessment fully captures the chronic pain experience, and the degree to which their HCPs utilize those assessments when evaluating pain. The eight assessments respondents were asked to evaluate were:

1. Brief Pain Inventory
2. Global Pain Scale
3. McGill Pain Questionnaire
4. PROMIS-29
5. Quality of Life Scale
6. University of Washington Pain Tracker
7. Visual Analog Scale
8. West Haven-Yale Multidimensional Pain Inventory

Recognizing that respondents might not be familiar with the assessments by name, each assessment was hyperlinked (see resources) to the survey instrument so that the questions raised by each were easily accessible. Except for

the Brief Pain Inventory, survey respondents were more likely to be unfamiliar than familiar with these instruments. Following the Brief Pain Inventory, assessments with which 1,419 survey respondents were most familiar (25% or higher) were the Visual Analog Scale, Global Pain Scale, McGill Pain Questionnaire, and Quality of Life Scale (Figure 7). When respondents were asked if their HCPs utilize these assessments when evaluating pain, with the exception of the Brief Pain Inventory, they selected 'never' most often, followed by 'not sure' (Figure 8). When asked if the established pain evaluation assessments

were useful, approximately 45% of respondents indicated 'somewhat' across all of the scales, with <10% feeling they were 'completely' useful. Respondents were also asked if they thought the established pain questionnaires fully capture the chronic pain experience and the majority of the responses indicated 'no' (36%) or 'not sure' (47%), on average across all pain scales. Of the scales evaluated, respondents thought the McGill Pain scale somewhat captures the chronic pain experience (23% yes) and that the Visual Analog scale is least likely to capture the chronic pain experience (10% yes).

Figure 7: Respondents familiarity with select chronic pain assessments (n = 1,419)

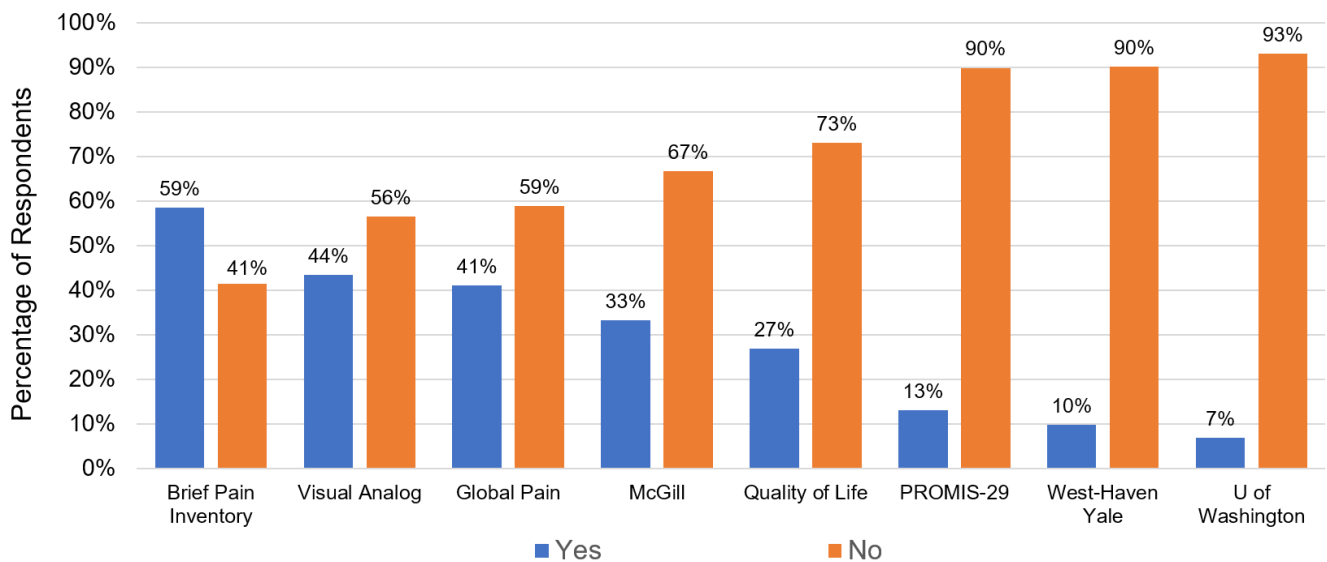
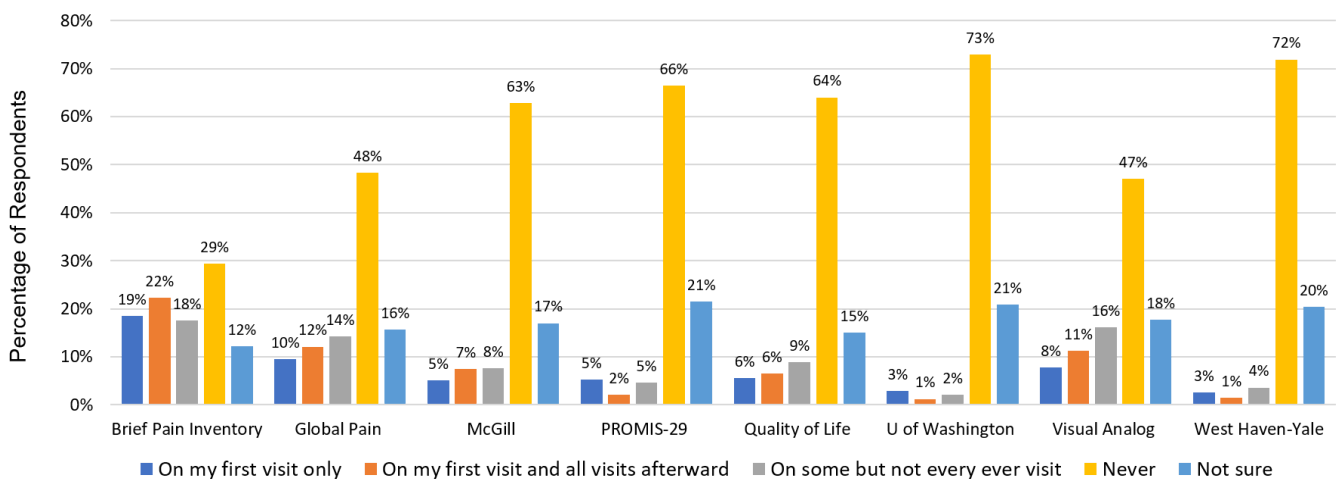


Figure 8: Percentage of respondents health care professional that have used this assessment to evaluate their chronic pain (n =1,419)



Pain scale experience and areas for improvement

Survey participants were asked if they agreed with eleven problem statements around currently available pain assessment instruments and the use of those instruments to inform treatment plans and outcomes (Table 1). Of the 1,513 chronic pain patients that responded almost all (>90%) indicated that changes are needed to the way their HCP evaluates pain and over half (>54%) stated they want to work with their HCP to decide which questions about chronic pain, and what chronic pain measurements, are best for them. Suggested learnings from the problem statements are proposed (Table 1).

Survey participants were also asked to provide open-ended comments around how their HCP currently assesses chronic pain and suggest recommendations for improvements to the process. Responses from 1,513 entries were analyzed and concise descriptions of issues or areas for improvement identified. These identified areas for improvement, along with the suggested learnings from the problem statements, form the basis for patient-driven recommendations offered to improve chronic pain assessment.

"I wish pain management was about your entire person; your life, your hopes, your social interactions." – Chronic Pain Patient

Table 1: Implied key findings to improve chronic pain assessment based on survey participants responses to eleven problem statements (n = 1,513)

Learnings from Problem Statement Data		
Problem Statement	Agree	Implied Key Finding
No changes are needed to the way my health care professional (HCP) currently evaluates my chronic pain	9%	Patients would like to see changes made in the way HCPs currently evaluate chronic pain
There are enough useful chronic pain assessments available currently	11%	More useful chronic pain assessments are needed
I don't think my HCP needs to use a standardized chronic pain assessment to understand and treat my chronic pain comprehensively	19%	Standardized chronic pain assessments are important – they help HCPs understand and treat chronic pain comprehensively
There should be a small fixed number of chronic pain assessments from which my HCP can choose depending on my individual needs	20%	HCPs should not be limited in the number of chronic pain assessments from which they can choose according to individual patient need
Chronic pain assessments available today are not satisfactory because they don't measure what matters to me	28%	At least some currently available chronic pain assessments measure what matters to people living with chronic pain
It is important for my HCP to evaluate my chronic pain on a numeric scale	29%	Measurement of chronic pain on a numeric scale is not important for a preponderance of people living with chronic pain
I would benefit from one standardized chronic pain assessment that provides questions covering all aspects of my life	34%	More than one standardized chronic pain assessment is needed to meet the needs of those who live with chronic pain
New chronic pain assessments are needed to better assess chronic pain	44%	For many patients, new chronic pain assessments are needed to better assess chronic pain
Standardized pain assessments are important to help my HCP understand my chronic pain and treat my chronic pain more comprehensively	52%	Patients surveyed see standardized pain assessments as important to help HCPs understand and treat chronic pain more comprehensively
I wish I could work with my HCP to decide which questions about pain and what pain measurements are best for me	54%	People living with chronic pain want individualized, tailored care and should be able to discuss and agree with their HCPs which questions about chronic pain and what chronic pain measurements are best for them
My HCP should be able to choose from a wide variety of chronic pain assessments so that s/he can ask the questions that are right for me	61%	HCPs should have a wide variety of chronic pain assessments that ensure they are able to raise questions that are right for individual patients

RECOMMENDATIONS BASED ON PATIENT PERSPECTIVES

Comprehensive chronic pain assessment methods should reflect the multiple aspects of the patient's pain experience and capture chronic pain's impact on daily life. A recent article supports this approach and concluded that thorough pain assessments should be conducted consistently and assess four key components of pain in all patients: pain intensity, other perceptual qualities of pain, bodily distribution of pain, and temporal features of pain; combined with assessment of physical and psychosocial functioning. [31] Yet, our results indicate that for the patients surveyed this is often not their experience. Health care providers examine chronic pain's broader impact significantly less often than patients wish (Figure 5) and almost all respondents (>90%, Table 1) indicated that changes are needed to the way their health care provider evaluates chronic pain. Reasons for this include gaps in policy, attitudes, and education.[3]

Pain care in America is fragmented; 52% of patients with chronic pain are managed in primary care with the rest relying on specialty care providers. [30, 46] Survey participants mirror these statistics with nearly 60% of respondents regularly visiting primary care or family practice providers (Figure 4). But primary care is organized in ways that rarely allow clinicians time to perform comprehensive patient assessments. [3] The breadth of chronic pain conditions and the complex multi-system factors of disease contribute to gaps and variability in knowledge and competencies related to chronic pain assessment among providers. And system and organizational barriers associated with insurance access and current reimbursement policies can obstruct patient care.

By surveying patient awareness of and satisfaction with current pain assessment tools

we offer patient-informed recommendations for enhanced chronic pain assessment methods and tools. The below recommendations represent actions that the USPC believes can be taken immediately to improve the lives of people living with chronic pain.

Patient Advocacy Organizations

People living with chronic pain and their caregivers should be empowered to voice their interest in, concerns about and preferences for how their pain is assessed initially and in an ongoing fashion. To that end, we recommend organizations serving people with pain:

- Seek out or create education around the instruments available to assess chronic pain, and their different uses (e.g. to measure pain intensity, comfort, or functionality) to encourage patient-provider communication and informed decision making.
- Ensure patients have tools to document the temporal features of chronic pain such as the duration and pattern (e.g. episodic, constant but fluctuating in intensity) to facilitate recall when speaking with a health care provider.
- Offer tips on how patients and caregivers can open a conversation with their provider on their preferences for chronic pain assessment and frequency of use in the clinical setting.

Patients and Caregivers

Pain is universal, but unique to each person. People living with the daily impacts of chronic pain should feel vested in how their individual pain is assessed. To that end, we recommend patients and caregivers:

- Contact a patient organization to see what kinds of resources might be available to help advocate for their needs (see resources).
- Start a conversation with their health care provider to determine what improvements in their chronic pain would constitute improvements to their quality of life.
- Create their own list of the 'life aspects (see Figure 5) that they would like to routinely evaluate with their health care provider to measure any changes.

Health Care Providers

Patients are experts in living with chronic pain and the success of chronic pain management is enhanced through robust and individualized communication between the clinician and patient. Below are ways that providers can affect immediate change in their practice of treating individuals with chronic pain:

- Empower patients to discuss the impact chronic pain has on all areas of their life.
- Compare your particular way of assessing chronic pain to determine if it addresses the quality of life issues described in this paper as important to people with chronic pain.
- Discuss the assessment currently used with patients and caregivers to understand if it is the right tool; ask what the patient's quality of life goals are and determine whether the current assessment or another available assessment captures the patient's needs. If not, add their goals to your assessment.
- Administer chronic pain instruments consistently and longitudinally as it is key to understanding the patient's experience as it relates to the effectiveness of treatments and impact of chronic pain on quality of life.
- Find and use instruments which evaluate chronic pain's impact on quality of life and place emphasis on the personal goals and priorities of the patient's desired outcomes from treatment.
- Dispense assessment instruments before scheduled appointments (e.g. by mail or at previous appointment), to allow patients and caregivers time to fully and more accurately review and complete the assessment, and review them with your patient.
- Use the assessment as a guide for recommending treatments, lifestyle changes and practices and measure the success of interventions at subsequent appointments.
- Consider assessment with multiple instruments or an instrument which combines varied measurements (e.g. sensations of pain, functional limitations) to provide individualized and comprehensive information.

- Discuss the use of chronic pain diaries or other trackers with your patients to augment pain assessments that capture pain at one discrete point in time, to therefore more accurately capture the pain experience and track longitudinal trends in individual patients and identify chronic pain triggers.

Key Recommendations

- Patient advocacy organizations should seek out or create education around the instruments available to assess chronic pain, and their different uses (e.g. to measure pain intensity, comfort, or functionality) to encourage patient-provider communication and informed decision making.
- Patients and caregivers should start a conversation with their health care provider to determine what improvements in their chronic pain would constitute improvements in quality of life.
- Health care providers should empower patients to discuss the impact chronic pain has on all areas of their life.
- Health care providers should discuss the assessment they currently use with patients and caregivers to understand if it is the right tool; ask what the patient's quality of life goals are and determine whether the current assessment or another available assessment captures the patient's needs. If not, add their goals to your assessment.
- Policy makers should enact common use of online medical records with accessible, comprehensive and interdisciplinary records management so results from pain assessments can be more readily compared and utilized to inform treatment plans and improve outcomes.

Systems and Policy

Advocating for change at the policy and systems level should be aimed at ways to improve the patient experience with assessment tools and ensure meaningful measurement:

- Improve continuing education of health care providers around the diseases of chronic pain generally, and around the appropriate use of assessment tools specifically, to improve patient satisfaction and treatment outcomes.
- Provide reimbursement for longer appointment times to allow for more patient-provider communication and the opportunity to conduct a more inclusive assessment.
- Enact common use of online medical records with accessible, comprehensive and interdisciplinary records management so results from pain assessments can be more readily compared and utilized to inform treatment plans and improve outcomes.
- Establish reimbursement policies that recognize individuals may suffer from two or more co-existing chronic pain conditions to permit more thorough assessments and decrease visit frequency.
- Share these patient-driven results with the FDA to stimulate a dialog on how the agency could promote an improved pain assessment tool in clinical trials.

Conclusion

Chronic pain is a complex perceptual experience influenced by a wide range of factors. Pain management must be tailored to each person's unique experience and that care begins with individualized chronic pain assessment. Conceptually, standardized chronic pain evaluation instruments that could be used regardless of comorbid diseases and conditions, together with standardized discrete evaluations for each specific condition associated with chronic pain, would ensure a consistent approach to chronic pain evaluation across health care practitioners and irrespective of geographic boundaries. Practically, ensuring the assessment used is suitable from the patient's perspective, and consistent utilization of that assessment overtime, offers the most benefit for providers and patients.

"Due to billing structures, I feel like I can only discuss one pain condition at a time, but that's not what my life looks like. I wish I would simply be asked, what else hurts."

– Chronic Pain Patient

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RESOURCES

US Pain Collaborative

- Chronic Pain Research Alliance: www.chronicpainresearch.org
- For Grace: www.forgrace.org
- Hereditary Neuropathy Foundation: www.hnf-cure.org
- International Pain Foundation: www.internationalpain.org
- Reflex Sympathetic Dystrophy Syndrome Association: www.rsds.org
- US Pain Foundation: www.uspainfoundation.org

Pain Scale Assessment Tools

- Brief Pain Inventory: <http://bit.ly/BriefPain>
- Global Pain Scale: <http://bit.ly/GlobalPain>
- McGill Pain Questionnaire: <http://bit.ly/McGillPain>
- PROMIS-29: <http://bit.ly/Promis29>
- Quality of Life Scale: <http://bit.ly/ACPAQoL>
- University of Washington Pain Tracker: <http://bit.ly/UWPain>
- Visual Analog Scale: <http://bit.ly/VAScale>
- West Haven-Yale Multidimensional Pain Inventory: <http://bit.ly/WHYpain>

The Voice of the Patient

- A Series of Reports from FDA's Patient-Focused Drug Development Initiative: http://bit.ly/VoP_Pain

