

**NATIONAL ORGANIZATION OF
SOCIAL SECURITY CLAIMANTS' REPRESENTATIVES
(NOSSCR)**

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Executive Director
Barbara Silverstone

February 6, 2019

Nancy Berryhill
Acting Commissioner
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235-6401

Submitted via www.regulations.gov

Re: Advanced Notice of Proposed Rulemaking on Consideration of Pain in the Disability Determination Process, 83 Fed. Reg. 64493 (December 17, 2018), Docket No. SSA-2018-0017

Dear Acting Commissioner Berryhill:

These comments are submitted on behalf of the National Organization of Social Security Claimants' Representatives (NOSSCR).

The National Organization of Social Security Claimants' Representatives (NOSSCR) is a specialized bar association for attorneys and advocates who represent Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) claimants throughout the adjudication process and in federal court. Founded in 1979, NOSSCR is a national organization with a current membership of more than 3,000 members from the private and public sectors and is committed to the highest quality representation for claimants and beneficiaries. NOSSCR's mission is to advocate for improvements in Social Security disability programs and to ensure that individuals with disabilities applying for SSDI and SSI benefits have access to highly qualified representation and receive fair decisions.

Introduction

Thank you for the opportunity to provide information regarding the consideration of pain in the Social Security disability programs in response to this Advanced Notice of Proposed Rulemaking (ANPRM). The evaluation of pain plays a central role in determining whether an individual is entitled to Social Security disability benefits under Title II or Title XVI of the Social Security Act in hundreds of thousands disability claims each year. Pain is a symptom of a multitude of

impairments and is considered in determining disability in the listing of impairments for nearly every body system.¹ Many impairment-specific Social Security Rulings (SSR) also include specific instructions for the evaluation of pain relating to the impairment and some pain related symptoms can be integral to meeting or equaling a listing at step three of the five step sequential disability evaluation process.² Given that the evaluation of pain is involved in such a significant percentage of disability claims, it is important that the Social Security Administration's (SSA) rules regarding its consideration be based on the most up to date science regarding diagnosis, evaluation, and treatment of pain. Fortunately, SSA's current regulations and Social Security Rulings (specifically SSR 16-3p), do reflect current clinical and scientific research and findings. There is no scientific research or clinical findings to support changing the way the Social Security Administration (SSA) considers pain in its disability determination and adjudication processes.

Pain Evaluation Must Be An Individualized Determination

The Social Security Act requires that the decision on an individual's claim for Social Security disability benefits be made based on an evaluation of the individual's conditions and the evidence provided by the individual to support her claim.³ This requirement for an individualized determination is particularly important in the context of considering pain and the impact pain has on a claimant's ability to function. The way people experience pain is inherently subjective. Despite centuries of research to attempt to develop a method to objectively measure pain, no such measure exists.⁴ The most widely relied on (and clinically accepted) measures rely on self-reporting of pain using a variety of pain scales.⁵ This is because science has neither discovered objective ways to measure or test the existence of pain, nor to determine its scope or intensity. Science can tell us the area or areas of the brain affected by other sensory processes such as hearing, seeing, tasting, smelling, and touching. Science has not, however, identified where in the brain pain comes from or how exactly it works in the brain when we experience it.⁶ As one brain researcher put it, "Pain is, literally by definition, a subjective experience. That makes self-report the only true measure."⁷

1 For example, the Musculoskeletal systems listings include the following instruction: "It is therefore important to evaluate the intensity and persistence of such pain or other symptoms carefully in order to determine their impact on the individual's functioning under these listings." 1.00 Musculoskeletal disorders, Appendix 1 to subpart P of 20 C.F.R. §404. Pain is also mentioned in 3.00 Respiratory disorders 4.00 Cardiovascular disorders, 5.00 Digestive system, 6.00 Genitourinary Disorders, 7.00 Hematological disorders, 11.00 Neurological Disorders, 12.00 Mental Disorders, 13.00 Cancer-Adult, and 14.00 Immune System Disorders-Adult. *Id.*

2 See e.g. Social Security Ruling 17-3p Evaluating Cases Involving Sickle Cell Disease and the discussion of acute pain crises, effective September 15, 2017, available at https://www.ssa.gov/OP_Home/rulings/di/01/SSR2017-03-di-01.html.

3 *Heckler v. Campbell*, 461 US 467, 1983, "It is true that the statutory scheme contemplates that disability hearings will be individualized determinations based on evidence adduced at a hearing. See 42 U.S.C. § 423(d)(2)(A) (specifying consideration of each individual's condition); 42 U.S.C. § 405(b) (1976 ed., Supp. V) (disability determination to be based on evidence adduced at hearing)."

4 Nicola Twilley, The Neuroscience of Pain: Brain imaging is illuminating the neural patterns behind pain's infinite variety, *The New Yorker*, July 2, 2018, available at: <https://tinyurl.com/y7pntnpt>.

5 See Appendix 1 for a table of 2 dozen recognized valid and reliable pain scales.

6 Twilley, *supra*.

7 Karen Davis, a researcher at the Krembil Brain Institute, in Toronto, quoted in Twilley, *supra*.

Brain imaging, specifically MRI, is the most promising line of research that could lead to an objective measure of pain at some point in the future. But science is not at the point where brain imaging can be used to assist SSA in determining the existence, or intensity, of pain. Scientists and researchers in this area concede that “the field is not far enough advanced for an fMRI scan to be used as legal evidence of pain, or to overrule a subjective report. Some are convinced that it will never reach that point.”⁸ Although some scientists are more optimistic that eventually brain imaging will provide useful measurements in Social Security and other legal contexts regarding an individual’s pain, even those hopeful scientists recognize that such outcomes are probably at least a decade away⁹

The lack of basic scientific knowledge regarding the pain process combined with two basic pain-related concepts that have been recognized for centuries - pain threshold and pain tolerance - strongly supports the notion that the evaluation of pain must be individualized and rely on self-reporting. Pain threshold refers to the level of a stimulus required for an individual to begin to feel pain. Pain tolerance refers to the amount of pain an individual can experience before the pain negatively affects the individual’s functioning. Both pain threshold and pain tolerance impact the individual’s experience of pain because what hurts to one person doesn’t hurt another and a level of pain that is completely incapacitating for one person barely impacts another person. Pain threshold and pain tolerance from an external stimulus can be measured through experiments that apply external stimuli (such as heat or cold) and observing the individual’s reactions and changes to other indicators such as heart rate or blood pressure. Measurement of an individual’s pain threshold or tolerance due to internal stimulus, especially but not limited to neurological stimulus, is not possible except through self-reports. Given the inability to measure how much stimulus a person can be receiving from a particular condition or impairment before they experience pain and the inability to know when the individual’s pain threshold is reached and it impacts her ability to function, evaluating pain in the context of a Social Security disability claim must necessarily be an individualized inquiry.¹⁰

In addition, a growing body of research indicates that not only does an individual’s state of mind about the pain (e.g. anticipating the pain, expecting something to hurt) impact and in many cases exacerbate the way that pain affects the individual, so does the person’s state of mind about other things going on in the individual’s life (e.g. stress - such as the inability to pay bills; anxiety; worry; and doubt).¹¹ It is important to take psychological and psychosocial factors into consideration when evaluating an individual’s self reports of pain and the impact the pain has on her functioning. It is not a stretch to say that every Social Security disability claimant is experiencing some level of stress and anxiety because of the process itself and the lack of income

8 Twilley, *supra*.

9 Twilley, *supra*.

10 See John Walsh, *How Much Does It Hurt*, The Independent, January 10, 2017 for a discussion of how pain impacts different people differently and a review of the current ability of science to explain pain. Available at <https://www.independent.co.uk/life-style/health-and-families/pain-how-much-does-it-hurt-pancreatitis-methods-doctors-measure-a7513101.html>.

11 See e.g. American Pain Society, “Biological, Psychological, and Social Factors Influence Individual Pain Differences,” May, 7, 2009, available at <https://www.newswise.com/articles/biological-psychological-and-social-factors-influence-individual-pain-differences>; see also Roger Fillingim, “Individual Differences in Pain: Understanding the Mosaic that Makes Pain Personal,” April 2018, available at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5350021/>.

due to the inability to work. The fact that research has established that someone's emotional and mental state impacts her experience of pain provides additional support for the use of an individualized assessment, which takes into account the totality of conditions and the life situation of a disability claimant when considering pain and evaluating the impact pain has on the individual's functioning.

The effect that an individual's state of mind has on the experience of pain is another reason some researchers are skeptical that objective testing, such as an MRI or other brain imaging, will ever be able to accurately assess the intensity or functional impairments resulting from pain. While the experience of having an MRI can be somewhat stressful, it only captures the individual's brain activity while the individual is lying still and is in a relatively relaxed state. It would therefore be difficult to argue that the MRI captures the intensity of pain an individual might experience when performing any physical activity or has other mental stressors added, such as the stress of working or completing daily living activities. "Researchers who have spent their careers investigating the ways that pain is altered by mood, context, and suggestion are naturally skeptical of the idea that personal testimony can be proved or disproved by making someone spend an hour lying horizontal and immobile in a rigidly controlled, socially isolated, loud, boring, and claustrophobic environment"¹²

There is also growing evidence that chronic pain can change the way that neurons function and create a hypersensitivity to pain in people that experience it. For example, according to Dr. Irene Tracy, sometimes referred to as the "Queen of Pain," we now know that chronic pain is "something new, with a life of its own, with its own biology and its own mechanisms, most of which we really don't understand at all."¹³ She goes on to say that "we may all be predisposed by our brain stems to feel pain more acutely or less, but that in chronic-pain patients it's as if the volume knob of pain were turned all the way up and jammed there permanently. No one knows why this hypersensitization occurs."¹⁴ Perhaps this phenomenon is why people who have never been in chronic pain can't understand the level of pain experienced by people who have. But perhaps, more importantly, it also emphasizes how little scientists, doctors, and other treatment professionals actually know about what causes pain, how to evaluate it, and how to treat it.

The implication of this lack of basic knowledge is that it is premature for SSA to change the way it evaluates pain. Basic science around pain has not advanced to a state where any objective, rigid, or standardized process could be helpful in evaluating a claimant's pain or the impact the pain has on the individual's ability to work. With this background in mind, NOSSCR provides the following answers to the specific questions outlined in the ANPRM.

12 Twilley, *supra*.

13 Twilley, *supra*.

14 Twilley, *supra*.

Question 1: Are there changes that we should consider about how we consider pain in the disability evaluation process? If so, what changes do you suggest we make?

SSA does not need to make changes in the way it considers pain in the disability evaluation process. The current regulations provide for a very individualized determination of the intensity and duration of the pain as well as the impact that pain has on the claimant's functioning, which is currently the only medically accurate way to consider pain.¹⁵ 20 CFR §404.1529 provides:

(3)...Factors relevant to your symptoms, such as pain, which we will consider include:
(i) Your daily activities; (ii) The location, duration, frequency, and intensity of your pain or other symptoms; (iii) Precipitating and aggravating factors; (iv) The type, dosage, effectiveness, and side effects of any medication you take or have taken to alleviate your pain or other symptoms; (v) Treatment, other than medication, you receive or have received for relief of your pain or other symptoms; (vi) Any measures you use or have used to relieve your pain or other symptoms (e.g., lying flat on your back, standing for 15 to 20 minutes every hour, sleeping on a board, etc.); and (vii) Other factors concerning your functional limitations and restrictions due to pain or other symptoms.

(4) How we determine the extent to which symptoms, such as pain, affect your capacity to perform basic work activities. In determining the extent to which your symptoms, such as pain, affect your capacity to perform basic work activities, we consider all of the available evidence described in paragraphs (c)(1) through (c)(3) of this section. We will consider your statements about the intensity, persistence, and limiting effects of your symptoms, and we will evaluate your statements in relation to the objective medical evidence and other evidence, in reaching a conclusion as to whether you are disabled. We will consider whether there are any inconsistencies in the evidence and the extent to which there are any conflicts between your statements and the rest of the evidence, including your history, the signs and laboratory findings, and statements by your medical sources or other persons about how your symptoms affect you. Your symptoms, including pain, will be determined to diminish your capacity for basic work activities to the extent that your alleged functional limitations and restrictions due to symptoms, such as pain, can reasonably be accepted as consistent with the objective medical evidence and other evidence.

This individualized assessment is important not only for all the reasons previously stated, but also vitally important when it comes to evaluating the impact treatment for pain has on functioning and evaluating whether a claimant has a disability. As discussed in the introductory section, the science regarding the causes and actual processes involved in pain, and a person's subjective experience of it, is in its early stages. Because the general mechanisms of pain in the brain are poorly understood by the scientific community, it is difficult to develop treatments to address it. Just as the intensity of pain a person feels from a given stimulus can vary significantly, so can a person's reaction to a given treatment for pain. Treatments such as physical therapy, rest, stretching or chiropractic adjustments might help one individual greatly, have no effect on another, and make a third person's pain worse. Also, that same treatment might lessen one claimant's pain at a particular point in time but eventually stop being effective as the nature of the pain changes or the person becomes hypersensitized to the pain.

It follows that the failure of a doctor to prescribe a particular treatment should never be taken as evidence that the doctor does not think her patient is in pain or an indication of the intensity of pain that an individual is experiencing. This is especially true when the treatment not prescribed

¹⁵ 20 CFR §404.1529 and 20 CFR §419.929 (future citations will refer only to regulations under Title II of the Social Security Act).

is an opioid or other narcotic pain relievers. Given the lack of evidence regarding the effectiveness of pain treatments, each doctor will consider what treatment to provide based on her experience with similar patients and that particular patient's history.

As SSA is aware, the United States faces an epidemic of opioid addiction and opioid related deaths, with more than 130 people per day dying from overdoses.¹⁶ Although standards of care might vary in different specialties and in different circumstances (e.g. post-surgical care vs. post traumatic injury), most counsel very short-term use and the prescription of alternate treatments. The Centers for Disease Control and Prevention (CDC) for example, states that opioids should not be the "first-line or routine therapy for chronic pain."¹⁷ The CDC also found "evidence on long-term opioid therapy for chronic pain outside of end-of-life care remains limited, with insufficient evidence to determine long-term benefits versus no opioid therapy, though evidence suggests risk for serious harms that appears to be dose-dependent."¹⁸ States have also limited initial prescriptions by statute, with some states prohibiting use longer than four (4) days with an initial prescription.¹⁹

A claimant's refusal to take opioids or other narcotics if prescribed should also never be viewed as a refusal to follow treatment under 20 CFR §404.1530. Given the lack of evidence regarding clinical effectiveness, the significant side effects (that often prevent people from working – such as extreme fatigue and inability to concentrate), and potential for addiction and other negative outcomes, in many circumstances, not taking opioids even if prescribed could be a rational and appropriate response from a claimant, irrespective of the intensity of her pain and the resulting functional impairment.

SSA's current policy, as outlined in both 20 CFR §§404.1529 and 404.1530 and SSR 16-3p²⁰ is appropriate in that it neither encourages nor discourages any specific treatment for pain, as there is no clinical evidence to support the efficacy of any particular treatment. It is also appropriate because it requires the adjudicator to make an individualized determination regarding the individual's pain, considering the self-reported levels of intensity, duration and resulting functional limitations, while recognizing that science cannot assist in those assessments because scientists are just beginning their journey and exploration to understand the causes, mechanisms, and processes surrounding pain.

16 See <https://www.drugabuse.gov/drugs-abuse/opioids/opioid-overdose-crisis>.

17 CDC Clinical Reminders for Prescribing Opioids for Chronic Pain, March 18, 2017,

<https://www.cdc.gov/mmwr/volumes/65/rr/pdfs/rr6501e1.pdf>.

18 *Id.* p. 9.

19 See <http://www.ncsl.org/research/health/prescribing-policies-states-confront-opioid-overdose-epidemic.aspx>.

20 SSR 16-3p provides for a detailed individualized analysis of self-reports of pain and the individual's treatment history. Regarding how SSA will evaluate treatment, the ruling provides exceptions that recognize the severe side effects, lack of consistency in effectiveness across individuals of various pain treatment options, among other factors that might lead a doctor not prescribe treatment or an individual not to continue treatment, reflecting the current state of research and science in pain treatment and management.

Question 2: Within the United States, which standard scales, questionnaires, or other methods to evaluate the intensity and persistence of pain that are commonly accepted in the medical community do you recommend we consider and why? What information exists about the efficacy or accuracy of those scales, questionnaires, or other methods?

Many pain scales exist that are commonly used and accepted in the United States. Estimates of the number of those scales range from approximately two dozen that are commonly accepted in the United States and have been found clinically valid and reliable to more than 75.²¹ **SSA should consider and accept all of them**, as they all are useful, but each has advantages and limitations. The scales differ in their complexity, the time they take to administer, and the detail of information collected. Some are unidimensional, asking the patient to rate their pain on a scale of 1 to 10, for example, and others ask more questions and attempt to capture the impact pain has on functioning and quality of life. Some pain scales are designed for specific conditions or types of conditions, such as the Clinical Global Impression Scale for psychiatric conditions, the Comfort Scale to assess pain in children who cannot articulate their level of pain, the Dallas Pain Questionnaire for spinal pain, and the Discomfort in Dementia scale for Alzheimer's and other dementia patients.

All of the pain scales listed in Appendix 1 to these comments have been found to be reliable and valid and can provide SSA with useful information to assess the intensity of pain and impact on functioning (and on other factors if additional questions are included in the questionnaire) at the point in time that the questionnaire was completed. But there is no evidence to suggest that one scale is better than another (e.g. more reliable or valid) that would support SSA considering one scale but not another or giving more weight to one scale over another.

When evaluating what a pain scale tells them about a particular claimant, it is important for SSA to remember that:

- Pain levels change over time. When evaluating whether an individual's self-report of pain using one of these valid and reliable scales is consistent with objective medical evidence (and other statements made by the claimant), it is important to remember that a pain scale often shows only how the claimant was feeling on a particular day or moment when the scale was administered. In other words, a low rating on a pain scale at a particular interaction with a health care provider is not inherently inconsistent with a report of much more significant pain on another day or time (or a low rating on a scale completed years ago). SSA's analysis should include the totality of the claimant's situation (e.g. does the claimant's pain wax and wane, was the claimant undergoing treatment that was effective at the time the scale was completed but later stopped providing pain relief, what else may have been going on in the claimant's life at that time that could have minimized or exacerbated the experience of pain) to determine whether that rating was inconsistent with other statements or evidence.
- A treating source might have a variety of reasons for using one scale rather than another that is perfectly legitimate and should not diminish the weight given to the scale when SSA considers it. For example, more detailed and complicated scales might provide SSA

²¹ See appendix 1 for a listing of those pain scales.

with more information but will take longer to administer or require a specialist or specialized training to administer not available to the claimant's treating source. The doctor might choose to administer a unidimensional scale (rate pain 1-10 or visually) because of the time constraints the doctor faces in performing patient exams or the exact reason that the treating source was administering the scale at that particular time.

- The fact that certain pain scales are primarily used to evaluate pain related to certain conditions does not mean that other scales are not valid and reliable to evaluate pain for people with that condition. For example, just because a questionnaire exists designed for adult cancer patients (the Brief Pain Inventory), does not mean the more general McGill Pain Questionnaire shouldn't be considered by SSA as valid and reliable for adult cancer patients. It is true the Brief Pain Inventory might provide more information about the impact the pain has on the claimants functioning because of the questions it asks than the McGill Questionnaire does not but SSA should consider both questionnaires and evaluate them under the procedures outlined in 20 CFR §§404.1519 and 416.929 and SSR 16-3p.

Question 3: How is pain and documentation of pain in the medical evidence assessed in other Federal, State, and private disability programs?

NOSSCR cautions against using procedures or processes for considering pain and documentation of pain in other public or private disability programs as a guide for developing policy in the Social Security disability programs. What is required to establish disability in other public or private disability programs is determined by the governing statute setting eligibility requirements or private insurance policy rules, which SSA itself has acknowledged “differ significantly” from the purpose and specific eligibility requirements under the Social Security Act.²²

For example, the United States Court of Appeals for the Federal Circuit recently found in *Saunders v. Wilkie* that, in veterans' disability claims, “...pain is [itself] an impairment because it diminishes the body's ability to function, and that pain **need not be diagnosed as connected to a currently underlying condition to function as an impairment.**”²³ (emphasis added) The Court in *Saunders* distinguished veterans' claims from Social Security disability claims by drawing a distinction between their authorizing statutes, citing to 42 USC §423(d)(5)(a), which specifically requires “medical signs and findings, established by medically acceptable clinical or laboratory diagnostic techniques which show the existence a medical impairment that results from anatomical, physiological, or psychological abnormalities which could reasonably be expected to produce the pain.”²⁴ The court reasoned that Congress would have included a requirement that a veteran tie the pain to an underlying condition with medical evidence to

²² See Revisions to Rules Regarding the Evaluation of Evidence, 82 CFR 5849: “As we stated in the notice of proposed rulemaking (NPRM), there are four reasons why we are not requiring our adjudicators to explain their consideration of these decisions [made by other entities for other disability programs]—(1) the Act's purpose and specific eligibility requirements for disability and blindness differ significantly from the purpose and eligibility requirements of other programs; (2) the other agency or entity's decision may not be in the record or may not include any explanation of how the decision was made, or what standards applied in making the decision; (3) our adjudicators generally do not have a detailed understanding of the rules other agencies or entities apply to make their decisions; and (4) over time Federal courts have interpreted and applied our rules and Social Security Ruling (SSR) 06–03p differently in different jurisdictions.”

²³ *Saunders v. Wilkie*, No. 17-1466 (Fed. Cir. 2018) p. 13

²⁴ *Id.* p. 15.

establish it in 38 USC §1110 had Congress wanted it to be required.²⁵ The *Saunders* decision was issued in April of 2018 and its lasting impact on the veterans' disability compensation programs rules and procedures for evaluating pain might still be evolving. It does, however, create significant differences in the evaluation and consideration of pain between the two programs that counsel caution in trying to replicate any pain documentation or evaluation policies or procedures from veterans disability compensation programs in the Social Security disability programs. However, when SSA receives or obtains evidence supporting a veteran's benefit determination, agency adjudicators should consider it and use it to determine whether SSA's disability standard is met.

Another difference between the veterans and Social Security disability programs that makes comparisons difficult is the way that health care is delivered to veterans. Because most veterans receive care from Veterans Health Administration doctors and at VA facilities, standardizing forms or scales might be easier. For example, only considering a standard or specific questionnaire regarding pain or requiring a particular pain scale be used by the treating physician might be easier to operationalize and might not hurt veterans whereas doing so in the Social Security disability programs might.

It is difficult to apply the rules and procedures regarding the consideration of pain used by private disability programs and state level programs such as workers' compensation as well. All have different definitions of disability (e.g. only being unable to perform own occupation in private disability policies, full and partial as well as temporary and permanent disability in workers' compensation). The definition of disability used for the program might have a different (or in the case of temporary benefits no) duration requirement that could lead to a difference in the way that pain is considered. Given these differences, NOSSCR urges caution in trying to apply procedures used in other programs to the Social Security disability programs.

Question 4: Should we evaluate chronic pain differently than acute pain? If so, how and why?

SSA should not consider chronic and acute pain differently. All of the previously stated arguments in the introduction section and those discussing the state of science on measuring and treating pain apply to both acute and chronic pain. Evaluating pain, whether chronic or acute, must involve an individualized assessment of the impact of pain on the claimant's functioning using the individual's self-reports and considering the totality of the circumstances in her life. Interestingly, there is not even a scientific consensus regarding how long someone must be in pain for it to be considered chronic. Many researchers and practitioners agree that pain that continues for more than 6 months and that pain from an injury after the injury has fully healed both qualify as chronic pain.²⁶ In addition, many disability claimants have multiple impairments and might be experiencing both acute pain from an accident, injury, or chronic condition and chronic pain from the same or a different condition at the same time. As with most science regarding pain, scientific evidence provides no clear lines between acute and chronic pain. Social Security disability claimants probably experience pain on a spectrum from acute to chronic.

²⁵ *Id.* p.12-13.

²⁶ Some medical sources define chronic pain as pain that lasts more than 12 weeks (*see e.g.* <https://medlineplus.gov/magazine/issues/spring11/articles/spring11pg5-6.html>) but most say pain lasting 6 months or more (*see e.g.* <https://my.clevelandclinic.org/health/articles/12051-acute-vs-chronic-pain>).

It is also the case that, because the disability application and appeals process takes so long, someone could apply with acute pain and have her pain evolve into chronic pain by the time of a hearing in front of an Administrative Law Judge. Under those circumstances, if SSA created policy to consider acute pain differently than chronic pain, different rules would apply at the application level for the consideration of pain for that claimant than at the hearing level, creating a confusing and unclear process for the claimant and adjudicators.

That is not to say that changes don't occur in the body and brain when pain becomes chronic. Some scientists now say that chronic pain is itself a disease.²⁷ As discussed in NOSSCR's answer to question 3, the Federal Circuit recognized that fact in *Saunders* and found that pain could itself be an impairment for the purposes of determining eligibility for veterans' disability compensation. However, the Social Security Act does not allow SSA to do so because there is no objective test or evidence to prove that a claimant has chronic pain, as is required by statute. As such, whether pain is acute or chronic is a distinction without a difference in this context based on the lack of scientific evidence regarding pain. SSA should focus on determining how the pain, whether chronic or acute, affects claimants' functioning and how those functional limitations affect her ability to work.

Question 5: Should we evaluate nociceptive pain differently than neuropathic pain? If so, how and why?

As discussed in the introduction and in answers to previous questions, the experience of pain is subjective and highly individualized. SSA's current policies for evaluating pain are appropriate based on the current state of science and research regarding the causes. There is no evidence that testing or treatment is more effective or accurate for nociceptive pain than it is for neuropathic pain or vice versa. As such, there is no scientific evidence to justify evaluating pain in any other way than obtaining self-reports of pain using an accepted scale and questionnaire and performing an individualized assessment of the individual's pain that incorporates the totality of the claimant's circumstances (especially psychological and mental factors as outlined in the NOSSCR's response to question 1) and the impact the pain has on the individual's ability to function.

Question 6: What information and evidence is available on the effectiveness and side effects of the traditional and alternative modalities for treating pain that we should consider?

The effectiveness of both traditional and alternative modalities for treating pain is individualized. As discussed in the answer to question 1, some treatments provide significant relief to some people, a little relief to others, and no relief to some. In addition, even if a treatment is effective at one point in time, the effectiveness of that treatment can change over time. Generally, studies that evaluate the effectiveness of treatments rely on self-reporting because it is the only way to

²⁷ "Chronic pain is often defined, somewhat misleadingly, as "pain that extends beyond the expected period of healing." In reality, once you've "gone chronic," as Tracey puts it, pain is the disease, rather than a symptom. That view represents a shift in understanding, brought about in part by her work. Until recently, chronic pain was thought of merely as prolonged "normal" pain. But neuroimaging has shown that, if a chronic-pain sufferer and an unafflicted person are given the same burn or pinprick, their brains manifest activity differently." Twilley, *supra*.

measure pain.²⁸ Often, research focuses on treatment regimens that incorporate a variety of treatment modalities (physical and occupational therapy, pharmacological interventions, psychological interventions, acupuncture and other alternative methods) and it can be difficult to isolate the effectiveness of any one treatment. Current research cannot quantify expected improvements for an individual's pain levels or functioning from any particular treatment. SSA should not change the way it considers pain-based treatment effectiveness because the current science and research do not support doing so.

Treatments for pain have a variety of side effects. However, individuals may experience some, all, or none of the recorded side effects of a given treatment; may have side effects that are not recognized by the manufacturer of the treatment; and may experience side effects continuously or sporadically. Different side effects cause different functional limitations for different people and as such, individualized assessments are critical.

Question 7: Can health care utilization and treatment regimens employed by physicians to manage patient pain provide objective insights into the intensity and persistence of pain? When should those regimens not be an indication of the severity of an individual's pain?

Please see NOSSCR's introduction section, answer to question 1, and answer to question 6 for a response to this question. It is also important to remember that given the lack of scientific evidence to support the efficacy of any one given treatment, the treatment that a doctor prescribes is influenced by a number of factors, including but not limited to: willingness or aversion to prescribing opioids, success or failure of a given treatment for past patients with similar conditions, the extent to which the practitioner uses an interdisciplinary approach, institutional culture, availability of a treatment modality in a given geographic location, insurance coverage of a given treatment modality (and the patient's ability to afford it). SSA will generally not have knowledge of how those factors influenced the source's decision to employ a given treatment regimen or not to employ a given treatment regimen.

Given the individualized nature of the experience of pain and its impact on individuals, the lack of scientific data and research to support the efficacy of any one treatment to address pain, and the myriad of factors that can influence what treatment modalities a treating source employs or does not employ, an individualized assessment that takes into account the self-reporting of pain by the claimant and takes into account the totality of the claimant's circumstances that might affect the claimant's experience of pain as is outlined in current SSA policy is the most appropriate approach to evaluating treatment when considering pain in the disability adjudication process.

Conclusion

The consideration of pain in the Social Security disability adjudication process is integral to hundreds of thousands of disability claims each year. SSA's current policy appropriately allows for a very individualized determination of the intensity and persistence of a claimant's pain, as well as the impact the pain has on the individual's ability to work. Current science supports the

28 See e.g. Svetlana Kurklinsky et al, *The Efficacy of Interdisciplinary Rehabilitation for Improving Function in People with Chronic Pain*, Pain Research and Treatment, Volume 2016, Article ID 7217684, 6 pages <http://dx.doi.org/10.1155/2016/7217684>.

use of self-reports to evaluate pain and confirms that no objective tests to establish the existence or intensity of pain are currently available, nor is any likely to be in the near future. Current research and evidence does not support SSA making changes to its current policies or procedures governing the consideration of pain in the Social Security disability programs.

Thank you for the opportunity to comment on this ANPRM.

Sincerely,

Barbara Silverstone
Executive Director

Appendix 1:

Table 1. Pain Scales – Reprinted from

https://www.practicalpainmanagement.com/sites/default/files/pain_scales_table.pdf

Pain Scale Name (Population)	Description	Validity	Comment
Alder Hey Triage Pain Score (Emergency care triage of pediatric patients)	Observational scale completed by staff, 5 items each scored 0 to 2 with total score 0 to 10 possible	Validated for inter-rater variability ¹	Easy to administer, takes about 10 minutes, patients need not be able to communicate
Behavioral Pain Scale (BPS) (Critically ill sedated adult patients)	Observational scale completed by staff, scores from 3 to 12	Validated for inter-rater variability and reliability	Validated for use with patients with a low level of consciousness due to head trauma ²
Brief Pain Inventory (BPI) (Adult cancer patients)	Self-report of pain intensity (sensory dimension) and how pain interferes with patient's life (reactive dimension)	Validated and translated into numerous languages	Has been validated for use in patients with chronic nonmalignant pain ³ and osteoarthritis ⁴
Checklist of Nonverbal Pain Indicators (CNPI) (Cognitively impaired adult patients)	Observational test completed by staff based on specific behaviors, restlessness, vocalization	Inter-rate reliability 93% ⁵	Requires staff training
Clinical Global Impression (CGI) (Psychiatric patients)	Observational assessment of patient's global function before and after study medication; it measures psychopathology severity on a scale of 1 to 7	Validated and reliable ⁶	Easy to administer
Critical Care Pain Observation Tool (CPOT) (Nonverbal critically ill adults)	Observational scale of behaviors, facial expressions, body movements, and muscle tension	Moderate to high inter-rate reliability and significant correlations between CPOT and self-reported pain scales ⁷ ; sensitivity 86%, specificity 78% in study of critically ill cardiac surgery patients ⁸	For intubated patients, compliance with ventilator is assessed; for non-intubated patients, vocalization is assessed
COMFORT Scale (Children unable to report pain [has been evaluated in patients age 12 to 36 months])	Observational care completed by staff evaluating alertness, anxiety, respiratory response, crying, movement, muscle tone, and facial tension	High inter-rater reliability	Requires staff training
Dallas Pain Questionnaire (DPQ) (Adult patients with chronic spinal pain)	16-item self-report measuring pain intensity, function, anxiety, depression, and social interest	Good external reliability and internal consistency ⁹	DPQ is divided into 2 sections called "factors"; Factor 1 represents functional activities, Factor 2 emotional capacities
Descriptor Differential Scale (DDS) (Alert and nonimpaired adults)	Self-report in 12-item questionnaire	Good reliability and is sensitive to even small changes in pain intensity ^{10,11}	Easy for patients to use but requires some training for health care team to interpret
Discomfort in Dementia (DS-DAT) (Adults with dementia or Alzheimer's disease)	Observational 9-item tool for completion by staff over 5-minute assessment period	Inter-rater variability exists in 3 of the 9 items	Requires staff training to administer accurately

Edmonton Symptom Assessment System (Palliative care patients, typically end-of-life cancer patients)	Twice-daily assessment using 8 visual analog scales to be completed by patient alone or by patient with assistance (from nurse or family member)	Validation evidence is not robust ¹²	Data from the 8 scales are transferred to a graph; the sum of all scores is the “symptom distress score” Has been translated into several languages
FACES (Wong-Baker) (Pediatric patients [age 3 to 7] treated for acute pain in emergency department)	Self-report using 6-item ordinal scale made up of 6 faces showing no pain (smiling face) to worst pain imaginable (grimace)	Validated with good agreement between FACES and visual analog scale ¹³	May also be used for adults when there is a language barrier
Lequesne-Algofunctional Index (1987, 1991, 1997) (Adult pain patients with circadian types of pain)	Self-report in 10-item questionnaire that puts pain in temporal context (pain at night, upon rising) and situations (pain standing, pain walking, and so on)	Validated	Easy to administer, takes about 10 minutes, and is well suited for pain that fluctuates over course of day
Mankowski Pain Scale (Developed for endometriosis patients but used with other types of chronic pain)	Self-report on 0 to 10 scale with descriptions to help better quantify pain (for example, 5=pain that can't be ignored for more than 30 minutes; mild painkillers reduce this pain about 3 or 4 hours)	Validated for chronic pain patients (not just endometriosis patients) ¹⁴	Developed by Andrea Mankowski, a chronic pain patient
McGill Pain Questionnaire (MPQ) (Adults with various pain syndromes)	Self-report, 20 items grouped as sensory, affective, evaluative, and miscellaneous; patients score each 0 to 5. The Pain Rating Index (PRI) is the sum of the rank values	Validated and designed to better capture the subjective experiences of pain patients ¹⁵	Also rates the Present Pain Index (PPI) as a separate scale (0-5)
Neck Pain and Disability Scale (NPDS) (Adults with cervical pain syndromes)	Self-report of 20 items as visual analog scales with descriptors, describing different aspects or behaviors associated with the neck	Reliable, internally consistent, correlates well with other scales ¹⁶	
Numerical Rating Scale (NRS) (Adult and pediatric pain patients)	Self-report on scale of 0 to 10 with 0 meaning “no pain at all” and 10 “the worst pain imaginable”	Reliable, validated, widely used	Minimal training required, easy for patients to understand; measures pain intensity only
OSWESTRY Disability Index (Adults with low back pain)	Self-report of pain intensity and function (disability)	Validated and correlates highly with the Roland-Morris Disability Index ¹⁷	Fast and easy to administer, easy for patients to understand
Palliative Care Outcomes Scale (PCOS) (Adult palliative cancer patients)	2 nearly identical tools: a self-report by the patient and corresponding observational report by staff; documents patient's well-being over past 3 days in physical, psychological, and spiritual domains	Validated with good internal reliability; good agreement between patients and staff on many items ¹⁸	May be useful in better determining prospective care for end-of-life patients
Pediatric Pain Questionnaire (PPQ) (Pediatric pain patients ≥6 years)	Self-report on visual analog scale of present pain, worst pain intensity, and disease severity	Good correlation between PPQ and health care professionals' observations	Easy to administer

Roland-Morris Back Pain Questionnaire (Adults with low back pain)	Self-report, 24-item checklist in which patients are asked which statements apply to them that day; all items have equal weight (1 point) and score is total	Validated and correlates highly with the OSWESTRY Disability Index ¹⁷	Short, simple, easy to use; each item on the scale begins, "Because of my back pain..."
Support Team Assessment (STAS) (Adults in palliative care)	Self-report and corresponding observational report (to be completed by family members or health care professionals)	Measures prospective outcomes	When observational scales were compared to self-reports, observations by health care professionals were closer to patient self-reports than observations by family members
Verbal Rating Scale (VRS) (Adult and pediatric pain patients)	Self-report by patient to verbal questions of health care professional, asking them to describe their pain using 5 categories (no pain, mild pain, moderate pain, severe pain, unbearable pain)	Correlates highly to VAS ¹⁹	Measures pain intensity only and is subject to variations depending on how each patient understands "mild," "moderate," and "severe" pain
Visual Analog Scale (VAS) (Adult pain patients)	Self-report by patient who selects a point on a 100-mm line that indicates pain level; in some cases, a percentage may be used (0 is "no pain" and 100% is "worst pain imaginable")	Validated, familiar, and among the most frequently used pain scales in the US	Easy to administer, fast, and easy for patients to understand but measures pain intensity only