The revised International Association for the Study of Pain definition of pain: concepts, challenges, and compromises

Supplement 1 – Public Consultation on the task force's initial recommendation

Methods

Members of the global pain community at large were invited to submit feedback on the proposed new definition of pain and notes via a web-based survey. The survey was developed by the task force and open from August 7, 2019 to September 11, 2019. Guidelines for survey completion included: 1) only one submission per person; 2) open to any member of the pain community and not restricted to IASP members; and 3) respondents must follow IASP's Public Comment Policy.[1] The survey was posted on IASP's website and distributed to all IASP members through email and to the general public over the official IASP social media platforms (e.g., Facebook and Twitter). IASP encouraged the public to share the public consultation survey link with interested colleagues, students, healthcare consumers, and other stakeholders.

The survey was in English and included eight questions (five demographic questions, one question on satisfaction with the proposed definition, and two open-ended questions regarding the proposed definition and notes). Regarding demographic characteristics, respondents were asked to indicate their IASP membership status, country of residence, occupation, work setting, and specialty. Next, respondents were asked to indicate on a 5-point Likert scale (ranging from very dissatisfied to very satisfied) what their satisfaction level would be if the current definition of pain was revised to the newly proposed version. Finally, respondents were invited to provide written comments to the following two open-ended questions: "Please share any written feedback you have on the proposed new definition of pain" and "Please share any written feedback you have on the proposed accompanying notes section to the revised definition of pain." All of the survey questions were optional to complete.

Descriptive statistics were used to summarize the sample characteristics and level of satisfaction with the proposed definition. Two researchers with previous qualitative research experience (PRT and KV) analyzed the responses to the two open-ended questions by conducting inductive qualitative content analysis using standard procedures.[2] Briefly, the two reviewers read all responses several times to become familiar with the data. Next, they coded similar ideas into content-related categories derived from the data using line-by-line coding. Then, they each independently coded the first half of the responses and met regularly to refine the coding scheme and compare coding to ensure consistency. One reviewer then coded the remaining responses. Responses were coded manually in data management software (NVivo 12, QSR International). Once coding was complete, the two reviewers collaboratively brought together the codes and abstracted them into higher order categories and subcategories based on between-code relationships. Data from the two open-ended questions were analyzed separately in two sets of higher order categories and subcategories; responses to the question focused on the proposed definition of pain were analyzed first followed by responses to the question on the notes. Several steps were taken to enhance rigor and trustworthiness, including maintenance of an audit trail detailing analytical decisions, frequent dialogue among the reviewers during the analysis process, and integration of representative quotes in the results to demonstrate the concepts presented.

Results

A total of 1052 respondents began the web-based survey. Respondents were included in the analysis if they completed at least one of the three questions on the proposed definition and notes. The final sample included 808 respondents (See Supplemental Table 1 for respondent demographic characteristics). In summary, the majority of respondents were not members of

IASP (n=578, 71.53%) and most were from the United States (n=511, 63.24%). The three most common occupations identified by respondents were “other” (n=302, 37.38%), clinician (n=181, 22.40%), and retired (n=136, 16.83%). Most commonly, those who identified their occupation as “other” specified that they were an individual living with pain. The three most common work settings selected by respondents were “other” (n=383, 47.40%), academic institution (n=157, 19.43%), and clinic/hospital (n=142, 17.57%). Those who reported their work setting as “other” most often reported that their pain rendered them unable to work. In terms of speciality, “other” was the most common (n=396, 49.01%) followed by pain medicine (n=83, 10.27%), and psychology/social science (n=59, 7.30%). Once again, “other” was the category most commonly used by individuals living with pain.

Supplemental Table 1. Respondent demographic characteristics (N=808).

Characteristic	**n (%)**
Member of IASP	
Yes	230 (28.47)
No	578 (71.53)
Country	
Argentina	2 (0.25)
Armenia	1 (0.12)
Australia	34 (4.21)
Austria	1 (0.12)
Belgium	4 (0.50)
Brazil	5 (0.62)
Canada	90 (11.14)
Chile	1 (0.12)
China	3 (0.37)
Denmark	4 (0.50)
Egypt	2 (0.25)
Ethiopia	1 (0.12)
Finland	1 (0.12)
France	10 (1.24)
Germany	7 (0.87)
Greece	1 (0.12)
Honduras	1 (0.12)
India	10 (1.24)
Indonesia	2 (0.25)
Israel	4 (0.50)
Italy	7 (0.87)
Japan	10 (1.24)
Kenya	1 (0.12)
Latvia	1 (0.12)
Lebanon	1 (0.12)
Malawi	1 (0.12)
Mexico	3 (0.37)
Nepal	1 (0.12)
Netherlands	3 (0.37)
New Zealand	12 (1.49)
Nigeria	2 (0.25)
Pakistan	4 (0.50)
Puerto Rico	1 (0.12)

Romania	1 (0.12)
Saudi Arabia	3 (0.37)
Singapore	2 (0.25)
South Africa	3 (0.37)
Spain	3 (0.37)
Sweden	6 (0.74)
Switzerland	3 (0.37)
Taiwan	1 (0.12)
Thailand	2 (0.25)
Ukraine	1 (0.12)
United Kingdom	39 (4.82)
United States	511 (63.24)
Uruguay	2 (0.25)
Occupation	
Administrator	18 (2.23)
Basic researcher	29 (3.59)
Clinician	181 (22.40)
Clinical researcher	69 (8.54)
Educator	51 (6.31)
Retired	136 (16.83)
Trainee/student	22 (2.72)
Other	302 (37.38)
Work setting	
Academic institution	157 (19.43)
Private practice/business	104 (12.87)
Clinic/hospital	142 (17.57)
Pharmaceutical	9 (1.11)
Research facility	13 (1.61)
Other	383 (47.40)
Specialty	
Anesthesiology	29 (3.59)
Complementary & alternative medicine	10 (1.24)
Dentistry/oral medicine	8 (0.99)
Family medical/primary care	9 (1.11)
Healthcare/research administrator	0 (0.00)
Internal medicine	6 (0.74)
Neurosurgery/surgery	4 (0.50)
Neurology	7 (0.87)
Neuroscience/pharmacology/physiology	23 (2.85)
Nursing	49 (6.06)
Obstetrics/gynecology	0 (0.00)
Oncology	3 (0.37)
Orthopedics/rheumatology	5 (0.62)
Occupational therapy	2 (0.25)
Pain medicine	83 (10.27)
Palliative medicine	2 (0.25)
Pediatrics	15 (1.86)
Psychology/social science	59 (7.30)
Psychiatry	0 (0.00)

Physical therapy	57 (7.05)
Physical med & rehabilitation	18 (2.23)
Other	396 (49.01)

A total of 808 respondents completed the question on their satisfaction with the proposed definition of pain. Respondents reported varying degrees of satisfaction: very satisfied (n=114, 14.11%), satisfied (n=223, 27.60%), neutral (n=150, 18.56%), dissatisfied (n=145, 17.95%), and very dissatisfied (n=190, 23.51%).

Additionally, 621 respondents provided written comments for the open-ended question regarding the proposed new definition of pain. Four categories (and 11 subcategories) were generated to describe respondents' feedback to the proposed new definition of pain: 1) the definition of pain should be simple and practical; 2) the definition should better capture the personal experience of pain; 3) the definition should provide more specificity regarding the various components of pain; and 4) the definition's reference to tissue injury should be better aligned with modern conceptualizations of pain. See Supplemental Table 2 for a summary of respondent feedback on the proposed definition of pain, including categories, subcategories, and illustrative quote(s).

Supplemental Table 2. Summary of feedback on the proposed definition of pain.

Category	**Description**	
1. The definition of pain should be simple and practical	Respondents expressed that the proposed definition should be amended to be more simple, easy to understand, and practical for use by clinicians and patients. Data in this category were described by three subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. Wording is cumbersome	Many respondents described the wording of the proposed definition as clunky and convoluted. This was particularly true for certain phrases such as, "caused by, or resembling that caused by".	*"The proposed definition is too cumbersome to be useful."* *"'or resembling that caused by' took a few reads for me to be able to follow. I understand what you are trying to relay, but it is not easy to follow."*
b. Reading level	According to respondents, the proposed definition included too much jargon, resulting in a reading level too high to be accessible and useful by the average patient and clinician. Specific terms that were not easily understood included "aversive", and "tissue injury" (which was often misinterpreted as solely related to injury of skin tissue).	*"I work in pain and find the new definition hard to understand. The average reading age of people in my city is 9 years old. The new definition utilising obscure words like 'aversive' rather than being written in plain, understandable and accessible language makes the definition more for clinicians than patients. A definition of pain should make sense to people who have pain."* *"I disagree with the tissue always being involved. I have*

		significant bone pain at times that has nothing to do with tissue."
c. Translation to other languages	Some respondents acknowledged the potential difficulty of translating the proposed definition into other languages. Certain words and phrases such as "aversive" were identified as challenging to translate.	*"This new definition and in particular the term 'aversive' will be difficult to explain and translate in French."*
Category	**Description**	
2. The definition should better capture the personal experience of pain	Respondents felt that the wording of and content in the proposed definition should be modified to better capture the individual experience of pain. Data in this category fell into three subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. "Aversive" as a descriptor of pain	Many respondents reported that the term "aversive" did not accurately describe the concept of pain. Two main reasons for this were described: (1) to some, describing pain as aversive was offensive because their personal experience of pain was far worse than simply aversive; and (2) others suggested that pain may not always be an aversive experience.	*"I do not like the word aversive. For many people this isn't a word associated with their experience of pain. Unpleasant was good…"* *"Pain is not always perceived as aversive, but rather can be viewed as enjoyable or necessary (i.e. masochism) particularly in the context of exercise-induced pain."*
b. Impact of pain on quality of life	Some respondents felt that the potential impacts of pain on a person's quality of life and functioning were core components of the experience of pain and should be acknowledged directly in the definition.	*"It should say something about the effects of pain, such as that it prevents normal functioning to a greater or lesser extent in each individual."* *"I wonder if there is something still missing about the profoundness of the pain experience and the meaning this has…"*

c. Subjectivity of pain	Respondents were generally pleased to see the subjectivity of pain recognized in the accompanying notes. However, many expressed that this element should be included in the definition itself to underscore the importance of trusting an individual's report of pain. Relatedly, respondents acknowledged the difficulty of defining pain at all given that it is such a personal experience that is unique to each individual.	*"It's great that the subjective nature is highlighted in the notes, but why not make this subjectivity central to the actual definition?"* *"While [the current and proposed] definitions acknowledge the subjective nature of pain, this profound core element is relegated to the footnotes provided beneath the actual definition instead of occupying text within it."*
Category	**Description**	
3. The definition should provide more specificity regarding the various components of pain	Respondents suggested that the proposed definition of pain should be revised to capture the granularity of what is known about the causes, classifications, and influences of pain. Data in this category were captured by two subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. Pain comes in many forms	Many respondents stated that the definition should acknowledge the various types of pain (e.g., acute versus chronic; neuropathic versus nociceptive; psychological distress as pain) and distinguish between them. Some suggested providing separate definitions for acute and chronic pain to highlight their key differences.	*"The difference between nociceptive and neuropathic pain should be addressed in any definition, as well as the difference between acute and chronic pain."* *"One single definition to satisfy both acute and chronic pain may not be an appropriate effort as both are quite different. In such a case, why not to have different definitions explaining both lucidly and having two different definitions."* *"…pure emotional pain, as such caused by devastating loss and/or other situational (passive/mental) trauma, is not well represented in the definition. This type of 'pain' does not, in any way, involve [tissue injury], yet encompasses a very large part of mental*

		anguish and pain among a large patient population."
b. Pain is influenced by many factors	Numerous respondents expressed that the definition of pain should be described in broader terms than simply a "sensory and emotional experience." Respondents noted that pain can be influenced by a wide range of factors, such as cultural, cognitive, social, and spiritual factors, and that these should be included. Some respondents also commented on the pitfalls of including emotion as a central factor of pain in the definition due to the potential for invalidation and dismissal of pain as a psychological condition.	*"Only providing sensory and emotional factors to the experience is limiting the full scope of the experience."* *"Social and cultural aspects should be clear in the definition."* *"The word 'emotional' opens the door to all those who would tell patients, "it's all in your head", or that they are only faking it to get drugs…"*
Category	**Description**	
4. The definition's reference to tissue injury should be better aligned with modern conceptualizations of pain	Respondents reported that the definition of pain should soften the implication that tissue injury "causes" pain. Data in this category fell into three subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. Tissue injury as a cause of pain	Many respondents stated that the proposed definition of pain should focus less on the causality between tissue injury and pain.	*"The proposed definition reinforces a biomedical, pathoanatomical approach to pain by its central focus around tissue damage."* *"I'd prefer the term 'associated with' rather than *caused by* because of the poor relationship with tissue states and the experience of pain."*
b. Pain as an interpretation	Some respondents expressed that the definition would be better aligned with modern conceptualizations of pain if it highlighted the role of the brain in the pain experience. This	*"Neuroscience research tells us that chronic pain is in the brain, often the result of CNS sensitization - and has very little (and sometimes nothing) to do with the tissues. Please consider*

	encompassed describing pain as an interpretation of nociception by the brain, as well as including reference to pain as the brain's perception of threat or danger.	*a revision that includes the role of the brain…"* *"It would be useful for the new definition to include a reference to pain being the outcome of perception of threat or danger."*
c. Pain resembling tissue injury	Many respondents commented on the problems associated with framing pain as "resembling that caused by tissue injury". Some expressed that this description does not fit with their personal experience of pain. For instance, not all pain resembles the sensations that would be caused by tissue injury (e.g., neuropathic pain). Further, respondents expressed concern that the phrase "resembling that caused by tissue injury" is ambiguous and could allow a clinician or another third party to make a judgement about whether pain could be present.	*"The proposed language improves by using 'resembling' rather than 'potential'. The point is to focus more fully on the experiential aspect of pain. That said, I'm not sure even the new definition does justice to the neuropathic pain experience. The kind of burning, searing pain in those cases I don't think 'resembles' direct tissue injury type pain. What it has in common is the unpleasant experience aspect. But, I think there is still too much reliance on the direct tissue injury in this proposed definition."* *"The term 'resembling' now included in the definition seems to connote judgement on the part of the observer that pain is present; it puts the defining of pain with an observer rather than the experiencer, and is thus open to observer bias about what 'resembles' actual or potential tissue injury."*

A total of 430 respondents provided written feedback regarding the notes to the proposed definition of pain. Seven categories (and 14 subcategories) were generated. One category was related to overall comments on the proposed notes, and the remaining six categories were specific to each of the six bullet points in the notes. See Supplemental Table 3 for a summary of respondent feedback on the notes to the proposed definition of pain, including categories, subcategories, and illustrative quote(s).

Supplemental Table 3. Summary of feedback on notes to the proposed definition of pain.

Category	**Description**	
1. Overall comments on the proposed notes	Respondents made comments that were relevant to the notes accompanying the proposed definition of pain as a whole. Data in this category were described by three subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***

a. Format, clarity, and relevance	Most respondents commented that the proposed accompanying notes were an improvement in terms of format, clarity, and alignment with current evidence. In particular, respondents stated that presenting the accompanying notes in bullet point format helped to improve clarity. Furthermore, respondents stated that the accompanying notes were more aligned with current conceptualizations of pain than the previous notes. In particular, many respondents were pleased with removal of the statement "Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons."	*"I like the accompanying notes section of the revised definition better than the current definition."* *"Having the accompanying notes in bullet points, as opposed to the previous paragraph format, makes them a lot clearer"* *"The old accompanying comments implied not everything a person reports as pain is pain (ie purely psychological origin). The new comments are much more encompassing of the uniqueness of the pain experience, and that pain experiences can result in the perception of pain even without an apparent cause. This is a much more current and accurate description!"*
b. Level of exposure	Most respondents reported that the revised accompanying notes were an improvement and contained important clarifying information. However, some respondents also expressed concern that the notes themselves will not get as much focus or attention as the definition of pain itself.	*"Currently very few people (at least that I come across) are aware of the additional notes to the current definition."*
c. Importance of pain management	The most common piece of feedback provided by respondents was that the proposed accompanying notes did not include a statement regarding pain management. The overwhelming feedback was that the notes ought to acknowledge the importance of pain management. In particular, many respondents noticed that the	*"Treatment, which was declared a must in the notes accompanying the old definition, goes unmentioned in the notes accompanying the new one."* *"Notes should indicate that pain should ALWAYS be treated."*

	statement “and is in need of appropriate pain-relieving treatment,” from the current accompanying notes was not included in the proposed accompanying notes.	
Category	**Description**	
2. Comments related to the first note: “Pain is always a subjective experience that is influenced to varying degrees by biological, psychological, and social factors.”	Respondents made comments specifically about the first accompanying note to the proposed definition of pain. Data in this category were described by two subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. Subjectivity of pain	Overall, respondents were pleased that the subjective experience of pain was highlighted in the accompanying notes. Despite the benefits of acknowledging that pain is subjective, many respondents also stated that the word “subjective” could be interpreted with negative connotations in some instances. Rather than subjective, many respondents described pain as a highly personal experience that must be believed by healthcare providers and others.	*“It makes more clear that pain is described in different ways by patients, and may even be indescribable. Pain is purely subjective and the practitioner must treat it as such.”* *“In the Notes the term ‘subjective’ is used and although it may sound like a simple term, it is not. It automatically summons the opposite qualities such as ‘not objective’ or ‘not real’ and as such distracts from what it necessary to convey, which is that pain is ‘unique to each individual’. Pain is ‘person specific’. This expression conveys an important characteristic of pain and at the same time completely avoids the dichotomous, negative weight of the term ‘subjective’.”*
b. Pain is influenced by many factors	Respondents were generally pleased to see that biological, psychological, and social factors were described in the notes. However, some respondents were critical about the lack of breadth in the list of factors. Most commonly, respondents stated that they would like to see other specific factors acknowledged (e.g. culture)	*“I wonder about the conspicuous absence of the word ‘culture’. Are we assuming that is covered under psychological and social? Would like to see it explicitly mentioned.”* *“I would like to see the bidirectional relationship between pain and social, psychological and biological factors emphasised more strongly.”*

	and that they would like to see the bidirectional relationship between pain and various factors emphasized to a greater extent.	
Category	**Description**	
3. Comments related to the second note: “Pain and nociception are different phenomena: the experience of pain cannot be reduced to activity in sensory pathways.”	Respondents made comments specifically about the second accompanying note to the proposed definition of pain. Data in this category were described by two subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. Relationship between pain and nociception	Some respondents stated that this note could be misinterpreted to mean that pain and nociception are completely independent entities. However, respondents expressed that the two are still related concepts and thus the relationship between them should be made clearer.	*“Although they are different in some respects, they are still related in other ways. The note above could theoretically apply to phenomena that are completely unrelated and have no association what-so-ever. Since we still have so much to learn, it would be more "forward looking" to somehow capture that inter-relationship so as not to be too literal.”* *“This is old-fashioned dualism...”*
b. Clarity of “sensory pathways”	A few respondents stated that the meaning of the term “sensory pathways” is unclear in this note. As such, these respondents stated that this term could be further operationalized.	*“…‘sensory pathways’: this is a vague term… ultimately brain areas not traditionally deemed to be part of the spinothalamocortical path[way] do eventually received sensory input through multi-synaptic pathways.”*
Category	**Description**	
4. Comments related to the third note: “Through their life experiences, individuals learn the concept of pain and its applications.”	Respondents made comments specifically about the third accompanying note to the proposed definition of pain. Data in this category were described by two subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. Lack of clarity about meaning	Many respondents stated that there was a lack of clarity regarding this note as	*“I can't quite figure out what this means, and I don't think the general*

	a whole and questioned whether it needed to be included.	*notion is really necessary to include with the definition."*
b. Implications for neonates and infants	Several respondents described concern that this note could be interpreted to mean that neonates and infants do not experience pain as they have not had previous life experiences.	*"[…] suggests that infants do not experience pain as they have not yet learnt a concept of it. We know this is not the case."* *"Does that mean that those without life experience, for example neonates, do not experience pain, or that they are merely unable to articulate their aversive sensory and emotional experiences?"*
Category	**Description**	
5. Comments related to the fourth note: "A person's report of an experience as pain should be accepted as such and respected."	Respondents made comments specifically about the fourth accompanying note to the proposed definition of pain. Data in this category were described by two subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. Personal experience of pain	Respondents were generally pleased to see that this note emphasized respect for the personal experience of pain. In particular, several respondents indicated that it was valuable to state that pain should be accepted and respected.	*"I like that the individual's report of pain 'should be respected'."*
b. Misrepresentation of pain for secondary gain	Although most respondents offered positive comments on this note, a minority expressed concern that some people with pain may misrepresent their symptoms for secondary gain (e.g. legal settlement). As a result, these participants suggested that the wording of this note could be tempered.	*"For a pain clinician it may be wise to always accept a patient's report of pain as true. For a judge, an employer, or even a spouse this is an incredibly naive and impractical piece of advice."*
Category	**Description**	
6. Comments related to the fifth note: "Although pain usually serves an adaptive role, it may have	Respondents made comments specifically about the fifth accompanying note to the proposed definition of pain. Data in this category were described by one subcategory.	

adverse effects on function and social and psychological well-being."		
Subcategory	***Description***	***Illustrative Quote(s)***
a. Not all pain is adaptive	Several respondents commented that not all pain (e.g., chronic pain) is adaptive. They suggested that acute and chronic pain be separated in the accompanying notes.	*"One might argue that this is true of acute pain but may not be true of chronic pain and I think it is important to make that distinction."* *"[…] seems to lack an emphasis that when pain becomes chronic, it is a pathology itself and not adaptive."*
Category	**Description**	
7. Comments related to the sixth note: "Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a non-human animal experiences pain."	Respondents made comments specifically about the sixth accompanying note to the proposed definition of pain. Data in this category were described by two subcategories.	
Subcategory	***Description***	***Illustrative Quote(s)***
a. Communication of pain	Some respondents stated that this note emphasized verbal expression as the only way to communicate, versus acknowledging other modes of communication. Some respondents also suggested that this note could be misinterpreted as associating people without verbal abilities with animals.	*"It is unfortunate that the notes equate communicat[ion] with verbal description. People and nonhuman animals communicate eloquently with one and other with the use of language."* *"I do not accept the last note because it expresses on the same level animal pain and human pain, and more precisely because it expresses at the same level pain in animals and pain in non verbal human such as newborns, infants, and humans with intellectual deficiencies. I think that it could bring confusion and introduce the possibility to consider non-verbal humans as animals."*

b. Inclusion of non-human animals	While some respondents were pleased to see non-human animals acknowledged in this note, others reported that they did not see the value of including them. Most respondents who offered positive feedback on this note believed it would be useful for basic science researchers.	*"I think that including non-human animals in the construct of pain a very good progress because even nowadays we don't evaluate animals' pain as equal as human pain."* *"I do not see the value of adding non-human animal experience."*

[1] IASP. [electronic source]. IASP Public Comment Policy. Available at: www.iasp-pain.org. Accessed Feb 28, 2020.
[2] Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008;62(1):107-115.