# **Supporting the Self-Management of Chronic Pain Conditions with Tailored Momentary Self-Assessments**

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## **ABSTRACT**

To better support the self-management of chronic pain, this paper investigates how those living with the condition prefer to self-assess their pain levels using smartphones. Our work consists of three stages: design ideation and review, an in-lab user study with 10 participants resulting in nine candidate interfaces, and a 3 week field trial of two further honed measures with 12 participants. This research firstly yields a better understanding of participants' strong and sometimes contrasting preferences regarding their self-assessment of pain intensity. We additionally contribute two novel interfaces that support accurate, quick, and repeated use along with other participantvalued interactions (e.g., familiar, relatable, and highly usable). In particular, we focus on designing tailored measures that both enhance respondent motivation as well as minimize the difficulty of meaningful self-assessment by supporting the cognitive effort in translating a subjective experience into a single numerical value.

## **ACM Classification Keywords**

H.5.m Information Interfaces and Presentation (e.g., HCI): Miscellaneous; J.3 Life and Medical Sciences: Health

## **Author Keywords**

Smartphone; Pain Assessment; Questionnaire Design

# INTRODUCTION

Chronic pain, defined as recurrent or long-lasting pain, affects an estimated 20% of adults globally [27] and 30.7% of adults in the United States [39]. Chronic pain is more common in women than in men [24], and prevalence increases with age (more than 50% of older adults and as many as 80% of older adults living in nursing homes experience chronic pain [23, 33]) — groups that are also at a greater risk of inadequate treatment, along with racial and ethnic minorities [64]. Indicators of poor socioeconomic status are also significantly correlated with chronic pain conditions [39].

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Still, chronic pain impacts a wide range of disease, demographic, and socioeconomic groups [27] and additionally takes a substantial economic toll. In the United States, the cost of chronic pain is as high as \$635 billion a year — more than the annual costs for cancer, diabetes, and heart disease [26]; and the economic burden of pain is similarly greater than most other health conditions around the world [55].

Common chronic pain conditions include osteoarthritis, rheumatoid arthritis, lower back pain, and headaches or migraines as well as repetitive stress disorders or other conditions resulting from injury or physical trauma. Patients with chronic pain are frequently severely debilitated, with significant limitations in their ability to function or work. Indeed, pain consistently ranks as a leading cause of years lost to disability (YLD) worldwide [75]. Chronic pain is also associated with depression, fatigue, sleep disturbances, decreased cognitive and physical abilities, and reduced quality of life overall [3].

As pain is a subjective experience, self-report is considered essential to assessing and, in turn, treating it. However, this can be a challenge both for instruments administered during doctor visits and for at-home methods. During doctor visits, pain intensity is commonly measured according to patient recall using one of several standard pen-and-paper or verbal self-report measures. However, such instruments that rely on retrospective reporting can have low test-retest reliability and be inaccurate due to recall bias, particularly for individuals with memory or other cognitive impairments [15]. These measures are also insensitive to the fluctuating nature of pain intensity over time, which can vary considerably from moment to moment and change depending on activities or other contextual factors [38].

At-home methods, which are typically diary-based, permit more frequent and in-situ assessment; but they can suffer from poor adherence and misreporting, especially if the instrument is cumbersome to use or doesn't suit a number of individually-variable reporting needs and preferences [8]. Attributes such as gender, ethnic and educational background, personality, visual ability, and the presence of affective or cognitive disorders can all influence pain measurement [25], as can pain sensitivity, which also varies dramatically between individuals [51].

This motivates a need for pain self-assessment tools that (1) provide accurate measurement, (2) can be deployed in-situ, (3) are low burden and pleasant enough to promote recurrent use, and (4) are tailored to a particular user's attributes and needs.

In this paper, we present two novel measures for the selfreport of pain intensity designed to meet each of these requirements. Each measure was developed through an iterative, usercentered design process involving chronic pain sufferers and was deployed in a field trial to establish validity and usability. Both measures also fulfill a series of design goals including high usability, sensitivity to potentially delicate content, and the cognitive translation process from subjective experience to quantified data point.

The specific contributions of this paper are:

- A series of design constraints identified as important to consider and satisfy when designing pain assessment interfaces.
- Nine candidate and two refined measures for the self-report of pain intensity using a mobile device, together with the results of in-lab and field study evaluations.
- A characterization of the ways in which individuals prefer to self-report pain, along with perceived benefits and challenges of this self-monitoring.

## **RELATED WORK**

## Pain and Its Assessment

Pain is often understood to consist of two dimensions. The labels most commonly used today are "pain intensity" and "pain interference", though the terminology used to refer to these two dimensions does vary (e.g., "pain intensity" and "reaction to pain" [6], "sensory-discriminative" and "attitudinal" [11], and "sensory" and "reactive" [12]). Pain intensity goes beyond the presence of pain to measure its severity, and pain interference describes the degree to which pain interferes with functioning (emotionally, physically, socially) and the distress it causes [13]. Pain intensity is considered the most salient dimension of pain [71] and is therefore the one we focus on measuring in this paper.

Self-report scales for pain intensity have been present in the literature since at least the 1940s [40]. Today, pain patients are usually asked to use one or more of the Visual Analog Scale (VAS) [35, 62, 76], the Numerical Rating Scale (NRS) [22], or a version of the Faces Pain Scale (FPS) [7] or Faces Pain Scale–Revised (FPS-R) [34]. Each of these is a unidimensional measure typically anchored with text descriptors at the extreme ends of the scale. These descriptors, as well as instructions for use, vary widely in the literature although the endpoints "no pain" and "pain as bad as it could be" are not uncommon.

These instruments offer several advantages such as brief and simple administration, easy scoring, and being understandable to most patients [25]. The main limitation relates to these unidimensional measures' questionable ability to capture the subjective and multidimensional aspects of pain [50], and studies do sometimes find mixed results in terms of retest reliability and sensitivity to measuring changes in pain levels [5]. These tools can also face well-known challenges related to inconsistent completion and retrospective recall, especially in their paper-based forms; though overall, the reliability of such measures is generally found to be sufficient to be practically and clinically useful [16].

## Pain Measurement in the mHealth Age

"mHealth" is an abbreviation for "mobile health" and refers to the use of mobile technologies to support healthcare. mHealth represents an opportunity to greatly improve the self-management of pain through self-assessments that are accessible, accurate, and effective and can support long-term, in-situ monitoring [59].

Today, 72% of U.S. adults already own smartphones [57], and up to 80% of adults worldwide are anticipated to own a smartphone by 2020 [21]. Further, though probability of smartphone ownership declines with increasing age, that trend is changing over time. Given this pervasive nature of smartphones and their embeddedness into daily life [42], methods such as Experience Sampling (ESM) [32] or Ecological Momentary Assessment (EMA) [63] are promising means of administering frequent, low-burden self-assessments in natural settings. Such approaches also sidestep recall and other biases [67], promote continued use [37], and are associated with a variety of positive health outcomes such as an improved ability to cope with pain [31].

Recognizing this opportunity, researchers have begun investigating the use of mobile devices for the self-report of pain intensity. The smartphone apps "ePAL" [2] and "Painometer" [19] use the mobile medium to deliver standard, validated pain intensity scales such as NRS and FPS-R. "Pain Squad", an iPhone app developed to support pain management for adolescents with cancer, provides an electronic pain diary of 20 questions of various types (e.g., VAS scales, body-maps, multiple choice, selectable words, and free-text) adapted from an arthritis diary to be cancer-specific [65].

Several commercial mobile apps are now available for self-assessing pain as well [60]. Studies have found that using these smartphone-based tools for pain reporting and intervention can improve pain management [72] and adherence [49] as well as prevent increases in emotional distress and symptom levels [45]. However, the number of randomized controlled trials conducted on these apps is relatively small, and more thorough evaluation is still necessary [18, 47, 58]. Further, the adoption of mHealth apps can be hindered by perceived barriers such as the need for interfaces to better address users' functional limitations (e.g., visual deficits) [54].

In particular, we see a need for more work to understand individual differences in the receptivity and use of pain assessment measures in order to enable the design of instruments that better meet users' potentially diverse attributes and preferences.

## **Designing Tailored Self-Report Instruments**

In completing a self-report measure, there are four basic cognitive components: *comprehension* (the respondent's ability to identify the question focus and interpret the intended meaning of the question); *retrieval* (the respondent searches his or her memory for all question-related information, recalls generic and specific memories, and fills in missing details); *judgment* (the respondent summarizes and integrates the retrieved information, draws inferences, and makes assessments); and *response* (the respondent maps their judgments onto a response category or value, editing the response as necessary) [70].

To achieve optimal response quality, measures should therefore both maximize respondent motivation to answer accurately as well as minimize the difficulty of responding by making it easy to interpret questions, retrieve and integrate relevant information from memory into a judgment, and report that judgment [73]. Specifically regarding pain self-report, four features have been outlined for the usability for self-reporting pain intensity on a mobile device: an interface must be learnable and easy to start using, reporting must be and feel efficient, a measure should be tested for usability errors, and an interface should be as satisfying and even pleasurable to use as possible [66].

Of course, different measures may maximize motivation and minimize difficulty in reporting for different people, who may also have varying reactions to the design of a measure. Indeed, personalized N-of-1 style medicine emphasizes that a one-size-fits-all approach is not appropriate for the self-management of chronic conditions in mHealth [69]; and rejecting the idea that biological responses are standard, some researchers have even called for a moratorium on randomized controlled trials [41]. Considering that individuals experience and process pain in idiosyncratic ways, it thus is important to design and deploy self-report measures that consider — even embrace — their participants' individuality in these respects.

#### **METHOD**

This study draws the above ideas together via an iterative user-centered research-through-design approach. Specifically, the research consists of three stages: design ideation and review, an in-lab user study with N=10 participants of nine candidate interfaces, and a 3 week N=12 participant field trial of two refined measures. The Cornell Institutional Review Board approved all procedures. We describe methodological details in the following subsections.

## **Design Ideation and Review**

We drew on the self-report and usability literatures reviewed earlier as well as our own experience developing and deploying experience sampling systems in order to ideate a large number of potential interfaces. We identified and tried to meet several design constraints:

- Design to be highly usable. Considering variations in psychomotor and perceptual capabilities (particularly agerelated changes, as one target population is older adults), any reporting interface should use large touch-target regions, simple interactions, low manipulability given potential hand or wrist pain, and readable fonts and font sizes.
- Design for the smartphone medium. The smartphone affords various interaction modalities (e.g. touch, reactive displays, memory of past reports, animations) that expand the range of ways through which individuals can express their pain. Which are the most appropriate for this context and preferred by individual users?
- Design for in-situ use. End-users would be using self-report measures at home but also potentially at work, in social situations, or in public. The interface should be usable on the go.

- Design for repeated use. These interfaces would be used regularly, perhaps over years. A measure usable enough to complete once or occasionally can become incredibly frustrating when engaged with more often. How should the interfaces change over time and with repeated use?
- Design to support cognitive translation processes. Can an interface support the effort of translating a complex subjective experience into a reportable value, perhaps by way of abstract representations that convey pain or its manifestations in a "legible" way?
- Design to elicit reports about sensitive content. Focusing on pain might make pain experiences more salient or increase anxiety, among other potential negative effects [77]. Could interfaces abstract away or ameliorate this process?

We were additionally informed by fundamental humancomputer interaction design principles [52] as well as the design thinking around microinteraction — a small piece of functionality that supports a user in completing a single task [61]. Figure 1 shows an example of one of our early sketches.

Through team discussion and review with designers, we combined and refined elements of the sketched interfaces to produce a set of designs aimed at meeting these constraints and principles (e.g., the slider of SuperVAS+ was intended to satisfy the highly usable constraint, while PhotosNature aimed to address the constraints regarding cognitive translation and sensitive content by supplying metaphorical representations of pain that could convey even intense levels but without disturbing content that might upset a user).

We also added designs for well-established pain assessment instruments mentioned earlier: usability-improved versions of the Visual Analogue Scale for Pain (VAS-P) [30]; the 11-point numeric rating scale for pain (NRS-11) [48]; and with permission from the creators, the Sydney Animated Facial Expressions (SAFE) scale [10], which is a computer animation of the Faces Pain Scale (FPS) [7] that has been deployed in a laptop version where pain is reported with the left/right arrow keys [28]. VAS-P, NRS-11, and FPS have all shown good usability and acceptability characteristics when deployed in a mobile app [19].

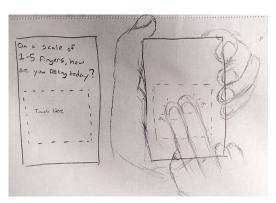


Figure 1. Example of a pain-assessment interface that was sketched during the ideation phase and aimed to meet design constraints as well as support microinteraction principles.

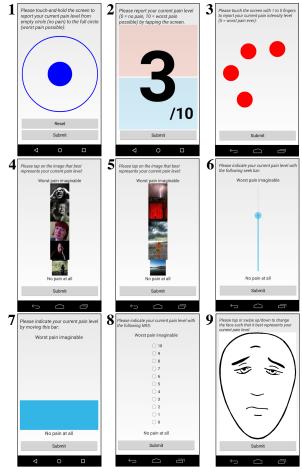


Figure 2. Our nine candidate measures for smartphone-based pain selfassessment resulting from our iterative design cycle.

The resulting nine measures were prototyped for the Android operating system as custom Views<sup>1</sup>. They can be seen in Figure 2 and are summarized as follows.

- 1. **Suureta**: An empty circle that slowly fills with color when any part of the interface is touched and held. Suureta can be completed by resting a knuckle, nose, or chin on the screen.
- 2. **TapTap**: An oversized number picker widget for reporting on a numerical 0–10 range. The currently selected value is displayed in a very large font on the screen. Tapping anywhere on the top half of the screen increments the value; tapping anywhere on the bottom decrements it.
- 3. **ManyFingers**: Respondents report their level of pain by touching the screen with a certain number of fingers simultaneously. Figure 1 shows the design's early-stage sketch.
- 4. **PhotosPeople**: A vertical five-item NRS that displays pain levels using photographs of faces instead of numbers. To generate a set of photos that portray varying levels of pain,

- we harvested photos from Flickr tagged with 18 words describing degrees and qualities of pain, following a protocol described in prior work [56].
- 5. **PhotosNature**: Same as PhotosPeople but with pain levels conveyed via abstract and landscape images (e.g., of a lightning bolt or a serene lake) rather than faces.
- SuperVAS: Standard VAS-P with vertical orientation, using a custom seekbar widget.
- SuperVAS+: VAS-P with vertical orientation but using a custom seekbar widget that dramatically increases the target touch region.
- NRS-11: Standard NRS-11 with vertical orientation, using native radio buttons.
- 9. SAFE: A version of SAFE where the user can smoothly transition across the face images by tapping on the screen between the two anchors or by sliding a finger up or down the screen. This interaction is more natural for the smartphone medium and also avoids the practical issue of simultaneously displaying multiple face images on a small screen.

## In-Lab User Studies

Through campus mailing lists, on-site physiotherapy center flyers, and snowball sampling we recruited 10 participants, each of whom experienced some form of waxing and waning chronic pain. We refer to these participants as P1–P10. Participants' recent experiences with pain ranged from low-level recurring joint pain or injury recovery up through severe arthritis or back and neck pain from a recent car accident.

Nine participants were female, though gender skew is not uncommon in smaller-scale pain studies (e.g., 51 of 78 participants were female in recent related work [29]), and chronic pain is more common in women than men [24]. Half our participants were 55 years of age or older, and nine were reasonably to very comfortable with smartphones; the other owned a smartphone but used it only as an emergency device and map.

The 40–60 minute lab session had three portions. During the first portion, we asked questions about the participant, any recent experience(s) with pain, how the person had reported pain in any setting in the past, self-tracking practices (if any), and familiarity with smartphones. In the second portion, the participant interacted with each of the nine candidate measures, used them to report current pain level, and provided feedback. We also recorded observational notes. The final portion was a reflective compare-and-contrast, where the participant qualitatively compared measures as well as used ordinal rankings across four usability dimensions to rank preferences. An opportunity was also offered to provide any additional free response. Each participant was compensated \$10.

## **Field Trial Evaluation**

Balancing design guidelines outlined in prior work [52, 61, 66] with feedback from the in-lab study (described further in the Results section), we selected, combined, and refined elements from the candidate interfaces. For instance, participants largely did not enjoy using photo-realistic images to report pain levels

<sup>&</sup>lt;sup>1</sup>https://developer.android.com/reference/android/view/View.html

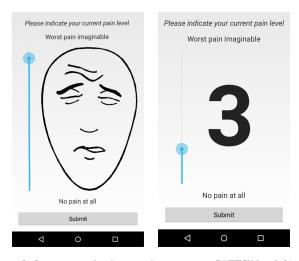


Figure 3. Our two novel pain reporting measures, SAFESlider (left) and SuperVASNumbered (right), designed based on our in-lab study results and deployed in a 3 week field trial.

(as employed in PhotosPeople), encouraging us to move in the more abstract direction of SAFE. Participants liked the oversized display of TapTap but thought tapping to report was time consuming, and the small touch targets NRS-11 often led to misreports. Given the importance of quick and accurate reporting, we therefore used SuperVAS's standard slider widget, which participants considered more intuitive than SuperVAS+; though the latter's large target region was appreciated and so we incorporated a generous touch area.

Figure 3 illustrates our two resultant measures: **SAFESlider** and **SuperVASNumbered**. Both had dual interaction modes; the user could either tap anywhere on the screen (as if underneath the screen lie a standard NRS-11 or VAS-P with low pain at the bottom through high pain at the top) or swipe anywhere on the screen to control the slider on the side.

We deployed these two new measures in an ESM-style field trial lasting 3 weeks (a length of time comparable to deployments of related mHealth pain assessment apps [65] and sufficient to capture declines in quality of data reporting, according to the ESM literature [68]). Campus mailing lists, on-site physiotherapy center flyers, and snowball sampling were again used to recruit another set of 12 participants, who were required to be experiencing some form of chronic pain and be Android smartphone users since our measures were developed to work on that operating system. We refer to these participants as P11–P22. Nine participants were female, four were 50 or older, and all reported being comfortable with their smartphones. Participants' current experiences with pain ranged from low-level pain through severe arthritis, compartment syndrome, or fibromyalgia.

Participants installed two applications onto their smartphones: Meter<sup>2</sup>, a custom-developed app that housed our two measures (SAFESlider and SuperVASNumbered) as well as Ohmage<sup>3</sup>,

<sup>3</sup>http://ohmage.org

an open-source participatory sensing platform that allowed us to administer our measures together with a set of survey questions listed below. Specifically, participants were prompted via a notification from Ohmage to complete a short 1–3 minute survey twice a day, once in the morning and once in the evening. Each survey consisted of four questions:

- 1. Self-reported pain level using a version of NRS built into Ohmage
- Self-reported pain level using one of our two measures (SAFESlider or SuperVASNumbered)
- 3. Subjective usability rating of that measure on a 5-point Likert scale
- 4. Unstructured feedback about the interface (optional)

At the end of 3 weeks, all but 2 participants also completed a 30–40 minute semi-structured interview about their experiences during the field trial. Participants were compensated \$10 for each week of survey responses and \$10 for the interview, for a possible total of \$40.

## **RESULTS**

This section provides usage statistics from the field trial followed by a description of qualitative themes from both the in-lab study and the field trial.

# **Usage Statistics**

Our 12 field trial participants (P11–P22) completed a total of 453 surveys over the course of the study's 3 weeks, for an overall response rate of 90%. Participants completed SAFESlider 242 times (96% response rate) and SuperVASNumbered 211 times (84% response rate).

SAFESlider took a median of 5.0 seconds to complete, and the mean pain intensity value reported using SAFESlider was 2.74 on a range of 0 (no pain) to 10 (worst pain imaginable). The SuperVASNumbered measure was a bit faster to complete — taking a median of 3.6 seconds, and the mean pain intensity reported using SuperVASNumbered was also lower — a mean of 2.17 on on the same 0–10 range. Table 1 shows per-participant metrics when reporting with SAFESlider (abbreviated "SS") and SuperVASNumbered (abbreviated "SVN").

Participant	Response		Response Time		Pain Level	
ID	Rate		(seconds)		(0-10)	
	SS	SVN	SS	SVN	SS	SVN
P11	95%	57%	3.95s	2.97s	4.0	3.0
P12	90%	71%	3.03s	2.34s	1.0	1.0
P13	95%	95%	4.81s	2.74s	2.0	2.0
P14	100%	81%	3.23s	2.45s	2.0	2.0
P15	100%	95%	5.27s	5.92s	4.0	4.0
P16	86%	81%	8.93s	3.45s	2.0	1.0
P17	100%	81%	9.86s	5.60s	6.0	4.0
P18	95%	86%	3.30s	3.67s	2.0	1.0
P19	100%	100%	5.05s	2.90s	4.5	3.5
P20	71%	76%	5.62s	4.26s	1.0	1.0
P21	100%	90%	7.23s	4.81s	1.0	2.0
P22	90%	86%	9.62s	4.64s	1.0	1.5

Table 1. Per-participant metrics when completing SAFESlider (SS) and SuperVASNumbered (SVN). Response time and pain level are both median values within each participant.

<sup>&</sup>lt;sup>2</sup>https://play.google.com/store/apps/details?id=edu.cornell.idl.meter

Measure	Very easy	Somewhat easy	Neither difficult nor easy	Somewhat difficult	Very difficult
SS	39.2%	36.8%	12%	12%	0%
SVN	61.6%	29.8%	8.1%	0.5%	0%

Table 2. Percentage of usability reports that assessed SAFESlider (SS) and SuperVASNumbered (SVN) measures across levels of ease of use.

Though SuperVASNumbered aligned slightly better, pain reports from both measures strongly correlated with pain reported using the standard NRS (Pearson's  $r=0.93,\ p<0.0001$ ) for SAFESlider and Pearson's  $r=0.98,\ p<0.0001$  for SuperVASNumbered), indicating their validity.

Both measures were generally found to be somewhat or very easy to use according to 242 and 211 usability reports for SAFESlider and SuperVASNumbered, respectively, though participants found SuperVASNumbered somewhat easier. Table 2 provides the aggregated breakdowns about reported usability for both measures.

Importantly, we found that usability perceptions were not unanimous across participants or even within the same participant across different reporting sessions — which encourages a deeper look into what factors, both stable and temporary, might impact such reception and use of pain assessment instruments and how designs might be tailored accordingly. Toward this goal, we next present our qualitative themes that emerged from our semi-structured interviews with individuals that participated in both the in-lab study as well as the field trial.

## **Thematic Analysis**

To qualitatively analyze the data from the in-lab user study and the field trial, we conducted a thematic analysis [9] wherein the researchers reviewed the dataset to identify initial themes, which were shared, discussed, and iteratively refined. We found no strong correlations between the themes that emerged and demographics, level of pain, or type of pain experienced.

Overall, participants were diverse in the ways they thought about and wanted to report their pain. We believe our findings surface important topics and serve to suggest directions for advancing the development of tailored pain self-assessment measures that enhance patient experiences.

# Reporting Pain with Faces

Participants had (often very) strong feelings either for or against the use of faces for reporting pain levels (e.g., via PhotosPeople, SAFE, or SAFESlider). Those who valued reporting with faces were able to connect with the people and expressions displayed (e.g., "I can definitely imagine feeling the way this person looks" – P2; "I can kind of imagine him [SAFE] feeling what I feel, feeling more than just the sterile measure" – P3). Such individuals also thought using faces to express their pain felt more natural and intuitive, e.g.:

"With the numbers, my brain needs to actually think more about the body part and the pain sensation explicitly and somehow try to map that onto a number. Face is a different translation channel that goes through emotion and feeling, though the underlying component is still my pain." (P3) However, just over half of participants felt that mapping pain to facial expressions simply could not work for them. Several participants doubted the accuracy of facial expression based measures (e.g., "I don't like coordinating pain to facial expressions because I just can't believe it's accurate" – P4) or had a hard time reading pain in faces (e.g., "I don't know what pain looks like on a face" – P7). PhotosPeople and SAFE were also rejected when participants did not feel the faces resembled their own (e.g., "I am in pain, but I don't look like any of these people" – P4) or could not connect those faces' expression of pain with their own self-image or experience:

"I think the [SAFE] person was enough of a blank canvas that I could express myself through it, but these [PhotosPeople] are real people who are different from me—that's a disconnect. When the person in the picture is different from me, and I can't connect it with myself individually, it's harder to pick that one, even if it's the right degree in the scale." (P3)

One specific issue underlying an inability to identify with face-based interfaces was a difference between the gender of the participant and that of the face (e.g., "I wonder if the male/female thing is a problem. You know, if I'm a female, I won't choose the male pictures" – P4). Two participants suggested that using photos of their own faces to report pain would be more useful instead.

Several participants had quite visceral responses to PhotosPeople or even SAFE during in the in-lab sessions and reported feeling uncomfortable with images of humans (or representations of humans) in pain (e.g., "Okay this I really don't like. I don't like seeing people in pain" – P5). Others were not incapable of using the measure but did have a negative affective response (e.g., "I don't have a problem reporting pain with people's faces, but I feel sad for the sadness of these people's faces" – P6).

It is quite possible that beyond individual preferences — or perhaps correlated with preference — there are individual differences regarding the ability to make sense of the levels of pain expressed by a face in these interfaces. In fact, there is growing evidence that in non-clinical populations, capabilities in facial expression processing can vary considerably across people [53].

## "Numbers People"

Analysis clearly revealed that about half the participants had a strong preference for reporting with numbers. Such participants were often self-described "numbers people", e.g.:

"I tend to be a numbers person, so I like [reporting with] numbers. I relate to them." (P5)

In some cases, this was due to being familiar with using this sort of representation for self-reporting, which participants felt had become ingrained over time (e.g., "Everywhere you're taught to think in: one to ten, what's your pain level" – P4). Such participants made observations about how their personal predilections toward numeric scales would typically lead them to attempt to quantify their pain-assessments even when pre-

sented with a more abstract or qualitative reporting interface. For example:

"I always think of a number out of 0 to 10 initially. So I mentally compute '3' and then try to use the interface to map [my 3] onto that measure." (P3)

The other half of participants rejected the number-oriented interfaces and strongly preferred the more qualitative instruments (e.g., "It's hard to put a numerical value on something like discomfort" – P9) or at least something they could play with and tune to their own subjective experience. These participants explained that the more abstract measures enabled them to be more descriptive and in turn more accurate in capturing their true pain levels. One participant described a sense that numbers might be better suited to scientific applications but are too sanitary and impersonal to reflect non-objective feelings like pain for all end-users:

"Numbers might make more sense for a health professional, but I'm not sure they do for me. No-numbers is somehow more descriptive. I think it's just got to be easier for a patient to do that, than try to put a number on it." (P4)

## Pliable Interactions

Whether they were numbers people or favored more qualitative interfaces, multiple participants valued being able to adjust their reported score in order to "dial in" to a pain level that seemed correct (e.g., "You've got the ability to move up and down while you think about it, until it [SuperVASPlus] kind of feels right" – P8).

This type of tuning was afforded by the slider-based interactions we used in some interfaces (e.g., SuperVAS+, SAFES-lider, SuperVASNumbered). Participants reported appreciating the flexible, modifiable nature of the slider (e.g., "I can change my mind because I can go up and down" – P2), which was seen as easier to use than instruments that provided a restricted set of choices (e.g., "It's just nice to be able to move things up and down without having to hit a whole bunch of different buttons [like in NRS-11]" – P10).

That said, selecting a value through a single-tap was still preferred by others (e.g., "I like filling in the dots" – P8), sometimes precisely because the array of options was constrained:

"This [SuperVAS] is more fine-grained than I need. Jeez, I don't know, I don't know! [NRS-11] with 10 [11] options is a relief, vs. having to finagle with an unlimited number [in SuperVAS]." (P3)

These quotes also speak to preferences around reporting resolution and ranges. For most participants, 0–5 was too small a range (e.g., "There's not a lot of variance from 1 to 5" – P7; "I would want to report 4.5/5. There's such a gap between 4 and 5" – P8) and 0–100 was too wide, while 0–10 hit the spot. In addition, nearly all participants felt that the low end of the scale in particular offered too little resolution, especially for NRS-11 and SAFE-based interfaces (e.g., "[NRS-11] should also have better resolution at the low end of the scale, like not 0 or 1 but .5 and 1.5 too" – P7; "There's a lot of 'being in pain' faces, but there could be a wider low-pain range" – P2).

Such responses also reflect the importance many individuals placed on being able to report (celebrate) no or very minimal pain levels. For example:

"I want it to go happier too! If I had no pain, I'd be grinning ear to ear!" (P2)

#### Designing for Delight

We aimed to make our interfaces pleasant to use, and many participants expressed that they did genuinely enjoy interacting with our measures. One noted reason was the attention we gave to aesthetics, which participants explained made instruments more alluring and encouraged their usage (e.g., "The visual is more attractive to me, rather than [NRS-11]" – P10).

A perceived element of playfulness was particularly appreciated (e.g., "It's not just about giving me information, or giving me good information — it should be fun to do" – P9). Participants explained that this enjoyability-factor strongly motivated them to use our measures, especially when considering usage over an extended period of time (e.g., "If it's something you'd use every day, it has to be a little fun, not boring" – P2).

In addition, participants provided a variety of helpful feedback on more traditional usability issues, ranging from the size of text and images (e.g., bigger is better), to expectations that a user should be able to tap on a scale's anchors in order to report extreme values. (We drew on such information when creating our two deployed measures, SAFESlider and SuperVASNumbered). It also became clear through observation during the in-lab study that many participants do not read scale instructions or anchor texts, even when explicitly prompted to do so (e.g., "I just assumed that the lower end... did it say no pain?" - P2). Such findings helped us recognize the need to ensure users are well-acquainted with the scales they will be using — something straightforward for us to do with our field trial participants but potentially challenging if measures are deployed more broadly or outside of clinical or otherwise overseen circumstances.

# No Evidence of Negative Reactivity

The literature makes conflicting claims as to whether frequent self-report of pain intensity might result in positive, negative, or neutral outcomes [1, 32]. Some evidence finds that recalling pain and coping strategies can lead to positive outcomes such as an increased sense of control over the pain [31]. However, other findings of particular concern suggest that repeated self-assessment of such a difficult and potentially traumatic experience draws more attention to and foregrounds that negative perception of being in pain — thereby making the subjective lived experience worse [43].

We therefore found it encouraging that among our participants, not a single one reported such negative consequences from repeatedly reporting pain levels. Participants experiencing a subjectively lower degree of pain than other participants conjectured that others in more pain might experience such negative effects; however, those participants with high pain levels did not find this to be the case.

Rather, several of the participants with high pain levels explained that the act of reporting in and of itself sometimes

helped to diminish pain they would be fully aware of anyway. For example:

"On the '7' [out of 10 pain level] days, it almost felt like the scales were an outlet for me, in a way. Like, I'm feeling bad, but it almost felt like I could report it in the thing [phone or measure] and maybe compartmentalize it. In a sort of a sense, it's maybe like the way I might vent if I'm upset. Somehow reporting it — externalizing it — actually eased it. When I'm at 7 or 8, it's not like the system is going to remind me I'm in pain — I'm not going to forget that!" (P13)

Participants explained other positive aspects to the mindfulness that self-reporting promoted, such as adhering to pain treatments (e.g., "I've been doing PT [physical therapy] at home... This reminder and filling out the measure didn't make my perception of the pain different, but it kept it on my mind so I would do things about it [like PT]" - P17). Similarly, P19 found that while reporting with our measures did not increase any negative preoccupation with her pain, it did help her think about and understand her pain differently — for example, by becoming more cognizant of the potential effects of contextual factors like weather (e.g., during one very cold week of the field trial). While outside the scope of this paper, such findings suggest the value in considering how future systems might further support individuals in reflecting on, acting on, or otherwise engaging with their collected data, detected patterns, or other synthesized feedback a system might provide.

# **DISCUSSION**

Modern technology is primed to improve pain measurement and management, and ensuring usability and relevance for both patients and clinicians is a foremost challenge [4]. Our aim in this research was to improve upon current instruments for pain assessment that are typically lab-based, burdensome, and/or generic, in order to not only increase the accuracy and adherence of such methods but also to enhance patient experiences. Our approaches and findings are relevant to designers, researchers, and practitioners working in the domain of pain.

In exploring the needs and preferences of a diverse set of individuals dealing with a variety of pain conditions, we developed an assortment of reporting interfaces. Each was intended to meet a series of design constraints that we outlined as particularly important to consider in this context, such as the need for interfaces to promote repeated use through pleasant interactions, support decoding a personal perception into a quantifiable and comparable output, and be highly usable including during periods when pain may compromise one's dexterity and ability to complete a self-report.

Through an in-lab study and a 3 week deployment, we evaluated our measures, which demonstrated reliability based on comparisons with an established, validated pain assessment instrument (the Numerical Rating Scale, NRS). Equally importantly, our measures saw high adherence rates and usability scores and were well-received by participants. Notable reactions fell into several themes related to feelings toward face-based vs. numerical interfaces, appreciation for flexible

and playful reporting experiences, and a sense that measures helped alleviate rather than aggravate pain perceptions.

Some findings were universal across all participants. In general, participants found playful interactions and aesthetic interfaces to be highly enjoyable and motivating to use including over extended periods of time, which is crucial given that chronic pain requires indefinite management. In addition, we did not observe any negative outcomes from self-monitoring pain using our tools (e.g., any increased preoccupation with pain or exacerbated symptoms); rather, our measures seemed to provide an outlet for participants that actually helped to alleviate pain perceptions in some cases.

However, many reactions were not unanimous. For instance, some participants strongly preferred a more qualitative form of reporting and favored instruments involving abstracted or face-based representations of pain. Others disliked interfaces involving faces, either because such measures did not personally resonate with a participant's own experiences and self-image or because it was upsetting to view a person (even a drawn face) in pain. Self-described "numbers people" also struggled with such measures and preferred more familiar, numerical scales (e.g., 0–10 Likert scales). In addition, some participants preferred slider-based interfaces that provided a seemingly unlimited range of malleable values that could be tweaked and tuned, while such boundless scales significantly bothered other individuals, who preferred a more scoped set of numeric values from which to choose. These rich yet sometimes contradictory findings demonstrate the need to move toward more personalized pain assessment approaches.

## **Tailoring Self-Assessment**

Our findings highlight that there is no one-size-fits-all solution for pain assessment. Across individuals, an array of variables can differ such as the type and severity of the pain condition, current activities and other situational circumstances, and personal preferences. Such idiosyncrasy necessitates the development of tailored assessment tools that better support diverse patient needs. In turn, these personalized interfaces can minimize difficulty and inadherence while optimizing response quality, accuracy, and user experience [73].

Our results similarly indicate that supporting these preferences lowers response burden and increases respondent motivation. Beyond external motivations, which can include a sense of accountability or an understanding of why reporting is important, motivation can further be enhanced by ensuring that completing the measure — potentially tens, hundreds, or thousands of times — is not only brief and unobtrusive but also enjoyable or even delightful.

One method of tailoring a measure to an individual and increasing the pleasurability of response is to allow each respondent to approach and engage with that measure's options differently. We do this in two ways. First, both our measures, SAFESlider and SuperVASNumbered, contain a VAS-style slider widget that can be appropriated to suit personal preferences (e.g., to accommodate spatial thinkers or optimize for more numerical, precision-based reporting). Second, these interfaces afford a tap-to-report interaction and also respond to swipes and drags,

allowing users either to report with one tap or to "dial in" their pain level and adjust the reported value in real-time until it "feels right".

Another way to tailor the measure to a particular user is to provide more than one measure and let the individual choose the one that best suits his or her preferences, present circumstances, and overall needs. Our measure SuperVASNumbered very explicitly speaks more to "numbers people" through its large numeric display while our SAFESlider measure is based on facial expressions and enables a response that feels more qualitative. Using different measures in within-subject studies is not a problem assuming each measure demonstrates construct and content validity; and if user ratings correlate well between scales, then it is acceptable to make between-subject comparisons or even allow users to choose which scale they use for each momentary measurement as long as normalization steps are taken [14].

Such tailoring techniques better fit with a respondent's cognitive process for recall and self-assessment, make questions more interpretable, and support the mapping of a self-assessment to the intended report — be it numeric value, face, or slider position. Each measure is further designed to optimize for meaningful responses by enhancing motivation to report, for example by being playful, which can also reduce respondent burden and fatigue. In our study, participants appreciated this playfulness and commonly reported that they genuinely enjoyed interacting with SAFESlider.

Overall, tailoring measures to an individual can thus have several positive outcomes. First, given that response burden is down, motivation to report is up, and the reporting interface is not exactly the same all the time, we anticipate participants will maintain their reporting habits longer. Second, tailoring recognizes a person's uniqueness and preferences — but also encourages systems (and care providers) to consider those consequential individual differences more explicitly. Finally, we expect satisficing (compromising standards and exerting less effort in responding in order to reduce reporting burdens [46]) will be far less common.

# **Augmenting Manual Self-Report with Passive Sensing**

Advances to relieve the burdens of self-report would be particularly beneficial in the context of pain assessment given that pain can severely interfere with the ability to perform daily tasks — including recurrent self-report activities [17]. One strategy is augmenting and integrating actively collected data with passively captured information pertinent to treatment regimens. Beyond enabling the deployment of more accessible self-report tools, smartphone technology facilitates precisely this: the near-continuous measurement of condition-relevant factors in ecologically valid settings, without requiring active user interaction [20].

Specifically, pain and related symptoms (e.g., fatigue or depressed mood) often affect various functional behaviors that can be assessed using well-established smartphone-based passive sensing techniques, for instance according to activity and location data [74]. As an example, data from a phone's accelerometer, barometer, GPS, and WiFi signals could be used

to evaluate the difficulty and required energy of a taken walking route and in turn infer functional capabilities and likely pain levels [4]. Further, machine learning algorithms could tune measurement and modeling to each patient based on their routines, attributes, and preferences in order to accommodate idiosyncratic experiences and manifestations of pain.

However, at the same time, self-report is an essential aspect of chronic pain management due to pain's subjective nature. In addition, the act of self-report can be beneficial in and of itself [44] — as we saw from our own participants who expressed that using our measures helped promote mindfulness and self-reflection, instill a sense of self-accountability, and provide an outlet that externalized and even eased pain perceptions. Care must thus be taken to strike a balance between relieving the intrusions, burdens, and limitations associated with pain self-report while augmenting such data with automated sensing strategies that preserve — rather than undermine — the positive aspects linked with more deliberate, manual forms of self-tracking.

## **Future Work**

Finally, we point out potential limitations of the research presented in this paper and outline room for future work.

## Target Populations

To begin, individual differences in the experience of pain can vary dramatically, as mentioned. While our participants represent a wide range of ages and deal with a variety of pain conditions, a larger-scale study with a more diverse sample (e.g., especially with respect to gender) would therefore be desirable in order to further expand our understanding of possible patient needs and appropriate tailoring techniques. Participants could also be offered a greater amount and variety of pain measures from which to choose in order to further evaluate patient choices at a larger scale.

In particular, though chronic pain affects all populations regardless of age, gender, ethnicity, income, or geographic location [27], prevalence rates are higher for older adults, yet these individuals are more likely to receive inadequate treatment [64]. Approximately half of our sample did include older adults, but an important next step is to even further target this at-risk and underserved age group.

Our findings specifically suggest the need to examine the requirements of elderly patients suffering from pain alongside dementia, as pointed out by one of our three participants who reported caring for an elderly relative. Without interviewer prompting, this participant also reflected on the older family member's anticipated reactions to our interfaces, suggesting the promise of applying our approaches to this target case:

"I've just gone through this extended illness with my mother, and they were always asking what's your pain level. She was never able to put things into words, especially as she got dementia. I really wonder if she had a scale to move her finger...and push the little ball up and down [SuperVAS], that might really be helpful with older patients. She [mother] would have been able to do that and be pretty accurate." (P4)

## Temporal Considerations

Similarly, given that pain is a chronic condition requiring ongoing management with symptoms that can potentially change over time, conducting longer term deployments is essential in order to evaluate the acceptance, engagement, and suitability of our measures over the long haul. Prolonged evaluation would also allow examination of behavioral and psychological impacts (both positive and negative) that may accompany extended self monitoring. For instance, with time, individuals can learn personal coping strategies and modify behavior in a way to minimize symptoms after gaining an increased understanding and sense of control over their pain condition [31]. However, repeated assessments can also lead people to become unusually aware of their behaviors or state and fixate on negative experiences. It is also possible that repeatedly reporting on the same construct may influence recall or self-appraisal.

Additionally, there is value in further experimentation on the time(s) of day at which momentary pain assessments are administered. We delivered prompts to our participants twice a day, in the morning and evening, but since pain can fluctuate widely over the course of a day [38], this temporal coverage should be expanded going forward. It is also important to consider the individually-suitable timing and frequency of prompts in order to minimize any sense of intrusiveness and annoyance as well as the lag between when a self-report prompt is received and actually answered.

## Integration with Clinical Care

High-quality pain management requires physicians to follow their patients' subjective experience of pain along with activities, psychological well-being, and additional traditional medical indicators. It is therefore necessary to investigate how the measures we have developed for this study — and more generally, our design process used to create these measures — fit with clinical practice. Similarly, there are additional stakeholders to consider such as other caregivers or family members who may also play a key role in a person's pain management, especially in severe cases.

Going forward, there is value in engaging with doctors in order to determine the potential impacts of our research on clinical workflows and to ensure such novel measures and outputs are relevant and useful to medical decision-making. The fact that half of our participants took issue with using numbers for self-report — the standard technique found in a doctor's office — could mean that integrating our measures with existing care practices may be a challenge. Nonetheless, our findings indicate the need to pursue development of pain-assessment methods (both on devices as well as perhaps face-to-face) that meet the diverse requirements of patients and other involved parties.

## Novel Assessment Modalities

Finally, in this study, we focused on developing pain assessment tools specifically designed for a smartphone, given the aforementioned advantages of this medium (e.g., ubiquity of ownership, portability and accessibility throughout daily

life, and interaction affordances that can support the cognitive translation process from pain to report). Still, it would be worthwhile to explore alternative interfaces for the self-report of pain, especially considering the potential difficulty in manipulating devices during a pain episode.

Particularly promising directions include the development of tangible user interfaces that do not rely on visual prompts and allow the report of pain through more natural touching or squeezing actions, much the same way a person experiencing pain might grasp a nearby object or loved one's hand [4]. This sort of reporting interface is also more unobtrusive and supports reporting in a more private manner, which can be particularly important to pain patients given the stigma many attach to their condition [36]. Going forward, we encourage others to continue investigating novel approaches and modalities to support the assessment of idiosyncratic, subjective pain experiences in a reliable, personalized, and sensitive manner.

# CONCLUSION

Self-assessment is integral to measuring the subjective experience of pain — a prevalent, debilitating, and economically burdensome condition. In this research, we set out to develop novel smartphone-based assessment tools that not only support reliable, repeated, in-situ measurement in a broadly deployable manner but are also pleasant to use and tailored to personal preferences. We focused on designing visual interfaces for the self-report of pain intensity on smartphone screens given the interactions smartphones afford and their embeddedness into daily life and, in turn, the opportunities they provide for more personalized, ecologically valid assessment.

Through an iterative, user-centered design approach, we demonstrated how individuals' receptivity of a measure can be strongly impacted by design features — in particular, when it comes to abstract or qualitative interfaces vs. numeric reporting, perceived "sweet spots" in the resolution and range of reporting scales, and playful, aesthetically appealing interactions. Importantly, our studies found that participants' preferences were strong and idiosyncratic — and not always unanimous, highlighting a need for measures that can better accommodate such individual differences. Our work indicates that supporting these preferences lowers response burden and increases respondent motivation, including over long periods of time, which is critical when monitoring a lifelong condition such as chronic pain.

Such tools that are practically and personally effective for self-assessing pain could have significant impacts on both societal and personal levels by cutting treatment costs, empowering patients in their self-care, and overall, improving daily life for the millions of individuals experiencing chronic pain.

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