

Redesigning the

# pain assessment conversation

**NEMA RAO**

A thesis submitted to  
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*Dan Boyarski, Aisling Kelliher*  
Advisors

# Redesigning the pain assessment conversation

A thesis submitted to the School of Design / Carnegie Mellon University / for the degree  
Master of Design / Communication Planning and Information Design

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NEMA RAO / GRADUATE STUDENT

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DAN BOYARSKI / PROFESSOR, SCHOOL OF DESIGN

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AIKLING KELLIHER / ASSOCIATE PROFESSOR, SCHOOL OF DESIGN

Dedicated to my parents

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Whatever pain achieves, it achieves in part through its unsharability, and it ensures this unsharability through its resistance to language. “English,” writes Virginia Woolf, “which can express the thoughts of Hamlet and the tragedy of Lear has no words for the shiver or the headache.” ... Physical pain does not simply resist language but actively destroys it.

If one imagines one human being seeing another human being in pain, one human being perceiving in another discomfort and in the same moment wishing the other to be relieved of the discomfort, something in that fraction of a second is occurring inside the first person’s brain involving the complex action of many neurons that is, importantly, not just a perception of an actuality (the second person’s pain) but an alteration of that actuality (for embedded in the perception is the sorrow that it is so, the wish that it were otherwise).

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ELAINE SCARRY, 1987  
THE BODY IN PAIN: THE MAKING  
AND UNMAKING OF THE WORLD

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Improving the Understanding of Pain

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## ABSTRACT

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Pain is the number one reason people access the healthcare system. Yet, it remains widely inadequately assessed, eventually leading to complications and compromises in quality of care. Self-report scales reduce the complexity to uni-dimensional statements of pain severity; for example, by asking patients to estimate their pain intensity on a 0 to 10 scale. While this is at best appropriate for acute pain, it is an oversimplification for chronic pain patients. This project investigates how patients and clinicians negotiate pain communication and proposes a novel way for patients and clinicians to assess and communicate pain, by using a set of expressive abstract animations which can be visually configured to reflect change in intensity. The project also discusses the dynamics between a patient and clinician, as well as the challenges inherent in the interactions.

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**Keywords:**

pain communication,  
assessment, patient-centric,  
animations, translation,  
patient-clinician conversation

**An overview**

## CONTEXT

Pain is more than common. In 2001, The Joint Commission (accrediting body for healthcare organizations in the United States), reported that 9 in 10 Americans regularly suffer from pain, and that pain is the most common reason individuals seek out health care. Each year, an estimated 25 million Americans experience acute pain due to injury or surgery and another 50 million suffer chronic pain.

In chronic pain there is seemingly no benefit to the patient, unlike acute pain, which represents *a protective feature* of the body (Craig, 2009). The link between effective pain communication, patient satisfaction and health outcomes is complex. However, it is believed that patients who trust their clinician and feel understood, benefit from effects of what is called a therapeutic alliance (Street, 2013). In chronic pain where the effectiveness of medication is limited, and pain management plays a much larger role; this alliance is all the more important (Institute of Medicine, 2011; Street, 2013).

## PROBLEM OVERVIEW

The practice of quantifying pain was introduced by the hospice movement in the 1970s with the goal of providing better care for patients who did not respond to curative treatment (Biss, 2005). Curative medicine is health care given for medical conditions where a cure is considered achievable. In many chronic conditions, cure is in fact not considered achievable (Institute of Medicine, 2011) yet many patients are still asked

to quantify their pain (Joint Commission, 2001). While this ‘oversimplification may be necessary for clinical purposes, it ignores the complexity of thoughts, feelings, and sensations during episodes of pain’ (Craig, 2009).

## GUIDING QUESTION

How can we design a solution that addresses the communication needs of the patient? Specifically how can we design a patient-centric pain assessment tool, which aids the patient in their pain communication with a clinician? How can this tool further improve our collective understanding of pain, thereby bringing us closer to improved techniques for supporting communication, understanding and management?

## APPROACH

Through a human-centered design process involving patients and clinicians (nurses, physicians and clinical researchers) aimed at understanding pain communication and assessment practices, several opportunity areas were identified. The scope was then narrowed to focus on a problem that a communication design perspective was suited to meaningfully question and aim to improve. Through this process, a set of personas and design principles were created, guiding the formation of future scenarios; subject to the needs validation process of speed dating. Following this, one concept area was selected and evaluated.

## SOLUTION

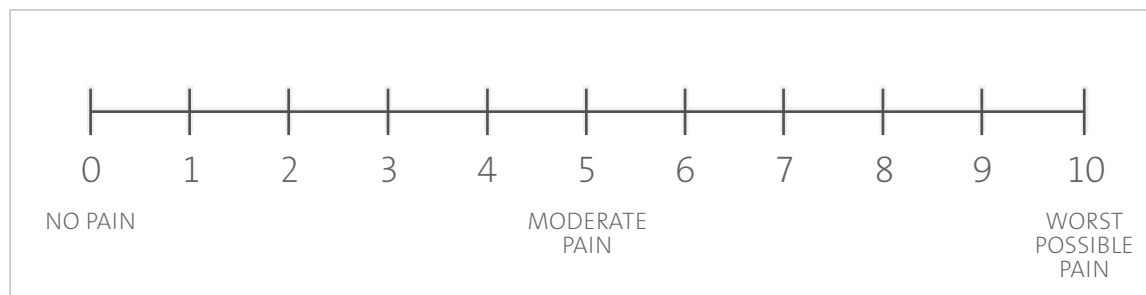
By understanding how patients and clinicians negotiate expression and assessment, this project investigates opportunities to create an application that utilizes a time based medium – animation – that can be calibrated by patients to represent their pain quality and intensity. Patients are provided with a selection of animations shown on a tablet that they use to describe the quality of their pain. The animations can be increased or decreased in speed, color saturation, focus and size, to reflect the intensity of their pain. While this solution is designed to improve the communication between patients and clinicians through the use of a patient-centric pain assessment tool, it also aims to provide the possibility of a translation mechanism with which clinicians are able to see the animations represented or translated into a number or a range of numbers.

However, the majority of them, in some way, employ a numeric scale (Joint Commission, 2001). See *Figure 1*.

While much remains to be quantitatively and qualitatively evaluated, this project should be of interest to many due to the large numbers of people affected by pain as well a high prevalence of people who have attempted to answer and been frustrated with this crude question (on a scale of 0-10, rate your pain intensity). The impact of this work lies in exploring and discovering the dynamics of pain assessment between a patient and provider; consideration of if, and what value, alternate methods and tools bring to the patients in communicating their pain sensations; and supporting the complex transaction between the patient and provider.. This work aims to bring back considerations apparently lost, such as personal pain thresholds and elements of time, that make pain complex but that are mostly ignored in a seemingly oversimplified question.

## IMPLICATIONS/IMPACT

Pain assessment in America is mandated. Since there are many types of pain – sometimes pain is a symptom, other times pain is a disease in itself – it follows that there are also many pain assessment forms and differing pain assessment guidelines.



**FIGURE 1** NUMERIC RATING SCALE (NRS)

The image features a solid red background. Overlaid on this background are several thin, dark lines that intersect at various points, creating a complex geometric pattern. The lines are primarily black, with one line being a lighter shade of red. The text 'Exploratory Investigations' is positioned in the upper left quadrant, rendered in a bold, white, sans-serif font.

# Exploratory Investigations

## THEORY

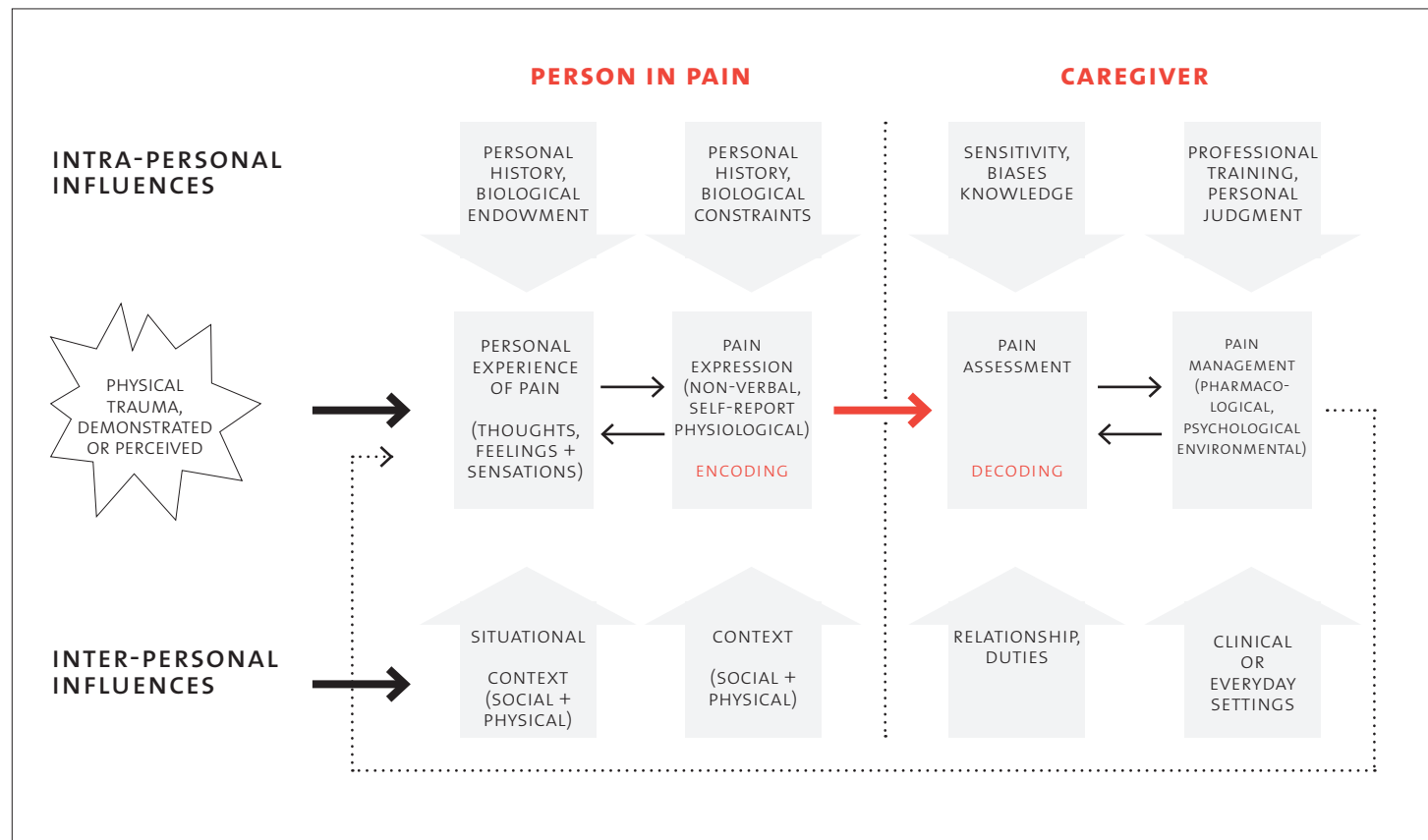
The literature review aims to establish an understanding of the human dynamics of pain communication (outside of the jargon of medical expertise) and the link between effective pain communication and positive health outcomes. Additionally, a brief overview of related work in the area is provided.



## SOCIAL COMMUNICATION MODEL OF PAIN

The work of Craig (2009) argues that a ‘formulation of pain that explicitly focuses on social factors would more readily address human needs than models that focus upon biophysical and/or psychological factors alone (intra-personal processes).’ See *Figure 1.1* for his model, which offers ‘an alternative approach to organizing our understanding of pain by drawing attention to unique and important cognitive and social factors that characterize pain as a human phenomenon.’ His model is of significance because he argues that ‘biomedical models concentrated only upon sensory features of pain incompletely

represent pain in humans and fail to give consideration to social parameters.’ Further, he says, ‘care begins with assessment and understanding people’s problems. Unfortunately, neglect of assessment is often accompanied by systematic underestimation of other’s pain.’ This model is of relevance to this investigation because it establishes the importance of a social model of pain rather than one that is focused on biology. It makes us aware of the person in pain as well as who they are communicating with and the complex system of variables that surround all these people.

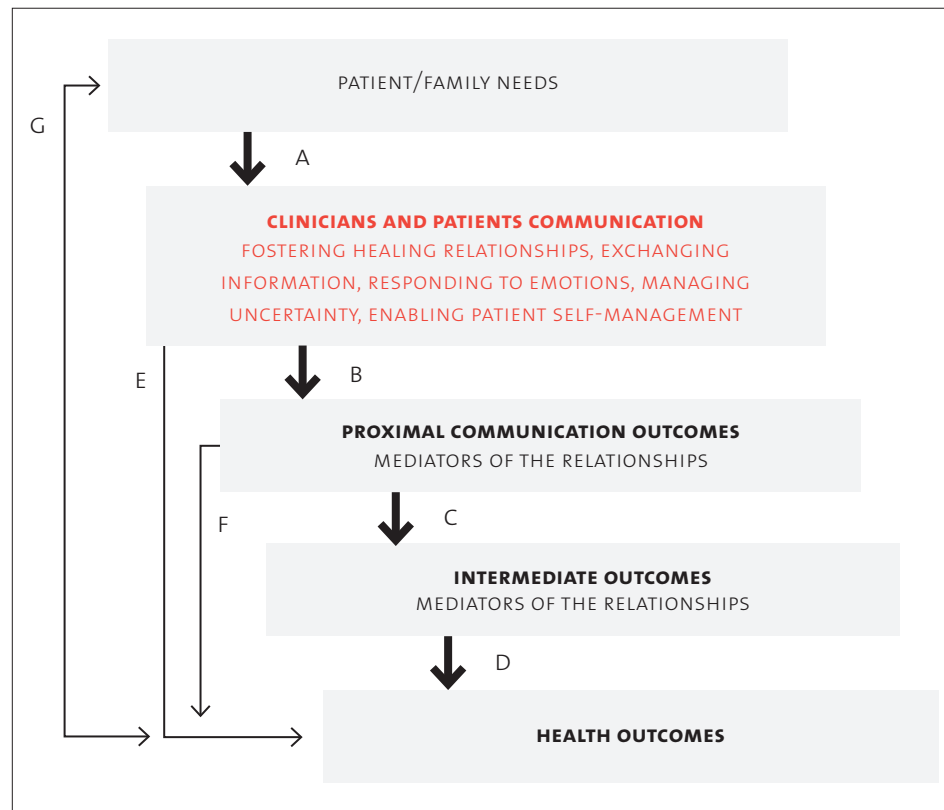


**FIGURE 1.1**  
CRAIG'S MODEL  
OF SOCIAL  
COMMUNICATION  
OF PAIN

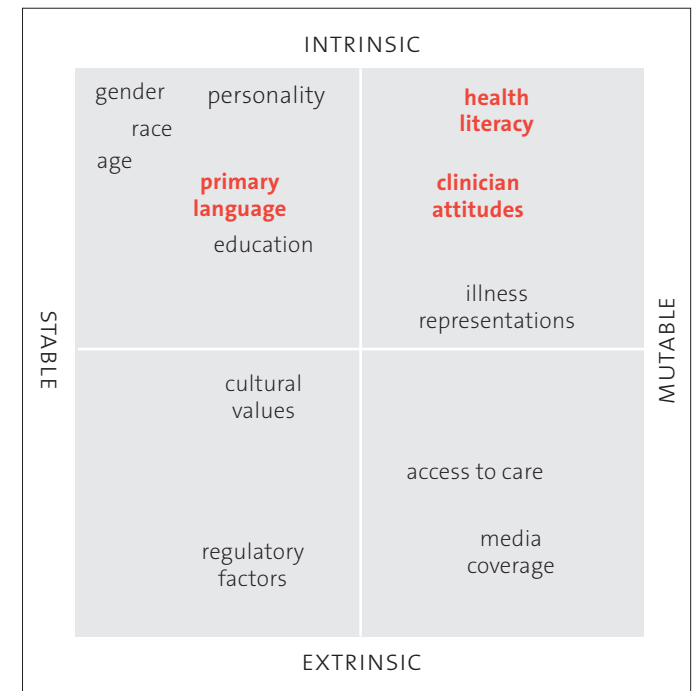
## MEDIATORS AND MODERATORS

In order to understand the link between effective health communication and health outcomes it is useful to look at the work of Street (2013). He refers to ‘mediators,’ examples of which are ‘exchanging information,’ and ‘responding to emotions’ (see *Figure 1.2*). According to Street, mediators, or mediating pathways are what connects health communication to health outcomes. What makes these pathways extremely variable is the presence of moderators (see *Figure 1.3*). His matrix of intrinsic and extrinsic moderators helps us to understand that

things like health literacy, primary language and clinician attitudes are moderators, which lie on a spectrum of change-ability or stability vs. mutability. What this implies is that while there are links between health communication and health outcomes, it is an indirect link (not direct cause and effect). However, it is understood that ‘feeling respected and supported emotionally is therapeutic’ to the patient and although patient’s emotional distress can originate from many non-clinical sources; poor communication with clinicians can compound this distress.



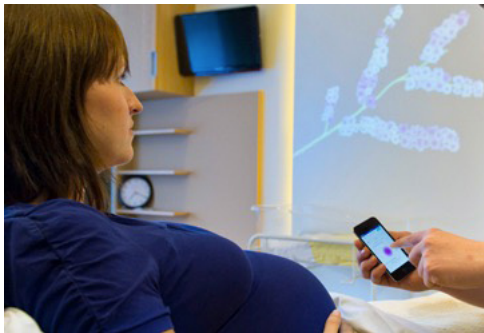
**FIGURE 1.2**  
STREET'S PATHWAYS



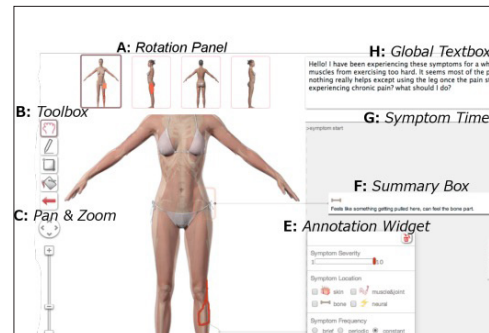
**FIGURE 1.3**  
STREET'S MATRIX OF INTRINSIC  
AND EXTRINSIC MODERATORS

## RELATED WORK

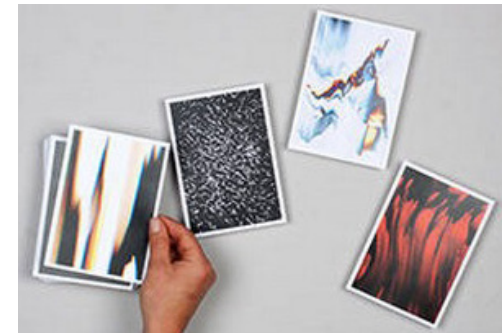
To benchmark existing concepts and research, I surveyed solutions catered towards aiding patient pain communication.



Philips Labor and Delivery Experience concept (2013) is an interactive visual animation projected on the wall of the delivery room that grows and changes in response to the progress of the birth. Based on the data from monitoring contractions, it gives the woman and her partner a simple and attractive visual impression of progress. While this project is very relevant, the solution is in response to a study aimed at solving for post-partum depression. However, its documentation validates the case for making the invisible, visible.



Thousands of people go online to discuss pain symptoms. While communication between patients and physicians involves both verbal and physical interactions, online discussions of symptoms typically comprise text only. BodyDiagrams (2014) is an online interface for expressing symptoms via drawings and text. BodyDiagrams augment textual descriptions with pain diagrams drawn over a reference body and annotated with severity and temporal meta-data. The documentation of this project is of relevance as it shows patient's prefer having visuals as a support tool for aiding communication.



The Dolorografie (2013) is a visual tool that promotes the therapeutic conversation between treating pain expert and pain patient by allowing targeted and differentiated speaking about the various components of pain. Through practical tests in pain therapy conversational situations at Bern University Hospital it has been demonstrated that the Dolorografie has a therapeutic effect for patients. Once again this is of relevance to the project as a visual tool is seen as benefit to the patient-clinician interaction.

While social models of pain communication laid the basis for my exploratory research, in-depth interviews with patients provided a more contextually rich look at experiences with pain assessment. In the initial research and exploration phase, I interviewed both chronic and acute pain patients. This approach allowed me to understand the differences between the two.

PARTICIPANT  
INTERVIEW  
PART ONE

GENERAL PERSPECTIVES  
ON PAIN COMMUNICATION

I began this process from an open-ended perspective and interviewed patients with a wide range of pain experiences. In order to account for this, I conducted individual interviews with patients using **directed storytelling**. This helped me to understand their contexts as well as how they described successful and unsuccessful interactions with their clinicians. It also helped me understand what participants had in common as well as where and how they deferred. *Figure 2* is a sample of a directed storytelling interview prompt. I created another for unsuccessful experiences.

A *successful* experience I’ve had with a clinician around my pain assessment and management was.....**SHORT STORY**.....

I describe the pain communication between myself and my clinician as.....**ADJECTIVE**.....

I summarize my clinician’s understanding of and assessment of my pain as.....**ADJECTIVE**.....

I describe my communication ability as.....**ADJECTIVE**.....

FIGURE 2 INTERVIEW PROMPT

RESEARCH PARTICIPANTS (10)

**Acute pain** participants had experience with temporary bouts of pain and brief pain communication experiences with clinicians in emergency cases.

A1	M, 30	Hairline fracture
A2	M, 60	Kidney stones
A3	M, 60	Pulmonary embolism
A4	F, 50	Post-surgery pain
A5	F, 25	Root canal
A6	F, 30	UTI

**Chronic pain** patients had a range of pain experiences lasting more than 3 months. They had experienced pain communication with several clinicians on a long term basis.

C1	F, 24	Migraine
C2	F, 58	Fibromyalgia
C3	F, 28	Vulvodynia
c4	M, 50	Chronic back pain



## PARTICIPANT INTERVIEWS PART ONE

To understand participant responses, I organized the responses according to phase of care and condition. See *Figure 2.1* for one set of participant responses. Organizing responses according to phase of care, helped to establish a baseline of consistency for

plotting otherwise diverse responses. While there were common themes, responses varied and were representative of mediators and moderators (as mentioned in the literature review) between clinicians and patients.



**FIGURE 2.1**  
PLOTING INTERVIEW RESPONSES //  
LARGE PURPLE POST-ITS REPRESENT PHASES OF CARE (E.G. PAIN INCIDENT, DIAGNOSIS, TREATMENT)  
SMALL PURPLE POST-ITS REPRESENT THEMES (E.G. PATIENT CENTRIC LANGUAGE, TOUGH LOVE)  
DIFFERENT COLOR POST-ITS REPRESENT CONDITIONS

## FINDINGS PART ONE

### GENERAL PERSPECTIVES ON PAIN COMMUNICATION



PARTICIPANTS DURING INTERVIEW



All patients had experienced both high quality care and low quality care. Both chronic and acute pain patients said, *“pain is so hard to explain and describe”* – they were able to communicate in one way or another but felt the *“exact feeling”* was impossible to truly communicate because of the subjective nature of pain and the individual response to it both physically and mentally.

There was a tendency to not talk about pain and to be as positive as possible. Older participants with acute pain said *“it’s to be expected,”* while participants with chronic pain across ages said *“people get tired of hearing about it,”* and *“you get tired of focusing on it.”* Participants who had experienced episodic chronic pain across ages said they *“only mention it when it gets bad.”* Older, male participants said *“You don’t want people to think you’re old or getting weak.”*

Additionally, chronic pain patients talked about *“spending hours hunting”* for clues on the Internet and also mentioned the detrimental effect of strong drugs. Each of them talked about how they struggled to find doctors who knew and accepted their conditions.

### EXTRACTED QUOTES/ DESCRIPTORS WHILE COMMUNICATING WITH CLINICIANS:

#### SUCCESSFUL

Personable, friendly  
Professional  
Dead-on  
Light at the end of a tunnel  
Calming  
Relieving  
I felt in control  
I was actually being heard  
Improved over time

#### UNSUCCESSFUL

Zero understanding  
Accused me of lying  
Impossible  
Dismissive  
Limited  
Intimidating  
I felt stupid

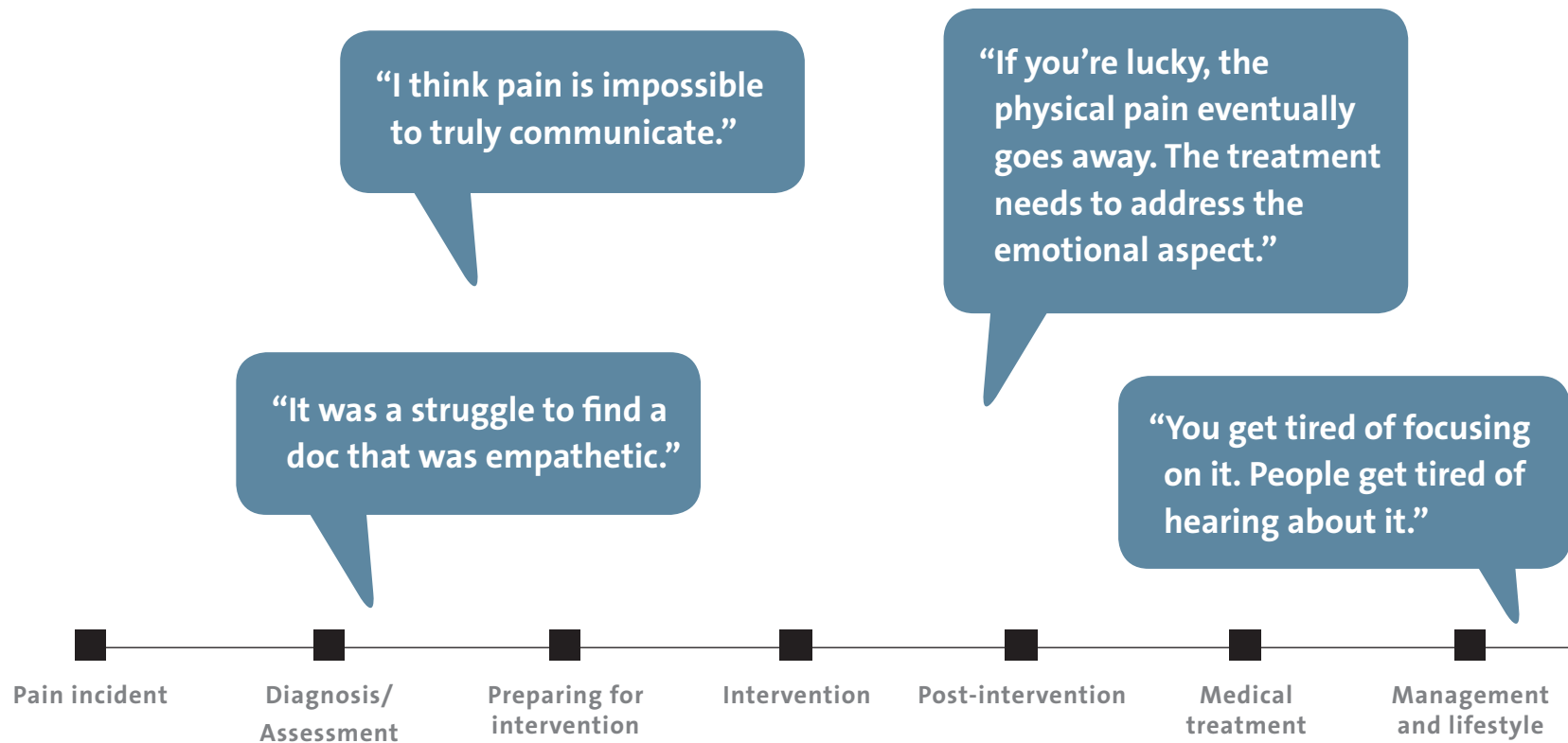
## FINDINGS PART ONE

### CONTEXTUAL SYNTHESIS / UNDERSTANDING OF FINDINGS

In analyzing these responses, it seemed to make sense to continue to plot them on a spectrum of care, because otherwise there is little contextual understanding of their significance. See *Figure 2.3*, which represents paraphrased quotes that occurred most frequently and that all participants communicated.

**FIGURE 2.3**

QUOTES EXTRACTED FROM THE  
EXPLORATORY RESEARCH INTERVIEWS  
AND ARRANGED BY PHASE OF CARE





## PARTICIPANT INTERVIEW PART TWO

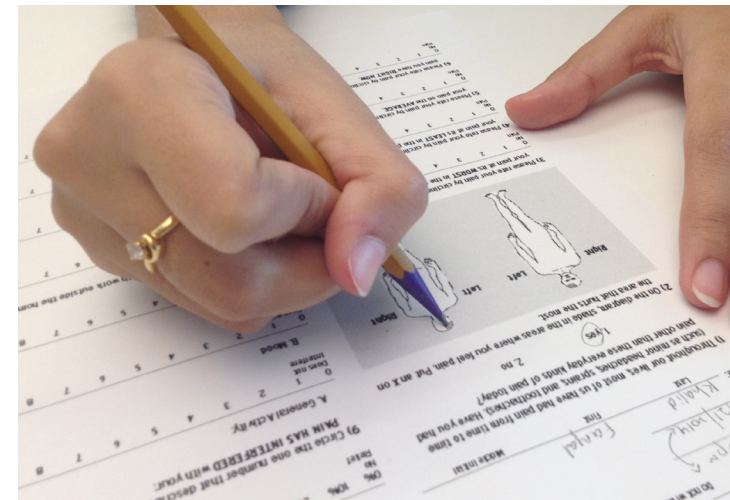
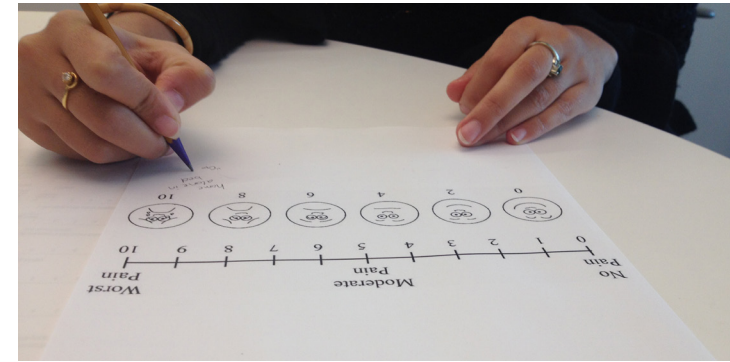
### SPECIFIC PERSPECTIVES ON PAIN ASSESSMENT

The next part of the interview was a modified version of the **think aloud protocol**, where I gave participants the Wong-Baker faces scale (top image on right), the Numeric Rating Scale and an interview prompt (*Figure 2.3*) and asked them to talk me through how they would use these forms as a support tool while describing their pain. While this exercise relied upon recall (since patients were not in pain while filling out these forms) it was important towards understanding the specifics of how people think through these types of artifacts.

I have been asked to rate my pain intensity on  
a scale like this.....**YES/NO**.....

The experience of using the scale was.....**ADJECTIVE**.....

During that interaction, I communicated the pain  
intensity that I felt.....**YES/NO**.....



PARTICIPANT TALKING THROUGH FILLING OUT  
PAIN ASSESSMENT FORMS

## FINDINGS PART TWO

### SPECIFIC PERSPECTIVES ON PAIN ASSESSMENT

Both chronic and acute pain patients expressed some **confusion** around the scales. They found the experience of using them “vague,” and “ambiguous” because worst possible pain for each person is different. Several people said “I had no clue what it actually meant.”

Additionally, participants said, the scales doesn’t accommodate for a variety of answers; one might want to say, it’s an 8 when I am applying pressure, and a 7 when I am resting, and a 10 early in the morning, which they described as “lacking specificity”. Chronic pain patients said they “usually didn’t remember” what they said the last time they came in.

Despite the above, patients said they *were* able to communicate their pain intensity using this scale because *they had to*, however, half of them said it **didn’t feel accurate**.

Additionally, several patients said that it was the **lack of reaction** they received towards the number they said (usually high), that made them feel that this tool or the protocol was lacking in some way (and many of them thought out loud that ‘this must just be for documentation’ or ‘to avoid lawsuits later’).

To the point above, it was said that if the emotional component of pain is not taken into account on this scale then that is another reason why even though a number might be forced out of them it might not convey how they feel.

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While these concerns surfaced during this exercise, it was important to remember that it was lacking from an observation of a patient-clinician interaction, in which the interpersonal influences play a major role.

## FINDINGS PART TWO

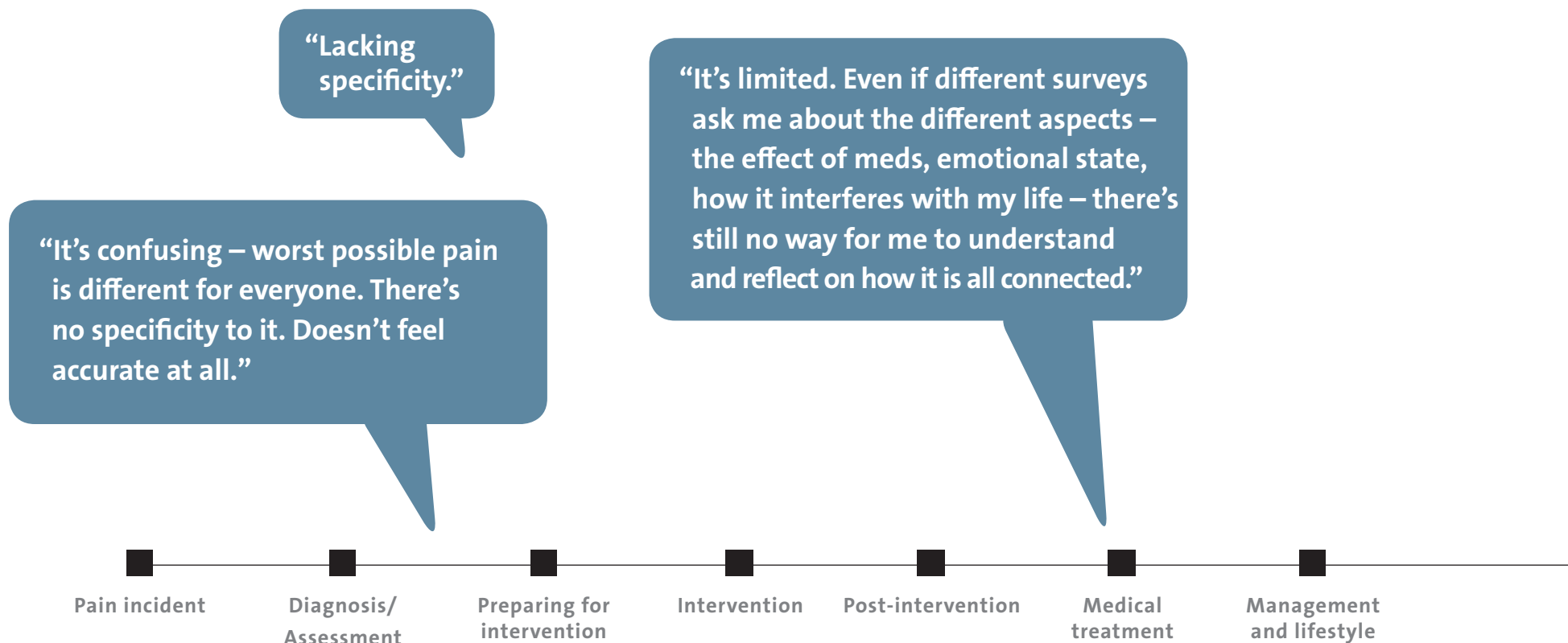
### CONTEXTUAL SYNTHESIS / UNDERSTANDING OF FINDINGS

In further analyzing these responses, it seemed to make sense to once again plot them on the spectrum of care; see *Figure 2.4*.

**FIGURE 2.4**

QUOTES EXTRACTED FROM THE  
EXPLORATORY RESEARCH INTERVIEWS  
AND ARRANGED BY PHASE OF CARE

● PATIENTS



## SYNTHESIS

**PAIN PATIENT ARCHETYPES**

The interviews were rich – with both convergent themes and divergent perspectives. From a design standpoint, creating archetypes would aid in responding to the question, *for whom is accurate pain communication most important?*




Based on my research participants, pain communication is most difficult for those that have either been recently diagnosed with a chronic condition (transitioners) or for those that have yet to be diagnosed (strugglers), see *Figure 3*.

For these archetypes, continuous pain is a confusing, new and unfamiliar experience which makes the process of explaining it and describing it a struggle. It is less relevant for people who were diagnosed several years ago and hence are more adept at managing their communication according to their needs (the independents).

While those who experience acute pain also struggle with communicating their pain, the emergency room is a much more complicated space than the clinician's exam room. The emergency room deals with drug abuse and addiction in an environment of heightened tension (more on this in the clinician interview findings). Since the ER would be hard to get access to and further exploration into this space would be extremely challenging, it was not within the scope of these explorations.

## SYNTHESIS

## PAIN PATIENT ARCHETYPES

	 <b>STRUGGLER</b>	 <b>TRANSITIONER</b>	 <b>INDEPENDENT</b>
<b>Distress from not being able to communicate*</b>	Very pronounced	Somewhat pronounced	Less pronounced
Pain type	Unknown	Chronic (e.g. fibromyalgia)	Chronic (e.g. migraine)
Phase of care	One month since first PCP visit: undiagnosed  Diagnostic tests: Ongoing, unavailable, too expensive or cumbersome	Ten months since diagnosis  Visits PCP for flare-ups every 9-10 months; has experienced initial adverse reactions to medications	Five years since diagnosis  Visits specialist every three months to keep in check
Interference	High to medium	Medium to low	Low
Medication	No prescriptions or general pain killers	Daily + during emergencies; currently adjusting to medicines; period of trial and error	Herbal medicines during mild flareups; strong medications during emergencies

**FIGURE 3**  
PAIN PATIENT  
ARCHETYPES

Having heard what patients say about their experiences, the next step was to understand the perspectives of clinicians and researchers. I was able to speak with folks at the Department of Medicine; Center for Pain Research; and the Department of Anesthesiology (at the University of Pittsburgh). I was also fortunate to interact with nurses from Charles MGH in Boston.

PARTICIPANT  
INTERVIEW  
PART ONE

GENERAL PERSPECTIVES  
ON PAIN ASSESSMENT

This interview was also conducted as a **directed storytelling** session (*Figure 4*) which helped scope the conversation. I wanted to learn about clinician’s expertise and experiences in interacting with patients.

The pain assessment protocol I follow is

**BRIEF OVERVIEW**  
.....

Pain assessment is part of every interaction

I have with a patient.....**YES/NO**

I use the following tools.....**LIST/DESCRIBE**

I document in the following way.....**ADJECTIVE**

(Numeric) pain scales are an effective/ineffective

.....**CHOOSE**.....tool because.....**REASON**

RESEARCH PARTICIPANTS (7)

**Clinicians** had experience caring for chronic and acute pain patients.

- |    |       |                        |
|----|-------|------------------------|
| C1 | F, 35 | ER Nurse               |
| C2 | M, 30 | ER Nurse               |
| C3 | M, 50 | Physician (generalist) |
| C4 | F, 30 | Physical therapist     |

**Clinical researchers** provided a rich perspective into current research, challenges and opportunities

- |    |       |   |
|----|-------|---|
| R1 | M, 36 | Clinical psychologist, professor                  |
| R2 | M, 58 | Hematologist, translational researcher, professor |
| R3 | F, 58 | Anesthesiologist and genetics researcher          |

FIGURE 4 INTERVIEW PROMPT

## FINDINGS PART ONE

### CLINICIAN AND RESEARCHER PERSPECTIVES ON PAIN COMMUNICATION AND ASSESSMENT



CLINICIAN INTERVIEW  
LOCATIONS

The **protocol in every hospital is slightly different.**

Clinicians and researchers explained that a numeric value is only meant to be **in relation to one person's pain**; one person's 5 can be compared to their 9, but you cannot compare two people's 9's.

They talked about how this is especially useful in the context of post-surgery pain when **clinicians are actually not all that interested in the number itself** – just that either medication or treatment has been effective and that the pain *is less than it was before* the intervention. As a result (and as mentioned in the introductory overview) the numeric system was designed to provide a system for clinicians to note this (in the case of acute and curable pain). For e.g., if before medication, pain was a 10, and after medication pain is still a 10, it would mean the medicine has been ineffective.

Further, a numeric value is useful for clinicians who take over from one another by providing a system that is well understood internally.

Still, some clinicians say that, in the ER, there is *some aversion to the numeric system*, even from the clinician's perspective. This is because patients both lie and exaggerate. They say that the ER sustains the problem of addiction because they cannot deny patients medication especially if they have a prescription. There are also clinicians that believe that pain *is not* what the patient says it is (going against nursing 101).

An additional interesting finding is that the Wong-Baker Faces scale was originally designed for children. However, apparently it has caused confusion because children sometimes choose a number (because it is their favorite number) or a face because they like it or find it cute or appealing in some way.



## FINDINGS PART TWO

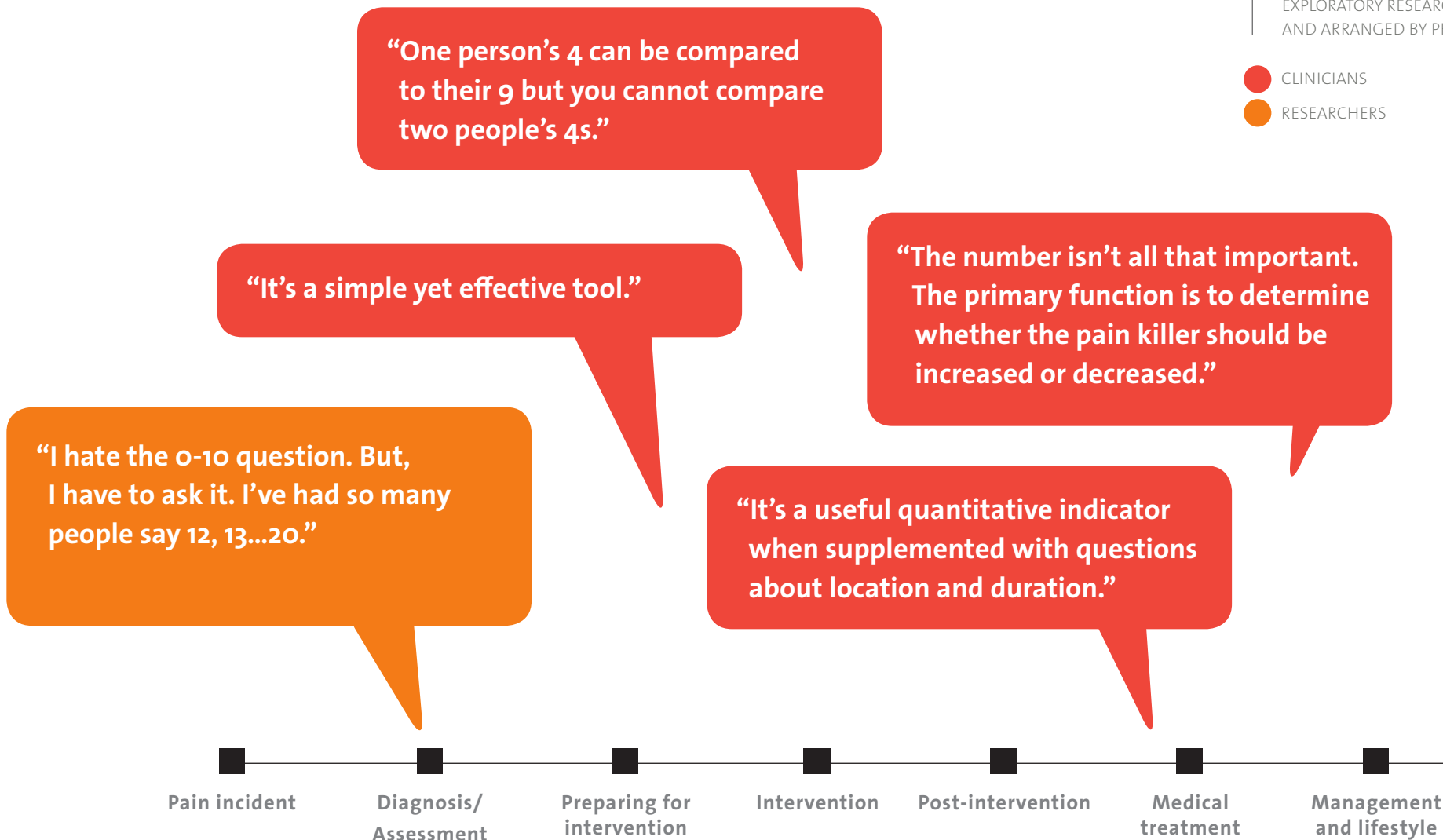
### CONTEXTUAL SYNTHESIS / UNDERSTANDING OF FINDINGS

While once again coming across some very interesting findings, the scope of the project determined what was to be included for further consideration. See *Figure 4.1* for responses plotted in context of care.

**FIGURE 4.1**

QUOTES EXTRACTED FROM THE  
EXPLORATORY RESEARCH INTERVIEWS  
AND ARRANGED BY PHASE OF CARE

● CLINICIANS  
● RESEARCHERS



## KEY FINDINGS

My exploratory research revealed a glaring disparity in how the pain intensity scales are understood by the patients and clinicians. The key findings for design are:

- 1 Pain is **qualitative**, yet patients are required to quantify it.
- 2 **Time + context** are poorly represented in assessment forms yet they are essential for understanding the characteristics of pain.
- 3 Patients want to feel **emotionally** taken care of, otherwise pain assessment isn't considered successful.
- 4 Current system affords abuse (patients say 50, 100). Still, clinicians say, a number is a useful **comparative indicator**.

# Generative Investigations

The background is a solid red color. Overlaid on this are several thin, dark lines that intersect at a single point located in the upper right quadrant. These lines extend across the frame, creating a series of triangular and quadrilateral shapes. The lines are dark, possibly black or a very dark red, and have a slight transparency, allowing the red background to show through.

My initial explorations synthesized key findings into the four main points on the previous page. After this, I looked for literature that supported an argument for redesigning the pain intensity scale. After that, I began another exploratory phase which was about investigating through making.

## VALIDATION

Though my primary research had pointed me in the direction of probing further into the space of redesigning the pain scales, I wanted to support that finding with some validation in the literature. I found the following material in Craig's (2009) research to suggest that other researchers also see problems in the pain scales.

## Oversimplification

While the experience of pain is comprised of thoughts and feelings as well as somatic sensation, **many self-report scales reduce the complexity to unidimensional statements of pain severity**; for example, asking patients to estimate their pain on a 0 to 10 scale.

This is known as oversimplification, ignoring variation in key features of experience and opportunities to target therapeutic interventions on well-defined targets.

Jensen & Karoly, 2001; Stinson, Kavanagh, Yamada & Stevens, 2006

*Additionally...*

Expressing our pain on the scale of 1 to 100, or even 1 to 10, seems more difficult – and arguably less meaningful – than on the scale of 1 to 3. Expressing subjective assessments with a high accuracy is really impossible, therefore a smaller comparison scale is more appropriate.

Nguyen, Kowalczyk, 2010

Since the scope had been sufficiently narrowed, some design principles would support the creation of some storyboards by establishing criteria:

**1****AID PATIENT IN DESCRIBING**

Given the scope of this project, the attempt is not to remove patient description or report altogether (with automated pain detection, for example) but rather to aid and support that verbal description.

**2****QUANTITATIVE AND QUALITATIVE**

Patients want to know that their qualitative experiences matter as much as the quantitative selection. Clinicians on the other hand, need a number.

**3****PERSONALIZED**

Patients need to feel that assessment is personalized to them and their pain thresholds. With chronic pain it is all the more important to allow conversations to address the emotional (physiological side).

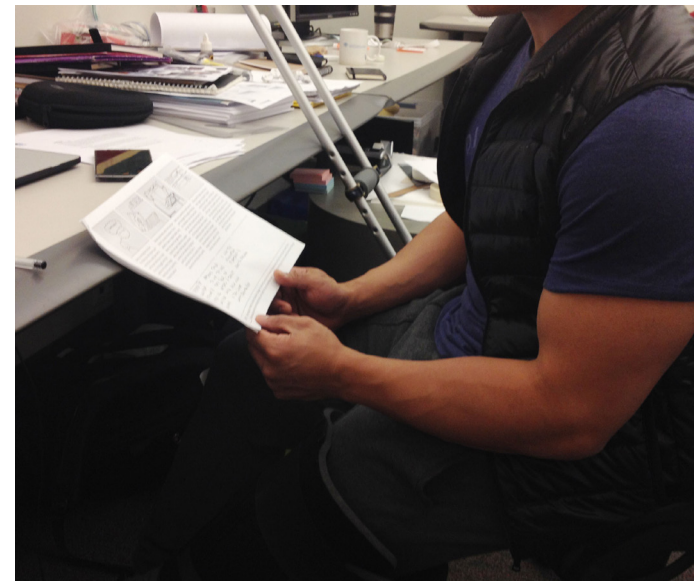
**4****CONCISE**

Since time is limited (and this assessment is just one part of the interaction between the patient and clinician) the procedure needs to be short yet very effective.

**5****AIDS THE CONVERSATION**

Based on my research, the scope of this project is still very much around aiding the *conversation* between the patient and the clinician.

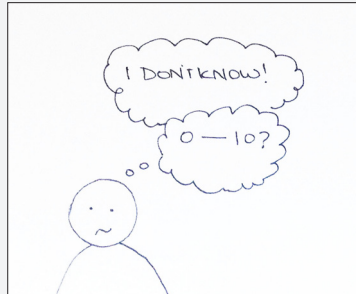
To test out the principles, I developed 3 concept storyboards illustrating how the principles might fit into various scenarios. I conducted needs validation sessions which helped guide the transition into concept and user evaluation.



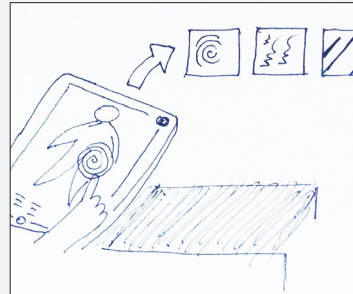
SPEED DATING WITH CLINICIANS, RESEARCHERS AND PATIENTS

## GENERATIVE STORYBOARDS + SPEED DATING

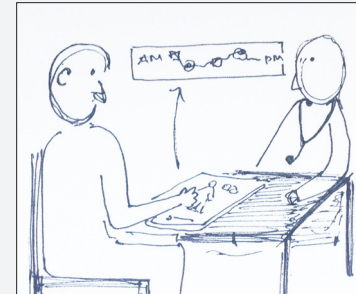
### 1 EXPRESSIVE ANIMATIONS



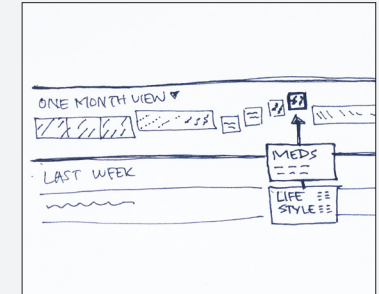
Nancy is visiting her clinician for a flare-up in her chronic pain. Her clinician usually asks her to rate her pain intensity on a scale of 0-10. She struggles with that question as the number changes depending on time of day/activity. She dreads the question!



When she meets with her clinician there is a new procedure. She is asked to (use a digital tablet) and mark the area that generally locates her pain. Next she is asked—what does it feel like, and is shown a series of animations ranging in quality and intensity.



Next, she is asked to mark how her pain changes throughout the day, on a time line. Her clinician and her can both visually see how it is worse in the morning than later in the day. Later her clinician translates the animations into a number which is used for clinical purposes.



A few months later when Nancy visits, she doesn't dread expressing her pain. She feels her clinician has a better understanding of her pain. She is able to see where she was during her last visit, what some of the influencing factors may be. Together they make informed and shared decisions.

### KEY FINDINGS

#### DESIRABILITY

*Patients* ✓

loved it because animations are more expressive than words or images alone can be. Animations have an emotional quality to them and can incorporate the element of time.

*Clinicians and researchers* ✓

thought this could definitely work and were happy to test it in their clinic. They felt it would help create rapport between patients and clinicians.

#### FEASIBILITY

*Patients* ✓

felt some might prefer words over images (or may not understand the animations). Using both words, images and the animations should be considered. It would have to be very easy to understand.

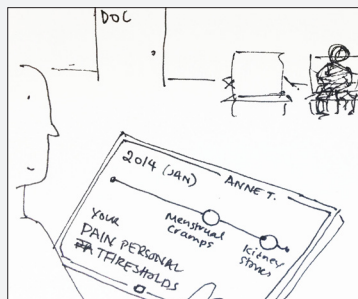
*Clinicians and researchers* ✓

would still need a number – and they would need to create a translation mechanism for that. This solution is feasible – and would be cost effective and easily implementable. Best if concise.

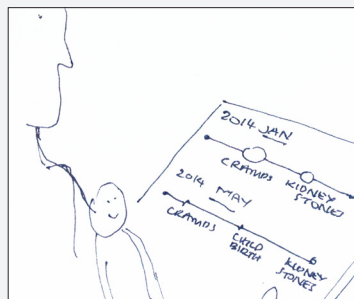


## GENERATIVE STORYBOARDS + SPEED DATING

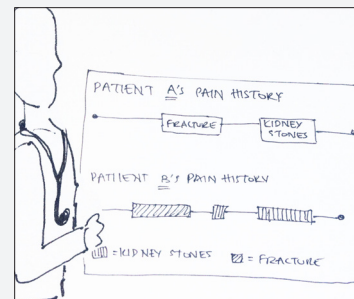
### 2 PERSONALIZED PAIN THRESHOLD SCALE



When Anne is waiting to be seen by her clinician she is requested to edit her personal pain thresholds since her last visit. She is in for her pre-delivery check up and thinks it looks accurate. No updates needed.



A few months later, post delivery, Anne is back at the clinic and she is able to adjust her thresholds based on her new experience with pain. She feels that she is being treated personally, according to her individual thresholds.



Later on, in patient training, senior clinicians are able to show new clinicians their latest patient data which visualizes the individual nature of pain and how there are ranges that a patient might feel for a condition, as well as variations across patients. This contributes to clinician empathy/understanding.

### KEY FINDINGS

#### DESIRABILITY

*Patients* ✓

were intrigued by this idea because it makes you feel that you're being treated personally, according to your own thresholds.

*Clinicians and researchers* ✓

thought this would make a great patient centric education tool for clinicians/researchers with further refinement and research.

#### FEASIBILITY

*Patients* ✗

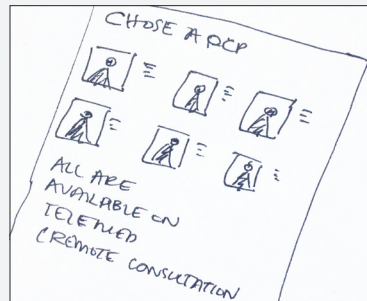
however felt they would have trouble remembering what their numbers were (and might get confused by it) so if it could be ranges that would work better.

*Clinicians and researchers* ✗

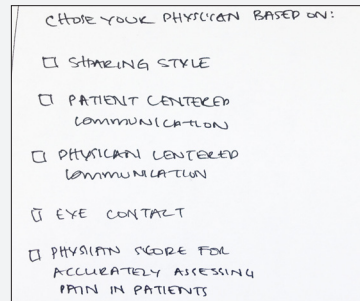
questioned whether this would help patients to set realistic expectations for their pain levels. There seemed to be interest in this idea but it would need further research and investigation to clarify more.

## GENERATIVE STORYBOARDS + SPEED DATING

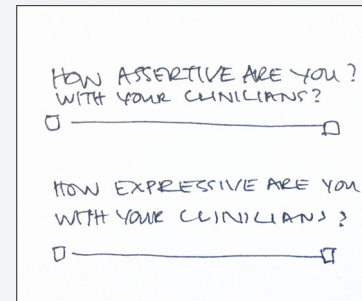
### 3 COMMUNICATION STYLE MATCHING



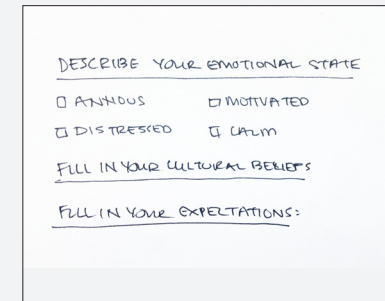
When signing up for health insurance and choosing a PCP, Joe now also has the choice to make his decision based on communication styles of PCPs.



His is able to choose based on the following factors about his PCP.



He is also able to input information about his communication style and preferences.



Prior to his appointment he is able to mention his emotional state, which both prepares the physician for their interaction and allows him to express how is he feeling.

## KEY FINDINGS

### DESIRABILITY

*Patients* ✓

liked to know information about their doctor and felt this could help set their expectations. They were also interested in knowing about their doctor's experience with their condition.

*Clinicians and researchers* ✓

thought it was important for patients to be aware of how anxiety might influence their self-reporting during assessment and thought that should be included in all self-reports.

### FEASIBILITY

*Patients* ✗

didn't comment on feasibility.

*Clinicians and researchers* ✗

felt it might be too complex to assess/report PCP communication styles. Also it is not feasible to always get your PCP of choice due to an increased demand.

## ANALYSIS

Only the pain animations concept qualified as both desirable and feasible for both patients and clinicians. Based on this analysis, I decided to pursue the animations concept further. If I think back to where the animations idea originated from, I believe it germinated in the Philips Labor Delivery Care concept mentioned in Related Work. However, more prominently, it came about as a result of ideating on what could be both visual while representing change and time.

## REFLECTIONS

At this point I was also reminded of the work of Forlizzi, Zimmerman and Stolterman (2010) on *Research Through Design* in which they say, “Methodological frameworks promise rigor but jeopardize the possibility for designers to invent ad hoc approaches, or draw inspiration from unorthodox sources, or take inexplicable imaginative leaps — all forms of a productive indiscipline that we see as integral to design practice.”

While I was methodical about my process, there was also a point at which I just needed to create and see where it went.

## GENERATIVE INVESTIGATIONS

### CONCEPT DEVELOPMENT — ANIMATIONS

I started out with all the words that are currently used to describe *qualities of pain* on the BPI (Basic Pain Inventory) form (see *Figure 5*). I then clustered these and reduced them down to a few groups, to have fewer choices to pick from

and also to reduce repetition (*Figure 5.1*). The first three types I chose to focus on were **throbbing**, **shooting** and **cramping**. These were different enough to begin an exploration. I also realized that some like deep and dull are qualities that could be *applied to qualities*, so I clustered these separately.



**FIGURE 5**  
ORIGINAL LIST OF QUALITATIVE WORDS  
USED ON BPI FORM

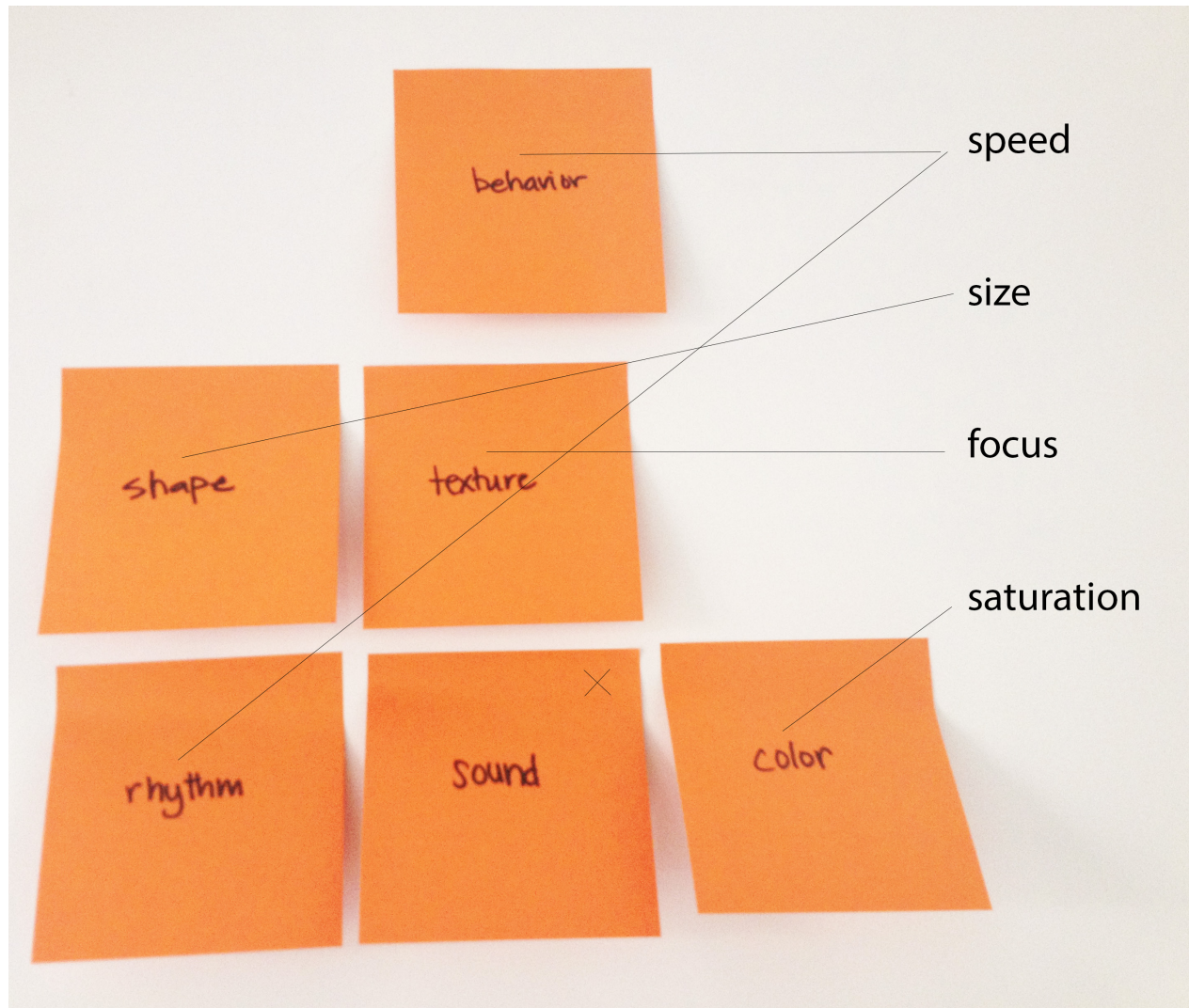


**FIGURE 5.1**  
RECLUSTERED ACCORDING TO SIMILARITIES



Next, I listed the visual variables that the animations would represent or communicate. The initial list is below (Figure 5.2); the final list being *speed, saturation, focus and size*. Changing these would change the intensity of the pain depicted. I decided not to deal with sounds as that was not something my initial research had inquired about.

**FIGURE 5.2**  
VISUAL VARIABLES

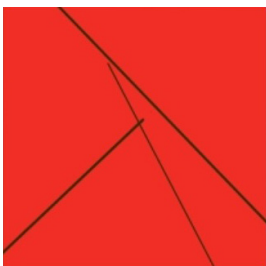


As an initial test, I created a set of three animations (to depict **throbbing, shooting and cramping**). The goal was to create animations that represented these sensations. At this point it was less about creating a wide range of variety (intensities) within the sensations themselves; each animation was simply

meant to represent some ‘high’ intensity of itself, without a specific number or degree attached to it. *Figure 5.3* represents some considerations of how to use visual elements to communicate these sensations or qualities.



**THROBBING**



**SHOOTING**



**CRAMPING**

**FIGURE 5.3**  
VISUAL CONSIDERATIONS

<b>Shape and focus</b>	Square to indicate sharpness	Lines (pins/sharpness)	Mimicking electricity
<b>Focus</b>	In focus to communicate intensity	In focus to communicate intensity	In focus to communicate intensity
<b>Color and saturation</b>	Shades of red	Red and black for contrast	White instead of black (looks more like electricity)
<b>Movement and speed</b>	Coming at you to suggest it originating at a certain point and radiating from there	Having a central point but shooting in all directions	Having a central point but shooting in all directions
<b>Fluctuating or consistent</b>	Fluctuating to indicate change over time	Fluctuating to indicate change over time	Fluctuating to indicate change over time
<b>Size</b>	Go out of frame in certain places; to communicate intensity	Go out of frame in certain places; to communicate intensity	Stays mostly within frame

## GENERATIVE INVESTIGATIONS ANIMATION SURVEY

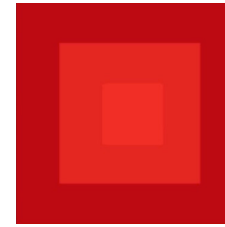
### SURVEY DESIGN

I sent out these animations in a survey with the question, **what kinds of pain do you believe these animations evoke?**

The goal was to understand how participants would describe the qualities of these animations, given the context of pain. See *Figures 6, 6.1, and 6.2* for full participant responses and for word frequency.

*Participant responses from the survey separated by a line to indicate a different person:*

throbbing pain | the pain you have when you cut or burn yourself... throbbing pain...might be associated with headache as well | thumping pain, severe pain all over an area | throbbing acute pain, panic/anxiety and shortness of breath | it feels like rhythmic pain | throbbing headache in temple or ankle pain after twisting it | headache, pain in the back of the eyes, throbbing bruise | hurts like something is jumping on it | pain that fluctuates in intensity | throbbing, maybe even burning, like when i come in from outside when it is cold and my ears heat up uncomfortably, or if I jam my finger and it swells to the point i can feel my heartbeat in my finger | throbbing | pulsing pain but also very erratic pulsing... i could see this being acute, like if i really badly jammed my toe | throbbing and pulsing pain... this could easily resemble how I felt after getting my wisdom teeth out... i think the bright red color makes the throbbing seem more intense than just mild annoying pain | pulsing, sharp, beating, heavy, dull | headache | throbbing, pulsing, ever present in my mind |

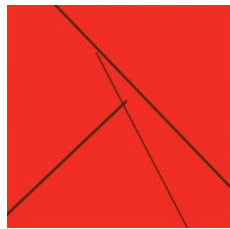


N = 16

ADJECTIVES		NOUNS		ADVERBS	
throbbing	11	pain	13	badly	1
pulsing	5	headache	5	mild	1
acute	2	finger	2	really	1
burning	2	ankle	1	very	1
annoying	1	anxiety	1		
beating	1	breath	1		
bright	1	bruise	1		
cutting	1	cold	1		
dull	1	color	1		
erratic	1	ears	1		
fluctuating	1	eyes	1		
heavy	1	heartbeat	1		
jammed	1	heat	1		
jumping	1	hurt	1		
rhythmic	1	mind	1		
severe	1	panic	1		
sharp	1	red	1		
swelling	1	teeth	1		
thumping	1	temple	1		
twisting	1	toe	1		
uncomfortable	1				

**FIGURE 6**  
ANIMATION #1 RESPONSES

GENERATIVE  
INVESTIGATIONS  
ANIMATION  
SURVEY



N = 16

throbbing pain | shooting pain | light sensitivity that you experience while having severe headaches | nausea | sharp, pins and needles | pinching pain in particular spots occurring rapidly, needle pricking in a small area | a quick surge of injury... a sharp feeling that occurs with one quick action | cutting, burning, pinching | scratching | sharp, sudden bolts of pain... ant bites, bee stings, quick and intense | stinging... visually this looks like cuts or slicing... a type of pain that stings... when you get lemon juice in a cut | like stabbing pain | darting pain, vicious migraine | piercing headache with static | intense pain that is modulating up and down quickly | shooting, bursts, not localized, sharp, frequent | scratches, flowing pain from one part to another | piercing stabbing pain...shooting pain into your heel after standing for too long | sharp |

**ADJECTIVES**

quick	5	modulating	1
sharp	5	pricking	1
cutting	3	sensitive	1
shooting	3	severe	1
stinging	3	scratching	1
intense	2	slicing	1
piercing	2	small	1
pinching	2	static	1
stabbing	2	sudden	1
burning	1	surge	1
bursting	1	vicious	1
darting	1	throbbing	1
flowing	1		
frequent	1		
long	1		

**NOUNS**

pain	11
headache	2
needles	2
ant	1
bee	1
bites	1
bolts	1
heel	1
injury	1
lemon juice	1
light	1
migraine	1
nausea	1
pins	1

**FIGURE 6.1**  
ANIMATION #2 RESPONSES



GENERATIVE  
INVESTIGATIONS  
ANIMATION  
SURVEY



N = 16

deep muscle pain or a headache | toothache,  
headaches | aching pain, some pain exacerbated  
by an outside force like moving in the wrong way  
| headache or muscular pain | slowly beginning  
with mild intensity, rising in a crescendo to a near  
blinding, wince-inducing pain - reminds me of  
when I was having my broken arm bent by a pair  
of nurses to be put into a cast | Something that  
starts out in one area and spreads across the  
body | burning, hot pain, tingling, shooting kinds  
of pain | split | it feels like sharp pain | dull pain...  
i fell down two weeks ago, and my elbow still  
hurts... this feels like it could describe that pain  
well.... a constant dull pain, but occasionally acute  
if I put pressure at the right angle on my elbow |  
chronic, continuous, flowing, specific area |  
subtle back pain or muscle pain that irritates you  
by coming up and then dying back down | like a  
slow storm, maybe a headache... this one does not  
evoke quite the same memory of a pain as the  
others do, but i think the strong visuals might  
really speak to some people | deep tissue pain |  
pulsating muscle pain | back pain |

**ADJECTIVES**

dull	2	hot	1
deep	2	hurts	1
slow	2	irritating	1
acute	1	mild	1
aching	1	muscular	1
bending	1	pressure	1
blinding	1	pulsating	1
broken	1	shooting	1
burning	1	split	1
constant	1	strong	1
continuous	1	subtle	1
dying	1	sharp	1
exacerbated	1	tingling	1
falling	1		
flowing	1		

**NOUNS**

pain	17
headache	4
back	3
elbow	3
muscle	3
arm	1
body	1
cast	1
crescendo	1
force	1
nurses	1
storm	1
tissue	1
toothache	1

**FIGURE 6.2**  
ANIMATION #3 RESPONSES

## SURVEY DESIGN — ANALYSIS — PART 1

The first animation had the highest responses of one particular word, which was *throbbing*. The second one, *quick* and *sharp* got the same number of occurrences; in the third one there was a tie for *dull*, *deep* and *slow*. While these findings were revealing in themselves, there was rich language within the responses which

I then organized into emergent themes (see *Figure 6.3*) which aided in an understanding of, firstly, what is the communicative value of these animations, and secondly, what does interpreting them allow for?

### THEMES

#### RECALL

Participants used the animations as a starting point to recall certain pain incidents and memories:

---

*Reminds me of when I was having my broken arm bent by a pair of nurses to be put into a cast.*

*Like when I come in from outside when it is cold and my ears heat up uncomfortably, or if I jam my finger and it swells to the point I can feel my heartbeat in my finger.*

#### TIME + CHANGE

Participants mentioned the temporal or changing nature of pain:

---

*Pain that fluctuates in intensity.*

*Very erratic pulsing.*

*Something that starts out in one area and spreads across the body.*

*Coming up and then dying back down.*

*Slowly beginning with mild intensity, rising in a crescendo to a near blinding wince-inducing pain.*

#### REPRESENTATION

Participants indicated satisfaction and comfort with using these animations to represent a sensation:

---

*This feels like it could describe that pain well.*

*I think the strong visuals might really speak to some people.*

*This could easily resemble how I felt when I got my wisdom teeth out.*

FIGURE 6.3

ANIMATION RESPONSES ORGANIZED BY EMERGING THEMES

## SURVEY DESIGN — ANALYSIS — PART 2

While one of the themes is **time and change** and the word *intensity* was mentioned in two of the representative quotes within that theme, the presence or indication of **a range of intensities is missing in these animations and descriptions**. This is understandable since the animations were not designed to include that.

One additional participant quote suggests the variation that these animations need to have within them to work across a range of pain sensations. That quote, in response to throbbing, was:

*“I think the bright red color makes the throbbing seem more intense than just mild annoying pain.”*

## GENERATIVE INVESTIGATIONS DRAWING EXERCISE

### DRAWING EXERCISE

The first exercise helped to establish how people describe pain through these animations and that there is a connection between the communication and the visuals.

The next part was to figure out how people would draw pain on a spectrum. The purpose of the next activity was to determine whether people were able to distinguish and then represent those differences (high and low intensity) in their drawings. Since this was a group of design participants, it was not a stretch to imagine that they would be fairly comfortable with drawing. Additionally, having seen the animations, the same group of 16 participants may have been better equipped or to continue to use abstraction to create their depictions.

For this exercise, I gave people a list of qualitative words which are currently used on the pain assessment forms like stabbing, pounding, shooting, and asked them to draw those words for me, creating a low or medium version, and a high version for each word. I took the results from that and clustered them.



## GENERATIVE INVESTIGATIONS DRAWING EXERCISE

### DRAWING EXERCISE — ANALYSIS

I clustered the drawings based on approach and also arranged them according to intensity (see *Figure 7*). The finding from this exercise is that they mostly looked quite similar. While

there were some differences, it seems as though it was easier to draw and imagine a middle intensity, rather than a low one. The highs were always clearly the ones with the most contrast.



**FIGURE 7**  
CLUSTERING PARTICIPANT  
DRAWINGS. SEE FULL SET  
IN APPENDIX.

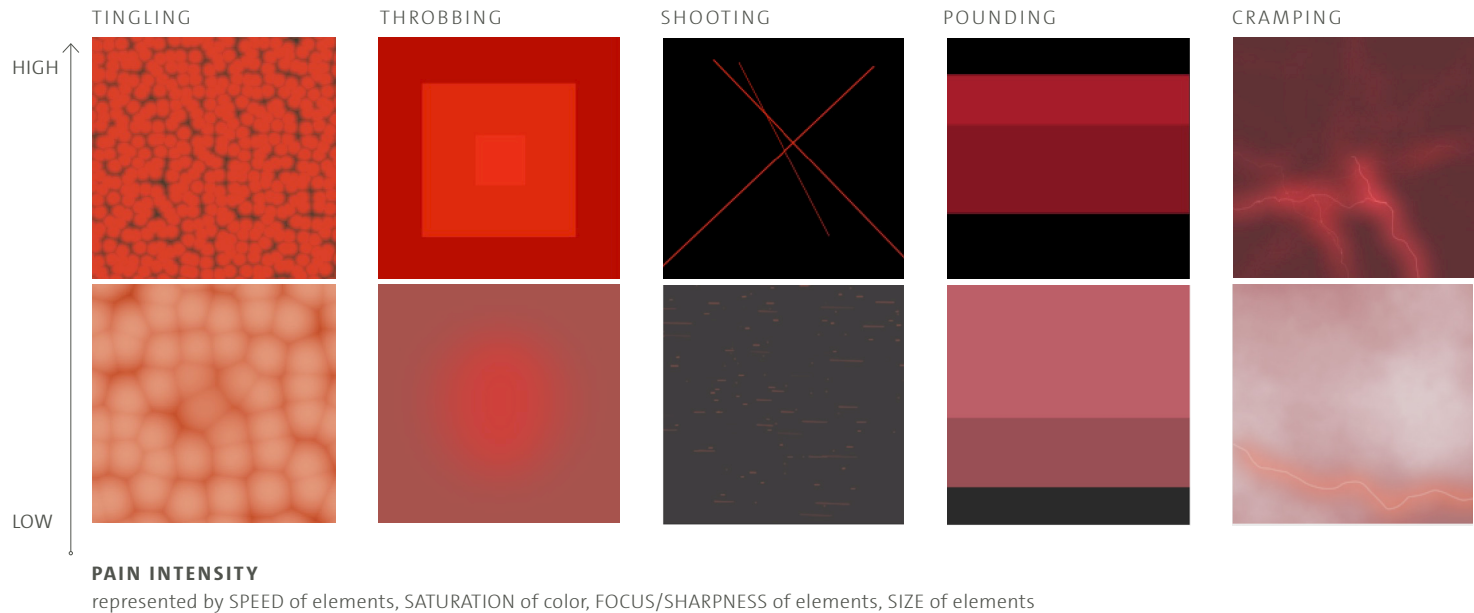


## GENERATIVE INVESTIGATIONS DRAWING EXERCISE

### DRAWING EXERCISE — ANALYSIS

This study informed the total set of animations which I created. First, I created low-medium intensity versions for the initial three animations (throbbing, cramping and shooting). Next I created two new animations (pounding and tingling), with a high and medium each. These two words came from the original list and were created to provide more variety into the animations to allow for a range of responses.

The full set is below (*Figure 8*). Ideally these would have been coded (allowing for a workable slider) which would change the intensity of each animation from medium to high. However due to time constraints they were created in After Effects and the effect of a slider was simulated (by toggling the slider between the two states) in the prototyping application InVision.



**FIGURE 8**  
FULL SET OF ANIMATIONS

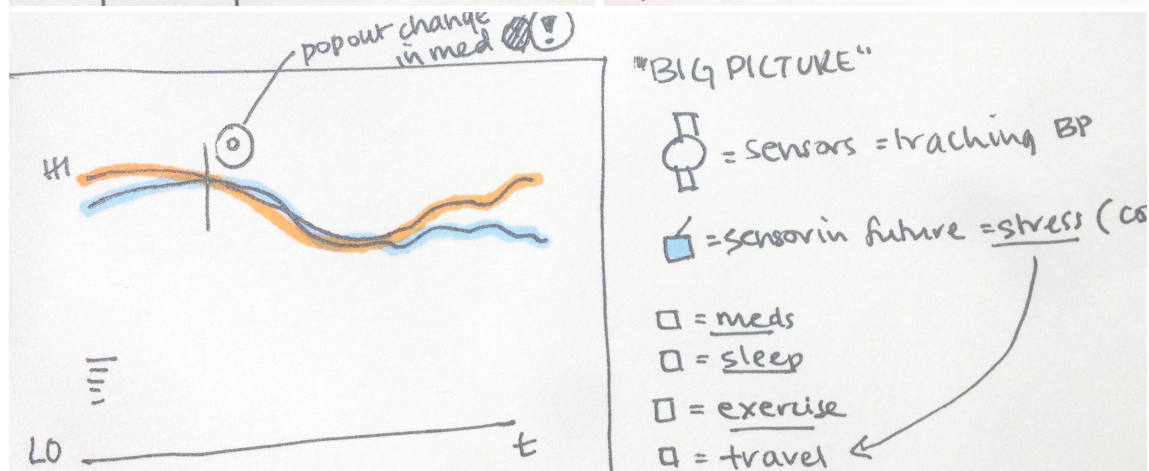
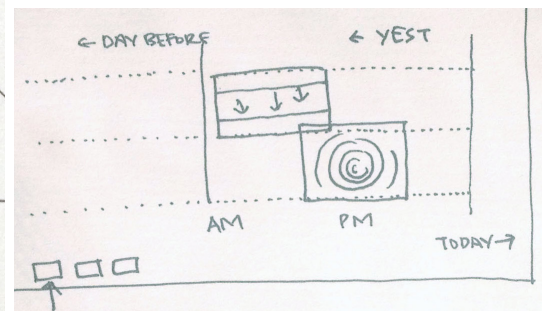
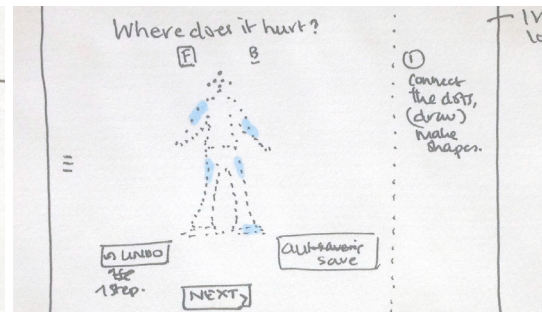
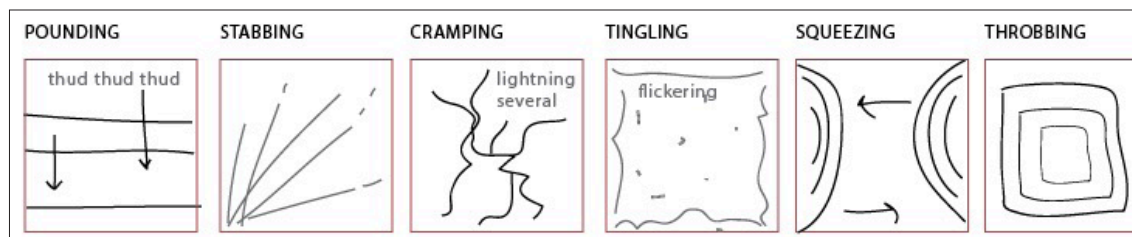
# Evaluative Investigations

The background is a solid red color. Overlaid on this are several thin, dark lines that intersect at a single point located in the upper right quadrant. These lines create a star-like or web-like pattern across the right side of the image. The lines vary in orientation, with some being nearly vertical and others being more diagonal.

In this phase of evaluative testing, I worked with a new set of participants to assess the animations as well as the context of use. Although this project was not meant to go too far into the realm of interface design, I created basic wireframes for the animations, in order to provide context for the animations. These went through one round of iteration.



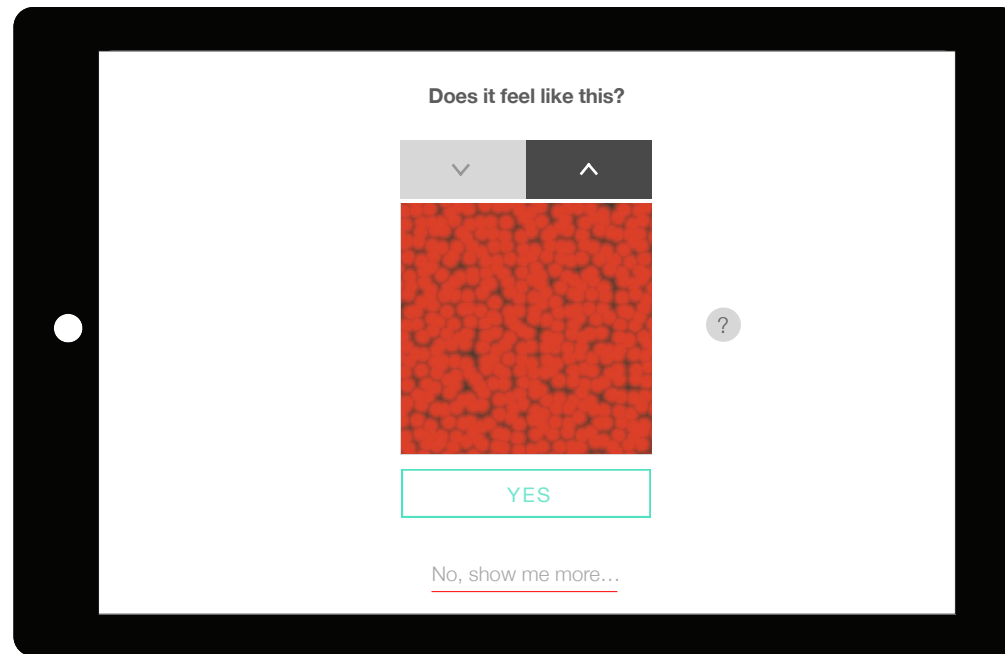
# EVALUATIVE TESTING WIREFRAMES SKETCHES



EVALUATIVE  
TESTING  
THINK ALOUD  
PROTOCOL:  
5 PARTICIPANTS

## PHASE 1: CHOOSING A QUALITY

For choosing a quality, you see one of the animations, and you cycle through to choose which one you want. Arrows indicate you increase and decrease the intensity.



### PARTICIPANT RESPONSES

- Wanted to see the whole set of animations so they know how many choices they had
- Would prefer for the intensity to be depicted through a slider
- Would prefer to have the text visible instead of having to click on the question mark

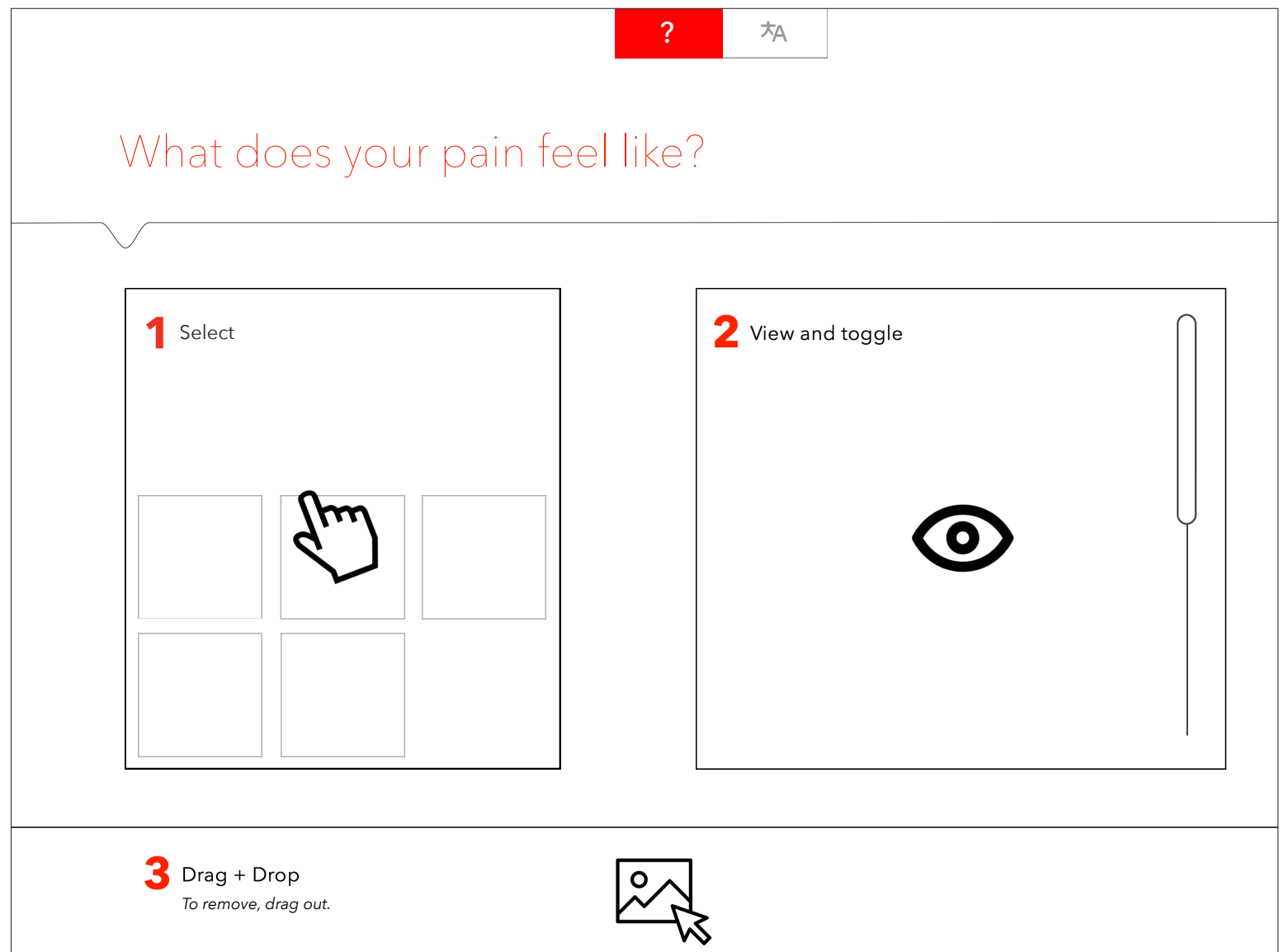
### RESOLUTION

- Create an instruction page (preceding the animations) that would walk them through how to choose the animations and increase and decrease the intensity
- Show thumbnails of all animations on each screen, with textual description
- Replace arrows with slider, and make slider prominent
- Since the user needs feedback after making their selections, create a panel at the bottom where the chosen animations can be dragged and dropped

## EVALUATIVE TESTING

### PHASE 1: CHOOSING A QUALITY

Instructions screen





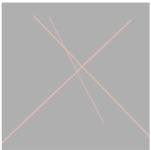


## EVALUATIVE TESTING

### PHASE 1: CHOOSING A QUALITY


?

★


What does your pain feel like?




Pounding



Add at least 2.



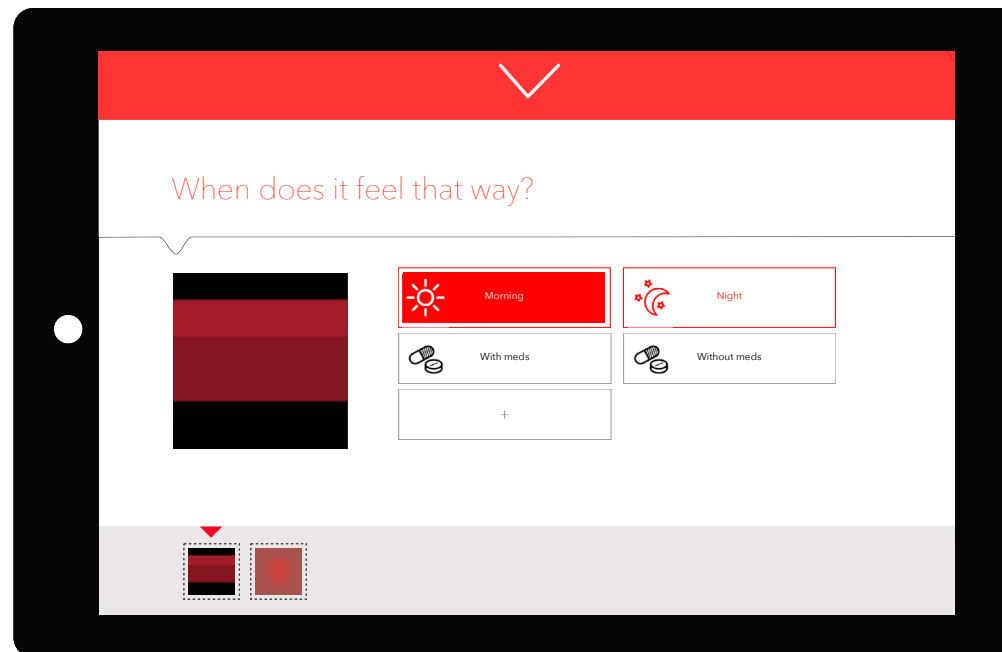


## EVALUATIVE TESTING

### PHASE 2: ADDING CONTEXT (A/B TESTING THINK ALOUD)

This step of the application would happen after a user has chosen their qualities. Using the same content, two options were presented. The goal of this part is for participants

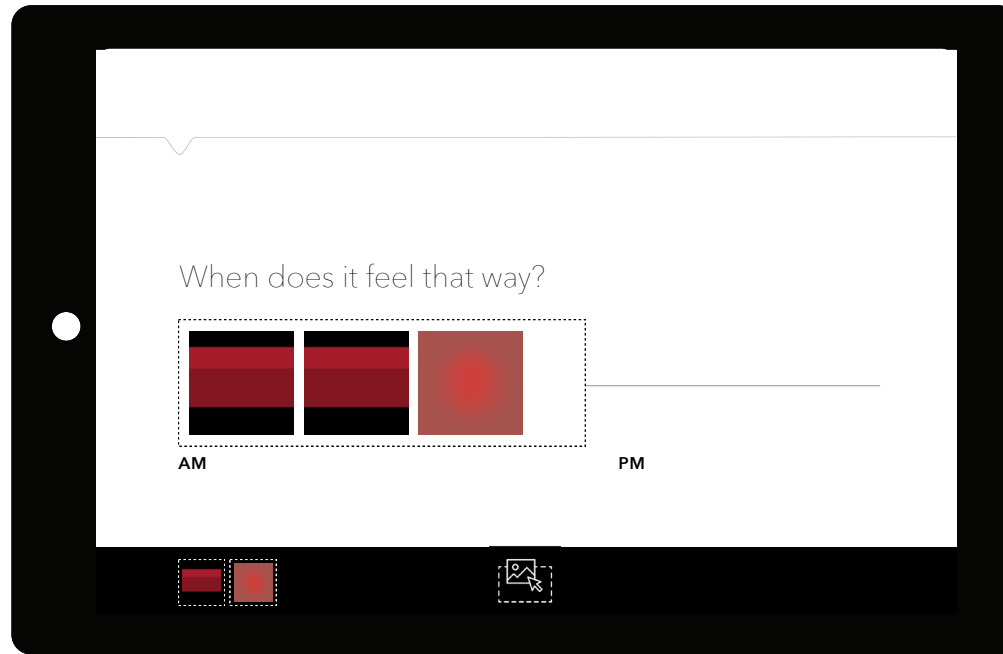
to create and share (with their clinician) an understanding of their pain with relevant context, *over time*.



### OPTION 1: TAGGING

Participants see their chosen animations on the next screen, and tag it with relevant time based and contextual information, such as “morning” or “without medication” and also have the option to create their own tags such as “when applying pressure.” They would do this for all the animations they have chosen and could go back and add more animations with tags. Though the screen that follows this one is not designed; it would function to provide further context to the chosen animations.

## EVALUATIVE TESTING



### OPTION 2: SELECT TIME PERIODS

Participants see their chosen animations on the next screen and adjust the widths of the animations, to represent how pain changes during the course of the day. If one type of pain (quality and intensity) occurs multiple times, then one would create copies. Additionally, the tagging system for other information such as medication could also be incorporated into this version.

### PARTICIPANT RESPONSES

- Participants found it easier to use Option 1
- Option 2 felt a bit too overwhelming to use because you had to think about times of days on the timeline rather than just saying, "morning" (like in Option 1)
- However, Option 1 could also get complicated and confusing with too many choices.

### RESOLUTION

In order to make Option 1 easier to use, determine the best contextual information (whether it is time of day, or medication) and limit the number of choices

## EVALUATIVE TESTING

### PHASE 3: FINAL SET OF ANIMATIONS

The general question was *how effective do you think this tool (choosing a quality and adding context to it) is in aiding your pain communication?* The participants were a group of 5 people who were different from the ones involved in the drawing exercise and survey. This round of evaluation was carried out in a modified version of the think aloud protocol. *Below are themes which responses were clustered into:*

#### POSITIVES

##### REPRESENTATION

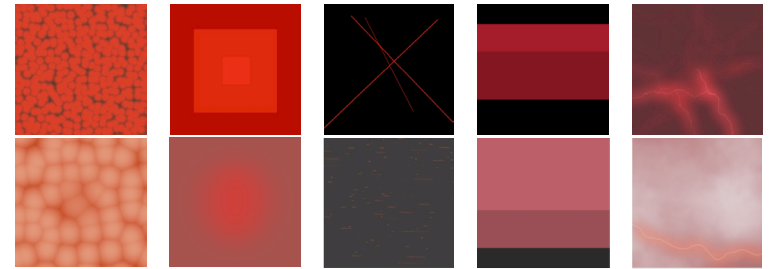
- The animations continue to resonate with patients. Participants would look through them, chose one or two and say:

*“This one really feels like my headache, exactly!”*

- Other general comments about the idea itself:

*“These animations feel like the aha moment for me. Hopefully doctors will see it soon, too.”*

*“Just knowing that doctors are asking us this question with a tool that comes closer to what we’re feeling, shows that they are being empathetic and less dismissive.”*



#### LIMITATIONS/CHALLENGES

##### RECALL

Participants expressed concerns about how they would know what they chose last time, and how to understand the differences between the two:

*“If the doctor said, last time you were here you chose this animation, it would take me a while to assess what level that one was, and then decide how I felt about it now. Even though the numeric system is terrible, it is quickly understandable in this case – for example, if the doctor says last time you said 8, what would you say now, I could say 9 if it is more than that, or 7 if it is less than that.”*

##### RESPONSE

Whether, how, and how well, the visual system carries over into the numeric system is an aspect of the project that will need further rigorous investigation. It is entirely possible that a solution would be reached but as of now this remains one limitation.

## EVALUATIVE TESTING

### SIMILAR PROBLEMS AS NUMERIC SCALE

While patients acknowledged the benefits of seeing something more qualitative and contextual, they were also concerned about the limitations of the current system:

*What is to stop me from getting frustrated with this system in the same way that I currently get frustrated with the number system (wanting to increase the value of the slider to more than what is possible?)*

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### RESPONSE

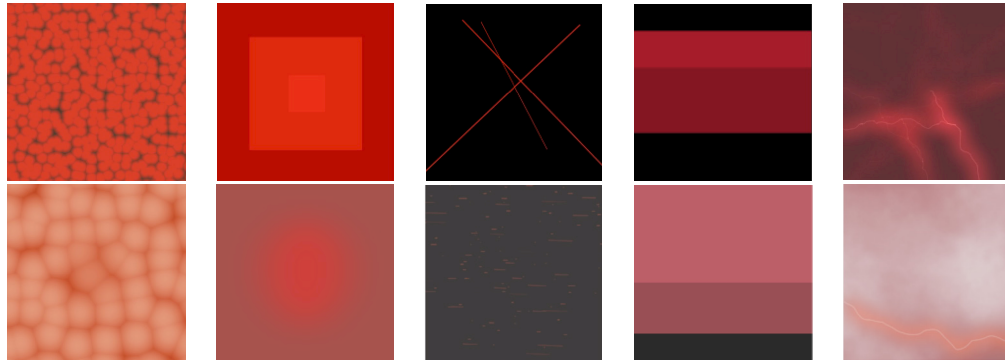
To address this concern, the slider could be built to seemingly go on 'forever', while reaching a cap (max) on the number it shows the clinician. The animation could also seemingly keep increasing in the quality of speed for example. However, this would have to be within possibility, and need to be tested.



EVALUATIVE  
TESTING  
WITH 4  
CLINICIANS  
+ RESEARCHERS

## FINAL SET OF ANIMATIONS (THINK ALOUD )

The general question was: would something like this work?  
Why or why not? Below is the main concern of the clinicians:



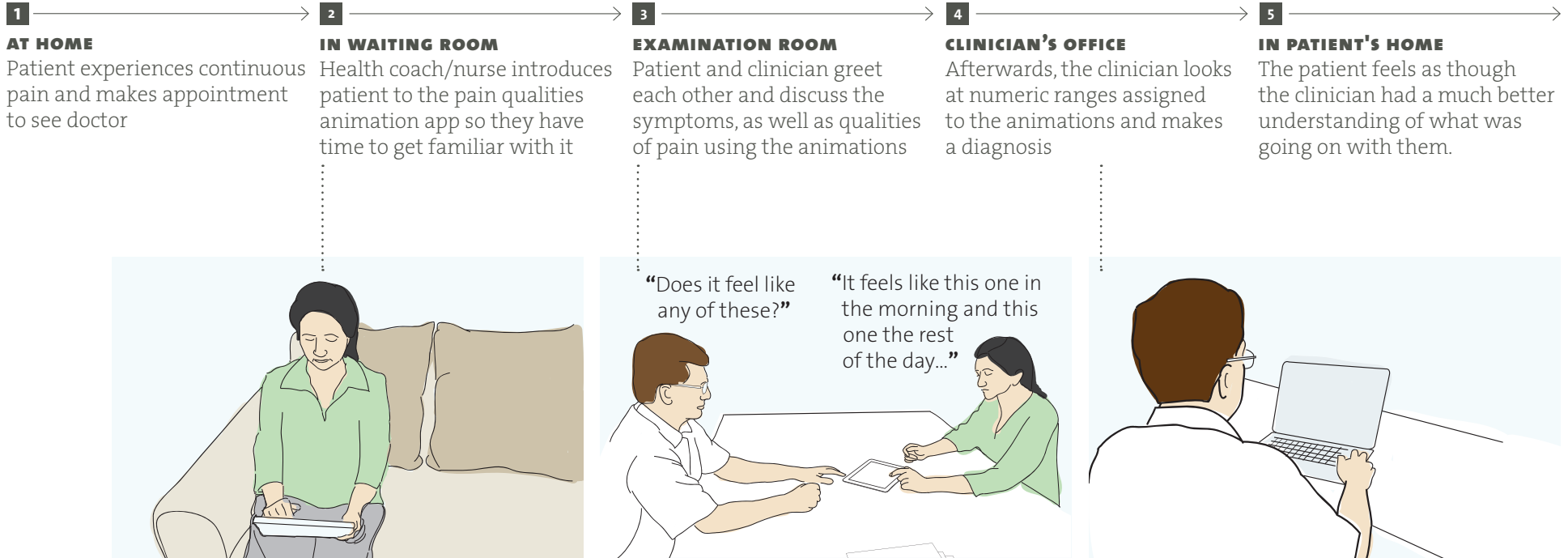
## TRANSLATION

These animations would need to go through several rounds of repetitive testing (with a test group and a control group) in order to develop reliable and credible numerical correlations (e.g. a particular animation calibrated at a certain level by a patient using the slider, equals an 8).

## CONTEXT

## SCENARIOS

The final design evaluation reveals several possible areas for refinement and development. To conclude this round of investigation, here is a look at the scenario in which this tool will be used.



## CONCLUDING GENERAL RECOMMENDATIONS

While clinician training (and focus on empathy) differs from institution to institution (and is influenced by personal clinician style) from a communication design perspective, this project sheds light on patient-centric principles which will improve the quality of the tools and service provided to patients or the customer:

### 1 *Level the playing field*

While there are complicated power dynamics between a patient and a clinician, it is in the patient's best interest to see visuals and language which are on a level playing field – and which provide a tool upon which to build conversation. As evidenced by this project, providing something that is removed from medical jargon or systems (which were not designed from a patient-centric perspective) allows patients to express themselves comfortably, knowing that their comments are valued, heard and hopefully understood.

### 2 *Patient endures, doctor interprets*

While clinicians have reason to be frustrated with difficult patients, it is important for them to remember that pain is a subjective and personal experience, which warrants adequate attention. It is important for clinicians to always remember that while they may see 100 patients a day, for that one patient, this is the one chance they have to speak with a professional, and hence they should be treated with utmost respect. Several general recommendations already exist in the realm of language guidelines to be used while talking with patients. This is to say that since conversation is a large part of the assessment, respecting the intelligence of the patient without pandering or dumbing down the conversation is essential. Further, any tools that are used to aid the conversation should be easy to understand and follow, without adding further frustration to an already difficult experience.

## FUTURE WORK

Limitations of current scope and approach:

### 1 *Specific patient populations (and chronic conditions)*

How particular pain characteristics (conditions) might influence the further development of alternate methods (including this one) needs to be considered.

### 2 *Emotion and stress*

While some assessment forms do ask about emotion and stress, these animations do not explicitly incorporate those elements (which is a vital component of the experience).

### 3 *Immersion*

While these animations have proven to have resonance with participants in this study, there is much to be done to develop them further. For example, a doctoral project at the Norwegian University of Science and Technology in Trondheim is exploring how virtual reality can help nurses develop and sustain their empathy (as clinicians becoming desensitized is a reality. It simulates morning sickness (nausea and dizziness, for example) through a headset that nurses wear. In relation to this project it could be said that these animations could go much further in recreating the nausea or disorientation that pain patients would experience.

## SUMMARY

My thesis looks how at patients and clinicians negotiate the act of assessing something qualitative into something quantitative and whether an alternate method is desirable and feasible. Through a combination of exploratory and generative investigations, I drew out opportunity areas in which a human-centered design process could intervene to first understand and then help patients in their endeavor to communicate their pain. The primary scope of the project was addressing the finding that patients struggle with expressing their pain to clinicians on static forms asking them to estimate their pain intensity on a scale of 0-10. The solution, the expressive pain animations, aims to improve the communication between patients and providers through the use of a patient-centric pain assessment tool. Instead of the standard 0-10 scale, patients are provided with a selection of animations that they can use to describe the quality and intensity of their pain. The animations can be increased and decreased in speed or color saturation to reflect the pain intensity.

It was my goal and attempt to provide some insights into aspects of pain communication that seem to be lost, forgotten or seldom discussed. The participant investigations were extremely insightful in bringing to light the unique needs of those in pain. Overall I believe this project opens the doors for designers to explore alternate means of pain communication. Through my investigations, I uncovered a vast array of unique design opportunities and implications that make this topic a contextually rich area to explore. Patient centric care is being considered more and more important and the proliferation of mobile technologies expands opportunities for innovation.

This thesis was an extremely challenging one for me, entering the world of clinical care and designing for a special set of users. As designers, it is easy to get caught up in creating different features and focusing on the details of an interface, but the design process throughout the year taught me several important lessons about designing through a human centered process, and for pain communication specifically.

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