

**myWeekInSight: Visualizing Personal Data for Chronic  
Pain Management through Youth-Centered Design**

by

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The following individuals certify that they have read, and recommend to the Faculty of Graduate and Postdoctoral Studies for acceptance, the thesis entitled:

**myWeekInSight: Visualizing Personal Data for Chronic Pain Management through Youth-Centered Design**

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# Abstract

Chronic pain is a common and costly condition in youth. 20-30% report recurrent pain that is not disabling, but still interferes with academic, social, and recreational functioning, and has significant effects on mental health (e.g. higher rates of anxiety, depression, and post-traumatic stress symptoms). Existing digital applications to help patients self-manage chronic pain often report low engagement and typically focus narrowly on either symptom tracking (emphasis on user providing data), or intervention delivery (translating an in-person intervention into a digital format).

We hypothesize that if youth with chronic pain could actively explore data from their lived experiences, they could better relate their symptoms to other areas of their lives and improve their general functioning. Our approach novelly uses interactive visualization of self-reported data as an intervention. We contribute design principles for engaging youth-centered visualizations of personal health data, and discuss metrics that can be used to measure their efficacy. Both were derived through the development of *myWeekInSight*, a visualization-based web application for teens to interactively explore personal health data, using data collected via thrice-daily surveys (Ecological Momentary Assessments) to capture in-the-moment a youth's everyday circumstances, symptoms and experiences.

We developed these visualizations iteratively with guidance from pediatric chronic pain clinicians, a patient partner, and experts in information visualization and human-computer interaction. We evaluated them in two phases, both with members of the target population: (1) design evaluation (N=10): assessment of comprehensibility, usability, and engagement through semi-structured interviews and question-

naires, followed by a qualitative analysis using affinity diagramming; and (2) utility evaluation (N=50): through a 2-week clinical deployment of a fully-functioning prototype developed in collaboration with a health tech firm, followed by semi-structured interviews and questionnaires with a subset of the participants (N=10) analyzed using affinity diagramming. Youth found the visualizations to be reflective of their experiences, interesting and useful, and were able to extract actionable insights; they also confirmed their interest in using the application in their daily lives, and described possible usage scenarios. We close by discussing our learnings from the evaluation studies, and implications for next steps.

# Lay Summary

Chronic pain is a common, costly condition in youth, with many reporting pain that is not disabling yet interferes with their academic, social and recreational functioning as well as impacts their mental health. Existing digital applications for self-management of pain report low engagement and typically focus on either only symptom tracking, or digital intervention delivery.

In this thesis, we study the potential of interactive visualizations of personal health data in engaging youth in the self-management of their pain. We designed and evaluated a two-week deployment of a survey and visualization-based application for teens with chronic pain, obtaining their feedback on our designed visualizations and usage scenarios. Youth found the visualizations to be reflective of their experiences, interesting and insightful, and also confirmed their interest in using the application in their daily lives.

# Preface

All the work done in this thesis was a collaboration between different groups and teams, including the SPIN lab at the University of British Columbia (UBC) and the Oberlander lab at BC Children’s Hospital and Research Institute (BCCHR). We use the pronoun ‘We’ throughout to refer to the collaborative nature of the work done, referring to Dr. Karon MacLean (co-supervisor), Dr. Tim Oberlander (co-supervisor), Dr. Katelynn Boerner, Dr. Tamara Munzner, undergraduate student and research assistant with the SPIN lab Haley Foladare, and me, who made up the core team. However, over the course of the project, there were several significant contributors in different areas, who we wish to acknowledge in the relevant chapters. Thus, below, we detail work done per chapter to show individual efforts and areas of expertise.

In Chapter 3, we discuss the work done as a part of the Designing for People (DFP) course (CPSC 554K) at the University of British Columbia, where the ‘we’ refers to the collective team, specifically team members Katra Farah, Devarsh Bhonde, Haomiao Zhang, Rubia Guerra, and myself, with equal efforts from each team member.

In Chapter 4, we discuss the iterative design and development of the visualizations. While I was the intellectual lead on the design and development of the visualizations, we collaborated heavily through multiple cycles of feedback and revisions on the visualizations. Dr. Munzner guided the visualization process, Dr. MacLean supervised the Human-Computer Interaction (HCI) aspects, while Drs. Oberlander and Boerner provided clinical expertise.

In Chapter 5, we discuss the first evaluation study. The interviews were conducted primarily by me, while Foladare assisted in transcribing. I led the qualitative and quantitative analysis process, with Foladare assisting as a secondary researcher. Recruitment for the interviews was conducted by Marie-Noelle Wharton, a research assistant with the Oberlander lab. Discussions and design iterations and decisions were taken collaboratively, with Drs. Munzner and MacLean guiding the design and visualization aspects while Drs. Oberlander and Boerner provided clinical guidance.

In Chapter 6, where we discuss our collaboration with healthtech firm CareTeam, I was the primary collaborator from the UBC/BCCHR team for the design iterations and collective work. For the clinical study, Jessica Luu and Marie-Noelle Wharton were the primary recruiters and administrators, while Foladare and I oversaw the participation of only the interviewed subset of participants. The design study interviews were primarily conducted by me, with Foladare leading the transcribing and cleaning process. Qualitative and quantitative analysis of the results was led by me, with Foladare being a secondary researcher on the same.

Research was conducted under the University of British Columbia's Children's and Women's Research Ethics Board (CREB), certificate #H20-02965: Remotely delivered data collection in youth with chronic pain: A pilot study.

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# Abbreviations

<b>ADHD</b>	Attention Deficit Hyperactivity Disorder
<b>ASD</b>	Autism Spectrum Disorder
<b>BCCHR</b>	BC Children’s Hospital Research Institute
<b>DFP</b>	Designing for People , human-centered design research cluster at UBC
<b>EHR</b>	Electronic Health Record
<b>EMA</b>	Ecological Momentary Assessments
<b>HCI</b>	Human-Computer Interaction
<b>JPEG</b>	Joint Photographic Experts Group file extension
<b>MARS</b>	Mobile App Rating Scale
<b>PDF</b>	Portable Document Format
<b>PNG</b>	Portable Network Graphics file extension
<b>RTDC</b>	Real-Time Data Capture
<b>SMS</b>	Short Message Service
<b>SUS</b>	System Usability Scale
<b>UCD</b>	User-Centered Design
<b>UEQ</b>	User Experience Questionnaire

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Finally, to my friends and family, who have often believed in me more than I did myself, thank you for your love and laughs that kept me going through the many late nights.

# Dedication

*To my parents, **Mayur** and **Gracie**, my strength and my joy,  
everything I am, I owe it to you.*

*And to **Buddy** and **Coco**,  
who continue to teach me to find happiness in the mundane.*



# Chapter 1

## Introduction

Personal health informatics has been a growing field over the last decade, with the pervasiveness of mobile and wearable technology allowing us to obtain more in-the-moment information about various aspects of our life, like sleep, physical movements and stress levels [71] than ever before. This has enabled users to reflect and learn more about their lifestyle and bring about self-motivated changes, as well as monitor the impact of those changes [39].

Within the field of personal informatics, visualizations play a major role in presenting the data back to the user in understandable formats, showing trends and outliers. Such visualizations require careful design, and are often geared towards the aspects they represent, with many even becoming recognizable globally, for instance the Apple Health sleep and fitness rings [8]. These visualizations, in the form of charts and graphs, are an excellent way of representing complex time-series data in a concise, user-friendly form, and can be designed and leveraged for different demographics.

We look at this potential of self-management from a chronic pain perspective, especially in a pediatric population. This is a population that needs continuous medical care and tracking, which is often not possible and has been especially exacerbated by the pandemic, and hence, tools that can encourage self-monitoring and management of their pain can be extremely helpful. We believe that if youth are able to reflect on their own personal health data in a youth-focused format, it can enable them to extract actionable insights, better understand how their pain

connects to other aspects of their lives, and improve their general functioning.

## **1.1 Motivation**

### **1.1.1 Obstacles to Youth Understanding and Managing their Chronic Pain**

Chronic pain is a common and costly condition in youth, which affects multiple spheres of their daily lives - their emotions, physical activities, sleep and social interactions. The subjective and individualized nature of chronic pain can further make it an isolating experience, affecting the patient's mental health. Thus, youth with chronic pain are in need of specialized personal healthcare that encompasses a holistic perspective.

For instance, consider Eleanor, who suffers from chronic stomach and back aches, and would be an archetypal user of the kind of visualization tool that we propose. Her symptoms, along with others like dizziness and nausea, occur multiple times a week, sometimes multiple times within a day. The intensity of these symptoms is varied, ranging from minimal to maximum pain. Her symptoms end up affecting her emotions, and she is constantly anxious about her health. Her school attendance is disrupted by days she needs to stay home due to pain, or days she needs to visit her doctors. This then affects her interactions with her peers, which consequently affects her emotions and perceptions about her interactions further. Eleanor's persona is based on the experiences patients shared during our second round of design evaluation interviews, and offers an inside view of how complex youths' experiences are and the need to be able to record that.

Or consider Johanna Young's account of how a chronic pain diagnosis affects her son, daughter and their lives [98]. Young talks of the day her son got diagnosed with Hypermobile Ehlers Danlos Syndrome (h-EDS) at age 9 in 2015, the importance of getting a diagnosis to explain the multitude of symptoms including daily dislocation, headaches and anxiety among others, and the impact the diagnosis had on their entire family. Young highlights how chronic pain becomes a part of their lives - "The kitchen counter is filled with medication, school calendars are constantly interrupted by medical appointments, mornings aren't just hard because

teenagers don't like waking up but because they are waking up with dislocations and migraines while preparing to go to school." - while also highlighting what has helped them the most - a balance of clinical, physio and mental therapy. In 2018, Young's daughter was diagnosed with the same condition, and later had the opportunity to present at a medical conference a youth perspective on living with chronic pain - her daily challenges, her perspective, and what she felt clinicians needed to know about a kid with chronic pain, from a kid with chronic pain. Young stresses the importance of having clinicians believe kids even when their pain is invisible, and recording their experiences outside of labs and hospitals is the first step towards that goal.

Youth aged 19 and under also represent a special demographic - one that is in higher need of guidance and support than an adult population, given their age. For such youth, things are further complicated by their susceptibility to their circumstances - social interactions and school can cause additional stress, emotion regulation might be tougher than it would be at a later age, and communicating with caregivers and clinicians, and recording their physical symptoms accurately and consistently, can be a challenge. Holistic clinical care is thus pivotal to their well-being.

Under current circumstances, delayed access to healthcare leads to communication gaps with healthcare providers, affecting the quality of care administered [34]. This has been further exacerbated by the COVID-19 pandemic [65]. Patients are also prone to *recall bias* [74, 91] (where memories of the event are altered due to the time passed between the event and recollection of the event) which only worsens over time, which results in inaccurate data and subsequently, less effective therapy. Thus, it becomes important for youth to record their own data on a more frequent basis outside of clinics, so clinicians can use it for reference on their visits.

Recording these aspects of the youths' lives outside of clinics and lab tests provides a 'bigger picture' - being able to see how their pain affects other aspects of their lives better equips clinicians to treat them. However, current methods like binders and journals often end up having inconsistent or missing data points, and existing pain tracking apps fail to capture data about other aspects of the youths' lived experiences like sleep and social interactions. Thus, there is no mechanism for youth to be able to reflect on how these aspects intertwine, which limits their

understanding of how impactful their physical symptoms actually are. These recording mechanisms end up being inefficient, and hence there exists a need for a holistic self-monitoring mechanism that enables patients to record their data in-the-moment, and is personalized for their needs.

### **1.1.2 Actionable Insights from Personal Health Data**

While recording and tracking data is an important aspect of enabling better self-management and treatment of chronic pain in youth, empowering them to being able to extract actionable insights from their data is just as important.

As Frank Bruni mentions in an interview with the Washington Post, “*You are never anything near the kind of priority to them [doctors] that you are to yourself, because you are your only priority*” [6]. Given the current status of the healthcare system - long wait times, extended periods between clinical visits, and lack of doctors [2, 14], giving patients the ability to understand their data and find ways to self-manage their symptoms outside of clinical visits can be empowering and incredibly useful.

The insights and knowledge a patient would have about their own health and lived experiences are important to record, and crucial to enable them in the self-management of their symptoms. However, designing applications to enable them to extract these insights is challenging, given the intricate differences between simply presenting the data as opposed to presenting it in a way that allows reflection and insights. Existing applications show a variety of ways to present patient information, but few enable reflection and comparison.

### **1.1.3 Use of Personal Health Informatics for Chronic Pain**

Personal health informatics can be used for the purposes of recording and managing data, and to that extent, there already exist multiple applications in the market, however few cater to the needs of this population.

While existing mobile applications like Daylio [13] and Moodily [23] help track mood and stress, they aren’t designed considering the needs of younger patients with complicated health issues. Other apps like manageMyPain [20] and mi-

graineBuddy [21] help track certain symptoms for adult chronic pain patients, but are not designed to take into account the different additional aspects for a younger population like school and peer interactions. These applications are also not stylized to be specially understandable by younger populations, using complex graphs and user interfaces.

Thus, while there are applications in the market that allow users to track certain aspects of their lives, and enable reflection and self-management, they miss taking into account aspects specific to these populations. Our goal is to enable youth with chronic pain to reflect on their daily lives experiences, and gain insights on how their pain impacts other aspects of their lives, thus creating scope for self-management outside of, but guided by, clinical care.

## 1.2 Research Questions

Our primary research objective was to explore the potential of data visualizations as a treatment intervention for youth with chronic pain. To that end, we aimed to answer:

1. How does equipping youth to reflect and interact with their own data affect their understanding of their pain and its connection with other aspects of their lives?  
Specifically,
  - (a) How can visualization be used to empower users to extract actionable insights from their data?
  - (b) How can such visualization methods engage youth in self-reflection and interactions with their data?
  - (c) How can data visualization be leveraged to reflect a holistic view of users' lives and their daily experiences in an accurate and youth-focused manner?
2. What design guidelines and practices will produce data visualizations targeted to the special population of youth with chronic pain?

- (a) What are the differences between existing guidelines for visualizations and designing visualizations for younger populations?
  - (b) What additional guidelines are required for this specific demographic of youth with chronic pain?
  - (c) How can we design to show huge amounts of chronological data in a way that enables quick reflection and engagement?
  - (d) How can we design visualizations that enable cross-comparison and highlight connections between them?
3. How can we best evaluate visualizations for this specific demographic?
- (a) What current metrics exist to measure the efficacy of data visualizations?
  - (b) How can we best evaluate the efficacy of our designed visualizations and how might that be different from existing evaluation methods?
  - (c) What are the most suited metrics to evaluate our designed visualizations?

## **1.3 Approach**

Our approach to achieve our goals was two-fold:

### **1.3.1 How can we best represent youths' holistic lived experiences?**

To this end, we began by interviewing various stakeholders to gather initial requirements for such an application. We spoke to clinicians, teens and adults with past experience of chronic pain, designers and Human-Computer Interaction (HCI) experts. Based on insights from these interviews, as well as literature reviews, we designed multiple versions of visualizations.

Throughout the design process, we iterated over the design of the visualizations in multiple rounds, with constant guidance from HCI and visualization experts, as well as continuous collaboration with clinical experts. We integrated existing visualization guidelines, while also focusing from a clinical perspective, to design

visualizations that were engaging and youth-focused, yet useful to clinicians and youth alike.

We also collaborated with a healthtech partner (startup firm CareTeam [10]) to deploy the Ecological Momentary Assessments (EMA) and visualizations in a fully-functional application so we could evaluate their impact through a longer, in-the-wild study. This involved close collaborations with the CareTeam development team.

### **1.3.2 How can we best evaluate our designed visualizations?**

We evaluated the visualizations in two phases. The first was with a limited clinical population, and the second was as a part of a larger, longitudinal clinical study. Access to both participant pools was facilitated by our collaboration with the clinicians at BC Children's Hospital Research Institute (BCCHR), specifically in Complex Pain Services.

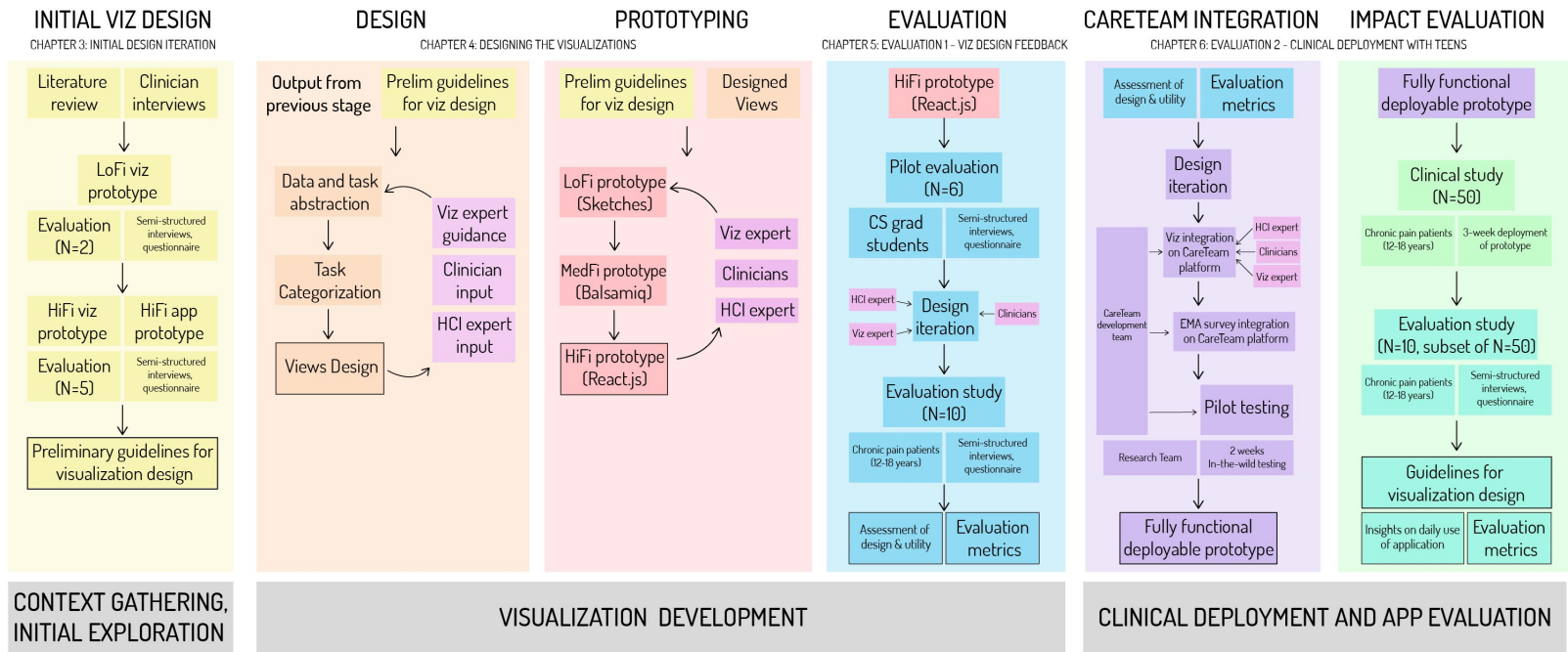
First, using a final version of the visualizations, we created prototypes with sample data and tested them with 10 youth with chronic pain, through semi-structured interviews and questionnaires. The purpose of this round was to assess the feasibility and design of the visualizations.

Second, towards the end of a longitudinal clinical study, where 50 youth used the CareTeam prototype over a period of three weeks, we interviewed a subset of 10 at the end of the study. Through this round, we aimed to gain insights on the reliability and usability of the visualizations and application, once youth had a chance to use them and see their own data visualized over a period of time.

In both these phases, we used a combination of interviews and questionnaires to gather quantitative as well as qualitative feedback on the design and impact of the visualizations. We evaluated the design and impact through metrics in the questionnaires such as Utility, Understandability, Interest and Accuracy. These metrics, as opposed to more standard metrics for visualization evaluation like usage metrics or performance statistics of the application, gave us more concrete feedback on the design and impact of the visualization tool. Our semi-structured interviews further gave us insights and unique perspectives from our participants regarding the feasibility of such a tool, and were corroborated by the questionnaire results.

Figure 1.1 lays out the design process overall for this project, detailing the design and evaluation phase, and highlighting the different stakeholders during each phase.





**Figure 1.1:** The overall design process, highlighting the different stages and stakeholders involved at each stage, with black-border boxes showing the output of each stage

## 1.4 Contributions

In this thesis we contribute:

1. A set of design guidelines for personal health data visualizations adapted for youth with chronic pain and highlighting engagement

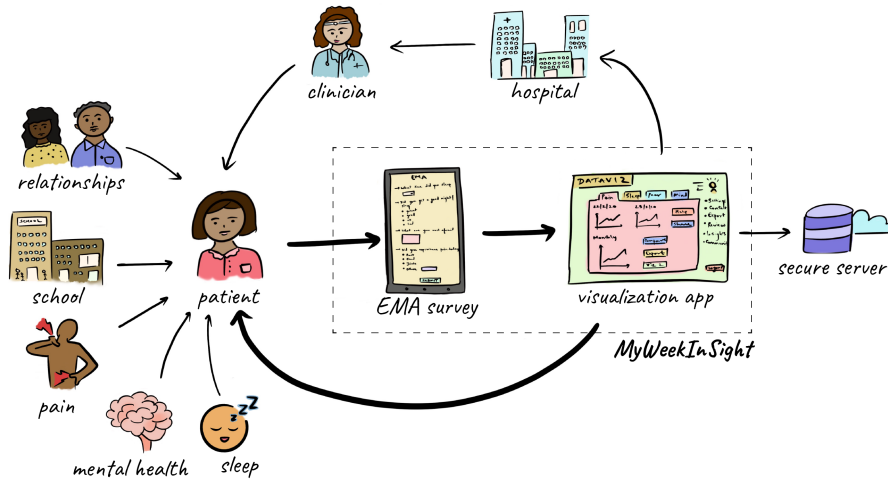
As we prototyped visualizations of personal health data and evaluated them with youth with chronic pain, we adapted existing visualization design principles for this population, which can be used by future researchers to create engaging and accurate visualizations for youth with chronic pain. Some of these principles are reflected in the designs, while other insights for the adaptation emerged from interviews with various stakeholders through the course of the project. We specifically detail them in Chapter 7, although they emerge through the design process discussed in Chapters 3 and 4, and through the evaluations in Chapters 5 and 6.

2. Metrics for evaluating visualizations designed to reflect personal data for self-management of health.

We discuss the evaluation metrics used to gauge the accuracy and usability of the visualizations in Section 5.1.2 and 6.3.2. These metrics were derived based on previous work in qualitative evaluation of visualizations and existing design evaluation metrics. We discuss why these metrics are appropriate for the evaluation of our visualizations which reflect personal health data, and how evaluation of similar visualizations can be based on similar metrics for qualitative feedback.

3. Insights on the design, deployment and use of a visualization-based web application for youth to self-manage their symptoms and explore their personal health data

We designed and deployed *myWeekInSight* (Fig. 1.2), a visualization-based web application, with youth with chronic pain, in a three-week clinical study, followed by interviews with a subset of the youth to gather feedback on the feasibility and usability of the application. We detail the study and results in



**Figure 1.2:** The *myWeekInSight* application conceptual model, showing its integration with the various aspects of a young chronic pain patient’s life

Chapter 6, where we discuss feedback on the prolonged use of the application - features and aspects that were liked by youth, improvements that could be made, and overall insights on the use and merits of a self-management tool for chronic pain by adolescents in their everyday lives.

We also discuss the impact and challenges of engaging youth with their personal health data, and the consequences of the same for them, their caregivers and families.

## 1.5 Thesis Organization

This thesis is divided into several chapters; here we briefly summarize what each chapter covers:

In Chapter 2, we discuss similar work done in this domain. We talk about existing methods for chronic pain management, user-centered design of self-monitoring applications, and the current status of data visualization in healthcare. We high-

light gaps at the intersection of these domains that we aim to address through our research.

In Chapter 3, we discuss the foundation laid for this project as part of the graduate course Designing for People Project (CPSC 554K) at the University of British Columbia. We cover initial stakeholder interviews and a preliminary design iteration that laid the ground for future iterations.

In Chapter 4, we present the iterative process of designing the visualizations. We discuss low and high fidelity versions of the visualization prototype, and highlight important design decisions.

In Chapter 5, we discuss the evaluation of the visualization design, through a preliminary pilot, and then a study with N=10 youth with chronic pain. We highlight our findings and resulting design decisions that are incorporated in another design iteration.

In Chapter 6, we discuss the impact and usability of the visualizations, post a three-week clinical deployment of the visualizations as a web-based application. We talk about the integration of the visualizations on the CareTeam platform and the clinical study as well as post-study feedback interviews with N=10 youth with chronic pain.

In Chapter 7, we summarize key findings from both phases of evaluation, and discuss resulting guidelines and implications for designing for this population. Finally, in Chapter 8 we discuss the limitations and future directions for this research.

## Chapter 2

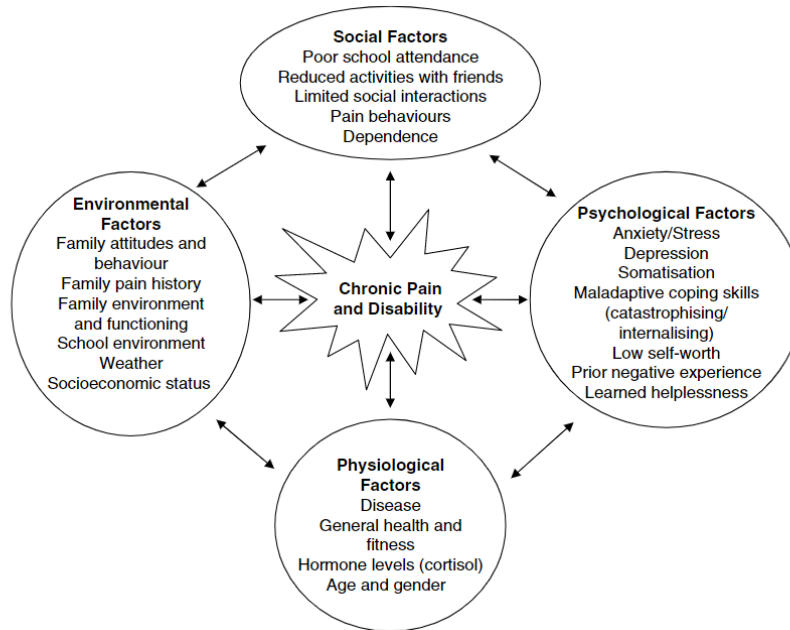
# Related Work

In this section, we discuss previous work done at the intersection of chronic pain and personal health informatics, and how our work builds upon those. We provide an overview of what chronic pain is, how it affects adolescents, current pain management applications and techniques and discuss their shortcomings or ways in which our approach builds upon them. We also discuss the current state of user-centered design (UCD) and data visualization in the healthcare domain.

### 2.1 Kids and Chronic Pain

As per Jackson *et al.* [56], chronic pain affects at least 10% of the world's population with estimates of prevalence closer to 20-25% in some countries and regions. An additional 1 in 10 people develop chronic pain every year worldwide. Chronic pain has been defined as any pain that lasts longer than three months, and may or may not have an underlying cause [67]. This type of pain can continue even after the injury or illness that has caused it has healed or passed.

In youth aged 19 and under, chronic pain is a common, costly condition, of whom 3-5% report disabling levels of pain [61]. Stinson *et al.* [82] discuss the various factors that can cause chronic pain (Fig. 2.1), which include social, psychological, physiological and environmental factors like stress, family attitudes, limited social interactions and age and gender, which are all interconnected as well. Kerns *et al.* [59] also discuss issues related to individual differences and disparities



**Figure 2.1:** Factors associated with chronic pain in youth, Stinson *et al.* [82] (2009)

in the experience of pain and pain treatment and special considerations that need to be taken for the management of pain in children. Chronic pain can cause varying levels of disability, and the various factors associated with chronic pain further influence the level of physical functioning kids can have.

Even more youth report recurrent pain that is not disabling but interferes with their academic, social and recreational functioning, and significantly affects their mental health and quality of life [47, 69, 70, 94]. Roth-Isigkeit *et al.* [77] studied adolescents' perceptions of restrictions in their daily lives and triggering factors for chronic pain, and found more than two-thirds of their respondents reporting restrictions in daily living activities due to pain. 30-40% of youth reported moderate effects of chronic pain on school attendance, participation in hobbies, maintenance of social contacts, appetite, and sleep. The authors further stress the need for additional research to enable healthcare professionals and parents to assist adolescents and children with pain management.

Chronic pain has also been shown to have adverse effects on patient's mental health, exacerbating depression and anxiety, in short as well as long-term [61, 69, 70]. Higher levels of functional disability are also associated with greater pain intensity and depression, as well as lower perceptions of self-worth [42, 48]. In addition to affecting the patients' lives and functioning, chronic pain affects the financial, social and mental aspects of their families' lives too, which cyclically affects the kids as well. Young [98] gives an honest account of how chronic pain permeates into a family's everyday life - the concessions and additional care that needs to be taken. Hunfeld *et al.* [54] studied the impact of chronic pain on children and their families, specifically mothers. They found that higher intensities of pain reported by children corresponded to higher social restrictions in the mother's life. Even when the pain mildly affected the child's functional status, changes in the pain behavior could still significantly affect their families. There was an overall negative impact on family life, including restrictions on family life and personal strain, based on changes in the kids' behavior. Parents reported marital and financial problems, feelings of helplessness, despair and depression [54].

Thus, chronic pain in children is common, undertreated, and affects them and their families negatively in several ways. It is a complex condition and can present through multiple symptoms, making it harder to diagnose. Multiple factors including family behaviour, age, stress and depression, among others, are associated with chronic pain, most bidirectionally, where the pain influences the factor and vice-versa. Chronic pain poses a constant challenge for kids, affecting their daily activities, social functioning, academic prowess, as well as sleep and physical fitness.

Many teens lead extremely busy lives, with chronic pain impacting multiple aspects, thus recording and documenting their everyday lives, and noting down pain events and medications, can be useful in tracking the progression of their symptoms, as well as the impact of interventions.

## **2.2 Recording for Clinical Diagnosis and Treatment**

A big part of the diagnosis and treatment of chronic pain for any age group is dependent on accurate records of pain episodes and symptoms. Given the complex

and multidimensional nature of chronic pain, patients need to maintain accurate records of their symptoms and medications, to enable clinicians to provide suitable care.

Much clinical research has been done on methods of recording chronic pain. This includes research in traditional chronic pain recording methodologies like pen and paper diaries and journals, as well as newer digital methods like electronic diaries and digital applications.

### **2.2.1 Traditional Recording Methods**

Traditional recording methods include diaries and journals maintained by patients. This approach typically results in huge binders, maintained on a regular basis, that need to be brought in on every visit to the doctor's office. Traditional methods such as these rely on the patient to accurately record and remember details, a practice which many patients are unable to effectively follow.

Recalled incidents are often biased, leading to inaccurate measures of pain and other factors - this is termed as *recall bias* and is one of the most crucial limitations of such methods that place the onus of pain recording on the patients. Diaries and journals are also often unstructured, which leads to inconsistent data over time. Such incomplete data points do not offer sufficient data for clinicians to analyze, which makes it tougher for clinicians and caregivers to diagnose and treat patients.

Van den Brink *et al.* [91] compared in-the-moment recording via diaries to recalling pain through an end-of-week questionnaire. Recalling prior headache episodes led to over-estimations of pain intensity. Giske *et al.* [43] also speak of the potential recall bias in weekly recollections of pain data, as compared to daily recollections.

Pen and paper diaries have also been found to have higher rates of non-compliance among adult populations [85]. Patients were far more compliant with electronic forms of recording, and also tended to be more punctual when recording data electronically.

To combat recall bias, a common technique is Real-Time Data Capture (RTDC). RTDC techniques enable clinicians to capture real-time data from patients in their natural settings, while also allowing measures of aspects of patients lives surround-



ing their pain that otherwise would be prone to recall bias. Stinson *et al.* [83] note that there exist few validated self-report pain intensity measures, indicating reliance primarily on the Pediatric Pain Questionnaire [92], the Pediatric Pain Assessment Tool [29] and the Adolescent Pediatric Pain Tool [40, 57] which are all single-point measures and prone to recall bias. RTDC methods, on the other hand, allow for data collection at multiple timepoints through the day, and are more holistic, thus capturing other events that can also contribute to pain, like worries and emotions, and hence providing a more accurate reflection of a patient's experience. A standard application of the RTDC method has been through EMA or Ecological Momentary Assessments.

### **2.2.2 EMA (Ecological Momentary Assessments)**

The Ecological Momentary Assessment [81] (EMA) is a common RTDC method that involves repeated sampling of the subjects' current behaviors and experiences in their natural environments. It reduces recall bias to a great extent, and also maximizes the ecological validity of the data captured.

EMA data can be sampled in two ways - event-based vs time-based sampling. Event-based sampling is suited for episodic data, for instance, substance abuse events that are not continuous. On the other hand, clinical phenomena like pain and mood can vary continuously and are not episodic, hence they are best suited to time-based sampling. EMA methods also tend to be idiographic (*i.e.*, a single user's data is in itself sufficient to assess and guide them, and does not require group data to be evaluated comparatively).

EMA data is usually collected through surveys answered by participants multiple times a day. These surveys can be administered through a mobile application or web links, and usually have set times throughout the day. Some studies also include reminders sent out to participants to fill the surveys, while others may allow participants to set custom timings that fit into their schedule as well.

While the EMA is subject to certain limitations, for instance, the onus to repeatedly input data still lies on the user, and recall bias albeit not major is still possible, it has quickly found acceptance in clinical studies - Wen *et al.* [96] in their systematic review of EMA studies found 36 studies using the EMA method

of data collection, with a 78% average compliance rate.

Cushing *et al.* [36] also conducted a study using the EMA data collection method where they surveyed 30 pediatric chronic abdominal pain patients using 4 surveys per day. They captured data around pain symptoms, affect, worries, social environment, sleep, and school attendance, among other factors. They found the data collection method feasible and acceptable, with 19/27 (70.3%) youth agreeing that answering surveys on the smartphone was easy. They also found 20/24 (83%) participants had within-subject emotional factors related to their pain, further validating the use of EMA surveys as an RTDC tool for recording chronic pain.

EMA also allows for remote care, since data can be captured in-the-wild remotely, opening up avenues of remote healthcare that can often be more accessible and perhaps even the only option in cases like pandemics. Eccleston *et al.* [38] also studied the impact of COVID-19 on patient care in May 2020, noting that children and adolescents report high symptom burden while waiting for evaluation. They found remote psychological therapies to show beneficial effects for reducing pain intensity, and found no difference between remote and in-person therapies, opening up potential for more remote alternatives to patient care.

While EMA data is useful for clinicians to assess and create personalized treatments for their patients, we are unable to find any research on the impact of EMA-collected data on the patients themselves. Most of the EMA data is captured and analyzed from a clinical perspective, and indirectly reflected back to patients through modified treatment methods by their healthcare team, but direct interactions of patients with the EMA data are limited. Other methods similar to the EMA that reflect data back to users include visualizations or graphs, usually through smartphone or web applications, however this data is often less holistic or customizable than EMA methods, further discussed in Section 2.4. This data can be an informative source for patients themselves to better understand how their pain affects and is affected by other factors in their daily lives. Reflecting this data back to patients through a medium that is familiar and easily understandable is a gap that we aim to address.

## 2.3 EMA Survey in this Thesis

When we talk about the EMA survey in the scope of this thesis, we are referring specifically to the survey that was previously developed by Drs. Tim Oberlander and Katelynn Boerner (currently unpublished), and is the same one used without modification throughout this thesis. This survey is designed to collect data related to the patients' symptoms, mental health, sleep, emotions and social interactions. The survey can be broken down into five main components that we capture data on:

- Physical Symptoms
- Sleep
- Emotions
- Mental Health (specifically worries and perception of events)
- Social interactions

The EMA survey in this case is administered 3x a day - morning noon and night. Each survey covers a subset or all of the categories mentioned above, with small changes among each of the three surveys.

The **morning survey** captures data around:

- What time the user went to sleep and woke up and the quality of their sleep
- What symptoms (if any) did they experience since the last survey (from a subset of predetermined symptoms) and the intensity of the symptoms
- If they took any medication/therapy to help with the symptoms
- How worried, happy, angry, miserable they feel
- How their interactions with other people have been and how worried they were about these interactions
- How worried they have been about experiencing physical symptoms
- What are they most worried about happening that day and what does that worry involve (from a pre-determined list of categories)
- How bad they expect the thing to be and how certain they are about it happening

The **afternoon and evening surveys** capture data around:

- What symptoms (if any) did they experience since the last survey (from a subset of predetermined symptoms) and the intensity of the symptoms
- If they took any medication/therapy to help with the symptoms
- How worried, happy, angry, miserable they feel
- How their interactions with other people have been and how worried they were about these interactions
- How worried they have been about experiencing physical symptoms
- If the thing they were worried about happened, and if so how bad it was
- If they avoided the situation they were worried about
- If they went to school that day and if not, why

The EMA survey was designed to collect holistic data about the patients' daily lives, in the hope that enabling them to review and reflect on the same can help them see how these different aspects are interconnected and how they can best manage them.

The full EMA survey can be found in the Appendix, as Section A.1.

## **2.4 Tracking for Interactive Self-Management of Pain**

While Section 2.2 details methods used to record chronic pain and other factors for clinical reference, there exist a host of personal informatics-based applications that can enable patients in the self-management of their symptoms outside of clinical care. These applications support users in understanding aspects of their life by providing means of collecting and viewing personal historical data [60] and enable reflection and self-management which can help users in understanding how to best introduce effective changes in their life. These applications can be used independently or in conjunction with clinical care.

### **2.4.1 Commercially Available Pain Management Applications**

In the field of healthcare, personal informatics has seen a drastic increase in the past decade, owing to the accessible mobile and wearable format of sensors and displays [46, 93]. For instance, common applications include the Apple watch and

Fitbit [8, 15] which track data including sleep, physical movement, diet and sleep. Other self-tracking applications like Daylio and Moodily [13, 23] help track mood and stress, and also allow users to add journal notes about their day, providing a complete view of their emotional state through the day.

Pain management applications abound in the market. As of October 2020, there are more than 431 pain management applications available on the Google Playstore and iOS Appstore combined [64]. Applications like manageMyPain [20] and migraineBuddy [21] further help track certain symptoms for adult chronic pain patients. These applications have gained popularity with the rising popularity of personal health informatics, as they usher in a new era of self-management for people with access to smartphones and the internet.

Most of these commercially available applications are similarly structured - they rely on users to input data on a periodic basis, and use some form of gamification or visualization to reflect patterns in their data and engage the user. Few of them are clinically validated. Lack of clinical validation means most of these applications fail to address clinical concerns or might even misrepresent user data with incorrect results.

These applications, including ones that are clinically validated, are also often not tested with the targeted end users or clinical populations. Testing with clinical populations is more complicated than with non-clinical populations, given the additional burden on these populations of possible triggers and having to relive or document stressful events. These and other ethical implications can lengthen the design process, often leading to researchers not testing with these demographics even while designing for them.

Taken all together, this situation means that the needs and requirements of these populations often end up not being addressed, leading to sub-optimal applications with low user engagement.

#### **2.4.2 Research-based Pain Management Applications**

On the other hand, there have been pain management applications created and validated by clinical research teams.

e-Ouch in 2006 by Stinson *et al.* [84] is one of the early examples of digit-

ization of pain tracking, in the form of an electronic chronic pain diary. Their evaluation study established the willingness of adolescents to use a digital medium to track pain, and the feasibility of use of the same. The e-Ouch study also used the EMA approach, where participants were asked to record pain from thrice a day - morning, afternoon and from the previous evening. The only drawback of this study was the fact that it was not conducted in the participants' natural environment, but in the lab, which does not take advantage of the EMA's ability to capture multidimensional data in the wild.

In 2017, Jibb *et al.* [58] created a web-based smartphone application that uses a 22-item questionnaire to assess adolescent cancer pain each morning and evening and tested it with 40 adolescent, aged 12-18 years of age. They measured aspects like intensity, location and duration of pain, treatment and control used in managing pain, as well as other measures like school attendance. They found significant improvements in social and emotional functioning, even though not in physical and social functioning, showing the potential of real-time pain management through smartphone applications.

Recently in 2020, Suso-Ribera *et al.* [87] devised a study involving an EMA setup along with an app with alarms sent to clinicians in case of undesired clinical events. They found significant results for the interference of pain with sleep, work, leisure, and social interactions, and also found clinicians willing to use the alarm set up to be more involved in patient care.

Other methods include use of strategies like meditation [95] or peer support [66] for self-management of chronic pain. Waelde *et al.* [95] studied the impact of mindfulness meditation on pediatric chronic pain patients, and found small improvement in functionality and disability, but not statistically significant results. They do note on the growing field of mindfulness applications for adults with chronic pain. Matthias *et al.* [66] devised a study where patients served as coaches for other patients, hypothesizing the support of a peer network would help in engagement and compliance, but did not find any significant results, with a low adherence rate.

However, research-based and clinically validated applications, while useful in providing methodological knowledge, rarely make it to commercial platforms. This means that non-validated applications continue to dominate usage. Thus, even

though these applications show potential, are tested and validated, and can be used for effective treatment strategies, they rarely reach the intended end users.

### **2.4.3 Gap between Commercially Available and Clinically Validated**

As Rosser *et al.* [76] reviewed in 2010, there seems to be a very low level of clinical engagement in the design and development of commercially available applications.

There is little or no evidence of trials or evaluation of these applications in any systematic review of mobile or e-health interventions. Lalloo *et al.* [63] in 2015 and Schults *et al.* [80] in 2019 further conducted reviews along the same lines, both times finding the lack of involvement of health professionals in the design of such applications to be a continuing trend. Lalloo *et al.* also noted the lack of multidimensional tracking in applications, seeing most identified applications focused primarily on monitoring only the intensity of pain and often did not collect detailed information about other important components such as pain quality and location.

Vega *et al.* [37] in 2014 conducted a similar review, but on both sides - commercially available applications as well as applications published in research only - and found a significant gap. None of the applications discussed or created in publications were made available on any app store, and out of 283 applications available on the app stores they surveyed (iPhone, Blackberry, Nokia, Windows, Android app stores searched for 'pain'/'ache' applications), none of the applications were backed by research published in any journal/conference/venue.

Thus, the current ecosystem seems to consist of, on one hand, a variety of applications that are commercially available but not validated by research; and on the other, a number of applications that are created with thorough research but don't end up on commercial platforms – with nothing in between.

This can be attributed to a number of reasons – accessing clinical populations or involving clinicians in design requires going through additional ethical processes, and can extend project timelines. From an industrial perspective, this might often not seem worth the effort, time or costs. For research-based applications on the other hand, finding industry partners to create functional and deployable applications can be difficult due to lack of connections, support or funding.

Bridging this gap is key, as applications that are validated are more accurate and effective compared to their non-validated commercial counterparts, and thus should reach more end users.

#### **2.4.4 Co-created Pain Management Applications**

In a research-based context, there have been applications that have involved other stakeholders through the design process. This is important as involving stakeholders like clinicians and patients brings in key user perspectives that can be pivotal in the design and development of such applications.

Schults *et al.* [80] note the beginning of involvement of consumers through all stages of the app development process near 2019, which signals more user-centered design and feedback, but they also stress the importance of increasing end-user involvement and multidisciplinary development teams in the future.

Among the few applications created with clinician involvement, Hoffmann *et al.* [53] in 2020 created a gamification-based app for adults with chronic pain in collaboration with 11 health professionals and 2 mobile health experts. They hypothesized that the use of gamification could positively influence patient motivation and engagement. The app includes personalized tasks and management exercises, as well as an avatar that provides feedback using the user's diary entries. They used the Mobile App Rating Scale (MARS) [86] to assess the design factors of the application, including engagement, functionality, aesthetics and overall quality and conducted semi-structured interviews with the experts to get further feedback on the app. While they got positive feedback for the potential of the app, they remain to test it out with their target chronic pain demographic.

Cooke *et al.* [35] in 2021 also created myPainPal, a similar mHealth app for the management of chronic pain in young people, that incorporates feedback from patients, parents, and clinicians, as well as a pain advisory group. The authors conducted semi-structured interviews to gather requirements for the app, followed by feedback on their prototype, followed by an in-the-wild test run for one week concluding with post-use feedback interviews and questionnaires. They also record pain, sleep, emotions, activity and energy levels, as well as feature goal setting and community building options. They received positive feedback from patients and



parents on the monitoring and tracking aspects of the application. Cooke *et al.* also included visual representations of the collected data, but fail to specifically evaluate the use of the visualizations and their potential impact on the self-management by patients.

Thus, in recent years, we are seeing a more inclusive and patient-centered approach to designing mHealth applications. While most such applications developed through research do not make it to commercial platforms, they are beginning to involve stakeholders at multiple stages of the design process, which has resulted in more compliant, successful applications.

However, the use of personal informatics for adolescents specifically is under-researched, and further so for adolescents with chronic pain. The applications discussed above use methodologies and track aspects relevant to adolescents, yet given the special care a younger demographic needs (considering the additional impact of chronic pain on their academic performance and social and recreational functioning, as well as higher mental and emotional stress), these applications need to be designed in a way specifically catering to younger audiences.

## **2.5 User-Centered Design of Pain Management Applications**

User-Centered Design (UCD) is an iterative design process in which designers focus on the users and their needs in each phase of the design process [3]. Keeping the user at the center of the design process leads to more inclusive, accessible design, and leads to better engagement in the long run.

In the field of healthcare and personal health informatics, UCD involves designing around the patient, taking into account their preferences, needs and individual circumstances. When considering the individualized and subjective nature of chronic pain, UCD becomes even more paramount, since each patient has a unique set of circumstances and conditions. It is also crucial to consider how an application might fit into the patient's everyday life, especially when considering methods like EMA surveys which can be a consistent disruptive cognitive burden for users.

### **2.5.1 Potential of Personal Informatics for Adolescents**

When considering adolescents and personal health informatics from a UCD perspective, Potapov *et al.* [72] studied the opinions of 18 teens on personal informatics and found that teens valued learning about their natural patterns. They mentioned looking at their data helped them reflect on things not being as bad as they thought they were, and also helped them externalize negative judgment by seeing things like their worries quantified. Visualizing their data also opened it up to more interpretation, which they preferred.

Teens reported they would have liked to have agency over what they chose to track and the ability to decide if what they were tracking was conceived as good or bad, for instance common ‘unproductive’ things like time spent on social media could be classified as ‘relaxation’, which has a different connotation than unproductive, and so affects how the teen might view their time spent. While Potapov *et al.*’s study was not specifically for adolescents with chronic pain, it does give an idea of how adolescents in general view personal informatics, which is important for our design process.

In summary, teens seem to find personal informatics useful, if allowed to personalize what they track and how often they track those aspects. From a UCD perspective, this highlights key features designers should keep in mind when designing for this demographic - allowing for personalization, highlighting patterns in data, and visualizing the data collected.

### **2.5.2 Need for Testing in Real-World Conditions**

As Thurnheer *et al.* note in their paper [88], pain management applications certainly possess the potential to help decrease the perceived severity of pain. However, the lack of usability standards and absence of scientific rigorous evaluation makes it difficult to assess their efficacy and impedes usability in real world settings. Baumel *et al.* [33] also note the limited impact of digital interventions owing to their inability to retain users.

This could be attributed to a combination of many such interventions being easily accessible online, leading to users trying out multiple options but complying with none, as well as compliance outside-the-clinic being lower due to lack

of accountability. They note the difference in engagement in study settings compared to real-world ones, citing incentivization and human contact by researchers as potential factors leading to better engagement in clinical settings, as compared to real-world compliance.

Reynoldson *et al.* [75] discuss UCD of chronic pain applications, assessing the usability of two existing applications using the System Usability Scale (SUS) [30], a design questionnaire and free-text responses. While response to the design and usability of the applications was good, they did not conduct field trials to see how the applications would actually fit into users' daily lives.

Low user engagement means lower compliance with data collection, which consequently decreases the potential for such applications, whether clinical or commercial, to be effective treatment or management interventions. Thus, chronic pain applications need to be tested in-the-wild, to get an accurate measure of user engagement based on how well they integrate with users' lives.

### **2.5.3 Lack of Clinical Involvement in Design**

Harle *et al.* [49] also discussed UCD from a clinician perspective in 2019, conducting a workshop as well as interviews with 10 adult primary care clinicians. Some of the requirements they received from clinicians included the need to identify treatment options and trends and changes in the patients' condition, as well as longitudinal displays that can help clinicians make sense of trends over time. Clinicians also mentioned the need to have limited use of colors and logical groupings for sections. While most of these are common *good design* [49] principles anyway, assessing clinicians' specific requirements and making sure they are included in the design of the application helps create applications that are usable by both clinicians and patients, which can help provide faster and improved care.

Kirchner *et al.* [62] prototyped a set of design cards that can help designers in designing for personal health informatics. The cards were devised through semi-structured interviews with designers and health-focused professional researchers and are thematic design prompts that help designers reflect on their decisions in the design process.

There is a need to involve clinicians in the design of pain management ap-

plications, to ensure clinically important features are included during the development process. While users might choose to use applications for personal self-management and tracking health data without clinical involvement, applications that are specifically catered towards monitoring medically-relevant health data and recommended for use in conjunction with clinicians must take a clinical perspective into account to make sure representations and features included are medically accurate.

Thus, while there exists potential for personal informatics to be leveraged for younger populations, it is also necessary to consider how such applications would integrate in their lives. The design and development of such applications must involve clinicians, for validity and efficacy, while also balancing the needs of this specific demographic, to ensure better user engagement which can lead to successful treatment interventions. Applications also need to be tested in real world settings to get accurate measures of engagement and usability, as well as insights on continued use.

## **2.6 Data Visualization in Healthcare**

Data visualization is the graphical representation of information and data. By using visual elements like charts, graphs, and maps, data visualization tools provide an accessible way to see and understand trends, outliers, and patterns in data. [25].

In the field of health informatics, data visualization has quickly become a useful tool to reflect trends and patterns in user data. Common health tracking applications like Apple Health and Fitbit make use of common graphs like line charts and bar graphs to show data like users' sleep and activity levels [8, 15].

Visualizations in general can be highly advantageous for inciting reflection in the user - they can help users spot trends and outliers, and reflect on what might be causing them. In a clinical setting, visualizations can help clinicians evaluate whether treatments are working or not, and change treatment plans accordingly. It also reduces recall bias, as captured data can be reflected over time, reducing the burden on patients. For chronic pain patients, visualizations can be helpful in showing the interconnections between different aspects of their lives, like their social interactions, pain symptoms, emotions and sleep.

While researching existing visualization methods, in CareVis by Aigner *et al.* [31], the researchers developed visualization methods to support medical personnel in computerized protocol care. They used a multi-step evaluation process including user studies, design reviews, and prototype evaluations, involving the end-users from the beginning, which helped them improve the quality of their design. Radhakrishnan *et al.* [73] used histograms and heatmaps to identify meaningful patterns in visualizations of large Electronic Health Record (EHR)-related datasets and West *et al.* [97] performed a systematic review of visualization techniques suggesting significant challenges to keep in mind when visualizing electronic health data. Some of the key points they mentioned were:

1. The difficulties in highlighting patterns in vast electronic health data.
2. The potential of temporal visualizations in reflecting data to the users.
3. Considerations needed for missing datapoints in visualizations.

While these were effective visualization methods, they were targeted towards clinicians or healthcare professionals, and not towards the patients themselves. However, these works do provide helpful context on the kind of visualizations used in the medical field, and how they can be used to highlight patterns in temporal health data.

### **2.6.1 Visualizing for Adolescents**

While there has been much research into visualization techniques and visualization guidelines, designing for adolescents requires careful consideration of their visual processing capabilities and the cognitive effort required in extracting information from visualizations, relative to their motivation and priority in spending time on visualization activities. There is a lack of research in visualization literacy in teens or younger demographics, with Herdal *et al.* [52] evaluating visualizations for improving soccer prowess in teens being one of the few papers addressing and evaluating visualization literacy in kids.

Most current visualizations in the healthcare space are often overloaded with information and impose a high cognitive load, for instance scatterplots overlaid

over line charts. Such charts, while relatively easy for adults to comprehend, can be cognitively difficult for teens, given most of them learn to compare graphs in middle school.

There have also been attempts to create resources for young audiences to learn more about data visualizations, for instance, the New York Time's *What's Going On in This Graph* educational feature [4] that encourages students to engage with visualizations published in the New York Times, or Tableau's *Kids + Data* [5] resource for introducing kids to data visualization. These tools, while helpful in introducing younger audiences to the world of data visualization, and in teaching teens how to decipher and understand visualizations, are not from a designer's perspective, and do not help designers effectively design visualizations for them.

Most visualizations targeting chronic pain, discussed previously, also fail to be holistic - simply given the nature of current pain tracking applications that focus on only certain aspects of the user's lives, there is just not enough multidimensional data captured for the visualizations to reflect. Thus, they fail to capture aspects that are relevant to adolescents' lives like social interactions or worries and anxieties. Most health tracking applications also focus on reflecting data just gathered from biometric devices, like heart rate or breathing patterns, or manually tracked mood or sleep. These visualizations are often not connected and hence make it difficult to see the interconnections between these different aspects of the patient's life.

Creating successful visualizations for this specific demographic will require establishing newer guidelines or altering common ones to best suit their requirements. For instance, while it is best to combine multiple aspects into a small chart for displaying data on a smartwatch, the same becomes cognitively complex when considering a young audience, and hence there remains a trade-off between screen space, visual complexity and cognitive load that needs to be made in the design process.

## **2.6.2 Evaluation Metrics for Visualizations**

When we consider the evaluation of visualizations, common quantitative methods involve tracking the amount of time a user spends on a visualization, or the amount of clicks to track their engagement. While these are reliable trackers of

user engagement and success of the visualizations, it is also important to note that sometimes the goal of the visualization might not be to engage the user as much as it is to impart new knowledge to the user, which could occur without heavy engagement.

To an extent, such quantitative methods are non-intrusive, and offer insights on use and engagement, but only for deployed or fully functional applications. On the other hand, for the evaluation of designs preceding deployment, more 'intrusive' methods like interviews and questionnaires can help provide feedback on similar metrics, which can then be used to refine the designs before deployment.

Saket *et al.* [78] discuss the qualitative and quantitative methods of evaluation, around user engagement and usability, for information visualization. They reviewed user studies that focused on goals and metrics other than standard performance measures, and found the use of self-reported subjective methods like interviews and Likert-scale based questions to measure the sense of enjoyment and engagement. Especially in cases where the goal is to facilitate a deeper interest in learning more about the data, as is our goal, it makes sense to assess the impact of the visualizations qualitatively rather than simply measuring the quantitative impact. We further discuss our process of deriving evaluation metrics for our visualizations in Section 5.1.2.

Thus, overall, data visualizations are heavily used in personal informatics, and show great potential in their ability to reflect information to users, but need to be designed through youth-focused formats given the additional considerations for younger demographics. Such visualizations aiming to provide added utility and engage users with their data should also be evaluated accordingly on qualitative measures like their utility, accuracy and insightfulness.

## Chapter 3

# Initial Design Iteration

Part of this thesis was developed as a part of the Designing for People (DFP) course project (CPSC 554K) at the University of British Columbia. In the scope of this course project, we aimed to understand our target population i.e. kids with chronic pain, and how data visualization could act as a treatment intervention. The project team consisted of Devarsh Bhonde, Katra Farah, Haomiao Zhang, Rubia Guerra and myself, comprising of students from the department of Computer Science, Education, Mechanical Engineering and Project and Construction Management. We were mentored by Dr. MacLean, and clinicians Dr. Oberlander and Dr. Borerer provided clinical context through interviews and input on the visualization prototypes.

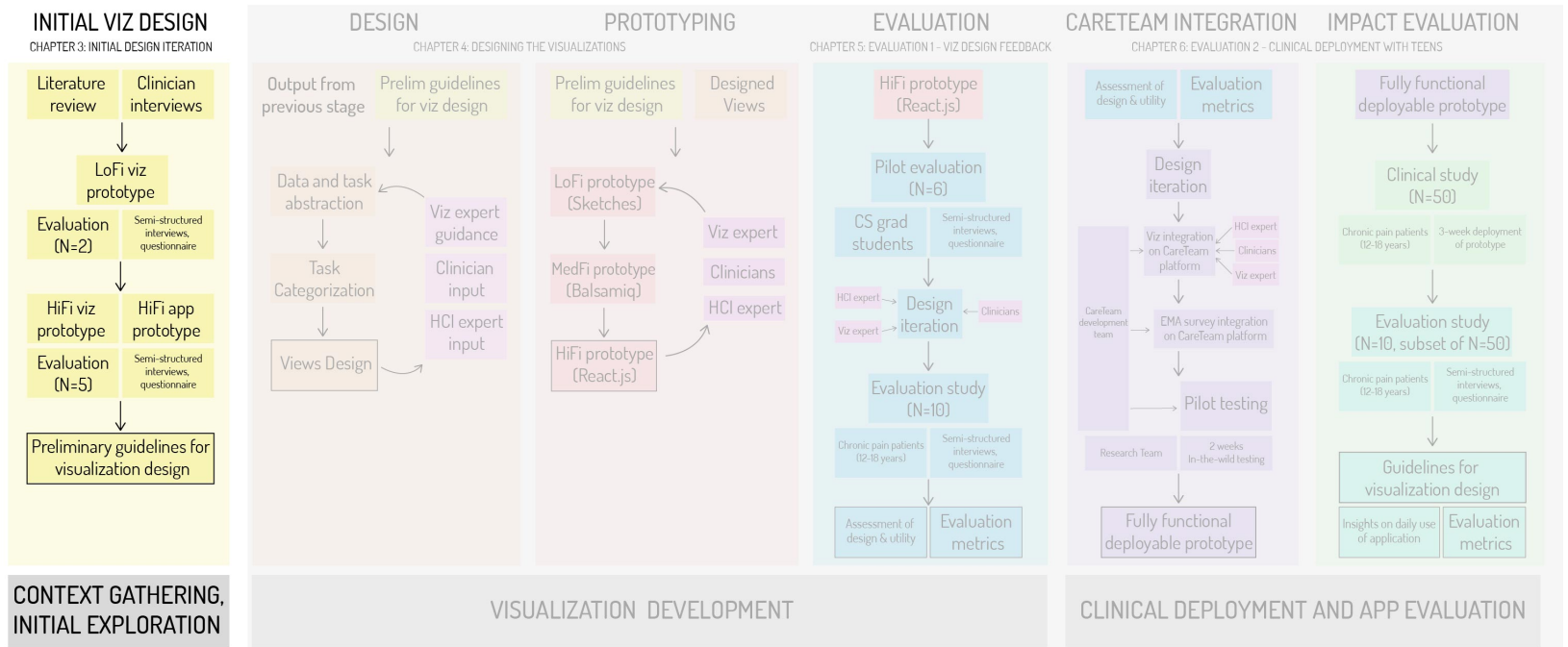
As a part of this course project, we conducted an initial literature review and piloted the EMA survey to gather initial context and data to begin the design process. We then conducted interviews with stakeholders including clinicians and designers and people with previous chronic pain experience and then created prototypes of the visualizations. That was followed by feedback interviews where we evaluated the visualizations with people who had previous chronic pain experience and developed initial guidelines for designing visualizations for this target demographic.

Parts of this chapter were adapted from the course project final report, written by all team members. Those part include Sections 3.1, 3.2.1, 3.3.3 and 3.4. The material in the remainder of the chapter is presented here for the first time in the present form, restructured to suit the purpose of the thesis, but adds detail to the



version in the project report. The work done throughout the chapter is through equal contributions of all the team members.

In Fig. 3.1, we show the work covered in this chapter relative to the overall project, as a part of the overall design process diagram.



**Figure 3.1:** Showing the Context Gathering and Initial Exploration phase discussed in this chapter

## **3.1 Initial Literature Review**

As part of the initial literature review for this project, we read about existing work in the field of chronic pain and data visualization. For conciseness and completeness, this review is included in the Literature Review in Chapter 2.

## **3.2 Design Process**

### **3.2.1 Context Gathering**

We began by interviewing the clinician mentors (Drs. Oberlander and Boerner) to get more context about the target demographic as well as gather clinical requirements for this project. The interviews were one-hour semi-structured interviews with questions focused on the impact of chronic pain on the daily lives of young chronic pain patients. From the interviews, we learnt about the multidimensional impact of chronic pain, as well as the need for an engaging long-term solution for self-management. An important clinical requirement brought forth at this stage was the need to visualize the temporal nature of the data - the need to view trends and patterns and outliers over time. The clinicians stated how progress over time was important not just for clinical decisions in the treatment for these youth, but also for the youth to self-identify progress and evaluate their condition.

### **3.2.2 EMA Pilot Data Collection**

We wanted to gain an overview of what the EMA (detailed in Section 2.3) data would look like and how the EMA data collection experience would be for the target users. Hence, we piloted the EMA survey by filling it out three times a day for two weeks. We used this pilot data to prototype visualizations in this chapter as well as in Chapter 4, in lieu of actual patient data.

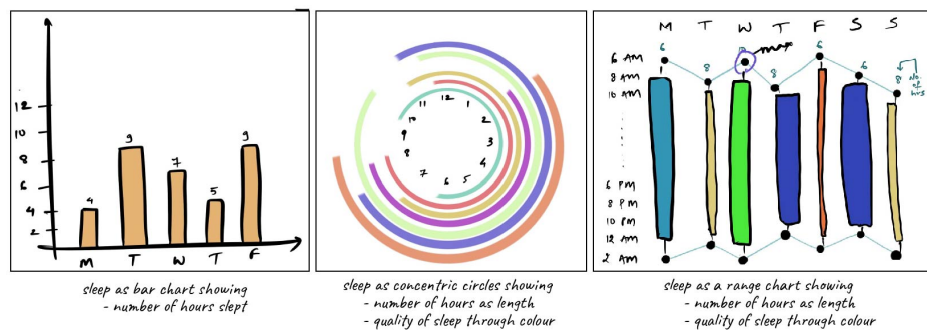
### **3.2.3 Low-fidelity Prototyping**

Armed with the context and clinical perspective, we moved on to prototyping.

Our initial prototypes were hand-drawn sketches that revolved around using different visualization concepts based on the EMA survey and existing commer-

cial visualization techniques used in health tracking applications. The visualization concepts focused on four different categories: physical pain, sleep, emotional health and peer interactions. For each of the categories, we generated several visualization concepts. Some of the concepts were based on traditional charts and graphs. One such example was using a bar graph to represent the hours of sleep with the color of the bar encoding the quality of the sleep. Other ideas were more creative such as using emojis to represent different feelings. After sketching out those concepts, we conducted a round of interviews to get feedback.

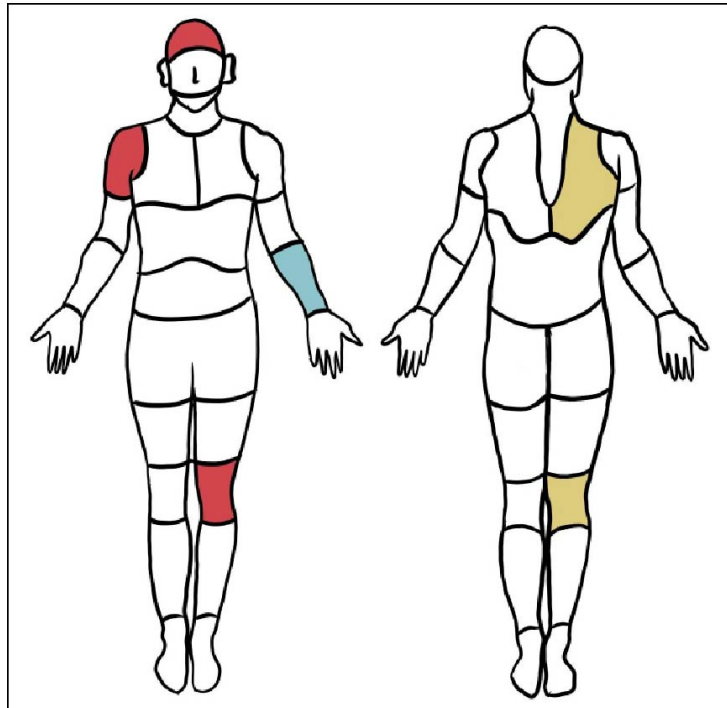
## Sleep



**Figure 3.2:** Three different prototypes for visualizing sleep data, from left to right: as a bar chart with height representing length of sleep; concentric circles showing number of hours as filled circumference and quality of sleep through colour; and as a range chart with height of bar showing length of sleep, position of bar showing time and colour of bar showing quality of sleep

We were uniformly agreed that the use of colour to represent sleep quality was effective, and tried to use familiar charts like bar or range charts, or the concentric circles which is Apple’s popular method of visualizing health data and hence might be familiar to most audiences.

## Physical Symptoms



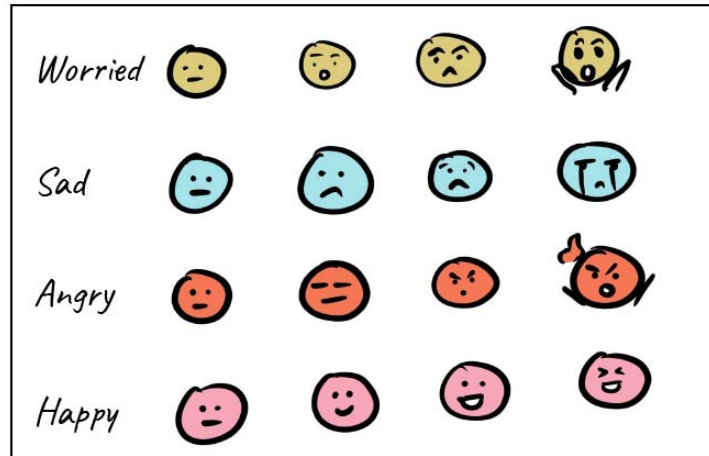
*silhouette map showing  
- location on silhouette as location of symptom on body  
- color as intensity of symptom*

**Figure 3.3:** Silhouette visualization showing intensity and occurrence of symptoms using body location to show type of symptom and colour to show intensity of symptom.

Given the choices in the questions in the survey regarding the intensity and occurrence of symptoms, we felt mapping the symptoms on a body silhouette would be an interesting visualization. The body silhouette would make it easy to associate the symptom with the body location, and we had just enough symptoms to place them on the front and back of the silhouette without any overlapping locations. We also thought using colour to show the intensity of symptoms would be effective. While silhouette maps are not used commonly, given the nature of this data we felt

this particular design would work best in this case.

## Emotions

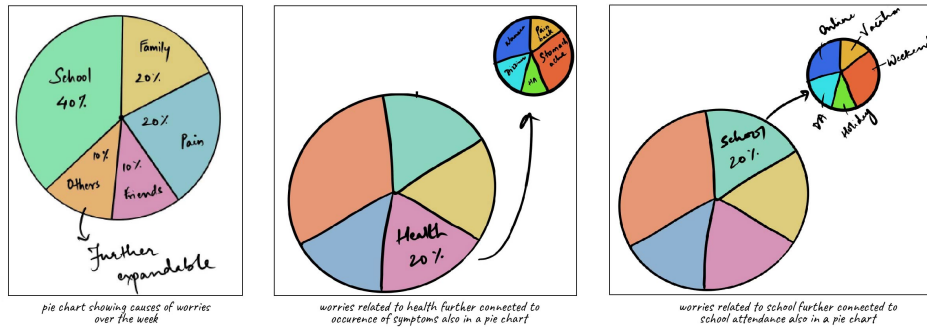


*custom emojis to show intensity of emotions*  
- color-coded per emotion  
- different intensities within emotion represented by unique emojis (increasing in intensity linearly)

**Figure 3.4:** Custom emojis to show intensity of emotions. Color-coded for each emotion, with different intensity of each emotion represented by an increasing intensity of expression of emoji

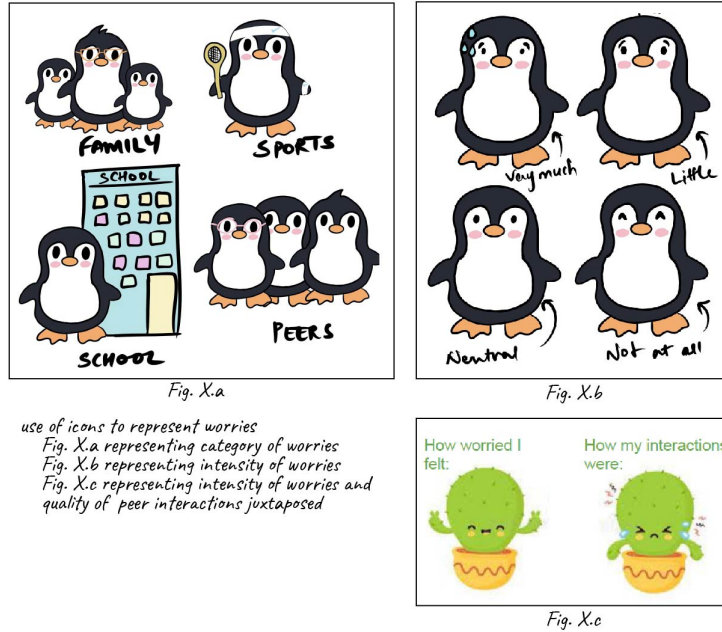
Given the popularity and common use of emojis in everyday life, especially for teenage youth, we felt emojis might be an effective means of visualizing the user's emotions through a design which might already be familiar and intuitive for them.

## Worries



**Figure 3.5:** Pie charts to visualize worries, from left to right: pie chart showing distribution among category of worries; health section connected to symptoms also shown as a pie chart; school section connected to attendance also shown as a pie chart.

We felt pie charts might be a good way to show the distribution of an attribute over categories, while also allowing the user to delve deeper into select categories. Pie charts could also be used to link sections to other attributes, like linking symptoms to worries about health or reasons for absence to worries about school.

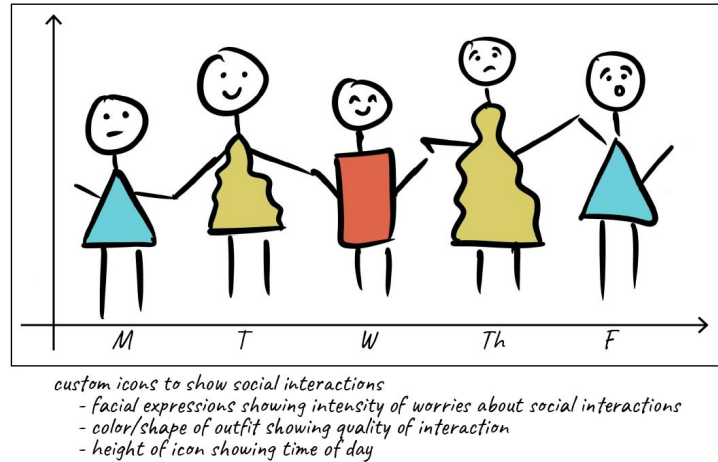


**Figure 3.6:** Custom icon visualization to show worries, from left, clockwise: categories of worries shown as different penguin icons, intensity of worries shown as different penguin expressions, intensity of worries and quality of peer interactions shown as different cactus expressions

The use of avatars to gamify pain management in Hoffman *et al.*'s [53] work inspired us to also think of custom drawn visualizations using icons. We thought of penguins as icons, with different expressions and surroundings to represent different things. We felt this might be a novel visualization style that might appeal to younger users. Similarly, we thought of other forms like succulents or other gender-neutral icons that might be appealing to youth. In this case, we thought representing the intensity and categories of worries could be a possible use-case for this style of visualization.



## Social Interactions



**Figure 3.7:** Custom icon visualization to show social interactions. Intensity of worry about social interactions shown through expressions of stick figures, height of figure indicating time of day (morning/afternoon/evening), colour/shape of outfit showing quality of interaction (negative/neutral/positive)

We further created visualizations using custom icons, like stick figures with different expressions and clothing to denote worry and quality of social interactions. Given the meaning of social interactions, we felt human stick figures would be an appropriate yet creative format of visualizing this data. We also thought the novelty of the visualization might make it more engaging for the users.

Post the design of our low-fidelity sketches, we conducted feedback interviews with two participants.

Our low-fidelity feedback interviews were to understand the graph literacy of our intended user demographic. The two participants were proxy users who had experience with graph literacy of youth. One of them was a young adult, and the other was a math teacher who taught youth in our target user age group. During this round, we had one-hour semi-structured interviews with a survey based on the User Experience Questionnaire (UEQ) scale [26, 79] for different visualizations. Five categories were selected from the UEQ scale: creativity, clarity, attractive-

ness, ease of understanding and motivation, and participants were asked to rate the visualizations on a scale of 1-7 for each of these metrics.

Through the interviews, we learnt that charts that had multiple axes or used multiple colors would increase cognitive load and be complex for our young demographic to understand. Our participants also stated that the use of simple graphs like traditional line/bar/pie charts would be the easiest to understand. This meant our bar charts and pie charts would be more effective than icon-based ones, as well as the more creative human silhouette and stick figure ones. We also realized we needed to focus more on the relatability and comprehensibility of the charts, rather than the creativity.

Based on this feedback, we refined our prototypes and moved on to high-fidelity prototyping in PowerBI [12] and Tableau [25]. We chose these tools since they are readily available and equipped for designing using traditional chart methods which we understood was what youth would prefer, and which would allow us to focus on the more detailed aspects of the charts rather than the structure of the graph itself. Both PowerBI and Tableau were better equipped for certain types of graphs - PowerBI offered us several choices for traditional graphs like bar charts, ribbon charts, pie charts - allowing us to customize aspects of the charts while accurately reflecting the data; Tableau allowed us to create custom charts using icons and emojis - giving us more control on the style and structure as well. Thus, we chose to divide the work among the team and prototype on both mediums to get a comprehensive high-fidelity prototype consisting of traditional as well as custom charts.

### **3.2.4 High-fidelity Prototyping**

We transferred our finalized low-fidelity sketches to PowerBI and Tableau.

We were also able to integrate the EMA data collected in our pilot to make the charts dynamic and realistic. Below, we show and describe our final high-fidelity prototypes:

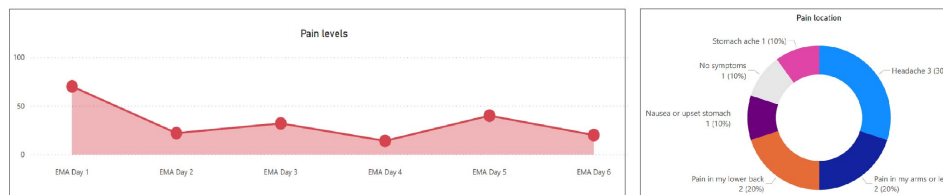
## PowerBI Sleep



**Figure 3.8:** Horizontal bar graph showing length of sleep through bar length and quality of sleep through color on left; Donut chart showing breakdown of overall sleep quality for one week

Based on the feedback on our low-fidelity prototype, we stuck to familiar chart formats like bar and donut charts. We felt using horizontal bar graphs for sleep would be good given how we could represent the length of sleep through the length of the bars and use color to encode the quality of sleep. We also use the donut chart to give a weekly summary and breakdown of the quality of their sleep.

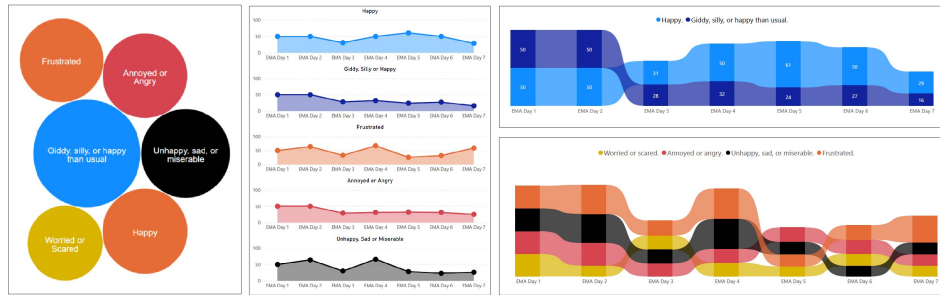
## PowerBI Physical Symptoms



**Figure 3.9:** Area chart showing intensity of symptoms daily over the week on the left; Donut chart showing breakdown of symptoms over the week

For the intensity and location of symptoms, we felt an area chart would be effective at showing the intensity of symptoms, with intensity on the Y-axis, similar to the worry graphs, and a donut chart to show the overall summary and breakdown of pain symptoms based on their location.

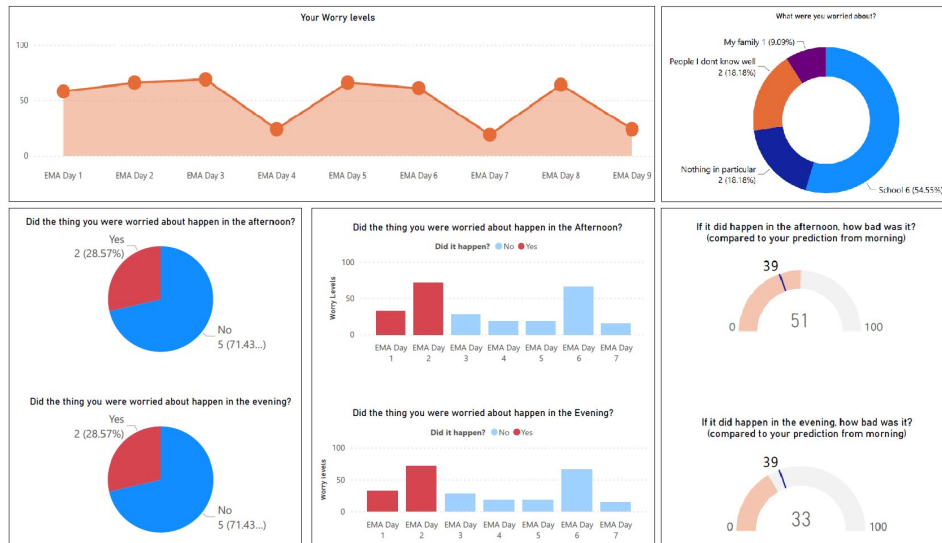
## PowerBI Emotions



**Figure 3.10:** From left to right: Bubble chart showing overall weekly total of emotions; Area charts showing detailed daily measures of each emotion; Ribbon chart showing daily emotions, with placement of ribbon on each day showing most intense emotion at the top

We thought a clustered bubble chart would be effective in showing a weekly summary of emotions, where users could spot the most intense emotion overall at a glance. For more detailed breakdowns, we had an area chart and a ribbon chart. The area chart made it easier to see individual emotions and their patterns across the week, while the ribbon chart shows the hierarchy, showing at a glance which emotion is most intense on a particular day based on the top-most emotion, while also showing an overall linear flow.

## PowerBI Worries

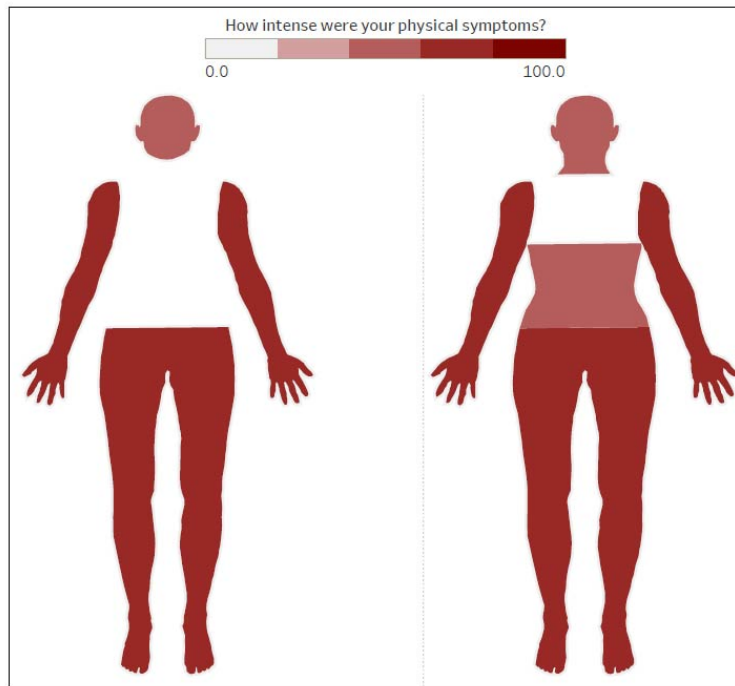


**Figure 3.11:** Top left: Worry levels over week shown through an area chart; Top right: Breakdown of categories of worries for full week as a donut chart; Bottom left: Breakdown of whether thing they were worried about happened or not as a pie chart; Bottom middle: Daily view of whether thing they were worried about happened or not as a bar chart, with height of bar showing how worried they were about thing; Bottom right: Gauge chart showing if thing happened, how bad it was compared to their prediction in the morning

We thought an area chart would be effective at showing worry levels as the shaded area and continuous nature of the graph would best depict worry changes across the week. An area chart would also be more impactful as compared to a line chart at showing the magnitude of the worry intensity due to the use of color. The donut chart would also show the weekly summary and breakdown of the categories of worries. We prototyped two versions of showing if the event happened, using a pie chart and a bar chart. While the pie chart was useful in understanding the weekly ratio of event happening vs not, the bar chart gave a better daily breakdown. The gauge chart would also help see how their predictions compared to reality, with the gauge reading showing how better or worse the event was compared to the

prediction.

### Tableau Physical Symptoms



**Figure 3.12:** Silhouette representation for intensity and occurrence of physical symptoms, with type of symptom shown based on location on silhouette, and colour representing intensity of symptom.

For intensity and location of symptoms, we felt the body silhouette graph was best, as it was easily understandable and relatable. We showed the intensity of the symptom using colour saturation, with the location of symptom based on the location of the body part on the silhouette.

## Tableau Emotions



**Figure 3.13:** Tabular representation of emotions over the week, with each day having three cells per emotion for morning/noon/evening surveys. Colour of the block represents the intensity of the emotion, legend on top right.

We prototyped showing emotions in a tabular format, with the emotions as the columns, represented using emojis which we thought might appeal to a younger audience. We also use colour to indicate the intensity of the emotion, with each day broken down into three cells, for morning, afternoon and evening.

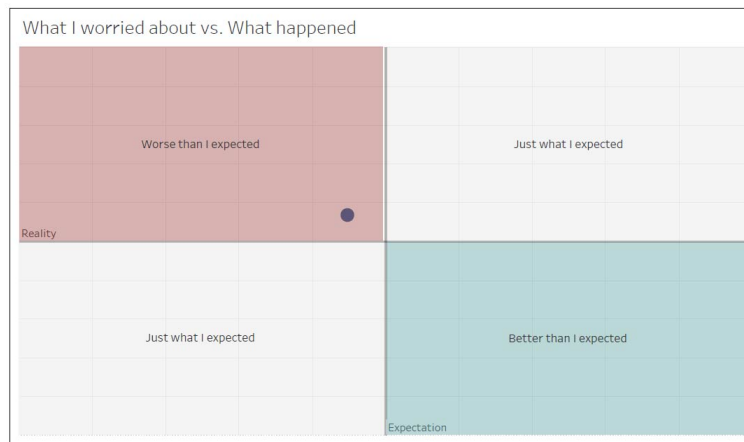
## Tableau Worries



**Figure 3.14:** Left: Icons showing what the user was worried about on a particular day, with colours to represent intensity of worries; Right: Weekly view of what worried the user, with the icon coloured according to intensity, shown for two weeks.

For showing what the user was worried about, we chose icons to represent different categories, and colour intensity to represent the intensity of their worries, with a weekly view that would show all the categories they were worried about in that week. We considered the full two-week study period here. We thought icons would be effective at representing the different categories in a constrained screen space.





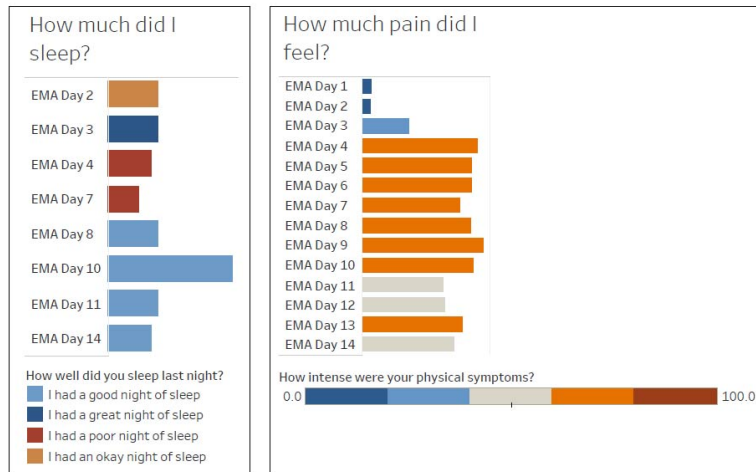
**Figure 3.15:** Quadrant representation for what user was worried about vs what happened, with expectation on vertical axis and reality on the horizontal axis

To represent the user’s view of how they expected events to be vs how they were, we thought a quadrant view would make it easier to understand. We broke the graph up into 4 quadrants, with the X-axis being reality and Y-axis being expectation. This would break the quadrants into three parts - one where reality is lower than expectation, so the event was worse than expected, on the top left; second where reality is higher than expectation, hence the event was better than expected, on the lower right, and finally two where reality and expectation are proportional, hence the event was pretty much as expected, on the top right and bottom left. While this would have some initial cognitive load for the user, we felt over time as users would get more accustomed to the visualization, this would be an effective way of showing the comparison between expectations and reality concisely.

### 3.2.5 High-fidelity Cross-comparisons

We further created prototypes of visualizations that span across categories like pain and sleep. We felt this was important as an integral part of this project was to highlight the connections between different aspects of users lives and the impact of pain symptoms on those.

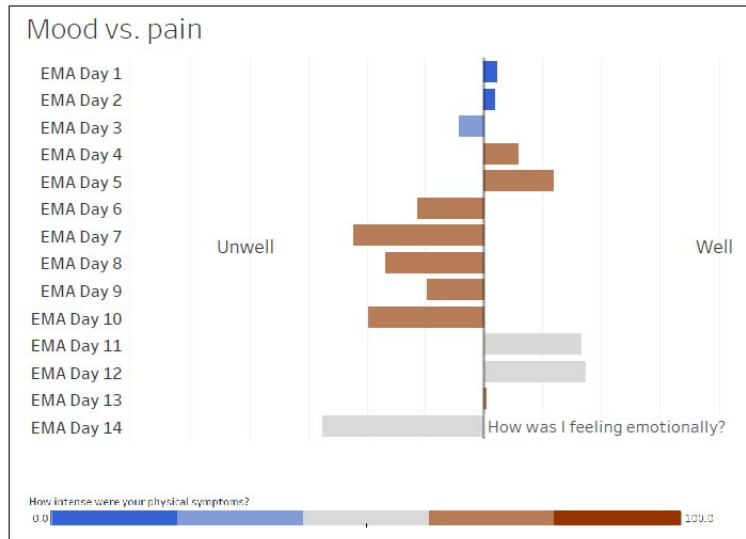
## Sleep and Physical Symptoms



**Figure 3.16:** Horizontal bar charts juxtaposed to show sleep in comparison with pain. Left chart showing length and quality of sleep, right chart showing intensity of symptoms.

We also tried to show sleep and pain juxtaposed, which we thought would help users see connections across the two categories. We kept the format consistent, using horizontal bar graphs in both places, using colour to encode the quality of sleep and intensity of symptoms. Additionally, we double encode intensity using the length of the bar, whereas in the sleep chart the length of the bar denotes the length of their sleep.

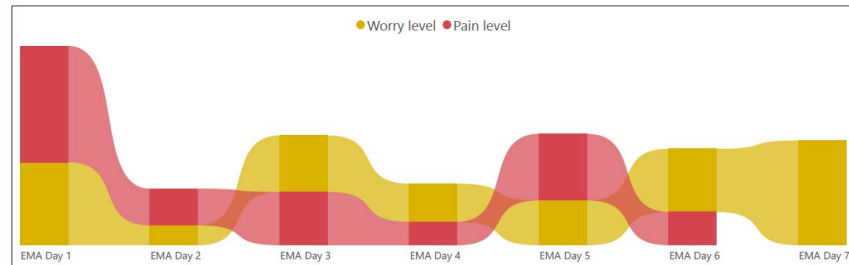
## Emotions and Physical Symptoms



**Figure 3.17:** Bidirectional horizontal bar chart showing emotions in relation to intensity of physical symptoms. Length of bar on right showed higher sum positive emotions, and length of bar on left showed sum negative emotions, with the colour of the bar showing the intensity of physical symptoms

We also integrated emotions and pain into a single visualization, as a bidirectional horizontal bar graph. The length of the bar denoted the sum emotions, with the direction on either side of the vertical axis denoting the polarity of the emotions. Additionally, the colour of the bar denoted the intensity of the physical symptoms, showing through one visualization how emotions and pain might be correlated.

## Worries and Physical Symptoms



**Figure 3.18:** Ribbon chart showing intensity of worries and intensity of symptoms, with position of ribbon on each day showing which was greater.

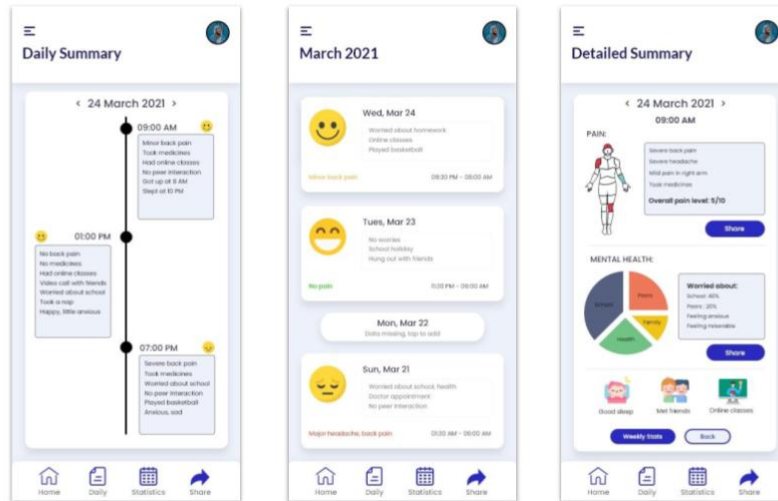
We thought showing intensities of worries and pain together might be useful, where through a ribbon chart users could see how proportional or not their worries were as compared to their pain symptoms. We felt the ribbon chart would also highlight which attribute was prominent on each day, while also showing an overall flow across the week.

### 3.2.6 High-fidelity App Prototype

We also designed a high-fidelity prototype for the mobile application that would contain these visualizations in Adobe XD, post a brainstorm and design process on the workflow of the application. The application would be a smartphone application that would visualize the data entered in the EMA surveys, on a daily, weekly and more detailed per survey basis. This would allow users to view their data at the granularity they desired, and let them engage with their data and obtain insights in a way that best suited them.

The application prototype was simply a dynamic collection of screens showing the various granularity levels of the visualizations, as well as other potential functionalities of the application like sharing and exporting data.

Below, we show some of the important screens from the app design:

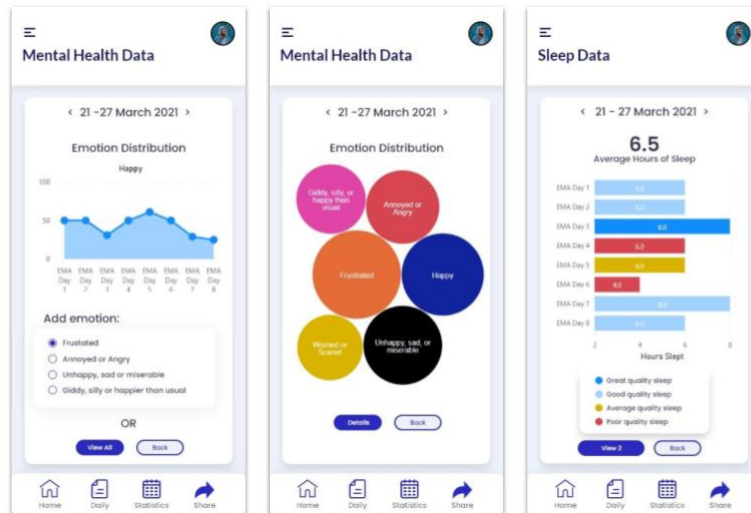


**Figure 3.19:** Mobile app screens showing, from left to right: daily summary of user health using a timeline; monthly scrollable summary of user health using tabs; detailed summary of user health by category

We wanted to design multiple views: a concise daily summary, a monthly summary, and a more detailed detailed summary, shown in 3.19. The daily summary (the left screen) would offer users a view of their day at a glance, summarizing data from the morning, afternoon and evening surveys, in concise blocks. This would allow users to track minor changes across their day. The monthly view (center screen) would be a scrollable list of more concise blocks, which would describe their worries, school attendance and activities, with a view of their overall emotion, for each day. The scrollable list would allow users to scroll through a whole month and see overall changes on a day-to-day basis at a glance, while having the ability to go into the more detailed daily view by clicking on any day they wanted to learn more about.

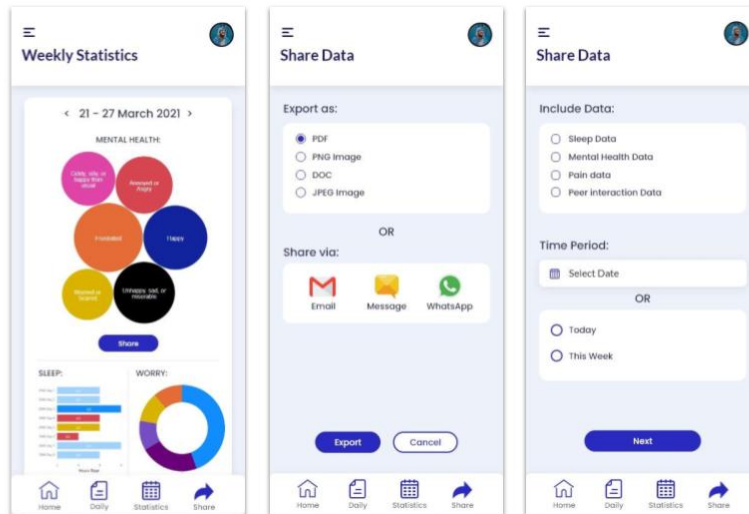
The detailed summary (right screen) screen would offer a breakdown of each of the surveys for each day, for instance presenting the data collected through the morning survey, showing the user’s pain, mental health and sleep in a concise summary and visualization. Users could navigate to the detailed summary screen from the daily view screen, clicking on each of the survey blocks for particular times

(morning/afternoon/evening) to see details for that time of the day.



**Figure 3.20:** Mobile app screens showing, from left to right: detailed emotion data through area chart, one emotion at a time; overall weekly summary of emotions through a bubble chart; weekly breakdown of length and quality of sleep

In 3.20, we show the more detailed views that embed the visualizations. The left screen would show the user's emotions, through the area charts, with an option for the user to select which emotion they wanted to view through radio buttons. On the center screen, we show the user's emotions, summarized for the entire week, through a bubble chart. On the right we show the user's sleep through horizontal bar charts. The user could navigate through weeks using the arrows near the top of each screen. Thus, screens were developed for each of the categories, some offering detailed weekly views vs other offering summarized views.



**Figure 3.21:** Mobile app screens showing, from left to right: weekly summary of mental health, sleep and worry though a bubble, bar and donut chart respectively; ability to export data; ability to selectively share data for certain categories or select time periods

In 3.21, the left screen would show the user’s weekly statistics, summarized. It would show a weekly summary of emotions, sleep and worries, giving a concise view of the whole week across multiple categories, as opposed to the more detailed views that show data for just one category at a time. On the center screen, we designed for the user’s ability to share data. One of the features we would like to enable was for users to export and share their data, and so this screen would show the options for the user to export the visualizations as a Portable Document Format (PDF), Portable Network Graphics (PNG) or Joint Photographic Experts Group (JPEG) image. They could also potentially choose to share their data through email or Short Message Service (SMS) or WhatsApp, or any other technologies they were familiar with. We realized users might also want to share only sections of their data or only certain categories with their caregivers or clinicians. They might also want to only share data for specific time periods. Thus, we added an option for users to export data only for certain categories, or only for certain time periods, which is shown on the right screen.

The design of the complete mobile application can be found in the Appendix,

as Section A.2.

We followed the designs of this prototype with another round of feedback interviews. Through convenient sampling, we scheduled five interviews with proxy users as a part of our final high-fidelity prototype feedback interviews. The participant demographics for this round of interviews were either young adults or people with chronic pain experiences. We expected young adults would have similar graph literacy as our intended user group, so they could fairly evaluate the ease of understanding of visualizations. People with chronic pain experience would fairly evaluate whether each visualization contained the information chronic pain patients would find helpful. Through this round of interviews, we aimed to obtain feedback on our high-fidelity prototype and finalize our visualization design. The general structure of this round was also a one-hour semi-structured interview session with User Experience Questionnaire (UEQ) for each of the visualizations. The UEQ scale focused on creativity, attractiveness, ease of understanding and motivation, for evaluating the visualization design. We went through all the visualizations in Power BI and Tableau first to ask for open feedback. Participants would fill out the questionnaire simultaneously. Time permitting, we also asked participants for feedback on the app design.

Feedback for the high-fidelity prototype:

- Participants liked visualizations where **only one aspect of data was displayed** as opposed to ones where we tried to show multiple aspects of data at once - this shows that highlighting only one attribute per graph was preferred as opposed to combining multiple attributes in one graph.
- **Careful use of colour** was recommended - participants found they could distinguish between and within attributes based on different colours and shades.
- Users found some charts like bar and pie charts easiest to understand, while others like ribbon graphs and treemaps required some explanation from the research team - this shows that **traditional and basic visualizations were preferred** over more complex ones. However, participants also noted that



the ribbon graph while tougher to understand, was definitely interesting - highlighting that with a proper guide/learning process, they could comprehend it.

- Participants **liked the use of graphics and icons**, but found some of them like the penguins were more suited to a younger audience.
- Users did not like the bubble charts when the difference was small as that made it hard to differentiate between the bubbles based on size alone.
- Although users found the pie charts easy to understand, they noted the absence of the temporal aspect which they felt was too important to ignore.
- There was a resounding need for the use of color consistency and saturation in showing the visualizations as certain colors weren't displayed well and would be a limitation for users with accessibility issues.

Based on the UEQ-based questionnaires:

- Participants found the visualizations overall creative
- Some visualizations were complicated and would require explanations
- The visualizations overall were motivating

These were mostly in line with their responses during the interviews as well.

### **3.3 Discussion and Next Steps**

#### **3.3.1 Drawbacks of Prototyped Visualizations**

As we evaluated our visualization prototypes with participants, we realized some of our designs were not as effective as we had hoped they would be for various reasons, which we detail below:

<b>Fig</b>	<b>Visualization</b>	<b>Design feedback and Insight</b>
3.8	Sleep pie chart	Loses daily level of detail, which is more helpful than a weekly breakdown
3.11	Worry pie chart	Not representative of what they were worried about each day, loses on daily level of detail, not useful
3.11	Worry gauge chart	Not easily understandable, not familiar to target users
3.10	Emotions ribbon chart	Hard to track individual emotions, ribbon format not providing additional value to justify use
3.9	Pain pie chart	Pie chart not effective at showing distribution throughout week
3.15	Expectation vs reality	Not easily understandable, not scalable to mobile screens
3.13	Emotions emoji chart	Too cluttered, hard to get summary, information overload, emojis on X-axis not universally understandable

### **3.3.2 Advantages of Prototyped Visualizations**

On the other hand, some of the designs were particularly liked, which gave us a helpful foundation going ahead:

<b>Fig</b>	<b>Visualization</b>	<b>Design feedback and Insight</b>
3.8	Sleep bar chart	Easily understandable, gives good insight into length and quality of sleep
3.11	Worry area chart	Shows progression of worry levels over the week simply
3.11	Event happened bar chart	Easy to see if event happened compared to worry about the event, easy to gather insights
3.10	Emotions bubble chart	Good to see weekly breakdown of emotions
3.10	Emotions area chart	Useful to see progression of individual emotions over the week
3.14	Worries icon chart	Easy to associate icons, concise way of showing worries
3.12	Pain silhouette chart	Useful to see location of symptom on body silhouette, color mapping for intensity easy to understand

### 3.3.3 Limitations

Given the timeline and scope of this project, we had certain limitations:

1. We were unable to gain access to our target demographic of teenagers with chronic pain, to involve them in our design process. We chose to substitute for the same using literature review, personas, and users nearest to the target demographic like teenagers who had just turned adults, or people with past chronic pain experiences, as well as clinicians.
2. We were limited to the number of users and recruitment methods for testing, due to time constraints. Over the course of the project, we interviewed 2 clinicians, 2 young adults, and 2 people with past chronic pain experience, as well as 3 people with design expertise, conducting overall 11 user interviews. We recruited participants we were already in contact with, or who we felt would be suitable for testing our prototype, as broadcasting calls for participation through typical sources did not yield many results.

3. Lastly, due to time constraints, we tested our user experience and data visualizations separately. This had the added cognitive load for participants to visualize what the integrated system would look like, and users might find the final integrated system more or less complex or motivating.

### 3.4 Overall Findings: Preliminary Guidelines

Based on our design process, prototypes and evaluations, we came up with the following preliminary design guidelines that could be used to guide the visualization of health data in an engaging and easily understandable format for youth with chronic pain:

1. **Use simple graphs** like line or bar charts, as opposed to more complex ones like scatterplots, or graphs with multiple coordinate systems like combo graphs. Multiple simple graphs are preferred over single complicated ones.
2. **Align labels** with spatial information in graphs as people with lower graph literacy tend to focus on spatial information and sometimes disregard labels.
3. **Integrate multiple layers of complexities**, providing users with a high-level summary of data and allowing them to explore further if they want.
4. **Use guides** to help users understand their data and provide analyses that enable them to reflect on the findings.
5. **Visualizing relationships** between data points could be more useful than simple representations of the data points for the users.
6. Clinicians and patients would find different aspects of the information useful, hence **visualizing the data in ways most efficient for each user demographic** is required.
7. Patients might not fill the survey each time accurately, which means designers **need to account for missing data points** when visualizing the data.
8. **Images, icons and colors are acceptable when they are easily associated with the intended purpose**, the difference between ratings is easily distinguishable and accessibility is considered.

9. **Temporal visualization** of data is useful for patients to track their progress.

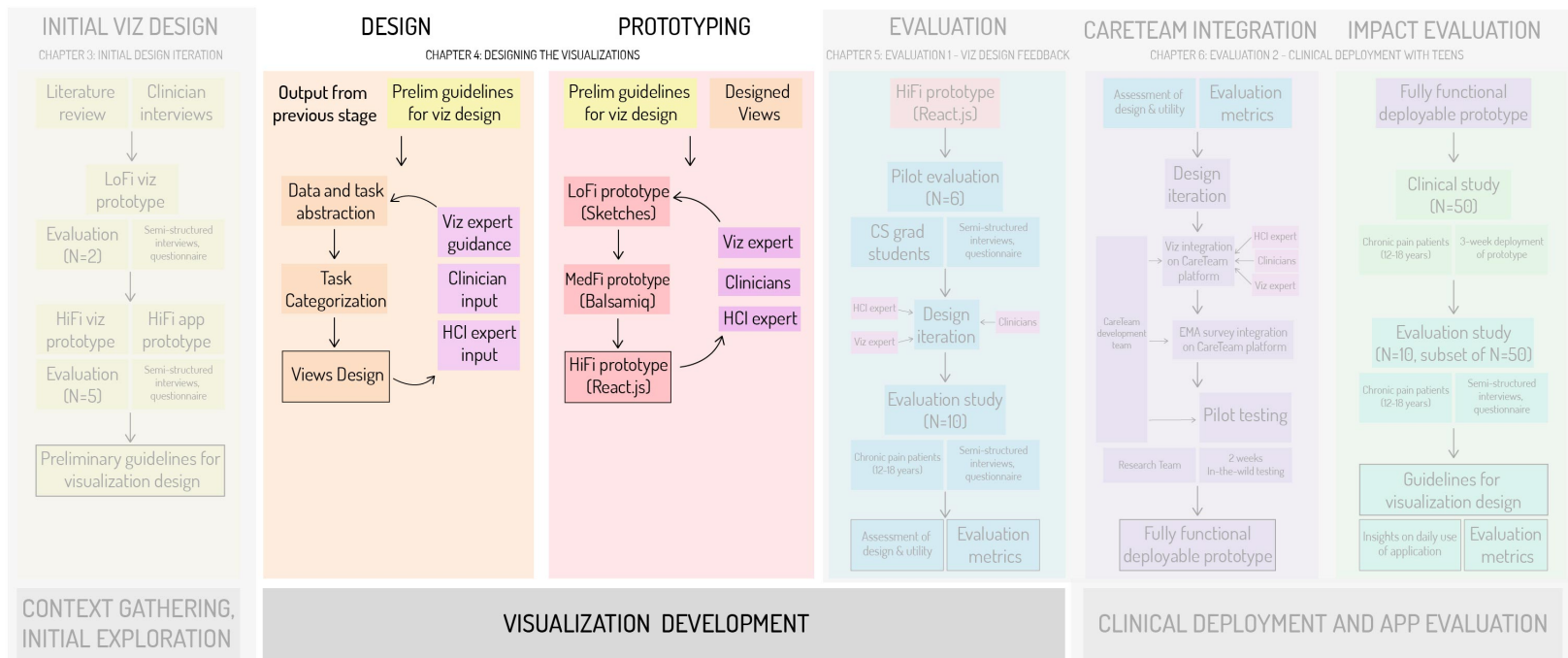
These guidelines and the feedback on aspects of the visualizations that were liked/disliked provided a strong foundation as we completed the course project and I continued on with this topic for my thesis. The preliminary guidelines were useful as we prototyped the visualizations in Chapter 4, essentially in Section 4.4. We were also guided by aspects we already knew young users would like, which simplified the design process to an extent.

## **Chapter 4**

# **Designing the Visualizations**

Post the completion of the CPSC 554K course, I decided to continue working on the project, expanding the scope and making it appropriate for a thesis. My work would continue towards the same objectives as the team project described in Chapter 3, but at a scope that enabled us to address some of the challenges exposed by the initial design pass. As a part of my thesis, we would also be able to complete the visualization design process and explore the impact of the same on the intended population in the form of a clinical trial.

In Fig. 4.1, we show the phases of the project covered in this chapter.



**Figure 4.1:** Showing the Visualization Design and Prototyping phases discussed in this chapter

While the focus during our Initial Design Iteration had been the holistic design of an application for teens that included visualizations, the goal of my thesis would be to focus on the visualizations themselves: their detailed, user-centered design and evaluation for potential impact as a treatment intervention for youth with chronic pain.

To that end, while we had followed a user-centered design process in the course of the DFP project, to focus now on the visualization design specifically, we needed to follow a visualization design process. We followed Munzner's [68] nested model for visualization design and validation.

## 4.1 Data and Task Abstraction

In her book *Visual Analysis and Design* [27], Munzner proposes the *what-why-how* framework for a visualization instance.

The *what* refers to what data the user sees. The *why* is the task - why is the user using the visualization tool. The *how* is the idiom or visual encoding created to answer the *why* using the *what*.

The dataset we were visualizing was a table comprising one individual's EMA data, collected three times/day for two weeks. Each row of the table was populated with the results of one complete EMA survey response. For this iteration, we focused on views that could accommodate two weeks of consecutive data, so one respondent's database held up to 14 rows of data.

In our visualization design process, Sections 4.1.1 and 4.1.2 answer the *what* and the *why* - what data the user will see and why will they be using the visualization. Section 4.4 answers the *how*, or the visual encodings created for the data.

**Data** in our case is defined as what the user would be seeing: the responses to the EMA questions assessed within the EMA categories defined in Chapter 2. **Tasks** operationalize the purpose that users would use our visualization tool for, *e.g.*, finding periods of high intensity pain or good sleep. This process helped us realize which aspects of the data we could visualize to what purpose.



### 4.1.1 Data Abstraction: Attributes, Classes and Types

In this stage, we defined our data *attributes* and *classes*. This helped us focus on what data we had that could be visualized. Further classifying the data attributes into *types* enabled us to see what attributes could be grouped together in a single combination, what attributes might need to be derived, and which might need to be modified.

**Classes (of Attributes):** As overarching classes, we used the aspects of users' lives that the EMA categories focused on, explained in Section 2.3: Sleep, Worry, Emotions, Peer Interactions, Physical Symptoms, and School.

**Attributes (Direct and Derived):** In our database we designated each EMA question as a *direct* attribute, and then assigned each attribute a column in our database. We defined some additional *derived* attributes from existing ones based on task abstraction, *i.e.*, based on the tasks defined in our task abstraction below (Section 4.1.2).

**Types:** We further classified the attributes based on their type: either *categorical*, *quantitative*, *sequential*, *ordinal*, or *open-ended* [27].

**Thus to illustrate:** Sleep became a class, whereas the time the user went to sleep and awoke became attributes – *time of going to sleep* and *time of waking*, respectively. The duration of their sleep became a derived attribute, calculated from the previous two rather than being explicitly asked. Sleep (class) *quality* (attribute) was of categorical type because it could be one of [great/good/okay/poor]. Conversely, the Sleep attribute of *time of going to sleep* was of quantitative type.

A more detailed breakdown of all the classes and attributes and their types is given in Table 4.1.

### 4.1.2 Task Abstraction

Task abstraction allows us to focus on why the user would want to use visualization - what are they looking for, how can we make the visualization useful for them? Munzner provides two abstract terms - *actions* and *targets* (types of *tasks*) – to frame the tasks and distinguish between user goals.

**Actions** are things the user could do with the tool. We ideated these actions by considering three higher-level motivating objectives:

**Table 4.1:** Data Abstraction: Our data classes and the typed attributes that describe them.

Class	Attribute ( <i>Attribute Type</i> ; * = <i>derived attribute</i> )
Sleep	Time going to sleep ( <i>Quantitative - numeric time</i> ) Time waking up ( <i>Quantitative - numeric time</i> ) Sleep quality ( <i>Ordinal - poor/okay/good/great</i> ) Sleep duration ( <i>Quantitative - count of hours</i> ) *
Worry	Most worried about ( <i>Open-ended, Unordered</i> ) Thing I am most worried about ( <i>Categorical - family/friends/-work/school/etc</i> ) How worried am I ( <i>Sequential - min 0 to max 100</i> ) How certain that thing will happen ( <i>Sequential - min 0 to max 100</i> ) How bad do you think it will be ( <i>Sequential - min 0 to max 100</i> ) Did the thing happen ( <i>Categorical - Yes/No</i> ) How bad was it ( <i>Sequential - min 0 to max 100</i> ) Did you do anything to avoid it ( <i>Categorical - Yes/No</i> )
Emotions	Worried or scared ( <i>Sequential - min 0 to max 100</i> ) Happy ( <i>Sequential - min 0 to max 100</i> ) Annoyed/Angry ( <i>Sequential - min 0 to max 100</i> ) Unhappy/Sad/Miserable ( <i>Sequential - min 0 to max 100</i> )
Peer interactions	Frequency of interactions ( <i>Ordinal - None/Some/A lot</i> ) Worry about interactions ( <i>Sequential - min 0 to max 100</i> )
Physical symptoms	Worry about experiencing symptoms ( <i>Sequential - min 0 to max 100</i> ) Symptoms ( <i>Categorical - Headache/Dizziness/Pain/Nausea/etc</i> ) How intense were the symptoms ( <i>Sequential - min 0 to max 100</i> ) Medications taken ( <i>Open-ended, unordered</i> )
School	Did you go to school ( <i>Categorical - Yes/No</i> ) If not, why ( <i>Categorical - Weekend/Home sick/Doctor appointment/etc</i> )

1. **Analyze:** Users can consume existing data by discovering or deriving new knowledge from existing data.  
*Example from this research:* Discovering nights when sleep was the best or worst.
2. **Search:** Users can also want to search for data.  
*Example:* Looking up days when symptoms were of particularly high intensity.

3. **Query:** Users might also want to query results that are an output of a **Search**.  
*Example:* When searching for days where intensity of their pain was the highest, compare pain intensities on two particular days.

**Targets** are aspects of the data that are interesting to the user. Targets of particular interest to us are of three types, all relating to the classes defined in Table 4.2:

1. **Temporal trends within a class:** Any pattern in the data for instance increases, decreases, peaks and plateaus. In our case, users might be interested in seeing trends of their worries: do their worries seem to increase on school days? Do they worry more on the weekends? Are there patterns in their worries across the weeks?
2. **Correlations between attributes:** Exists between two attributes if the value of one co-varies with another. A correlation between the quality and worry about peer interactions might be of interest to our users: does worry of the interaction vary based on the quality of their previous interactions?
3. **Cross-class comparisons:** In our abstraction design stage, we highlighted high-value cross-class targets (for instance, comparisons between *Emotion* and *Sleep* - does lower sleep seem to correspond to particular emotions, or do intense emotions seem to correspond to varied sleep quality?) so that we would be mindful of the attributes and connections required to visualize across classes when later designing *views*. Given the multidimensional quality of pain, we wanted youth to be able to reflect across classes and see if/how their symptoms affected other aspects of their life like their sleep, mental health and emotions.

A more detailed breakdown of all tasks is in Table 4.2.

## 4.2 Categorizing Tasks

Our next step was categorizing the tasks. Given the number of tasks generated in Section 4.1.2, we decided to categorize them in order to prioritize patient-centric tasks compared to designer/clinician-centric ones. We also narrowed down on tasks

**Table 4.2:** Task Abstraction – Data classes (Section 4.1.1) with the *actions* they support and data *target* that they will reveal. Cross-class targets are highlighted [**X-Class**].

Class	Task Type	Task Description
<b>SLEEP</b>	<b>Actions:</b>	Present overview of sleep/Summarize sleep data Discover nights where sleep was best/worst
	<b>Targets:</b>	Trends in sleep pattern
<b>WORRY</b>	<b>Actions:</b>	Discover what worries the user the most Compare expectation to reality (how bad it might be vs was)
	<b>Targets:</b>	Trends in how bad things actually are vs expected Trends in if things actually happen vs they're expected to
	<b>X-Class:</b>	Correlation between past sleep quality and worry intensity
<b>EMOTIONS</b>	<b>Actions:</b>	Summarize emotions over a time period Compare emotions over a time period
	<b>Targets:</b>	Trends for each emotion Identify periods of high-intensity emotions
	<b>X-Class:</b>	Correlation between sleep and emotions
<b>PEERS</b>	<b>Actions:</b>	Compare quality of interactions over a time period Compare worry about interactions over a time period
	<b>Targets:</b>	Correlation between frequency and worry of interactions Trend in interactions
	<b>X-Class:</b>	Correlation between emotions and peer interactions
<b>SYMPTOMS</b>	<b>Actions:</b>	Discover which symptoms are most common Discover when symptoms are most intense Discover which symptoms are most intense Compare symptoms over a time period Compare intensity of symptoms over a time period
	<b>Targets:</b>	Trend in intensity of symptoms Trend in which symptoms present when
	<b>X-Class:</b>	Correlation between sleep and intensity of symptoms Correlation between intensity of symptoms and peer interactions
<b>SCHOOL</b>	<b>Actions:</b>	Lookup days when not going to school
	<b>Targets:</b>	Trend in school attendance
	<b>X-Class:</b>	Correlation between physical symptoms and attendance



*flective*' tasks being those that would require or motivate reflection from the user. These tasks are the ones in lighter shades, *i.e.*, light yellow and light blue. For instance, when looking at the following two patient tasks, Task 2 (correlation) would require more cognitive effort and reflection:

1. Discover which symptoms are the most common (non-reflective: dark yellow)
2. Correlate between sleep and intensity of symptoms (reflective: light yellow)

Similarly, when considering the following clinician tasks, Task 2 (correlating how bad things are with avoidance) requires more reflection to analyze:

1. Discovering what worries the patient the most (non-reflective: dark blue)
2. Correlation between how bad things are and if they did anything to avoid the situation (reflective: light blue)

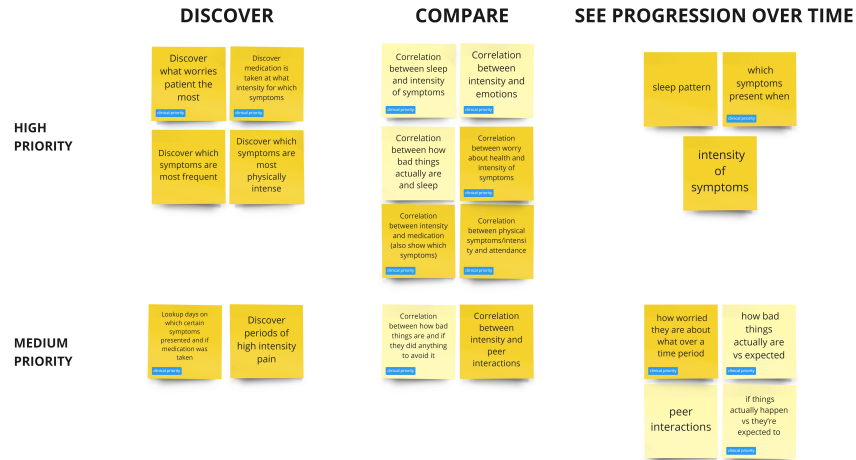
Since our goal was to enable personal data exploration as opposed to simply viewing it, we prioritized *reflective* tasks for *patients*, to elicit more engagement and reflection from our users of most immediate interest.

As we iterated upon this categorization, we realized designing for all of these tasks would be complicated and out of scope for this thesis. Not only were there a lot of tasks, but there were many correlations - many tasks that would use the same attributes in different ways, which would be more complex to design for. Given the scope of this thesis, we decided to focus on only on patient-centered ones, and to leave out low priority tasks for the present. However, to make sure we still were designing something that would be usable by both clinicians and patients, we consulted with the clinical team to find common patient tasks that would also be relevant to them, as well as added select clinically-relevant tasks to the final board.

We also split the tasks into three types: *Discover*, *Compare* and *See progression over time*.

In *Discover* tasks, users extract information from a single visualization, for instance discovering what worried them the most. In *Compare* tasks, users reflect on more than one visualization, *e.g.*, correlating between sleep and intensity of

## PATIENT TASKS



**Figure 4.3:** Final list of tasks, categorized as Discover/Compare/Progression over time, and prioritized as high or medium, with more 'reflective' tasks in light yellow

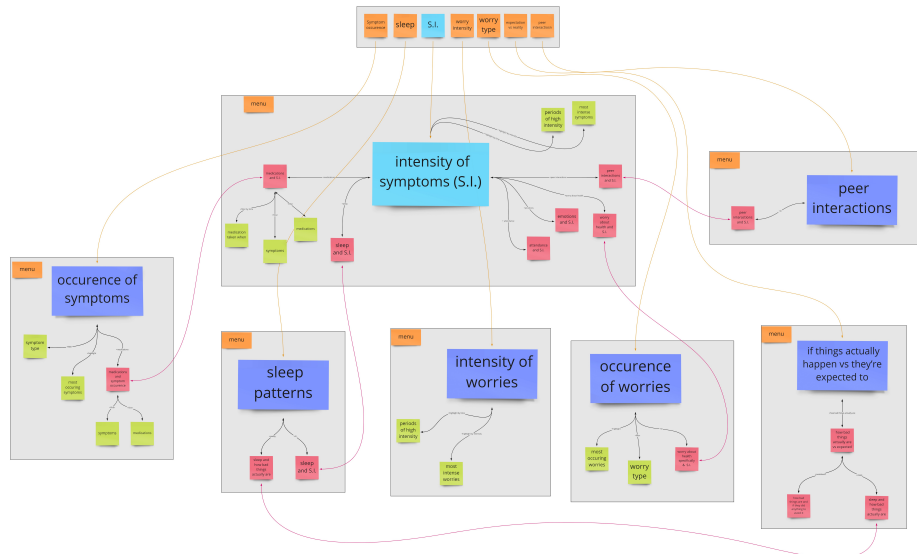
their symptoms. In *Progression over time* tasks, users would consider trends, for instance sleep patterns.

Figure 4.3 shows the final categorization. Tasks that were *also* relevant to clinicians have been tagged with blue tags in the lower left corner. As previously, reflective tasks are in light yellow.

### 4.3 Designing Views

With our tasks completed, we moved on to designing views, or how we wanted the user to be able to navigate the application.

Our final layout for this stage of the views is shown in Figure 4.4. We wanted *Intensity of symptoms* to be the central aspect of the visualization application, and hence show the same in the design above as well. *Intensity of symptoms* is the primary view, with all other views connected to it. We have a menu at the top, from where users can select other views they wish to navigate to. Each view is



**Figure 4.4:** Layout of views, with arrows showing possible user navigation workflows. Blue notes are the central visualizations for each view, orange notes are used as headings in a main menu, green notes are *Discovery* or *Progression* tasks and pink notes are *Compare* tasks.

based on the classes of the data and contains the categorized tasks from above, and is shown as a box with a grey background. Based on the tasks in 4.2 and their further categorization in 4.3, each view here has a central visualization, highlighted in blue. For instance, *Occurrence of symptoms* is the main visualization for the view on the bottom left. *Discover* tasks from Figure 4.3 are noted in green here, for instance highlighting the most occurring symptoms in the *Occurrence of symptoms* view. Each *Compare* task is shown as a pink note, with the attribute to be compared shown over the arrow. For instance, to compare medications and symptom occurrence in the *Occurrence of symptoms* view, one would need to add the medication attribute to the central visualization.

Views are further connected by *Compare* tasks, for instance medication and symptom occurrence is also connected to the intensity of the symptoms and so the two views *Occurrence of symptoms* and *Intensity of symptoms* are connected. Orange notes are simply the menu, with the orange arrows connecting all the views



to the main menu. Thus, Figure 4.4 above shows the design of all the views and how they are interconnected to complete the holistic visualization application.

This final design was also made through a process of iterations, with guidance from the clinical team as well as visualization and HCI experts. Through the iterations, we rearranged tasks, decided to highlight central visualization for each view, established navigation between views, and highlighted discover vs compare tasks for clarity.

## **4.4 Prototyping: Process and Evolution of Visualizations**

Once we had established our views and the overall layout, we were in a position to start prototyping the visual encodings. We went through three stages of prototyping: starting with low fidelity hand-drawn sketches, moving to medium fidelity in Balsamiq, and finally converging on a high fidelity version in React.js. At each stage in the prototyping process, we iterated on the designs with guidance from visualization and HCI experts, and taking feedback from the clinicians on the designs as well. Visualizations were designed and iterated upon with weekly check-ins for a period of 2.5 months. We discuss the visual encodings on a Class level (from Section 4.1.1), showing for each the low, medium and high fidelity prototype.

We evaluated these designs in a pilot described in Chapter 5, based on which we made a number of design changes. We include the final prototype version, post those changes, in the present section, to give a complete overview of how the final visualization evolved in each case and what it looked like before it was presented to our target demographic.

### **4.4.1 Design Principles: First Take**

Through this process, we initially followed accepted visualization design principles, aiming for high engagement as well as understandability. However, over the course of our research and including feedback from both users and domain experts, we found some areas in which it appears it may be appropriate to diverge from convention.

In Table 4.3 we state a first version of the “principles” which seemed to be

serving us, as well as the design decisions we made to integrate those principles in our visualizations, while also listing figures where those principles and decisions can be seen reflected. We also note instances where these principles seemed to differ from conventional guidance.

**Table 4.3:** Overall Design Principles and Decisions that evolved through the the Prototyping process (Convergence (C) and Divergence (D) of the principles from existing visual design guidelines is shown in the last column)

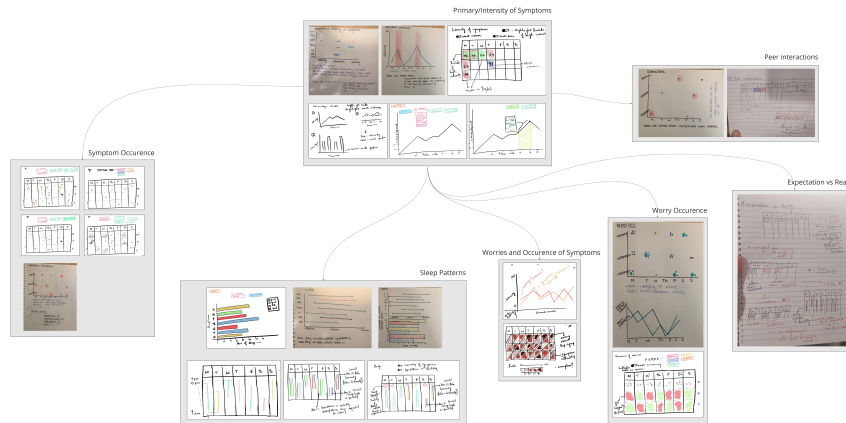
Fig	Design Principle [DP]	Design Decision	C/D
4.7	<b>DP1</b> – Using numbers to show intensity of symptoms or worries is not useful. Comparison to earlier intensity is better.	Switched to heatmap to show comparisons to earlier values.	C
4.7	<b>DP2</b> – Binaries like avoiding a task or taking a medication that only have Yes/No answers in the survey, can be represented simply by using icons.	Icons used to show medication or avoidance, overlaid on other visualizations.	C
4.6	<b>DP3</b> – Reserve colours for highlighting important information. Limited palette of contrasting colours available, thus use only for significant events.	Use of single colour within visualization, use of contrast to highlight differences, colour-coded categories of visualizations.	C
4.12	<b>DP4</b> – Highlight similarity, group similar visualizations logically.	Colour-coded visualizations based on logical grouping like Sleep, Physical Symptoms, Emotions, Mental Health, Social Interactions.	C

Table 4.3 continued from previous page

Fig	Design Principle [DP]	Design Decision	C/D
4.10	<b>DP5</b> – Maintain consistency for better comprehensibility and less cognitive effort.	Kept several visualization encodings consistent for similar mappings, for instance heatmaps for intensity of symptoms and worries, bar charts for worry vs certainty and worry about peer interactions.	D
4.9	<b>DP6</b> – Heatmaps are better than line charts or scatterplots, compact and easy to compare with other visualizations.	Used heatmaps for intensity of symptoms and worries, to allow comparison with other visualizations.	D
4.10	<b>DP7</b> – Facilitate easy comparisons across visualizations, show all information at once.	Vertical alignment of visualizations to allow for comparisons across charts, weekly format shows sizeable amount of data without information overload.	C
4.6	<b>DP8</b> – Prototype on target screen size.	Higher fidelity mockups were done on mobile screens as those were the dimensions end users would use.	C
4.7	<b>DP9</b> – Account for missing data points.	Distinction made for <i>data not filled out</i> vs <i>zero value data</i> points by using ‘X’s or other marks in the visualizations.	C
4.12	<b>DP10</b> – Allow for personalization and preferences of what users want to see.	Modular layout so users could potentially rearrange and sort the visualizations according to their preferences, keep only the ones they want.	C

## 4.4.2 Prototyping Steps

We carried out detailed design for a total of 11 visualizations, described in detail in the next section. For each, we moved through three phases of prototyping.



**Figure 4.5:** Miro board showing the result of the brainstorming process, employing hand-drawn sketches. The layout is the same as in Figure 4.4

**Low fidelity approach:** After designing the views, our next step was creating the visual encodings for the views. We began by creating hand-drawn sketches of the visual encodings, brainstorming to come up with a variety of visual encodings we could then refine (Figure 4.5).

**Medium fidelity approach:** Based on the design decisions made for the sketches, we moved ahead to designing our medium-fidelity prototype in Balsamiq. At this stage, we had begun to narrow down on what we wanted our final visualizations to look like. We decided to design a single scrollable screen, with modular visualizations that we would then ideally be able to move and rearrange as required, reducing the need for user actions. We also decided to be consistent with the format, i.e following a calendar-based weekly format, with all the days of the week for one week on the X-axis for all the visualizations, since this would make it easier for youth to cross-compare classes. We also decided to use color-coded classes,

so it would be easier for youth to visually group the visualizations. We designed using the mobile screen size ensuring the readability of the visualizations would remain intact for the end users and chose visualizations that were geared towards enabling users to reflect and derive their own interpretations rather than providing interpretations from the data ourselves.

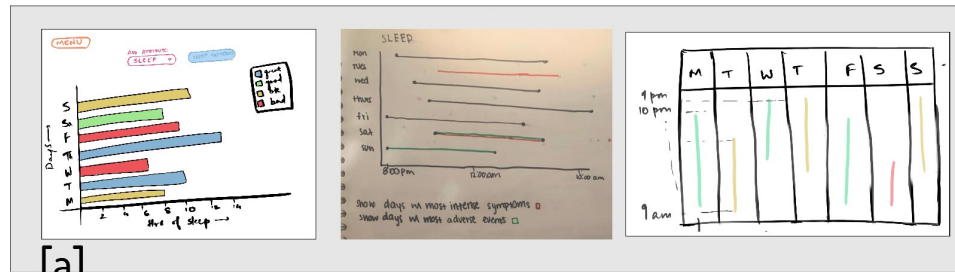
**High fidelity approach:** At a certain point, we were satisfied that we had iterated and refined the medium-fidelity prototype to the best possible version. At this point, we discussed the best medium for a high-fidelity prototype, among GoodData [9] or React.js [1]. Our options were constrained as we would be collaborating with CareTeam [10] to make the complete application on their platform. CareTeam uses React.js as their framework, and hence we arrived at a decision to use the same to create the high-fidelity prototype, to reduce deviation in the final deployment version. We discuss more about the collaboration with CareTeam and the final deployed designs and their deviation from our prototype in Chapter 6.

For our high-fidelity prototype in React.js, we used ApexCharts [7], an open-source charting library for React.js. This reduced our work of starting to code the charts from scratch, and allowed us to focus on the more intricate design details. For the data, we used the sample dataset we had created as a part of CPSC 554K. We also moved from a week span to visualizing over two weeks, given that the span of the study was two weeks and we felt it would be easier to see patterns over a longer period of time. The same was reflected in all the high-fidelity visualizations.

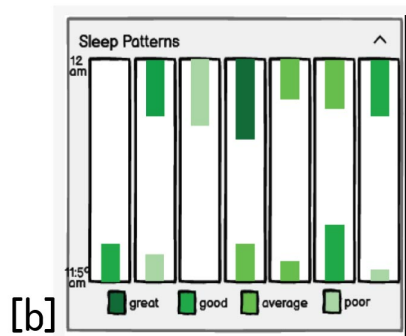
### 4.4.3 Individual Visualizations

We discuss the prototypes below per visualization, showing the low-medium-high fidelity evolution for each of them along with explanations on design decisions made. The high-fidelity versions shown for each visualization are post-pilot versions, and are the ones shown to the target demographic in our first round of evaluations, discussed in ??.

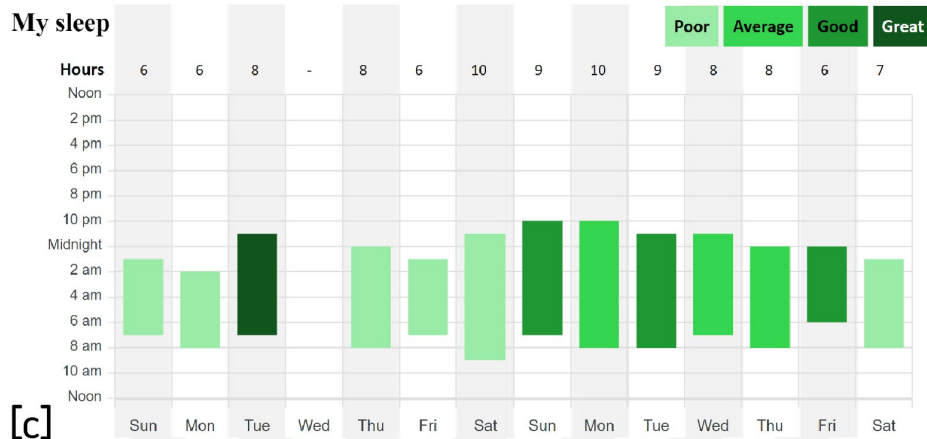
## Visualization: Sleep



[a]



[b]



[c]

**Figure 4.6:** Visualization prototype for Sleep showing the: [a] Low fidelity, [b] Medium fidelity, and [c] High fidelity prototype

For sleep patterns, we had three data points to plot:

1. The time the user went to sleep

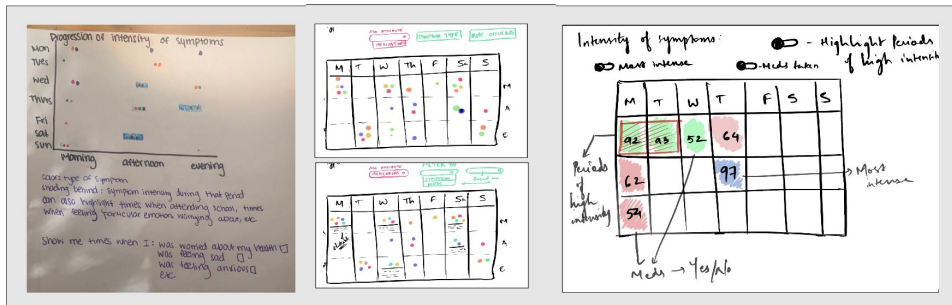
2. The time the user woke up
3. The quality of their sleep

*Low-fidelity:* [Figure 4.6 [a]] We began with two main design formats, one representing sleep horizontally and the other vertically. Horizontally, we thought of horizontal bar charts with the length of the bar denoting the length of sleep. We also thought of horizontal range charts with time on the X-axis to also encode the time of sleep. In vertical designs, we thought of range bars in a calendar format, which could also give us the potential to add more bars to compare other attributes like pain intensity in the same graph. We commonly thought of using colour to denote quality of sleep.

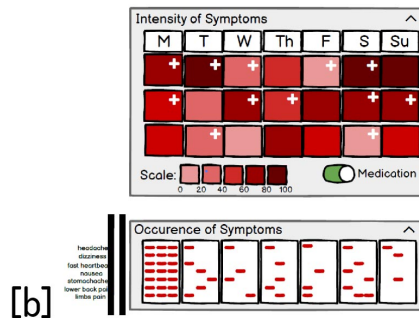
*Medium-fidelity:* [Figure 4.6 [b]] In the medium fidelity prototype, we chose to keep the range charts, but with a Y-axis that spanned from midnight to midnight. The Y-axis started from 12am and ended at 11:59pm. This would allow us to show sleep as an ‘overlapping’ entity - one that began on a particular day but ended on the next. Thus, each night’s sleep would be split across 2 days. This would make it easy for users to be able to see patterns in what time they went to bed or what time they woke up. We also used the color to encode the quality of their sleep, with 4 distinct levels of saturation for green, a colour now reserved for the sleep visualization.

*High-fidelity:* [Figure 4.6 [c]] We moved the legend to the top right, and also changed the order going from worst to best, as was also in all the other legends. We also changed the Y-axis to range from noon to noon across two days, as splitting the sleep bar across days was leading to losing the length of sleep data encoding. We also added the number of hours at the top, to better show the length of sleep information.

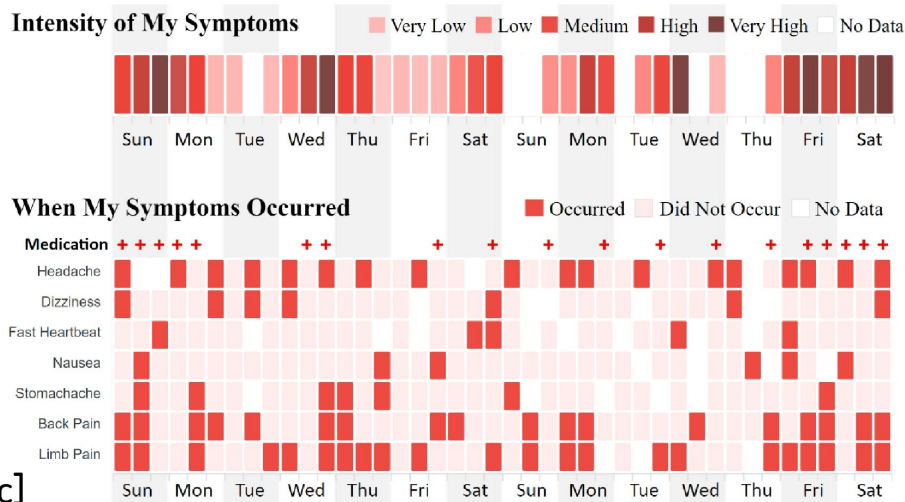
## Visualization: Intensity and Occurrence of Symptoms



[a]



[b]



[c]

**Figure 4.7:** Visualization prototype for Intensity and Occurrence of Symptoms showing the: [a] Low fidelity, [b] Medium fidelity, and [c] High fidelity prototype



For intensity of symptoms, we had three data points to plot:

1. The numeric intensity of the symptom (from 0-100)
2. The time and day it occurred
3. If any medication was taken

For occurrence of symptoms, we had three data points to plot:

1. The type of the symptom (from 8 predetermined categories)
2. The time and day it occurred
3. If any medication was taken

*Low-fidelity:* [Figure 4.7 [a]] For Intensity of Symptoms, we came up with a bunch of different ideas, ranging from line charts to bar charts, to heatmaps. All our ideas focused on showing the numeric intensity, allowing users to discover trends in the intensity of their symptoms. We also agreed on overlaying additional information like intense periods of pain or times medications were taken to highlight them.

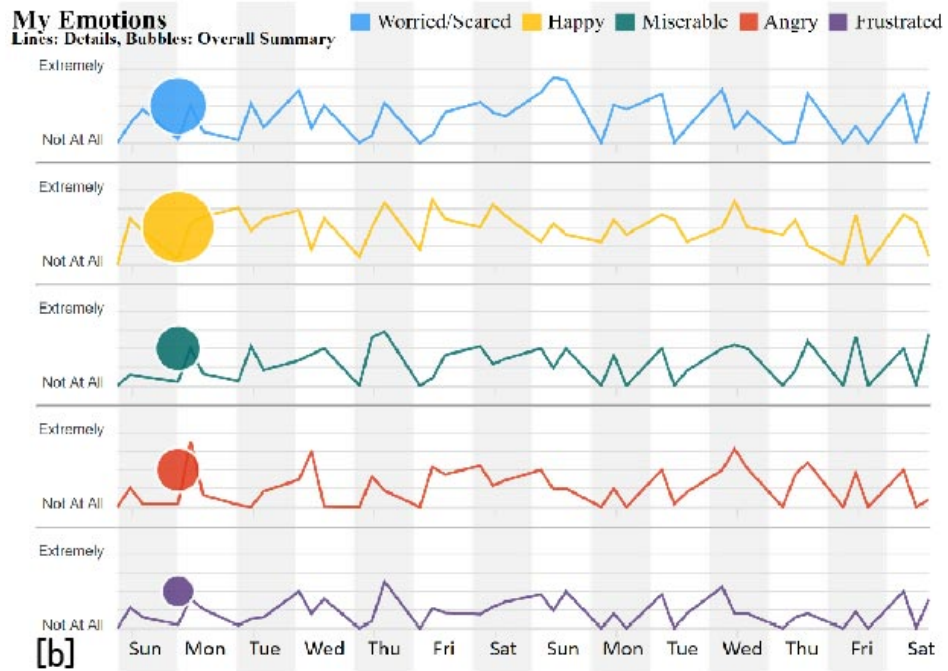
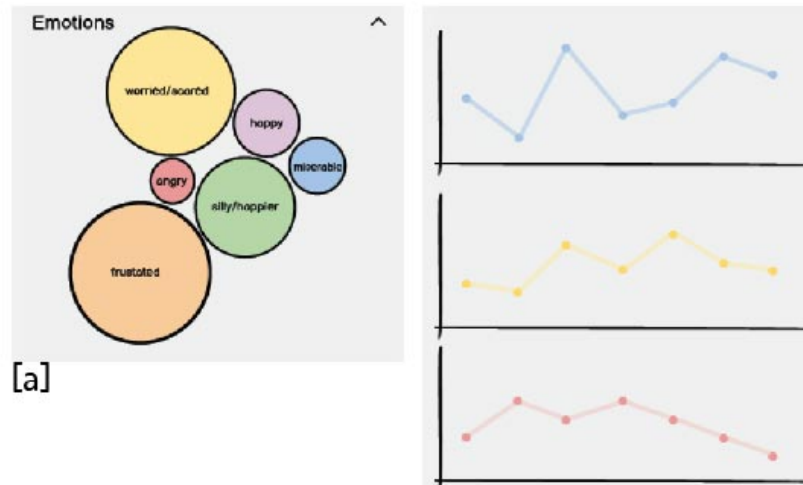
For Occurrence of Symptoms, interestingly, we all came up with dots on a calendar format, as we felt that was the best way to show maximum information through a single screen. We also liked the idea of being able to manipulate data through the same view, using filters, allowing us to highlight the most occurring symptom or specific ones.

*Medium-fidelity:* [Figure 4.7 [b]] For intensity of symptoms, we chose a heatmap for each week. We have three cells vertically per day since the data was collected in each of the morning, afternoon and evening surveys. We used a 5-point scale to represent the numeric intensity categorically through colour intensity. We used red for both the symptom charts, with 5 distinct levels of saturation to keep them clearly distinguishable. Based on if they took medication at that point, we showed a white plus sign on the top right for that cell, since the icon would also be globally familiar and associated with medicine. Since the symptoms are the central aspect of these visualizations, these are the first ones to be shown. For occurrence of symptoms, we used horizontal slotted bars, with each day horizontally divided into three segments for morning, afternoon and evening. If the symptom occurred,

we showed the filled red slot for that day and time, else it was blank. We also arranged the symptoms according to the way they might present in the human body, i.e. from head to toe. This visualization was also in red since it also belonged to the symptoms class. We also showed these two together, allowing users to compare both charts and be able to see associations and patterns between them.

*High-fidelity:* [Figure 4.7 [c]] An important change we made was moving the medication to the *Occurrence of symptoms* chart instead of the *Intensity of symptoms*. As we iterated, we felt it would be more valuable to users to see medication linked to particular symptoms as opposed to the intensity as the medication pattern might vary based on symptoms. For the ease of implementation, we also removed toggle buttons, instead simply choosing to show medication present at all times when it was taken. We also moved from a numeric scale to a more categorical one for the intensity of symptoms, since we felt that would be more understandable. We also integrated visualizing missing data points, by the addition of grey markers for *No Data* in the *Occurrence of symptoms* graph. We also decided to split the *Intensity* graph horizontally for each day, instead of vertically as in the medium fidelity, as we felt that would better allow readers to compare the two *Symptoms* graphs.

## Visualization: Emotions



**Figure 4.8:** Visualization prototype for Emotions showing the: [a] Medium fidelity, and [b] High fidelity, prototype

For emotions, we had five data points to plot:

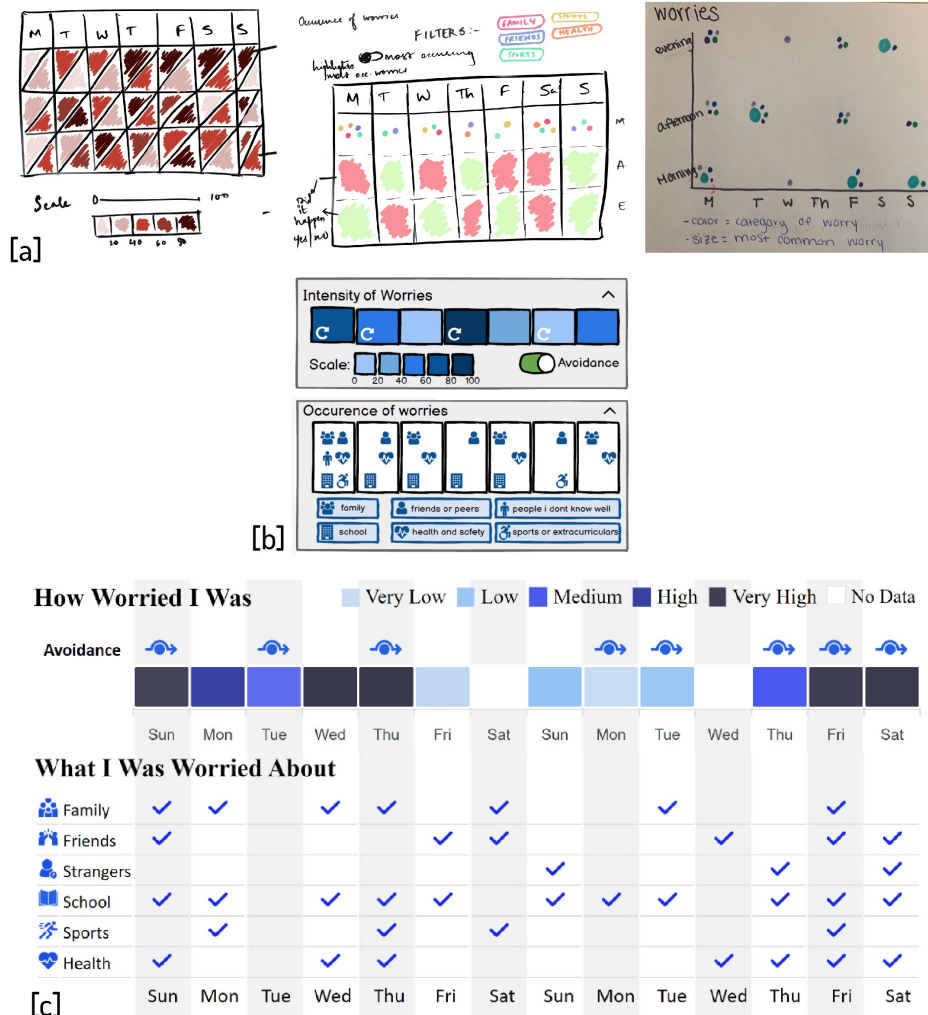
1. How worried/scared the user was (from *Not at all* to *Extremely*)
2. How happy the user was (from *Not at all* to *Extremely*)
3. How miserable the user was (from *Not at all* to *Extremely*)
4. How angry the user was (from *Not at all* to *Extremely*)
5. How frustrated the user was (from *Not at all* to *Extremely*)

*Low-fidelity:* During low-fidelity prototyping, we did not consider Emotions as a view that needed an encoding of its own, instead considering it as an overlay on the *Intensity of Symptoms* visualization, as seen in the view for Intensity of Symptoms in 4.4. However, as we moved on to medium-fidelity and decided to keep each visualization simple and modular, we created separate visualizations for Emotions as well.

*Medium-fidelity:* [Figure 4.8 [a]] For emotions, we liked the idea of having a summarized vs detailed version, and allowing users to focus on whichever one they wanted to. Hence, we used bubble charts, which showed summarized emotions for the whole week. This allowed them to see at a glance what emotion was the most or least intense. However, in case they wanted a more detailed understanding, there were also the line charts below, which showed the emotions across the whole week. This would enable them to spot trends across the week. Further given the continuous nature of an emotion compared to the more episodic nature of an interaction or pain episode, we felt a line chart with a continuous line showing movement would be more accurate rather than a scatterplot or bar chart. We also chose pastel colours not repeated anywhere else in all the visualizations to make sure users could distinguish easily and yet have the colours encode the distinct emotions.

*High-fidelity:* [Figure 4.8 [b]] We overlaid the bubbles on the more detailed line charts, based on feedback from the pilot in Chapter 5. We were unable to overlay the emotion labels on the bubbles, and hence a legend was added to the top right. The *Each emotion from 0 to 100* followed the same legend and order as the bubble chart for consistency. We also chose shades of colours that were not used anywhere else in any of the other visualizations, and associated colours with the emotions arbitrarily since we did not want users to explicitly associate any particular mood with a particular colour.

## Visualization: Intensity and Occurrence of Worries



**Figure 4.9:** Visualization prototype for Intensity and Occurrence of Worries showing the: [a] Low fidelity, [b] Medium fidelity, and [c] High fidelity prototype

For intensity of worries, we had two data points to plot:

1. The numeric intensity of the worry (*from 0-100*)

2. The time and day it occurred

For occurrence of worries, we had two data points to plot:

1. The category of worry (*Friends/Family/Strangers/Health and Safety/School/Extracurriculars/Others*)
2. The day

*Low-fidelity:* [Figure 4.9 [a]] We came up with two ways of representing it, one as a line chart, which would allow us to add more attributes to it as required, and the other as a heatmap in which we could split the cell to show other attributes as well. We thought this might be a chart best used in combination with other attributes, and so brainstormed ways in which this graph could accommodate other attributes like intensity of symptoms.

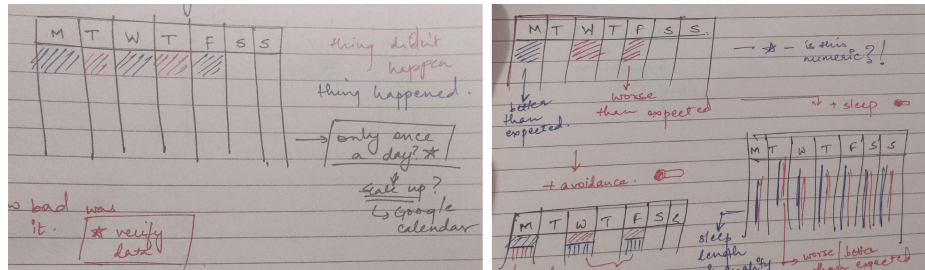
We mainly thought of representing the categories as dots, with colour encoding the category. In addition, in the top chart, we envisioned using size to denote the most common worry, so it would be easier to track at a glance. We also felt it would be most valuable tracking this in combination with the intensity of worries in general, with the intensity represented as a line chart below. In the bottom chart, we also additionally encode if the event they were worried about happened or not, also encoded by colour, as we felt this might be useful information tracked in the afternoon and evening, while the worries were tracked in the morning.

*Medium-fidelity:* [Figure 4.9 [b]] Keeping consistency in mind, we kept intensity of worries same as intensity of symptoms, except for being just one cell per day since the question was asked only in the morning surveys. We used the same 5-point scale, and kept the *Avoidance* option similar to the *Medication* toggle, showing the icon on the bottom left for each cell. We chose the position of the icon to be different than the one for medication, also using spatial encoding which might help familiarize the icon and its meaning to the user over time. We chose to keep all worries and mental health visualizations as blue, and so chose 5 distinct levels of saturation to show the intensity. For occurrence of worries, we chose icons, since we had 6 distinguishable categories. The icons are distinct, but in addition we also used spatial encoding - each icon appeared at a fixed location for instance, family always appeared on the top left if it was present on that day. We also designed the

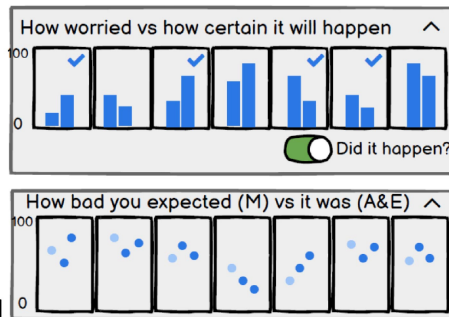
legend to work as toggle buttons, so users could filter the chart based on categories they wanted to see. We also chose to group these two graphs together since it might be interesting for the user to track how worried they were and what was worrying them together, and be able to spot any patterns.

*High-fidelity:* [Figure 4.9 [c]] Here too, we changed from a numeric to a categorical scale for the *Intensity of worries*, and also changed the icon for avoidance. The newer icon better represented Avoidance as ‘moving around something’ rather than the previous icon, and was taken from TheNounProject [24]. We also changed the *Occurrence of worries* graph to be more horizontal as compared to the two columns per day in the low-fidelity version. This was partly to accommodate two weeks of data in the graph, and partly for better readability. We also moved the legend to the top, and shortened words to make it fit in a single line for better readability. We also replaced the icons with checkmarks on each day in the *Occurrence of Worries* chart, using the icons as a legend on the left instead. This was based on pilot feedback, and improved the readability of the chart.

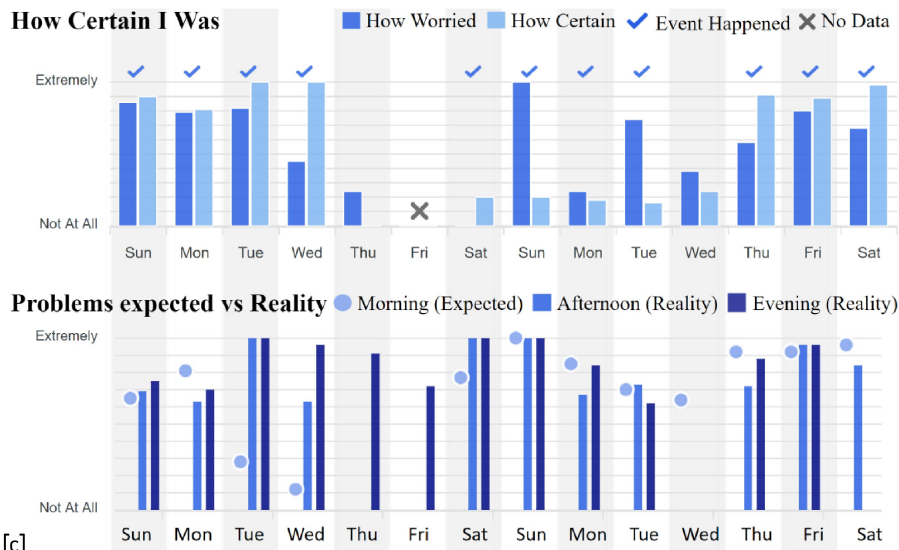
## Visualization: Worries and Certainty, Expectations and Reality



[a]



[b]



[c]

**Figure 4.10:** Visualization prototype for Worries and Certainty, Expectations and Reality showing the: [a] Low fidelity, [b] Medium fidelity, and [c] High fidelity prototype



For worries and certainty, and expectations vs reality, we had four data points:

1. How worried they were about the event?
2. How certain they were the event would happen?
3. Did the event happen?
4. If it did, how bad was it compared to their expectation

*Low-fidelity:* [Figure 4.10 [a]] We thought this chart was best shown in addition to other classes like sleep or symptoms, hence here we brainstormed on how best to create a visualization that could be overlaid or added to others. We thought having cells in a calendar format that could be added to other visualizations might work, where we could use colour to show if the event was better or worse than expected by using two contrasting colours. In the bottom graphs we show how this could be used in addition to other graphs, like avoidance or sleep, by overlaying these cells in those visualizations.

However, when we moved on to higher fidelity versions, we realized it would be good to split this into two distinct visualizations for better comprehensibility. We also chose to go with simpler encodings like a bar chart and scatterplot to keep the visualization easy to understand and compare.

*Medium-fidelity:* [Figure 4.10 [b]] For *How worried vs how certain it will happen*, we wanted to show the juxtaposition of how worried the user was vs how certain they were the event would happen. This would help them see if they were exceedingly worried, or any other patterns in their worries. We chose a dual bar chart since that would make it easy to compare the two measures. The Y-axis here was kept numeric since what we really wanted to show was not the number but the relationship between the two attributes via the height of the bars. We also added a check mark if the event did happen with a toggle option, which would allow users to see if they were unnecessarily worried about events that did not happen or any other such patterns related to their worries.

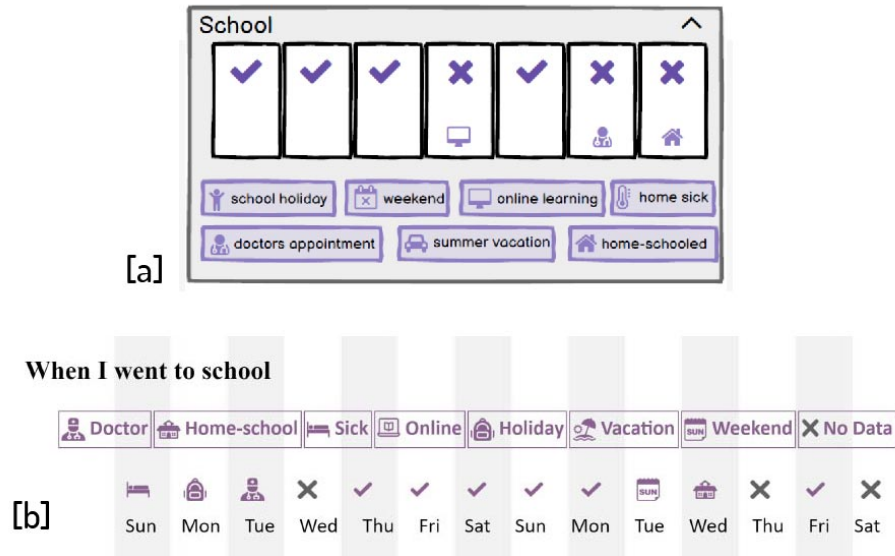
For *How bad you expected vs it was*, we again wanted to highlight the difference between their assumptions and reality. We decided to use a scatterplot, since it would be concise, and yet fit in all the information in the reduced screen space. Each data point of how bad the event was expected to be/actually was is shown as a dot, with three dots per day (morning/afternoon/evening). Since we asked how

bad the user thought the event would be in the morning, and it was an assumption, we colored the corresponding dot light blue to make it easier to distinguish. The dots for afternoon and evening were a darker shade of blue. Again, we retained the numeric axis, but focused on highlighting the mismatch, allowing the user to interpret the relation. We also decided against using a line chart, since a line chart would show a trend across time even if one did not exist.

Given how these two graphs are also related to worries and mental health, we kept them in the blue color theme as well. We also grouped them together since there might be relationships between how worried one was about an event vs how they expected it be, or how certain they were something bad would happen and how bad it was, which could be explored if the charts were juxtaposed vertically.

*High-fidelity:* [Figure 4.10 [c]] We differentiated between the two bars in the *How certain I was* graph by using two different shades of blue for the worry and certainty bars, which would make it easier to track and see patterns. The toggle for whether the event happened was also removed, keeping it 'on' at all times. We also changed the scatterplot for the *Expectations vs Reality* graph, by adding bars for the afternoon and evening EMA survey responses, to be better able to differentiate between the three timepoints.

## Visualization: School Attendance



**Figure 4.11:** Visualization prototype for School Attendance showing the: [a] Medium fidelity, and [b] High fidelity prototype

For school attendance, we had two data points:

1. Did they go to school that day? (*Yes/No*)
2. If not, why? (*from 7 pre-determined options*)

*Low-fidelity:* School attendance was initially not in our list of items to visualize, and not in the Views diagram as well 4.4. However, as we moved on to higher fidelities, we realized school attendance could be useful to visualize to compare with the peer interactions visualizations as well as symptoms visualizations. Thus, we do not have a low-fidelity sketch for this attribute, but only medium and high fidelity versions.

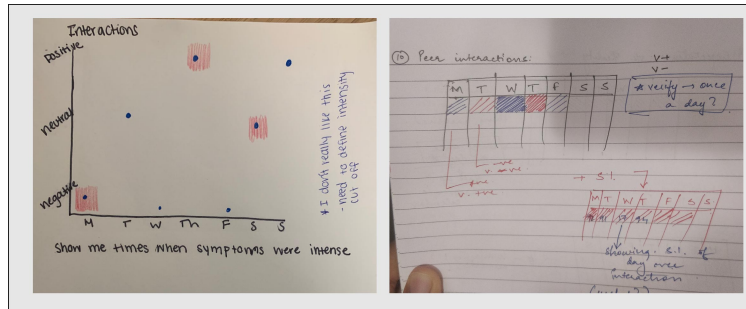
*Medium-fidelity:* **[Figure 4.11 [a]]** We chose to track school attendance using icons - given the short, predetermined list of reasons, we thought an icon-based system would be easy enough for the user to comprehend. Since the data was collected just once a day, this also reduced the cognitive load on the user as there

were a only limited number of icons to process. We also decided to show icons only for days they did not go to school, since other days when they did go would be self-explanatory and doing so would reduce icon clutter on the screen. Here again, as with category of worries, the legend would act as a toggle button allowing users to filter data.

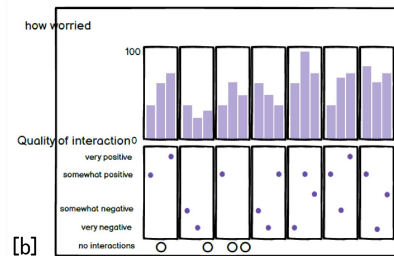
We decided to color school and other peer interaction visualizations purple, since these were all connected through a similar theme.

*High-fidelity:* [Figure 4.11 [b]] Here too, for ease of implementation, we removed the filtering functionality from the legend, and moved it to the top for consistency. We also changed the icons, using ones that more accurately represented the label, licensed from Flaticon [16]. We also shortened the legend to fit it in one line horizontally for better readability and consistency across graphs. We also switched from showing an ‘X’ along with the icon for absence or not attending school, to simply showing the icon, as the X was redundant - the presence of the icon would automatically imply there was an absence. We used the ‘X’ instead to represent *No Data*, coloring it grey to distinguish it from the rest of the graph.

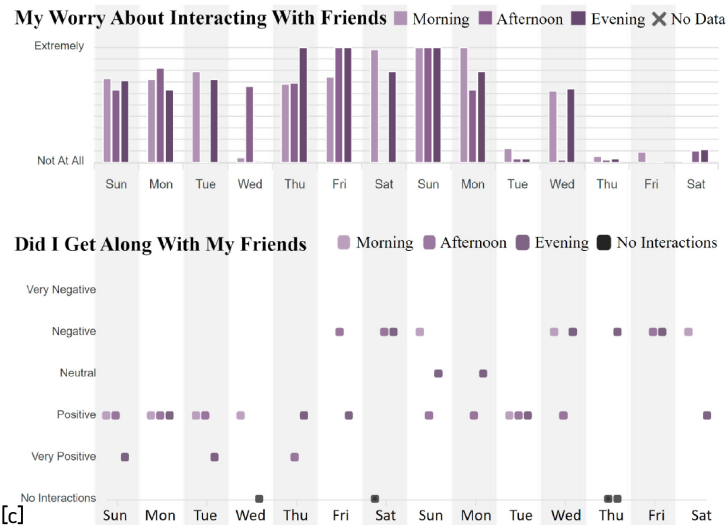
## Visualization: Peer Interactions



[a]



[b]



**Figure 4.12:** Visualization prototype for Worry and Quality of Peer Interactions showing the: [a] Low fidelity, [b] Medium fidelity, and [c] High fidelity prototype

For showing the worry and quality of peer interactions, we had three data points:

1. Worry about interaction (*Not at all to Extremely*)
2. Quality of interaction (*Very Positive/Positive/Neutral/Negative/Very Negative/No Interactions*)
3. Time and day (*Morning/Afternoon/Evening*)

*Low-fidelity:* [Figure 4.12 [a]] For showing peer interactions, we came up with two sketches, one was a scatterplot with the quality of the interaction on the Y-axis. Symptom intensity could be overlaid using background shading on the data points, to show times where symptoms were most intense. We did this as we felt there might be a relationship between how intense symptoms were and how their interactions went. We also thought of a heatmap version where a horizontal row of cells could be added to visualizations from other classes, to show the quality of interactions in addition to the other classes, where the colour of the cell would denote the quality of the interaction.

*Medium-fidelity:* [Figure 4.12 [b]] Again, as we moved on to medium-fidelity, we split peer interactions into two - one to show how worried the user was, and another to show the quality of the interaction for simplicity. Here again, for consistency, we chose chart formats used before, i.e. bar charts and scatterplots.

For worry about their peer interactions, we chose a triple bar chart (3 data points per day, morning/noon/evening), similar to the one for worries vs certainty. Again, though we kept the 0-100 vertical scale, our focus was on highlighting the difference through the day and week through the bars.

For the quality of interactions, we made a scatterplot similar to expectations vs reality, with the Y-axis split across 4 levels: *Very positive/Positive/Negative/Very Negative* from top to bottom, with an extra *No Interactions* row at the bottom. This visualization would also have three data points per day, for morning afternoon and evening. In addition, given that *No Interactions* did not fit anywhere on the scale from *Very positive* to *Very negative*, we decided to keep it as a separate row at the bottom. We also grouped these two charts together since there could be potential patterns between how worried they were about a social interaction and how the interaction was which we wanted them to be able to see.

*High-fidelity:* [Figure 4.12 [c]] We added a legend for *My worry about interacting with friends*, along with ‘X’ for *No data*, as well as one for *Did I get along with friends*. We also distinguished between the morning/afternoon/evening time points by using three different shades of purple. We used the same shades to distinguish the same in *Did I get along with friends*, keeping the colour scheme consistent. We changed the mark from dots to filled squares to reduce the illusion of a scatterplot, and make it seem more tabular. We also changed the mark from circles to filled squares for *No Interactions* to make it more consistent with the other marks.

#### 4.4.4 Summary

Through the visualization design process, we iteratively prototyped visualizations for the different classes of the EMA survey following a data-task abstraction model. We took input from HCI and visualization experts, as well as clinical feedback to create optimal versions of the visualizations. Through the process, we followed the preliminary guidelines from the Initial Design Iteration phase, as well as evaluated how our designs might align with or diverge from existing design guidelines based on the needs for this demographic detailed in 4.3.

At the end of this process, we had a version of the prototype ready for further evaluation. We felt we had reached a stage where we would most benefit from getting end-user feedback on the design of the visualizations. Before we integrated these prototypes into the CareTeam platform for the larger clinical study (discussed in Chapter 6), we felt we needed to specifically evaluate the design of the visualizations in terms of their comprehensibility, utility and whether teens felt these were interesting enough to engage with, and thus conducted the first evaluation study as a usability test of the visualizations (Chapter 5).

## Chapter 5

# Evaluation 1: Visualization Design Feedback

We refer to this initial phase of evaluations as **Phase 1**. The goals for this phase were to evaluate the design of the visualizations; specifically the utility, comprehensibility and reliability for the target audience.

We evaluated the visualization design in two phases: first, a pilot study with six adults aged 25-30 years old with no chronic pain experience, but with varying levels of expertise in design and visualization recruited through convenience sampling, and second, a study with ten youth with chronic pain aged 12-18 years old, with chronic pain experience recruited through a tertiary-level pediatric hospital. In both stages of the evaluation, we used the high-fidelity prototype described in Section 4.4.

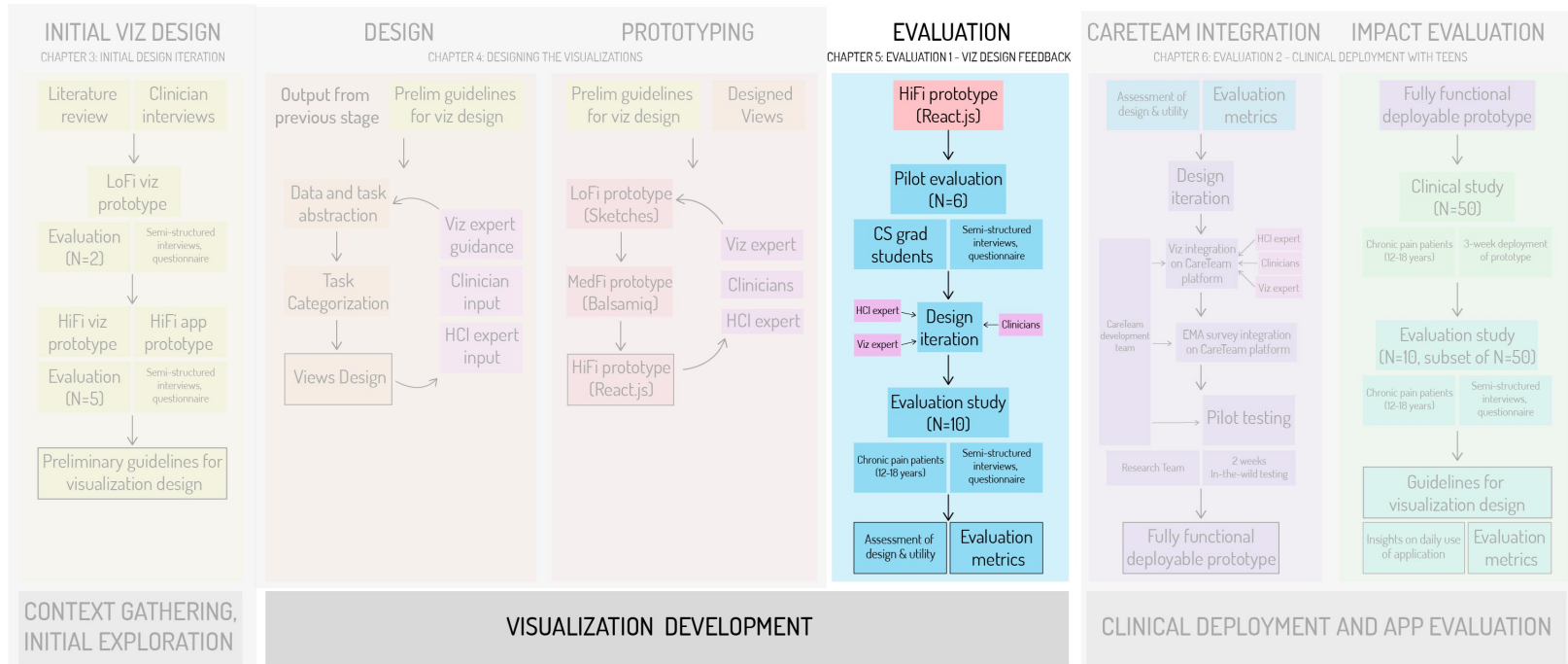
The goals for the pilot were to evaluate the basic usability and comprehensibility of our visualizations. Given the limited access we had to the target population, we wanted to ensure we conducted a usability test before taking the prototype to them, and iterate on the designs if necessary, thus the pilot was conducted with a more easily accessible non-target sample population.

The goals for the full evaluation study were to evaluate the design of the visualizations with the target population before conducting a larger clinical study, so we could improve the designs if needed before the clinical deployment. We felt an initial evaluation with a subset of the target demographic would give us useful



insights on changes we might need to make to ensure the visualizations were engaging and useful for youth. To this end, we chose to recruit a small sample of the target demographic from a chronic pain clinic at a tertiary-level pediatric hospital, the same place we would be recruiting from for the larger clinical study. Given this would be an initial evaluation of the design before the larger clinical study, and the limited participant pool we had, we thought it was most feasible to recruit a small sample of 10 youth. We also wanted to avoid overlap with the clinical study participant pool, and so a small sample size was appropriate for this phase.

In this chapter, we discuss the process of both the pilot and the actual study, and the findings, through individual sections. Figure 5.1 indicates where this phase fits into our overall project process.



**Figure 5.1:** Showing the Visualization Design Evaluation phase discussed in this chapter

## 5.1 Methods

In this section, we describe the recruitment, study design and analysis methods for both the pilot and the full study. We also describe the evaluation metrics used, which are used throughout this thesis, as well as our rationale behind selecting them.

### 5.1.1 Recruitment

*Pilot:* Given our goal was to receive feedback on the design of the study and visualizations and the limited access we had to our target population, we piloted the visualizations with a non-target participant pool of graduate students with design expertise. We felt this set of participants would be best suited to provide the tailored design feedback we were looking for, before we took these designs to our target demographic.

*Full Study:* For the full study, we recruited 10 youth with chronic pain currently being seen at a chronic pain clinic at a tertiary-level pediatric hospital. Recruitment was done by research assistants at the regional pediatric hospital accessed through our clinician-scientist collaborators, with scheduling of interviews coordinated with me. Participants were compensated \$20 CAD for participation in a one-hour remote interview conducted over Zoom [28].

### 5.1.2 Quantitative Evaluation Metrics

Most of the past research we surveyed used existing scales like the SUS or UEQ along with interviews for open-ended feedback for assessing the usability of their applications. For instance, Reynoldson *et al.* [75] in their work assessed the quality and usability of two smartphone applications for self-management of pain with people with chronic pain experience. They used the SUS scale to assess ease of use, along with a Likert-scale based questionnaire for the aesthetic of the application and free-text responses for open-ended feedback. Irvine *et al.* [55] also used the SUS scale for assessing the usability of their website intervention for management of lower back pain. Cooke *et al.* [35] conducted interviews with a subset of their participants post prolonged use of their mobile app for chronic pain in

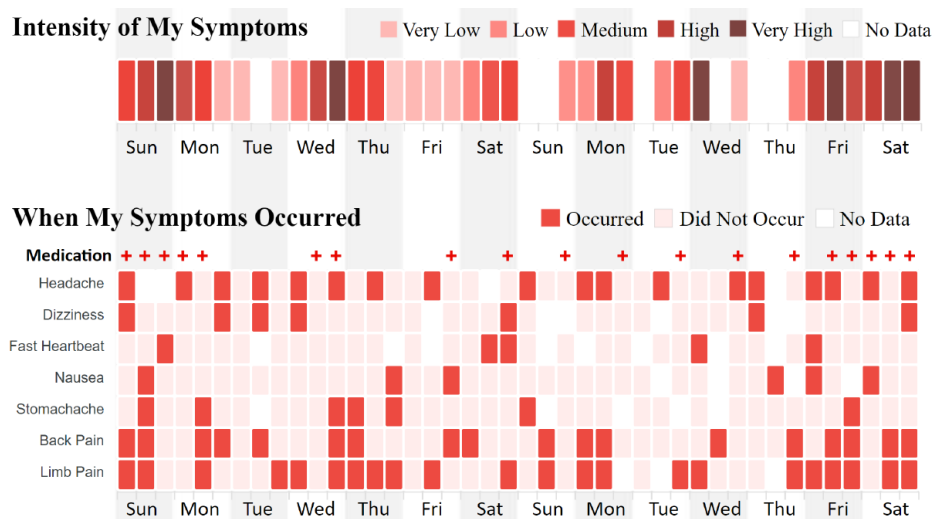
young people, along with surveys. From a user-centered design perspective, existing standards in the field seem to suggest the use of interviews coupled with more specific questionnaires or surveys to capture open-ended as well as detailed feedback.

When it comes to evaluating visualizations, Saket *et al.* [78] discuss qualitative and quantitative methods of evaluation, around user engagement and usability. They reviewed user studies that focused on goals and metrics other than standard performance measures, and found the use of self-reported subjective methods like interviews and Likert-scale based questions to measure the sense of enjoyment and engagement.

Based on this research, we focused on finding evaluation metrics for our study that would encompass similar methods to measure the usability and utility of our visualizations. Our goal was to find whether users could understand the information shown in the visualizations, and felt the visualizations were engaging enough to consistently interact with them over prolonged periods of time. We also wanted to learn what users thought of the visualizations and whether they found them relevant to their lives. Thus, we decided to use **Utility** and **Understandability** as two of our metrics. While we wanted to measure engagement, given that we would be showing participants sample data, we felt the format of this evaluation would not support evaluation of engagement and thus did not keep Engagement explicitly as a metric. However, we felt we could still learn about the potential for engagement by assessing if they found the visualizations interesting and liked how they looked, thus we added **Interest** and **Aesthetic** as our other two metrics. We also wanted to keep the list minimal so as to not exhaust participants, and thus restricted ourselves to these four key measures. As we had multiple categories and different encodings of visualizations, we imagined users would have differing opinions on each, and hence decided to use the metrics to gauge each visualization individually.

However, one of our goals was to enable users to see patterns across visualizations, and be able to correlate aspects of their lives. For this purpose, we decided to evaluate ‘*screens*’ or logical groupings of the visualizations together, in addition to assessing them individually where we grouped together:

- **Intensity and Occurrence of Symptoms:** We felt it would be important



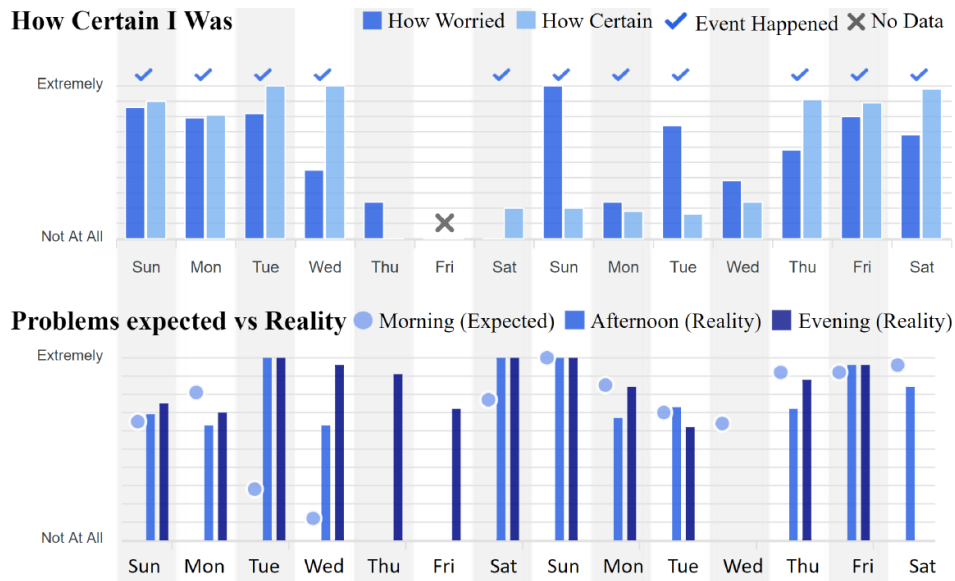
**Figure 5.2:** Screen showing *Intensity* and *Occurrence of Symptoms*

for users to be able to relate the intensity with the frequency and individual symptoms, as well as associate medication with the intensity of symptoms, shown in 5.2.

- **Worry vs Certainty and Expectations vs Reality:** We felt users would be able to look at these two graphs and get a larger idea of how their worries compared to their expectations and reality of events, shown in 5.3. It could also be interesting to see how their certainty about events compared to the reality of the events.
- **Worries and Quality of Peer Interactions:** We felt the quality and worry about an interaction went hand-in-hand, and being able to see these two graphs together would let users assess how their worries mapped to the interactions in reality, shown in 5.4.

These screens are different from the *Views* defined in Section 4.3 - Screens are smaller logical groupings of 2-3 visualizations **within** a Class, whereas Views were groupings of **all** the visualizations in a Class.

Thus, we converged on four metrics [Utility, Understandability, Interest, Aesthetic], which we felt best met our goals, along with an Understandability metric



**Figure 5.3:** Screen showing *Worries vs. Certainty* and *Expectations vs. Reality*

Metric	Description
Utility	Assessing if the information shown in the visualization would be useful to the user personally
Understandability	Assessing if the information shown through the visualization was easy to comprehend
Interest	Assessing if the visualization seemed interesting or motivated them to interact with it
Aesthetic	Assessing if the users liked how the visualizations looked
Understandability (Screens)	Assessing if users could understand information shown across visualizations

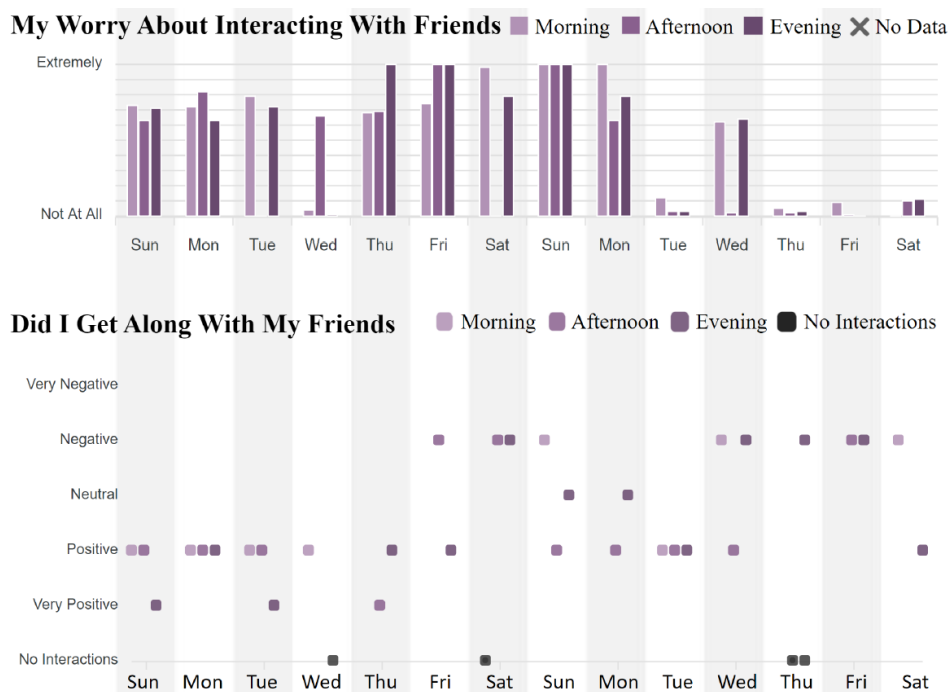
**Table 5.1:** Evaluation Metrics for our Visualization Design

for ‘screens’, shown in Table 5.1:

*Utility* and *Interest* would help us gauge the perceived usefulness of the visualizations, and *Understandability* to gauge the usability.

These were asked for each of the visualizations individually using a 5-point Likert scale from 1 (*Highly Disagree*) to 5 (*Highly Agree*).

For both the pilot and full study, we implemented the questionnaire using RED-



**Figure 5.4:** Screen showing *Worry* and *Quality of Peer Interactions*

Cap [50, 51], shown in the Appendix as Item A.4.2.

### 5.1.3 Qualitative Interview Design

We conducted semi-structured interviews with the participants to gather in-depth feedback on the design of the visualizations.

We grouped our questions per category of the visualizations, and at the end of each category asked the participants what would they think if they would be able to see the graphs with their own data instead of the sample data we had now. We hoped this might help participants relate more to the visualizations and enable them to give more open-ended feedback. Specific questions for each visualization included asking participants to identify periods of intense symptoms or worries, differentiate between different data points on different days, and discern patterns across the week, evaluating if they were able to understand the information shown.

Pre-test questions asked about previous experience with health tracking and

Visualization	Questions
Intensity of Symptoms	What do the differently coloured columns indicate?
Occurrence of Symptoms	Do you see connections between the intensity and occurrence of symptoms?
Intensity of Worries	Which days show highest worry and avoidance?
Occurrence of Worries	Can you tell most frequently occurring categories?
Worries and Certainty	What is the difference between the graphs on two days?
Expectation vs Reality	Do you see any patterns across the week?
School Attendance	Can you tell days when school was not attended?
Worry about interactions	How would you describe the overall worries between week 1 vs 2?
Quality of interactions	What is the difference between the graphs on two days?
Emotions	When was anger or happiness the most?
Sleep	Can you tell days when sleep was the best?

**Table 5.2:** Subset of the interview questions for evaluation of the Visualization Design

visualizations, while post-test questions asked for open-ended feedback on what participants might have liked, found confusing, or improvements they thought could be made.

The primary interview questions were asked per visualization, with participants asked to imagine they were looking at Alice’s (persona) EMA data. The visualizations were made using the EMA pilot collected data from Section 3.2.2 and participants were also given a brief description of what the EMA questions looked like for each of the visualizations. A rephrased subset is shown in Table 5.2, with the full set in the Appendix as Section A.4.1.

#### 5.1.4 Study Design

The study consisted of 1-hour semi-structured interviews, which combined a questionnaire with open-ended but specific questions related to the understandability, usability, and appeal of each visualization.

#### 5.1.5 Visualization Prototypes Used

*Pilot:* Given that the purpose of the pilot was to get design feedback from graduate students with HCI expertise, we continuously modified the visualizations prototype between pilot participants based on feedback from each interview. This was done to get iterative feedback on newer versions to keep improving the designs. At the end of the pilot, we made final design changes to get a final version which was



then kept the same for all of the full study participants. The initial version of the prototype can be viewed in the Appendix in Section A.5.1.

***Full Study:***

The final version of the High Fidelity Prototype for each of the visualizations is shown in Section 4.4.3, and was the version used in the full study. The visualizations were shown vertically aligned (to facilitate cross-comparison across visualizations) in the form of a scrollable *dashboard*. The complete dashboard can be viewed in the Appendix in Section A.5.2.

The complete list of the final interview questions and the visualization questionnaire is attached in the Appendix as Item A.4.1 and A.4.2.

### **5.1.6 Analysis**

Given our goals for this phase were to conduct a usability test and evaluate the design of the visualizations, we felt *Affinity Diagramming* would be a suitable method to analyse the qualitative data from the interviews in both the pilot and the full study.

For the pilot study, as the interviews progressed, we saw feedback based broadly on two aspects - feedback on the overall utility of the visualizations and feedback per visualization. We discuss the utility split up in two sub-categories in Section 5.2.3 and individual visualization feedback in Section 5.2.4.

Figure 5.7 shows the affinity diagram, with the black notes indicating the categories, and coloured notes being participant feedback.

For the full study, post the interviews, we conducted a round of affinity diagramming on the transcripts, and classified participant statements under four broad categories, shown in 5.13, with the notes color-coded by participant ID. These feedback categories were different than those we found in the pilot study; as in our evaluation with the target population we focused on getting overall feedback on aspects participants liked or did not like about the visualizations and EMA questions in general. Given the demographics of our participants, they also did not have detailed design feedback as compared to our pilot, hence there were no individual visualization categories. We started with two broad categories of Aspects liked and disliked, but as interviews progressed, we saw many responses about

additional features or utility of the visualizations, and hence separated them as individual categories, thus having a list of final four categories:

1. Aspects of the visualizations liked by the participants
2. Aspects of the visualizations that were complex or confusing for the participants
3. Additional features participants would like to track
4. Utility and relevance of the visualizations for the participants

For the quantitative metrics, we created heatmaps to assess the averages across the visualizations to get an understanding of what aspects needed to be modified for them. These are detailed further in Sections 5.2.2 and 5.3.2.

## 5.2 Usability Pilot (Non-Target Participants): Results

### 5.2.1 Demographics

We recruited six Computer Science graduate students from a North American university with varying levels of expertise in HCI and data visualization (n=6; 1M, 5F), aged 25-30 years, with no chronic pain experience.

Three of our six participants had both collected data and seen visualizations, through a mix of methods - one used Google Fit for fitness tracking and Rescue-Time for productivity tracking, another used the Apple Watch and the third had used sleep tracking applications and journaling. Thus, our participant pool had a good mix of people who had used traditional as well as modern methods of data tracking, and had seen visualizations of various aspects of their life.

### 5.2.2 Quantitative Results

Analysing the results from the REDCap questionnaires:

Some interesting insights from the quantitative results:

- **Interest** was high for both the *Symptoms* visualizations, although our non-target participant group rated them low on Utility, which promisingly indicates that if our non-target group found these visualizations interesting even

	IoFS	OoFS	IoFW	WC	WvsC	EvsR	SA	PIW	PIQ	Emotions	Sleep	Average
Utility	4.17	3.83	4.33	4.00	3.50	4.33	3.33	4.50	4.50	4.50	5.00	4.18
Understanding	4.33	3.50	4.83	4.50	4.00	3.50	4.83	4.50	4.00	4.00	4.67	4.24
Interest	4.83	4.67	4.33	4.33	3.67	4.00	3.33	4.50	4.50	4.00	4.50	4.24
Aesthetic	4.33	4.17	4.50	4.33	4.17	3.83	4.67	3.67	4.17	4.00	4.00	4.17
<b>Average</b>	<b>4.42</b>	<b>4.04</b>	<b>4.50</b>	<b>4.29</b>	<b>3.83</b>	<b>3.92</b>	<b>4.04</b>	<b>4.29</b>	<b>4.29</b>	<b>4.13</b>	<b>4.54</b>	

**Legend:**  
 IoFS: Intensity of Symptoms  
 OoFS: Occurrence of Symptoms  
 IoFW: Intensity of Worries  
 WC: Category of Worries  
 WvsC: Worries vs Certainty  
 EvsR: Expectations vs Reality  
 SA: School Attendance  
 PIW: Worry about Peer Interactions  
 PIQ: Quality of Peer Interactions

**Figure 5.5:** Heatmap showing the quantitative responses for each of the visualizations, color-coded to show highest and lowest ratings and averages for all metrics and visualizations

if they weren't relevant to them, these visualizations would also potentially appeal to our target group for whom these should be more relevant.

- **Understanding** was high for the *School Attendance* visualization, although **Utility** and **Interest** were both low, which indicates that while this visualization is understandable, it wasn't of particular interest or relevance to our graduate students population as they had passed that phase in their life. This did show the understandability of the visualization though, which was important for us.
- *Sleep* and the *Intensity* heatmaps scored the highest overall, showcasing the potential of heatmaps as an effective encoding medium, and the high understandability of range charts.
- **Understanding** and **Interest** was high for charts overall, while **Utility** and **Aesthetic** could be improved. We felt **Utility** would be higher when testing with our target population as these visualizations would be more relevant to them.
- Ratings were the worst for *Worry vs Certainty* and *Expectation vs Reality*, indicating we needed to revisit our designs for those - *Worry vs Certainty* was a bar chart with icons overlaid to show events happening whereas *Expectation vs Reality* was a scatterplot. We revised the design for the *Expectation vs Reality* visualization to make it more comprehensible.
- *Emotions* was rated high on **Utility**, but low on all other metrics - we revisited the design to overlay the graphs and make them more coherent.

	lofS+OofS	WvsC+EvsR	PIW+PIQ	Average
Understandability	3.17	3.50	4.33	3.67

**Legend:**

lofS: Intensity of Symptoms

OofS: Occurrence of Symptoms

lofW: Intensity of Worries

WC: Category of Worries

WvsC: Worries vs Certainty

EvsR: Expectations vs Reality

SA: School Attendance

PIW: Worry about Peer Interactions

PIQ: Quality of Peer Interactions

**Figure 5.6:** Heatmap showing the Understandability ratings for the three screens, color-coded to show highest and lowest ratings, along with the average

Overall, all the graphs were rated above 3, with averages above 4, for all four metrics. The ratings further corroborated the interviews where participants expanded further on things they particularly liked or did not like. Based on this feedback, we performed revisions to the design, highlighted in 5.8 and 5.9.

For the screens, cross-comparison across the *Peer Interactions* was rated the easiest (4.33), while the *Symptoms* ones weren't as easily comparable (3.17).

### 5.2.3 Feedback Categories from Interview Analysis

#### Pre- and post-study guidance

Participants mentioned the need for an onboarding process, to initiate teens with the dashboard before they started using it, due to the complexity and variety of visualizations. They also mentioned not understanding what to do with the insights from the visualizations - highlighting the need for clinical guidance to truly understand what the visualizations conveyed and how it could help them.

Based on this feedback, we decided to have an onboarding process for the larger clinical study where we would familiarize the participants with the visualizations before they began the study, to make sure they would have a preliminary



**Figure 5.7:** Affinity diagrammed MIRO board consisting of feedback from the pilot interview, colour-coded by participant ID, with black notes representing high-level categories of the feedback

understanding of the visualizations. The guide document is attached in the Appendix as Section A.6.2. For post-study guidance, while we did not implement any techniques on our end, in an ideal situation, a patient would be able to discuss the visualizations with their clinical team to validate and utilize the insights from the visualizations.

### Utility

Participants mentioned how they'd find the visualizations useful and the value they saw in them, not just for tracking physical symptoms, but also other aspects of their life.

[P4] *“If I had chronic pain, yes I would find this useful. If not, I would just like to understand like how these different things are affecting my life”*

[P5] *“I think it would be a really effective way of being able to look back and communicate that with other people or like parents, doctors, people that are helping you out”*

At least one indicated needing further assistance to learn how to use this insights: [P6] *“It’s just like, what, what do I do with this information? Now that I know?”*

Overall **Utility** was also rated 4.18/5 (Figure 5.5), which shows participants definitely saw utility in the visualizations, even if there was room for improvement for some of them.

## 5.2.4 Responses to Individual Visualizations

### High Level Takeaways

Overall, some visualizations were easily understandable and liked by all participants, for instance *Sleep* and *Intensity of Symptoms*. Others, like *Expectations vs Reality*, were deemed more complex. There were no extreme responses overall that warranted a complete redesign of any of the visualizations, but as we went through the interviews, participants highlighted minor fixes and features that were easily implementable and would improve the visualization design which we added in our modifications of the prototype throughout the pilot. Participants also noted how some of the visualizations were more relevant to them than others, but these responses were varied across the participants, which highlighted the possible differing **Utility** and **Interest** for each of the visualizations based on individual preferences. In the following sections, we describe feedback per visualization, and resulting design decisions, if any.

### Sleep

For the sleep graph, participants mainly noted how the Y-axis with the hours on it was confusing. They would have preferred the Y-axis to not split the sleep bar into two parts, so maybe changing it to a scale other than going from midnight to

midnight. One participant also mentioned how the military time labels made the graph harder to read. Another participant noted how they would have liked to see the number of hours they slept. Overall however, this visualization was rated the highest (Figure 5.5), especially in **Utility** and **Understanding**, so we did not have any major changes here.

**Resulting design decision:** We added a row at the top of the visualization that would show the number of hours the user had slept. We also changed the labels to show am/pm times as opposed to the previous military version. We hoped this would improve comprehensibility, and the additional information of number of hours would generate more interest.

### **Physical Symptoms**

Participants found the graphs understandable, but one participant highlighted how the vertical alignment of morning-afternoon-evening in the *Intensity of Symptoms* changing to horizontal alignment in the *Occurrence of Symptoms* chart threw them off. One participant mentioned how they would have preferred a body silhouette chart instead of a heatmap to show the occurrence of symptoms, similar to our prototype in Chapter 3 (3.12). Participants did note how there was ambiguity regarding the source of the pain - in our current setup, we did not gather data for which symptom was how intense, we only gathered cumulative data of overall pain levels. However, participants felt they would have liked more clarity on that front.

Overall, the *Intensity of Symptoms* visualization was quite favoured, with a rating of 4.42/5, while *Occurrence of Symptoms* needed to improve **Utility** and **Understanding** (3.83/5 and 3.83/5) (Figure 5.5).

**Resulting design decision:** We changed the alignment of the *Intensity of Symptoms* graph to horizontally split a day into three segments, morning-afternoon-evening, instead of vertically. Thus, each day now had three columns, and the two graphs were more consistent with each other.

While we saw value in gathering additional data about the intensity of each symptom, we also realized this may be more information than the teens would want to provide, and it would substantially change the EMA surveys, and hence decided to leave it out for a future iteration.

## Emotions

Participants overall found this graph to be the most confusing. They felt the overall summary bubble chart would be more useful, and didn't see any added value in the more detailed line chart, but felt an explanation was definitely required to be able to parse and understand the graph.

**Resulting design decision:** We decided to overlay the bubbles on top of the line chart as we felt that would:

- Reduce whitespace
- Provide a more cohesive view of emotions across the week
- Allow for easier comparison with other charts

## Worries

Participants mentioned wanting to record which specific worry they might have tried to avoid. One participant also mentioned how it might be better to have the icons on the Y-axis for the *Occurrence of Worries* chart. Participants also noted that the dots and wording were confusing for the *Expectations vs Reality* graph. *Expectations vs Reality* and *Worry vs Certainty* fared the worst quantitatively (Figure 5.5), with a need to improve **Utility** and **Understandability**.

**Resulting design decision:** In a later version of the visualizations, we ended up moving the icons to the left, and replacing them with simple check marks for occurrence. This would clutter the graph less, and require less cognitive effort from users to associate the icons to the labels. We also modified the *Expectations* graph to show bars instead of dots for the real events based on the afternoon and evening surveys. This would make the graph easier to process.

## School

Some of the participants felt the school graph was not the most relevant for them at this point in their life, with one reporting they felt looking at their attendance would just stress them out.

**Resulting design decision:** Given that school and attendance would still be relevant to our target demographic, we did not make any changes to this design.



## **Peer interactions**

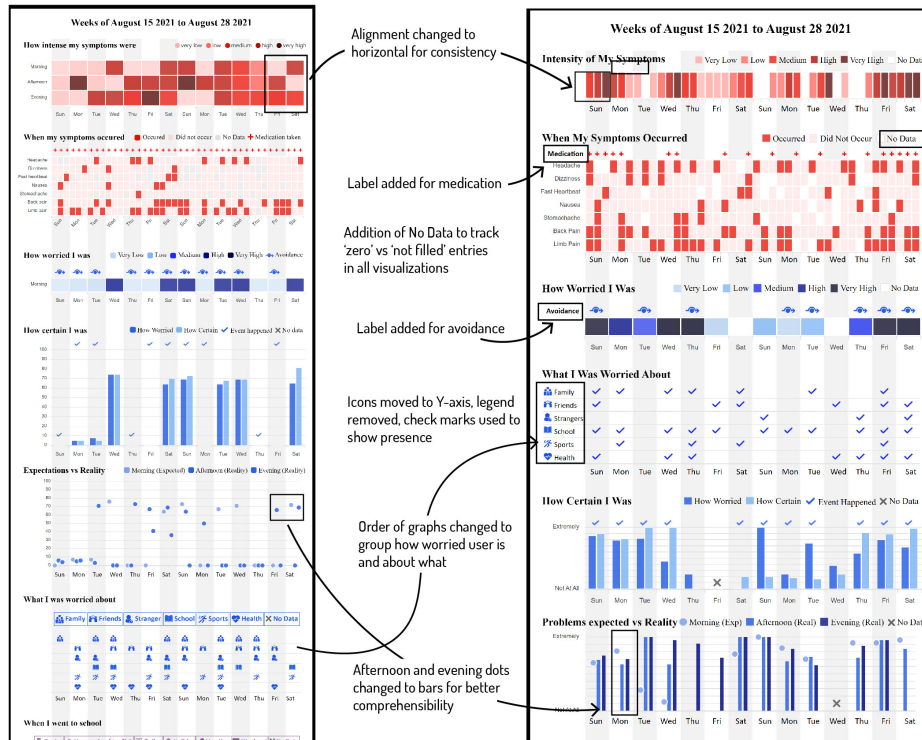
The peer interactions graphs were interesting - while two participants noted they would not be interested in seeing them as they weren't very worried about their peer interactions, another noted they would be very interested since as they had social anxiety, the graphs helped put things in perspective. Overall ratings for these visualizations were also average (Figure 5.5). Some participants mentioned how the graphs could be more similar in structure, or have the quality of interactions graph overlaid on the worries one, for ease of comparison.

**Resulting design decision:** While we did not overlay the two graphs, we did change the Y-axis order for the quality of peer interactions graph. Instead of going from Very Positive to Very Negative (top to bottom), we switched it to go from Very Negative to Very Positive. We figured that as in the above *Worries about Peer Interactions* graph, lower worries would be considered the ideal scenario, the *Quality of Interactions* graph should reflect the same and have the preferable scenario at the lower end of the graph. Thus, by switching the Y-axis, we kept positive interactions at the bottom, hoping this would help in the comparison of the two graphs.

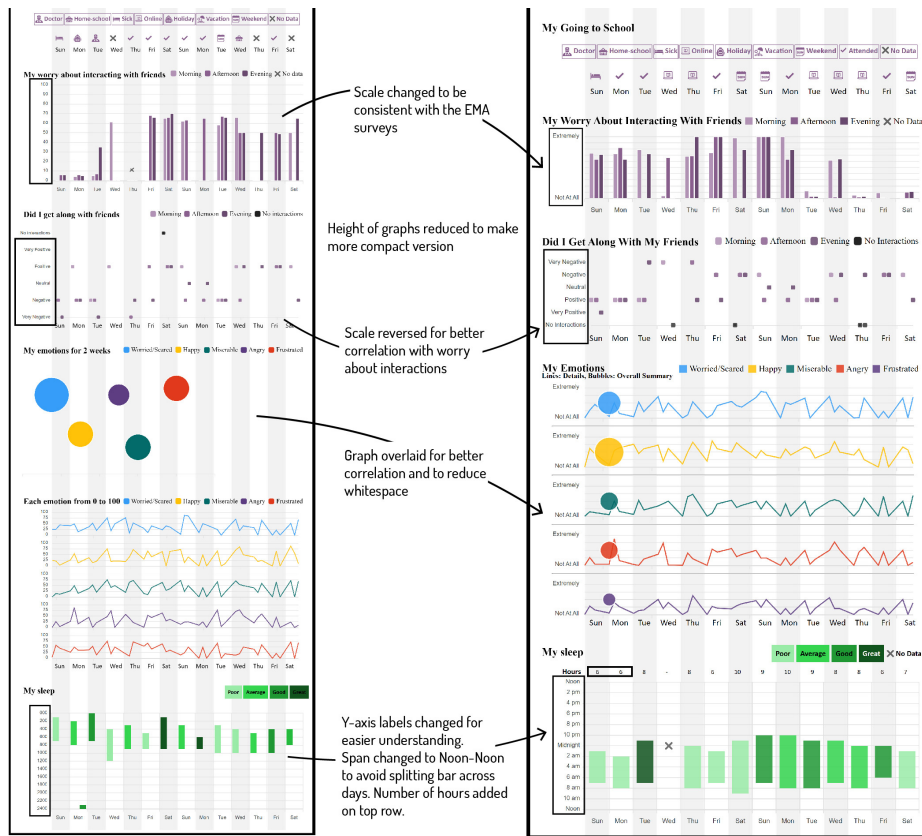
### **5.2.5 Resulting Visualization & Procedural Modifications**

The designs of the visualizations were modified iteratively over time between each of the interviews, so we could continue to get feedback on the design changes we were making. Thus, some of the visualizations ended up looking quite different for the last pilot participant than they did for the first. We highlight this difference in Figures 5.8 and 5.9

Both versions are attached in the Appendix, the initial version in Section A.5.1 and final in Section A.5.2.



**Figure 5.8:** Part 1: The visualization dashboard prototype versions from the start and end of piloting shown juxtaposed, with changes made based on the pilot feedback highlighted



**Figure 5.9:** Part 2: The visualization dashboard prototype versions from the start and end of piloting shown juxtaposed, with changes made based on the pilot feedback highlighted

## 5.3 Full Study (Target Participants): Results

### 5.3.1 Demographics

For the study, we recruited 10 (7F, 3M) youth with chronic pain, aged 12-18 years, typically developing (children who do not have a diagnoses of cerebral palsy, Autism Spectrum Disorder (ASD), learning disabilities, Attention Deficit Hyperactivity Disorder (ADHD) or a genetic/metabolic disorder).

	lofS	OofS	lofW	WC	WvsC	EvsR	SA	PIW	PIQ	Emotions	Sleep	Average
Utility	4.6 <sup>c</sup>	4.2	3.7	3.7	3.5	3.5	3.5	3.3	3.1	4.2 <sup>c</sup>	4.7	3.82
Understanding	4.3 <sup>A</sup>	3.4	4.5 <sup>A</sup>	4.4	3.8	3.4	4.7 <sup>A</sup>	4.3	3.5	3.7	4.6 <sup>A</sup>	4.05
Interest	3.8	3.8	3.9	3.9 <sup>E</sup>	4	4	3.5	3.6	3.7	4.2	4.6	3.91
Aesthetic	4.1 <sup>A</sup>	3.1	4.3 <sup>A</sup>	3.9	3.8	3.5	4.1 <sup>A</sup>	3.9	3.6	3.5	4.3 <sup>A</sup>	3.83
Average	4.20	3.63 <sup>F</sup>	4.10	3.98	3.78	3.60 <sup>D</sup>	3.95	3.78	3.48 <sup>D</sup>	3.90	4.55	

**Legend:**  
lofS: Intensity of Symptoms  
OofS: Occurrence of Symptoms  
lofW: Intensity of Worries  
WC: Category of Worries  
WvsC: Worries vs Certainty  
EvsR: Expectations vs Reality  
SA: School Attendance  
PIW: Worry about Peer Interactions  
PIQ: Quality of Peer Interactions

**Figure 5.10:** Heatmap showing the quantitative responses for each of the visualizations, color-coded to show highest and lowest ratings and averages for all metrics and visualizations

### 5.3.2 Quantitative Results

Analysing the results from the REDCap questionnaires:

Overall, **Utility** was the highest for *Sleep* (4.7), and *Intensity of Symptoms* (4.6), while lowest for *Worries and Quality of Peer Interactions* (3.3 and 3.1 respectively). **Understandability** was the highest for *Sleep* (4.6) and *School Attendance* (4.7) while lowest for the *Expectations vs Reality* and *Occurrence of Symptoms* (3.4). Participants found the *Sleep* and *Emotions* graphs most **Interesting** (4.6 and 4.2 respectively) while the *School Attendance* one the least (3.5). In terms of **Aesthetics**, people found the *Sleep* and *Intensity of Worries* graph to look the best (4.3), while *Occurrence of Symptoms* was the least liked (3.1).

Some interesting insights from the quantitative results, annotated in Figure 5.10 with the bullet number:

- A **Aesthetic** was rated high for the heatmaps, range chart for *Sleep*, and the icons for *School Attendance*. **Understandability** was also high for these. This confirms that these encodings in particular are well suited for this demographic.
- B **Interest** was moderately high but quite consistent for all visualizations except *School Attendance* and *Peer Interactions* - this leads us to believe most youth would not be interested in tracking these aspects, as also confirmed by their interview feedback.
- C **Utility** was highest for the *Symptoms*, *Sleep* and *Emotions* visualizations,

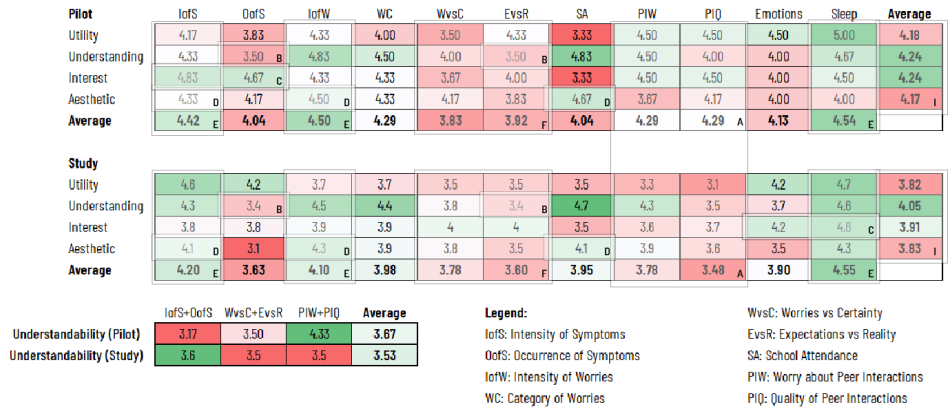
	IofS+OofS	WvsC+EvsR	PIW+PIQ	Average
Understandability	3.6	3.5	3.5	3.53

<b>Legend:</b>	WvsC: Worries vs Certainty
IofS: Intensity of Symptoms	EvsR: Expectations vs Reality
OofS: Occurrence of Symptoms	SA: School Attendance
IofW: Intensity of Worries	PIW: Worry about Peer Interactions
WC: Category of Worries	PIQ: Quality of Peer Interactions

**Figure 5.11:** Heatmap showing the Understandability ratings for the three screens, color-coded to show highest and lowest ratings, along with the average

- similar to feedback in the interviews on what participants would like to track.
- D *Expectations vs Reality* and *Quality of Peer Interactions* fared the worst on average, meaning we did need to reconsider their designs. However, we felt for *Expectation vs Reality*, participant feedback might be different if they were looking at their own entered data, as that would be more relatable and understandable. Thus, we did not redesign that particular visualization. *Quality of Peer Interactions* underwent a minor redesign during deploying the same on the CareTeam platform, discussed in Chapter 6, Section 6.1.1.
- E **Interest** was high for *Expectations vs Reality* and *Worry vs Certainty*, even though they fared low on **Utility**, **Understanding** and **Aesthetic** - this shows that these are aspects teens would like to track, even though we might not have designed the encodings optimally for them.
- F **Utility** was high for *Occurrence of Symptoms*, but all other metrics were low, meaning while the participants thought that was a useful aspect to track, the encoding was not easily comprehensible, and did not come across as interesting.
- G Overall ratings were highest for *Sleep* and *Intensity of Symptoms*.

For the screens, cross-comparison across all the screens seemed to be at the



**Figure 5.12:** Heatmap showing the ratings for the visualizations and the screens for both the pilot and the study

same level, with all three screens rated 3.6, 3.5 and 3.5. These were concerningly low ratings, which meant we did need to reconsider what could be done to highlight the cross-comparison aspect of the visualization dashboard.

Overall, all the graphs were rated above 3, with averages above 3.5, for all four metrics. The ratings further corroborated the interviews where participants had expanded further on things they particularly liked or did not like.

We compare the quantitative findings of this study to the pilot, with the overall ratings shown in 5.12

We saw some interesting differences between the pilot and main study ratings (also annotated in Figure 5.12 with the bullet number) which we discuss below:

- A Utility of Peer Interactions graphs:** While the *Peer Interactions* graphs were rated the most useful in the pilot, in the study participants reported finding them the least useful, instead favouring *Sleep* and *Intensity of Symptoms*. This could be attributed to the different demographics in the two studies, as participants in the full study stated in the interviews how they felt Peer Interactions wasn't something they would necessarily want to track, as opposed to ones in the pilot study who stated for them, Peer Interactions would be an important aspect to reflect on.
- B Understandability** remained the lowest for *Expectations vs Reality* and *Oc-*

*currence of Symptoms*

- C **Interest** was the highest for the *Symptoms* charts in the pilot, whereas study participants reported actually being the most interested in their *Emotions* and *Sleep*. *School Attendance* was voted as lowest interest in both.
- D The *Intensity of Worries* encoding was the most preferred both times when it came to the **Aesthetic**, along with *Intensity of Symptoms* and *School Attendance*. The *Sleep* aesthetic was also highly favoured by the study participants.
- E Overall, the most favoured visualizations on average remained the same through the pilot and the study: *Intensity of Symptoms*, *Intensity of Worries* and *Sleep*.
- F The least favoured also remained mostly similar: *Worry vs Certainty*, *Expectations vs Reality*, and *Peer Interaction Quality*.
- G There was also a consistent pattern of **Understanding** and **Interest** being high on average, whereas **Utility** was lower with **Aesthetic** being the lowest.
- H While the *Peer Interactions* screen was the easiest to understand according to the pilot, the study participants did not have a preference and found all three moderately understandable.
- I Overall, ratings were lower in the study than in the pilot, but fairly high throughout. This can be explained to an extent by the fact that the pilot was conducted with university graduate students in Computer Science, while the study was conducted with middle- and high-school aged children with lesser analytical experience and lower familiarity with the idea of self-data tracking.

### 5.3.3 Feedback Categories from Interview Analysis

Below, we discuss the 4 major categories of qualitative feedback we received from our semi-structured interviews:

#### **Category 1: Aspects of the visualizations liked by the participants**

The various aspects participants liked about the visualizations can be categorized under the four metrics - Utility, Understandability, Interest and Aesthetic:

**High utility:** Four participants reported how they would definitely find it useful





very easy to understand”). They also appreciated the simplicity of the graphs used ([P1] “My favorite were the bar graphs because bar graphs are always really easy to read.”) **Understandability** was also the highest (4.05/5 - Figure 5.10), which was in line with this feedback.

**High overall interest:** Participants liked how the graphs looked, and found it interesting to see how different each day was. As P9 stated, “*In a nutshell, it’s a lot of data in a small graph. I think it’s pretty good.*” P7 also mentioned “*I think it’s interesting to kind of see just how different every day is*”. **Interest** was also fairly high (3.91/5 - Figure 5.10), indicating an overall interest in the visualizations.

**Varying opinions on aesthetic:** Participants mentioned how they liked the color coding of the categories that made the visualizations easier to understand ([P4] “*I like it, they’re color coordinated and helps like separate them makes them easier to understand.*”). While all the visualizations rated higher than 3 (indicating agreement) on **Aesthetic** in the questionnaire (Figure 5.10), some visualizations like *Occurrence of Symptoms* and *Expectation vs Reality* scored lower, showing a need to revisit some of them.

Overall, participants liked the concepts behind the visualizations, as well as the encodings we had chosen for each visualization. They liked the colour coding, and found them understandable and liked the simplicity of the visualizations.

## **Category 2: Aspects of the visualizations that were complex or confusing for the participants**

**Confusing visualizations:** While some participants liked the visualizations and found them simple and straightforward, others found certain aspects that were confusing or affected understandability. For instance, P5 noted how they found the *Emotions* graph confusing, as it used a line and bubble chart encoding that was not used anywhere else through the dashboard: “*I think the only one that I found a bit more confusing was the emotion one with the line graph, just because it was a bit different than the other style of graphs.*” The *Emotions* chart was one that was not understood by other participants as well (3 out of 10), particularly the bubbles overlaid on the line charts ([P7] “*The bubbles kind of make it a little bit confusing.*”)

Participants also noted the *Quality of Peer Interactions* graph to be confusing (3 out of 10), as P10 said, “*Because the data points are so spread out it, it makes it hard for me to see.*”. This was corroborated by the rating for the visualization, 3.48/5, the lowest of all the visualizations (Figure 5.10)

***Better understandability over time:*** However, one participant (P10) also noted how familiarity with the visualizations increased with time, particularly “*I found the confusing the first couple of questions. And then we started to get the hang of it.*”

***Cost of cognitive and emotional effort:*** P1 also mentioned how they might set a time limit for answering the surveys, as “*Just because the more time you have to worry, then the more worried you’re going to get.*” While P1 was the only participant to mention this, it does put into perspective the cognitive and emotional effort required to supply the EMA data consistently over longer periods of time, which was something we would need to be mindful of.

### **Category 3: Additional attributes participants would like to track**

***Specific pain locations and times:*** Participants mentioned wanting the ability to record more details about their physical symptoms ([P1] “*I also think it might be important to be able to record where the back or limb pain was, and what times they occurred*”, [P2] “*I think, personally, sometimes I would feel new types of pain in different places, on certain days. So maybe it’ll be nice to have a section she just quickly jot down*”).

***Sleep during the day:*** Some participants also mentioned how they would like to track additional details for their sleep, including if they slept during the day ([P10] “*The only thing I would do is I would in the evening, I would ask if the person had slept at all during the day*”), as well as why they felt their sleep was of a particular quality ([P1] “*It’s recorded the data of whether she had poor or poor average or good sleep. It might also be important to put why she thought that*”).

***Menstrual cycle and physical activity:*** In terms of other features to track, participants stated how they would like to track their menstrual cycle given its impact on their physical symptoms ([P2] “*Sometimes my period gets affected by my pain*”),

as well as their physical activity in correlation to their symptoms ([P10] “*And that would be something else I’d like to track like, my actual physical activity level to the intensity of my symptoms.*”)

#### **Category 4: Utility and relevance of the visualizations for the participants**

Different visualizations were liked by different participants, based on which ones they thought would be the most relevant for them.

**Sleep:** 3/10 participants mentioned they would like to track their sleep ([P6] “*I do like this one. I have struggled with sleep for a bit. So yeah, I do like that one.*”) given tracking it could result in potentially useful insights. *Sleep* was also rated highest overall (4.55/5) (Figure 5.10).

**Physical Symptoms:** 5/10 participants stated they would definitely like to track their symptoms, as P8 mentioned “*Symptoms - I’d say that would be quite relevant. And they might give a better insight to how my medications might be helping or not helping.*”. This was supported by the high **Utility** for both the *Symptoms* charts (4.6 and 4.2 out of 5) (Figure 5.10).

**Emotions:** Some visualizations also got conflicting reviews on utility and relevance based on personal preference. For instance, while P8 felt they’d like to track their emotions (“*Emotional data is honestly something that I think would be pretty interesting to track for everyone, honestly.*”), P2 stated they might not want to given they wouldn’t be accurate in their reporting (“*I feel like if I were angry, I wouldn’t really say that I’m angry*”). *Emotions* was also varied in ratings - with high **Utility** (4.2/5) and **Interest** (4.2/5), but low **Understandability** (3.7/5) and **Aesthetic** (3.5/5) (Figure 5.10).

**Worries:** 3 participants also reported the mental health and worries categories wouldn’t necessarily be something they would look at, since it would not be relevant to them or since they weren’t very concerned about it ([P10] “*I don’t think I’d be too interested in section two (mental health). But section one (pain) I would definitely be interested in*”). This was echoed in the low **Utility** overall for the *Worries* visualizations (Figure 5.10).

**Peer Interactions:** 3 participants also noted the same for the peer interaction graphs

([P2] “So usually, I have fairly positive interactions with friends, so I don’t worry too much.”; [P10] “I have a specialized school program. So I probably wouldn’t use this (school attendance and peers) functionality at all”). This was also reflected in the **Utility** for these visualizations (Figure 5.10).

Thus, overall, while most participants reported finding all the visualizations interesting to look at and definitely saw value in tracking all the different aspects, they were partial towards certain visualizations that they felt were the most relevant to their experiences, and would like to look at those the most.

## 5.4 Resulting Modifications

Based on the evaluation feedback, we determined that there were no major changes required to the visualizations. Minor changes regarding readability and spacing would be addressed during the redesign for the CareTeam deployment, discussed in the next chapter.

However, there were two other general modifications we made:

- **Introductory Guide:** Based on the feedback from the participants regarding difficulties in interpreting the visualizations, we decided to create an introductory guide document to walk participants through the visualizations, attached in the Appendix as A.6.2. The guide describes each visualization and explains how to interpret them. We intended to request participants to review this guide as a tutorial prior to beginning their trial, and thereafter have access to it as a reference. We hoped this would help resolve complexities in understanding the visualizations, especially the *Emotions* and *Expected vs Reality* graphs.
- **EMA Changes:** We also noted that while many participants suggested additional things they would like to track, or changes they would like to the EMA questions, most of those changes would require a significant overhaul of the EMA survey. As such, we decided to keep all EMA changes for a future iteration, but made note of these suggestions.

With this, we moved on to the next stage: collaborating with industry partner CareTeam to design and integrate the visualizations and EMA surveys on their

platform, which we describe along with the larger clinical study in Chapter 6.

## Chapter 6

# Evaluation 2: Clinical Deployment with Teens

After validating the usability and usefulness of the visualizations, we needed to deploy them longitudinally in order to see how teens used and responded to them in the midst of their daily lives; and to get a first look at potential clinical efficacy in terms of finding insights that might lead to changing behavior.

This required implementation on a deployment platform, integrated with a daily survey (EMA) platform so that teens would be able to immediately see their responses fill out the visualizations over the course of days and weeks.

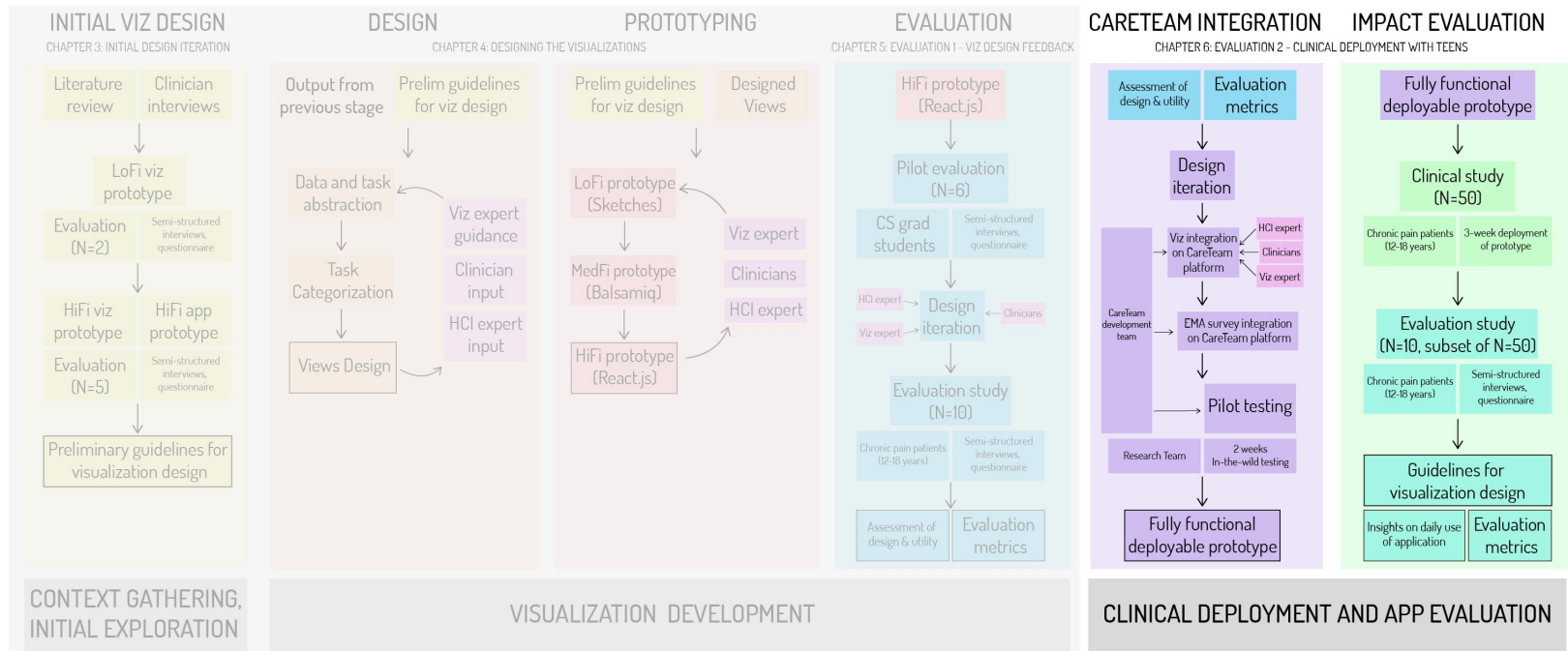
Thus, our approach at this point required several steps: Identification of a deployment platform and partner (CareTeam, a locally-based Canadian health-tech startup), implementation of the integrated application on that platform (entailing translating and to some extent redesigning our visualizations to match the capabilities and style of the new system, followed by a clinical study where we simultaneously evaluated clinical and user-interface objectives.

In this chapter, we describe the integration of the Chapter 4 visualizations onto the CareTeam platform; specifically, design iterations carried out in collaboration with CareTeam to optimize the visualizations for their platform, followed by piloting them on that platform.

We then discuss the clinical study to evaluate the impact of the visualizations combined with the EMA surveys as a holistic web application and results from the

study. We refer to this second phase of evaluations as **Phase 2**. In this thesis, our focus in the larger clinical study is mainly the impact of the visualizations and what teens thought of them, thus in this work we detail the post-study feedback interviews that were conducted specifically for that purpose. A detailed, deeper analysis on the clinical study itself can be found in a corresponding clinical research publication, to be published post the completion of the study.

Figure 6.1 indicates how this chapter fits into our overall project process.



**Figure 6.1:** Showing the Clinical Deployment and App Evaluation phase discussed in this chapter



## 6.1 CareTeam Integration

With its platform, CareTeam aims to reduce the communication gap between health-care teams and patients by leveraging patient-centered design. Their platform connects patients with their personal support teams - which can consist of multiple healthcare professionals - enabling instant communication and analytics.

The integration of the visualizations and EMA survey into their platform involved redesigning some of the visualizations alongside their design team to accommodate their design style, and piloting the whole application before the clinical study to ensure all components functioned as intended. For future reference, we will refer to this combined method of data collection through the EMA surveys and resulting visualizations all on the CareTeam platform as the *myWeekInSight* tool.

### 6.1.1 Deployment Platform Requirements and Rationale

The larger clinical study (Section 6.2) would require deployment of the visualizations and EMA surveys integrated on a robust, large-scale platform, for a multiple-week data collection period. Given that we would be collecting personal health data, we would also need to adhere to strict privacy and data security standards, as well as medico-legal requirements. We would further need to design a user interface that would be simple yet intuitive. The visualizations would also need to be integrated in a dynamic manner that would allow them to update real-time each time a survey was filled. As most of our target demographic would also be using the platform through their mobile phones, we would further need to make the platform responsive. Given the schedule we were working on, designing and deploying a platform for the sole purpose of this study and including all the mentioned features on said platform would require enormous efforts while also extending our timeline significantly. Hence, we decided to review existing platforms on the market instead of developing one from scratch.

In our reviews, we came across two platforms, GoodData [9] and CareTeam that met most of our requirements. While GoodData is an analytics software that would allow us to integrate our visualizations with some redesign, and update in real-time, we would need to develop a separate module for administering the sur-

veys to be able to link the survey data to the GoodData platform. GoodData is also a US-based software company, which would mean we would have to manoeuvre through additional legal requirements to make sure we were still maintaining Canadian data security and privacy standards.

The CareTeam platform, on the other hand, already followed Canadian data privacy and security standards, as well as met all medico-legal requirements. The platform was robust, responsive and user-friendly, as well as configurable. While CareTeam does not deploy visualizations and surveys as a part of their standard platform, they would be able to add these features in for our study in particular. Given that the platform then met all our requirements, and would be much less effort than starting from scratch, we made the decision to collaborate with them to customize their platform for our study.

The partnership took the form of a subsidized collaboration. A healthcare foundation development grant allowed the academic and clinical team to access Careteam's services at cost, while the company's interest was in developing a service category that was new to them while fitting well with the company's mission and past experience.

### **6.1.2 Adaptation of Visualizations to Deployment Platform**

In our preliminary discussions with CareTeam, while we were in the phase of low-fidelity prototyping of our visualizations (Section 4.4), we discussed the platform or medium to be used for our high-fidelity prototypes. This was done to ensure that we would have minimum deviation from the designs when they ended up being integrated on the CareTeam platform. The CareTeam platform is built on JavaScript [18], and hence we were directed to prototype the visualizations in React.js [1] if possible, as that would make it easiest to integrate the visualizations at a future stage. Hence, we developed our high-fidelity prototype in React.js.

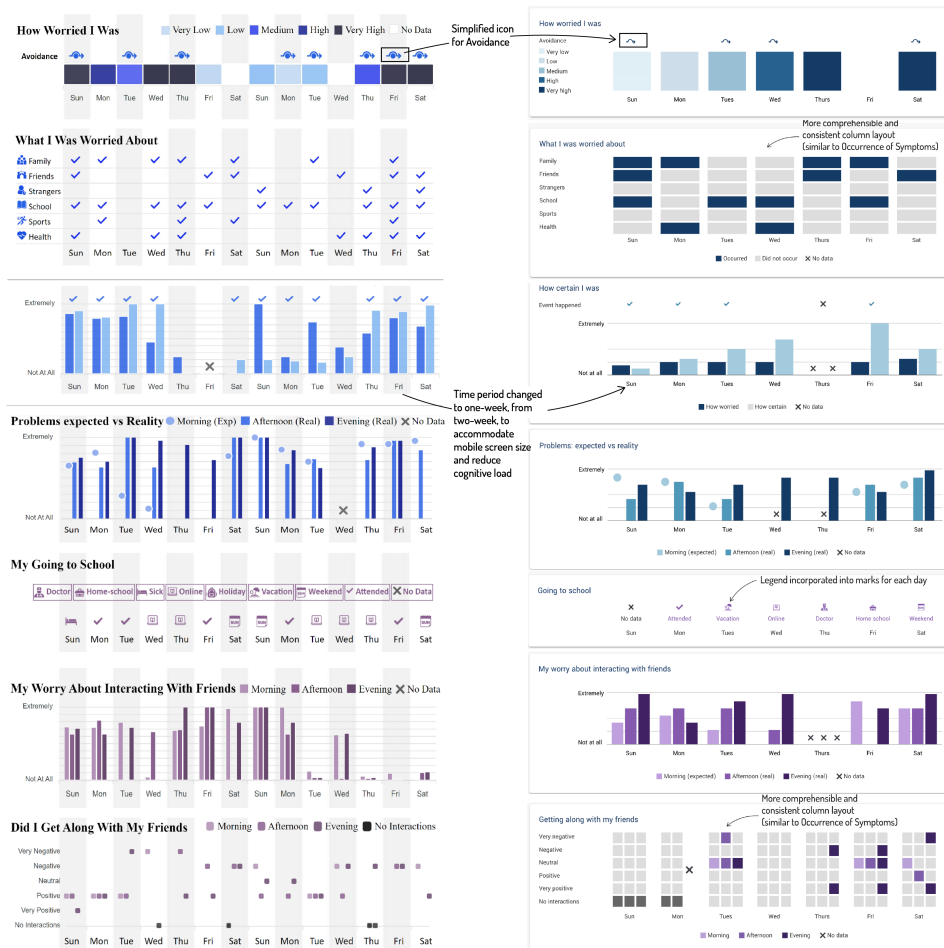
However, while our visualizations were now technically compatible, we still needed to incorporate the CareTeam platform's design language to ensure the visualizations integrated smoothly with the platform. For this, we established a collaborative iterative process with the CareTeam development team, where over a period of 2 months we redesigned each visualization to incorporate the CareTeam

design language. While this required minor changes to some visualizations, others underwent larger changes. We also incorporated some of the feedback from the Phase 1 interviews as we redesigned.

Below, we show our final prototype version alongside the CareTeam developed version, with the design changes summarized at the end. The CareTeam version was designed using mock data, while our prototype was based on the data collected during the pilot in the Initial Design Iteration (Chapter 3).



**Figure 6.2:** Our prototype (left) compared to the CareTeam platform version (right) of the Sleep, Symptoms and Emotions visualizations, with changes highlighted



**Figure 6.3:** Our prototype (left) compared to the CareTeam platform version (right) of the Worries and Peer Interactions visualizations, with changes highlighted

Below, we detail the design changes that were made to finalize the CareTeam version of the visualizations, as also shown in the images above:

- **Reordering visualizations:** Based on the feedback we received from the Phase 1 interviews, participants mentioned how they would like to see their *Symptoms* and *Sleep* and *Emotions* the most. On discussion with the clinicians, we received feedback that enabling participants to be able to see cor-

relations between their pain, sleep and emotions would be of most important, and hence we decided to reorder the visualizations, keeping *Symptoms* between *Sleep* and *Emotions* to relate *Sleep* and *Emotions* to *Symptoms* individually.

- **Increased day spacing in place of gray/white striping:** The CareTeam implementation would allow for increased spacing between days, which was something we also received feedback on from the interviews, to enhance readability. As we would be able to increase the spacing between days, that would serve as a demarcation between days, and hence we could remove the alternating grey-white column background that we had in the React.js prototype.
- **Colours:** To adapt the visualizations to the CareTeam design style, the visualization colours were modified. While we kept the main hues the same to maintain the color-coding of categories and scales within visualizations, the particular shade of each colour was modified to similar, pastel versions.
- **Icons:** Icon for Avoidance was simplified in 6.3. All icons were licensed from Flaticon [16] for personal use.
- **Legend moved to bottom:** The legends for each chart were moved to the bottom of the chart as that would be the easiest to implement on the CareTeam platform, while also keeping it consistent across the visualizations.
- **Removal of legend from the school visualization:** We realized the legend for the school visualization was redundant if we added the label simply to the icon within the visualization itself. Hence, we removed the legend from that visualization, making it more compact, as seen in 6.3.
- **Change to tabular-column encoding:** For two of the visualizations, *Category of Worries* and *Peer Interaction Quality*, we switched from the React.js format to more column-based formats, which were similar to the *Occurrence of Symptoms* charts. For *Category of Worries*, that meant we no longer needed icons and check-marks, but simply the labels on the Y-axis with filled

cells whenever that category was checked in the corresponding survey, seen in 6.3. For the *Peer Interaction Quality* visualization, that meant we did not need the scatterplot, which we had also been told was not the easiest to understand, and instead we would simply mark the corresponding cells for the quality of the interaction each time based on the survey entry, seen in 6.3

- **Change to one-week data:** Given the mobile device width we would be working with, we decided to switch to showing only a week's worth of data, instead of our original two-week plan. This would lessen the cognitive load on users as they would have less data to process, while also allowing 'cleaner' and 'larger' visualizations with the extra screen space.

### 6.1.3 Research Team Pilot

Once the visualizations had been integrated into the platform, the research team piloted the web application for a two-week study period to ensure the robustness and accuracy of the platform when generating the visualizations from the EMA data. The EMA surveys were integrated using the Ocean Patient Engagement Platform by CognisantMD [11], which allowed CareTeam to create digital versions of our EMA surveys compatible with their platform.

This process exposed and added detail to a number of technical requirements which may have previously been implicitly assumed, difficult to fully specify in advance of piloting, or surprisingly problematic to implement yet crucial. We list these painfully-met requirements in hopes that it will be useful to others following this path:

***Text (not just email) notifications are crucial for usable compliance (especially for teen respondents):*** While the CareTeam setup included email and text notifications that could be sent out to participants to remind them to fill the EMA survey each time, members of the research team were unable to receive text notifications during the pilot. This was as we were testing on a demo environment, while text notifications were only deployed on the production server. However, given that we felt text notifications would be pivotal for our young demographic, we further needed to do a shorter round of pilot testing on the production server to confirm

the text notifications were working as expected. This added to, and extended, our study timeline.

***Notifications must arrive reliably in a precise window of time:*** Email notifications for the surveys were initially backdated, or were sent repeatedly through the day for past filled surveys. This could be potentially confusing or concerning for participants, hence we needed to ensure that all emails were being received during the appropriate window of time.

***Ensure embedded modules work reliably:*** Early on in the pilot, we encountered a glitch where users would need to manually enable pop-ups for the Safari browser to be able to open and fill out the survey each time. This would need to be done on mobile and/or laptop, through the device or browser settings. This would add another layer of complexity as without this the surveys would not load at all. Fortunately, this turned out to be an iFrames global issue (specific to Apple devices, from the software developers themselves) which we were able to address quickly, but it highlights the need to ensure embedded or third-party modules within an application work reliably and stay updated.

***Only show users what they need to see:*** The CareTeam deployment of the surveys as a list on the user's frontend would technically allow users to forward-fill surveys, *i.e.*, fill them out for times that had not occurred yet like the next morning or evening. While we were unable to modify this in time as it would require a significant overhaul of their current code setup, we compromised by adding a note in our instructions guide to users instructing them to only fill current surveys. In retrospect, based on our follow-up interview feedback (discussed in Section 6.3.2), this confused many users and led them to fill out some surveys incorrectly, which shows the need to only display to users what they need or should be able to see.

***Allow user preferences during setup:*** Perhaps the biggest limitation in our implementation, the CareTeam platform would only allow users to begin the study on a Sunday morning. The reasoning behind this was that the visualizations were set up to run specifically from Sunday to Saturday to visualize a week's worth of data. However, this meant users could not sign up before 6pm Saturday (the evening EMA survey time) since if they did that the system would count them to have been a part of the earlier week ending that Saturday. Hence, there remained a nar-

row window for users to sign up, after 6pm on the Saturday and before 8am (the morning EMA survey time) on the next Sunday, to ensure they were enrolled in the correct week and were able to fill out all the surveys (the system also shows surveys only after the time of sign up, so for instance if someone signed up at 9am on the Sunday, they would be unable to fill the morning EMA survey as that would be published at 8am). As we were unable to make this dynamic and user-specific in time for the study, we ended up including this information in the sign-up emails sent to participants, as well as in the instruction guides sent out. This did, however, place the burden on our young participants to begin the study on time, and many participants did end up signing up late and missing initial surveys as mentioned in their post-interview feedback. Our takeaway here is to allow for user preferences in the application setup where possible so they can better integrate such applications in their daily lives.

While not all of these issues could be fixed in time, we were able to troubleshoot and settle on temporary solutions that would mitigate them to an extent. Overall, running the pilot and troubleshooting issues was an iterative process that took a month, post which we were ready to recruit and begin the clinical study.

## **6.2 Clinical Study: Feasibility of Approach for Personal Data Collection**

In this section, we describe the design of the clinical study, and how our evaluation of the visualizations fits into the same. The clinical study aimed to assess two aspects:

1. Teen responses to the *myWeekInSight* application from a clinical acceptance and efficacy standpoint. We provide an overview of this study in Section 6.2.2.
2. Evaluation of the usability and engagement potential of the visualizations. This aspect is discussed in Section 6.3.2, is the focus of this thesis, and the data for the same comes from interviews after participants had used *myWeekInSight* for two weeks.



### **6.2.1 Recruitment**

For the full study, we aimed to recruit 50 youth with chronic pain aged 12-18 years, currently being seen at a chronic pain clinic at a tertiary-level pediatric hospital, although recruiting would not be done by the clinicians themselves, but by me, Haley Foladare, and research assistants from the pediatric hospital (to avoid any perceived pressure from the clinicians involved in the study). For the interviews, we selected a subset of 10, randomly sampling from the participant pool of 50 youth. Participants were compensated 20 CAD for enrolling on CareTeam and beginning the study after filling out the baseline questionnaires, with an additional 10 CAD for completing each week of EMA data collection with at least two-thirds (*i.e.*, 14 of 21) of the data points completed. Participants who would also do the interviews would be compensated an additional 20 CAD.

Study participation (due to factors outside our control) ended up taking place spanning the end of the school term for many participants. This resulted in additional stress for some of them (mentioned during the feedback interviews as well) which did give range and emotional depth to our results, but also resulted in lower engagement and compliance with the tool.

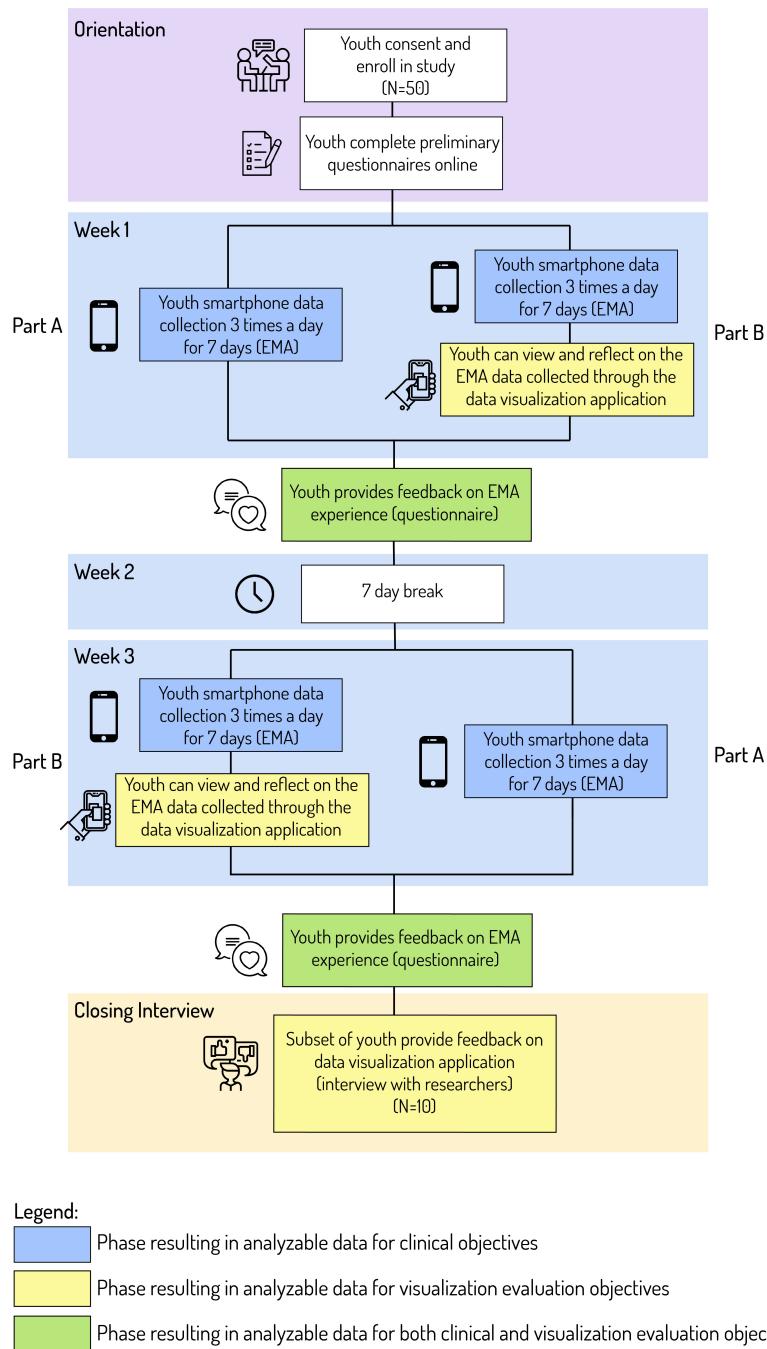
### **6.2.2 Study Design**

The clinical study, headed by Drs. Oberlander and Boerner, aimed to assess the feasibility of the EMA and visualization method of remote data collection for youth with chronic pain.

The study extended over three weeks, with a one-week break between the first and third week, intended to serve as a washout period. Before participants began the three-week study period, they would also need to fill out baseline questionnaires, administered via REDCap, that would capture details about demographics, pain, anxiety and somatic symptoms, for clinical purposes. For each of the two 'active' weeks, participants would receive the EMA surveys three times a day, but in one week, they would also be able to see the visualization dashboard where the EMA data would be visualized in real-time. Based on prior randomization, participants would be able to see the visualization dashboard either in their first or third week. This quasi-experimental design ensured both groups received the visualiz-

ations but at different points in the study, with a one-week break between the two weeks. At the end of both the first and third weeks, participants would receive a feedback questionnaire via REDCap that would ask for their input on the EMA [and visualization] experience through open-ended text-boxes that would allow youth to provide detailed answers. Following this three-week study, we conducted semi-structured interviews with a subset of the participants to gather detailed feedback on the visualizations in particular. All participants could select whether they would want to be contacted for interviews during the consent process for the study itself, but only a random subset would be selected later.

In Figure 6.4, we show the study protocol, with the *only EMA surveys* approach labelled **Part A** and the *EMA surveys + visualization dashboard* approach labelled **Part B**.



**Figure 6.4:** The study protocol for this phase of evaluation highlighting the different clinical and design foci during analysis

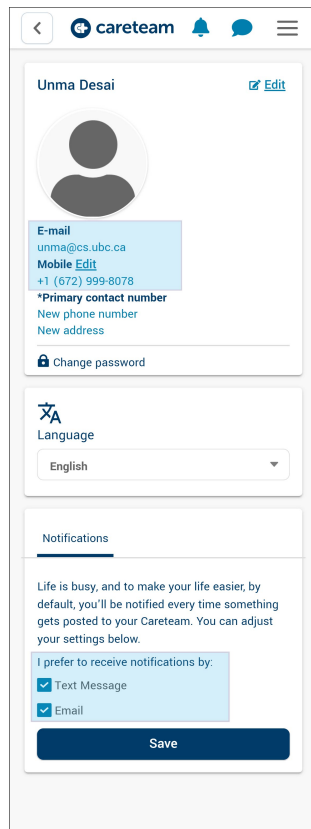
### **6.2.3 Study Deployment and Progress**

As of August 07, 2022, the clinical study ended for the last batch of enrolled participants, with 48 of 50 participants recruited. Recruitment began on May 30, 2022, with the first batch of participants beginning the study on June 5, 2022. Recruitment was conducted on a rolling basis, with new participants beginning every Sunday. In order to complete the post-study evaluation interviews and analysis in time for completion of this thesis, I was unable to randomly sample through the rolling participant pool, and ended up interviewing the first 11 who agreed to participate in the interviews. While we had planned to interview 10, given the rushed timeline, scheduling invites were sent out to all participants who had agreed to the interviews at the end of their third week. As such, at the end, two participants scheduled interviews on the same day and as we did not want to miss getting feedback from any participants, we conducted 11 interviews.

Participants would be sent an orientation guide with instructions on how to sign up to the CareTeam platform on the Saturday before the Sunday they were scheduled to begin. To divide participants in the two random flows of dashboard in the first week vs dashboard in the third week, CareTeam created two sign-up codes, which were added to the guides. Two versions of the guides were hence created, with each containing one of the codes. Based on which code participants signed up with, they would have the visualization dashboard either in their first or third week. One of the guides (dashboard in first week) is attached in the Appendix in Section A.6.1. Participants were also sent reminder emails on the Saturday before the Sunday they were scheduled to begin, as a reminder to sign up to the platform (the same was also mentioned in the orientation guide).

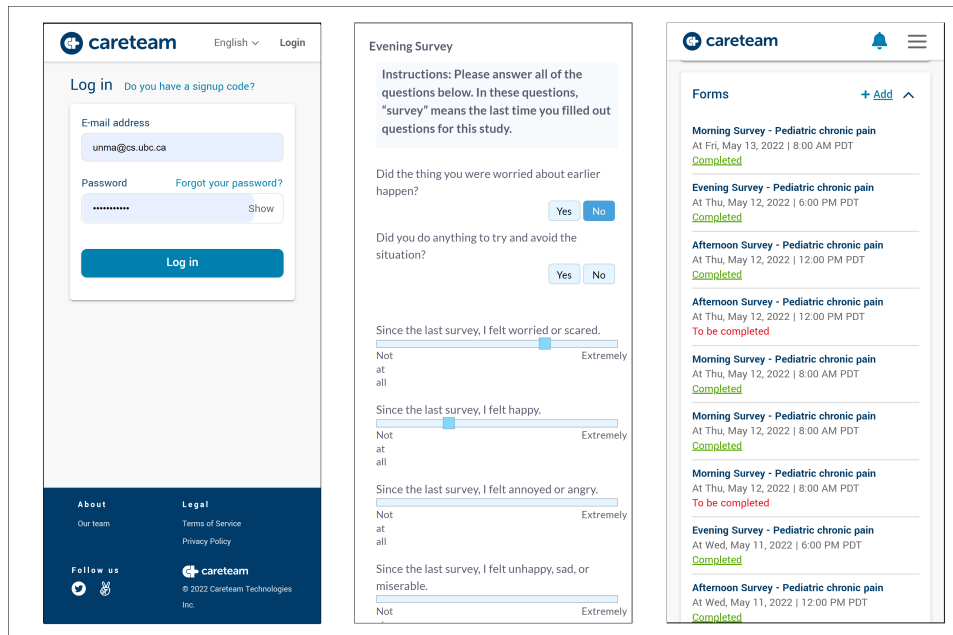
The recruiting team monitored sign ups to the platform, and in case participants missed signing up by multiple days, they were asked to wait until the next Sunday to ensure maximum data could be collected.

Below, we show screenshots of the basic CareTeam platform features that users would interact with, including the screens to sign up, register for notification, and fill the surveys (Figure 6.5 and 6.6). The visualization dashboard has been shown in detail in Section 6.2.3, with full versions of desktop and mobile available in the appendix in Section A.5.3 and A.5.4:



**Figure 6.5:** The ‘My Profile’ screen on the CareTeam application, where users can add their phone number and email address and select what kind of notifications they would like to receive.

As the study progressed, by analysing the feedback questionnaire results at the end of the first week, we realized participants were unable to find the dashboard on the CareTeam website, and hence unable to interact with it. For the purposes of the study, it was crucial for the participants to interact with the visualizations, so that we could assess their engagement with the visualizations and correlate it to their EMA responses to evaluate the use of the visualizations as a treatment intervention. To mitigate this to an extent, we enabled check-ins on the platform for the weeks where participants were to see the dashboard, where on logging in to the CareTeam website on the Monday of their dashboard week, they would be asked if they had

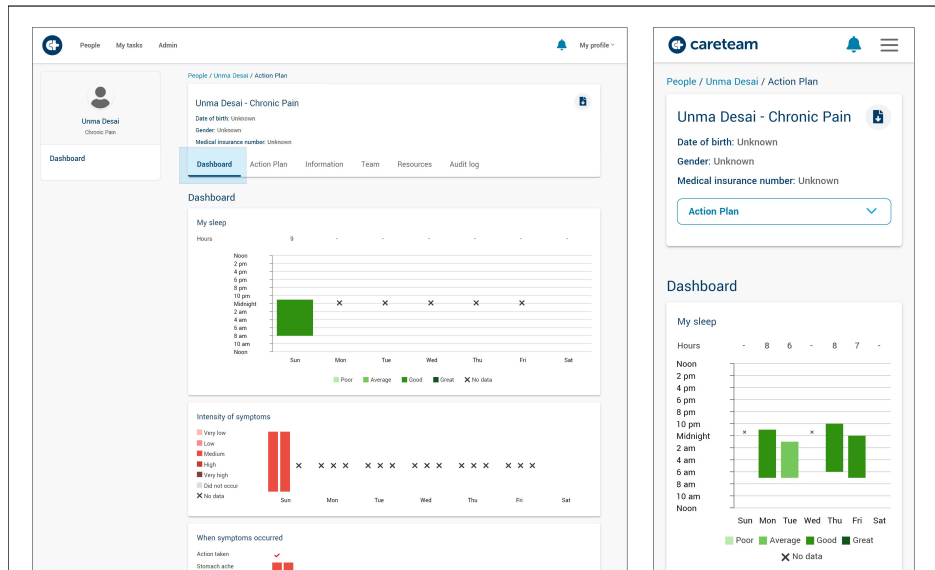


**Figure 6.6:** CareTeam platform screens showing: login screen (left), the EMA surveys that users can fill (centre), forms log showing whether users have completed surveys (right). All these screens are available throughout the three weeks of the study

been able to see the dashboard and they could request assistance if not, shown in Figure 6.8. This would help us monitor who was unable to find the dashboard and assist them. To ensure participants were not only finding the dashboard but also spending time interacting with the visualizations, we also began sending out mid-week emails requesting them to interact with the visualizations, while also including screenshots on where to find the visualization dashboard.

### 6.3 Design Study Component: Evaluation of Visualization Impact

As participants began the third week of the study, we contacted the ones who had consented to participate in the interview, to schedule the same post the end of the week. Even if participants had consented earlier, they were still free to withdraw their consent from participating in the interviews, which some did. The first batch



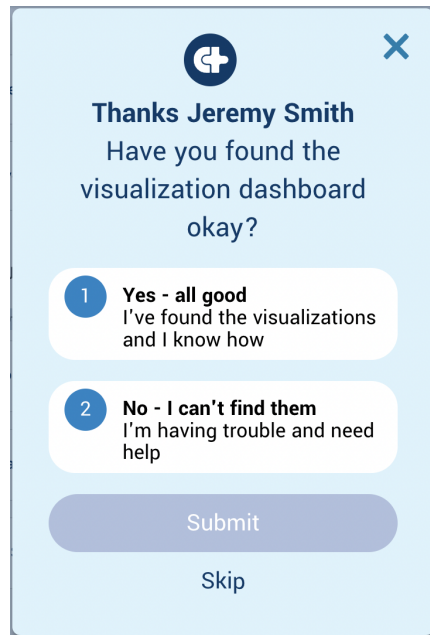
**Figure 6.7:** The visualization dashboard (partial screenshot cropped for length) seen under the Dashboard tab, on desktop (left) and mobile (right) on the weeks where participants can see the dashboard

to complete their three weeks completed the study on June 26, 2022, post which we conducted interviews with 4 of them. Over the next few weeks, as more participants completed the three weeks, we continued to schedule and conduct interviews, completing the last interview on July 15, 2022.

### 6.3.1 Final Evaluation Metrics

We modified the metrics for this round of interviews, given our focus was the usefulness and accuracy of the visualizations. Hence, we kept the same 5-point Likert scale, but replaced **Interest** with two new metrics - **Insightfulness** and **Accuracy**.

**Interest** had been included in Phase 1 to gauge if participants found the visualizations interesting enough to want to engage with them. Given that in this phase they would have had the opportunity to engage with the visualizations anyway, we chose instead to ask them about **Insightfulness**, i.e. if engaging with the visualizations had enabled them to see patterns in their data or learn things about how their pain connected to other aspects of their lives that they might have missed other-



**Figure 6.8:** A demo of the pop-up asking participants if they found the visualization dashboard or not

wise. We also wanted to know if the visualizations and EMA survey combination had managed to record their lived experience accurately, which would have further validated this method of data collection. Hence, we added the **Accuracy** metric.

Thus, for this round of interviews, we had the same questionnaire as before, only with updated metrics, shown in Table 6.1

We also retained the screen comparison questions from the previous evaluation study, as discussed in Section 5.1.2, as we wanted to evaluate if participants could see patterns across the visualizations.

### **6.3.2 Methods**

#### **Study Design**

Our subset of interview participants consisted of 11 (11F) youth with chronic pain, aged 12-18 years (one participant turned 19 during the course of the three weeks



<b>Metric</b>	<b>Description</b>
Utility	Assessing if the information shown in the visualization would be useful to the user personally
Understandability	Assessing if the information shown through the visualization was easy to comprehend
Insightfulness	Assessing if users could see new patterns or knowledge in their data through the visualizations
Accuracy	Assessing if the visualizations accurately represented the user's lived experience
Aesthetic	Assessing if the users liked how the visualizations looked
Understandability (Screens)	Assessing if users could understand information shown across visualizations

**Table 6.1:** Evaluation Metrics for Visualization Impact

but was 18 when they began). The study consisted of a one-hour semi-structured interview where we asked for feedback regarding the accuracy, understandability, insightfulness and utility of the visualizations. Post the interview, participants would be sent a REDCap questionnaire asking them to rate each of the visualizations on a set of metrics, similar to the process in the Phase 1 study (Section 5.1.2).

Compared to Phase 1's objectives of evaluating the design of the visualizations, we focused here on evaluating the usefulness and relatability of the visualizations. We had hoped youth would have had the opportunity to interact with the visualizations and hence would have detailed feedback on the same. However, given the technical obstacles some of the participants faced where they were unable to find the visualizations, we began sending screenshots of their visualization dashboards to them a day or so before the interview, to give them some time to still look at and interact with the visualization. These dashboards were mocked up based on their survey data, in the exact design style as they would have appeared on the CareTeam dashboard, in Adobe Illustrator [17].

For the questions for this round of interviews, we wanted to gain feedback based on their personal choices. We classified our questions into 8 categories, summarized in Table 6.2.

All questions asked for open-ended feedback based on their experiences. A complete list of the questions can be found in the Appendix in Section A.4.4.

<b>Category</b>	<b>Questions centered around</b>
Pre-test (Context gathering)	Previous experience with tracking health data Previous experience with visualizations
Design Guidelines/Aesthetic	Specific charts they liked Features they would have liked to see Charts they thought were unnecessary
Understandability	Charts they found complicated
Insightful	Interesting patterns they might have noticed
Encouraging/Motivating/Usefulness	Charts that help think of ways to manage pain Help in reflecting on pain management strategies Aspects of the visualizations that were motivating Aspects of the visualizations that were discouraging Value in looking at the visualizations
Relatability/Authenticity	Graphs accurately representing experience Things that could make graphs more relatable
Screen usefulness	Usefulness of comparing graphs Interesting correlations across graphs Connections between emotions and pain Connections between sleep and pain
Negative consequences	Reasons to not use this setup Graphs they disliked
Open-ended	Fitting tool in their daily life Effort/time in inputting data Effort/time in interacting with dashboard Additions to make experience better Issues they might have faced

**Table 6.2:** Categories and questions asked to participants in Phase 2, through semi-structured interviews

## **Analysis**

We report the results of the interviews and the questionnaire separately through subsections, for conciseness, using the qualitative analysis to corroborate the quantitative findings. For the interviews, while our original plan had been to perform a thematic analysis, as we conducted the interviews we realized the quality of data would not warrant an in-depth thematic analysis (as questions about engagement with the visualizations could not be successfully answered due to technical issues during the study, and these questions were a significant part of the protocol), but there was still significant depth and breadth in the answers we received, so we decided affinity diagramming would be an ideal method to analyze these results.

Two researchers used the affinity diagramming approach to analyze the interview transcripts, and extract insights from them. We then proceeded to categorize those insights under broad themes, which are described in detail in Section 6.3.5.

### **6.3.3 Demographics**

While our participant pool was completely female, below we explain the reason behind the bias, linked to the general prevalence of chronic pain in adolescents as well as the general ratio of chronic pain patients at the pain clinic at the pediatric hospital. We also collected data on participants' previous knowledge and experience with health data tracking and visualization applications, to provide context for their responses and perspectives overall. Only a small subset of the participants (3 out of 11) had previous experience with tracking and visualizing health data, but their experiences enabled them to provide novel insights like the potential of incorporating health wearable data or gamification.

#### **1. Gender imbalance in participant pool**

Our participant pool for the interviews consisted of all 11 females, aged 13-19 years. This gender imbalance could be attributed to a number of reasons:

- Chronic pain has been found to be more prevalent in women [45] and girls [44] globally. Girls are more likely to report pain in more sites than boys, with the prevalence only increasing with age. Mills *et al.* [67] review of population studies corroborates the same, discussing the pos-

sible influence of oestrogens and genetics as well. This could explain the imbalance to an extent, given girls are more likely to experience chronic pain than boys.

- The overall study had 42 participants (32F, 10M) at the time of this writing, which to an extent reflects the ratio in the interview subset.
- On consulting with our clinician partners, we were told the ratio was also representative of the patients being seen at the pain clinic - there are many more female patients than male, and even in previous studies at the clinic, the populations had been female-biased.
- While we tried to sample evenly through the subset, given our constrained timeline, we ended up front-loading the interviews. This meant we interviewed the first 10 participants who were available to schedule the same with us. Out of the total 10 male study participants, only 2 signed up within the timeframe of the interviews, and both did not respond to interview requests. The other 8 male participants signed up much later, hence our participant pool ended up being only female.
- We note anecdotally that our recruiting process often involved talking to mothers who would then forward the information to their children, which is how many of the study participants signed up. We believe it possible that mothers found it easier to talk to their daughters to bring them on board, as opposed to their sons. We did have some mothers respond that they felt their sons would probably not want to participate before they even asked them, while for most girls their mothers felt fairly certain they would. While this could just be representative of girls wanting to be more active in participating in the studies, it could also represent mothers being able to convince or reach out to their daughters more successfully than sons.

Thus, overall our pool being completely female could be due a number of reasons including population prevalence and interest in participation, but it is generally representative of the target population of youth with chronic pain. In future iterations though, we would like to have a more balanced

participant pool, as the individualized nature of chronic pain means every participant brings unique insights and perspectives.

## 2. Previous experience with recording health data

For response context and an assessment of our collection mechanism's novelty, at the start of each interview we asked participants if they had prior experience with tracking their personal health data. This could be as a part of a previous study, through a mobile application, a wearable or traditional methods like diaries and journals.

Of our 11 participants, 3 had previous experience with tracking their own health data. 1 participant had used a habit tracker for multiple months, another used Daylio on a daily basis, and one had been using the Fitbit wearable band for 4+ years. This shows a general mix of the kind of personal data being tracked. For P7 who used a habit tracker, they wanted to form and stay consistent in their habits, which they said had worked pretty well. The habit tracker app simply consisted of an on/off streak shown by coloured columns, where staying consistent with a habit and marking it daily led to 'filled' columns. This goal motivated them to stay consistent. This also reflected in P7's answers as to how the visualization dashboard could motivate them from a gamification perspective, and how they liked having the goal of getting 'complete' charts. Of the habit tracker they said *"I found it cool to just see how I could get consistent with certain things, how I could like make pretty much entire columns black by just doing it every day. [Did it help?] Yeah it did because it made me want to do it to get that reward of the column being blacked out."*

Daylio had in the past helped P6 track their mood, as well as things that affected their mood, on a daily basis. P6 was thus familiar with tracking their mood, and found the emotions visualization to be the most interesting. P3 had been consistently using the Fitbit wearable band to monitor different aspects of their daily life, and suggested integrating the same into our data collection method - the Fitbit tracking of sleep for instance could reduce the user load, and they felt that Fitbit data would be more accurate.

This feedback was useful in recognizing opportunities to use existing designs

and tools as a part of the *myWeekInSight* experience, given how some users might be used to them.

### 3. Previous experience with visualizations of personal health data

We asked participants if they had previous experience with looking at visualizations of their health data. This could include graphs seen from clinical charts, through smartphone tracking applications, or wearable data visualizations. We thought this would provide additional context for their responses on which visualizations they liked or disliked, as well as additional features or things they thought we should add.

3 / 11 participants had seen visualizations of their health data before, with two tracking their own data (discussed above.) P6 had seen Daylio visualizations that compared mood by days, which they spent time on at the end of a week. P5, had seen visualizations of their clinical pain data, which had helped them understand when and where their pain was most common, and what other factors influenced it. P3 had seen graphs on Fitbit, tracking their sleep and fitness, but did not really know what to do with the information shown.

Thus, a subset of participants had an idea of what health data visualizations could look like. However, they all mentioned that they had not seen visualizations like the ones we had, and were not sure how to interpret the information shown. This raises an interesting point of existing visualization methods in currently available commercial applications not being appealing or understandable enough for this demographic, and shows the potential of designing specifically for a younger or targeted demographic which will allow them to engage with the visualizations and extract actionable insights from them.

## 6.3.4 Quantitative Results

Analysing the results from the REDCap questionnaires (8 out of 11 completed):

Overall, **Utility** was the highest for *Intensity of Symptoms* (4.375) and *School Attendance* (4), while lowest for *Worries vs Certainty* and *Peer Interaction Worries* (2.875). This mostly matched what the interviews had revealed - the symptoms

	Sleep	IofS	OofS	Emotions	IofW	WC	WvsC	EvsR	SA	PIW	PIQ	Average
Utility	3.75	4.375	3.75	3.125	3.25	3.375	2.875	3.125	4	2.875	3.25	3.43
Understanding	4.625	4.375	3.625	3.875	4.125	4.125	3.875	3.625	4.625	4.25	3.875	4.09
Aesthetic	4.125	4.125	3.5	3.625	3.875	3.625	3.875	3.625	4	4.125	3.875	3.85
Insight	2.625	2.875	3.125	2.75	2.75	2.625	2.75	2.875	2.625	2.625	2.625	2.75
Accuracy	3.75	3.875	3.625	3.5	3.5	3.75	3.75	3.25	3.75	3.75	3.5	3.64
<b>Average</b>	<b>3.78</b>	<b>3.93</b>	<b>3.53</b>	<b>3.38</b>	<b>3.50</b>	<b>3.50</b>	<b>3.43</b>	<b>3.30</b>	<b>3.80</b>	<b>3.53</b>	<b>3.43</b>	

**Legend:**  
IofS: Intensity of Symptoms  
OofS: Occurrence of Symptoms  
IofW: Intensity of Worries  
WC: Category of Worries  
WvsC: Worries vs Certainty  
EvsR: Expectations vs Reality  
SA: School Attendance  
PIW: Worry about Peer Interactions  
PIQ: Quality of Peer Interactions

**Figure 6.9:** Heatmap showing the quantitative responses for each of the visualizations, color-coded to show highest and lowest ratings and averages for all metrics and visualizations

charts interested teens the most, while most of them did not find the worries for peer interactions particularly relevant or useful.

**Understandability** was the highest for *Sleep* and *School Attendance* (4.625), while lowest for *Occurrence of Symptoms* and *Expectations vs Reality* (3.625). This matches the interview responses, as participants had been easily able to understand the sleep and school attendance graphs.

In terms of **Aesthetics**, participants liked the *Sleep*, *Intensity of Symptoms* and *Peer Interaction Worries* visualizations (4.125) with *School Attendance* a close second (4). The remaining bar graph-based visualizations also ranked high, but *Occurrence of Symptoms* and *Category of Worries* as well as *Expectations vs Reality* were ranked the lowest (3.5 and 3.625 respectively). This seems to echo the feedback of keeping the graphs consistent and using simple encodings like bar graphs throughout.

For **Insights**, the *Occurrence of Symptoms* visualization seemed to be the most insightful for participants (3.125), while *Expectations vs Reality* and *Intensity of Symptoms* followed (2.875). This is in sync with what participants said they had found most interesting in the interviews - discovering the patterns in their symptoms or realizing things in reality were not as bad as they had thought them to be. This is also highly interesting as *Occurrence* and *Expectations* fared poorly on **Understanding** - meaning even though participants might not have understood those visualizations, they were able to extract insights from them, which shoes the

potential of these visualizations in particular. The *Category of Worries* and *School Attendance* visualizations along with the *Peer Interactions* visualizations ranked lowest (2.625), which figures given how participants mentioned they were already mostly aware of these aspects in their lives and did not think they changed much.

Given that we had a diverging Likert scale, with measures below 3 measuring the extent to which users disagreed with the prompt (which in this case was “*This graph shows me something new that I did not already realize*”), this means for **Insights** users mostly disagreed that any of the visualizations showed them new information. Most of the interview participants had noted how they had been unable to see cross-comparisons, and while some of them saw patterns they did not know before, it seems like overall the visualizations were not able to reflect data in a way that enabled users to extract insights. While this could partly be attributed to the incomplete data points from partially filled or missed surveys, it certainly raises the need for redesigning and increasing the simplicity and clarity of the visualizations.

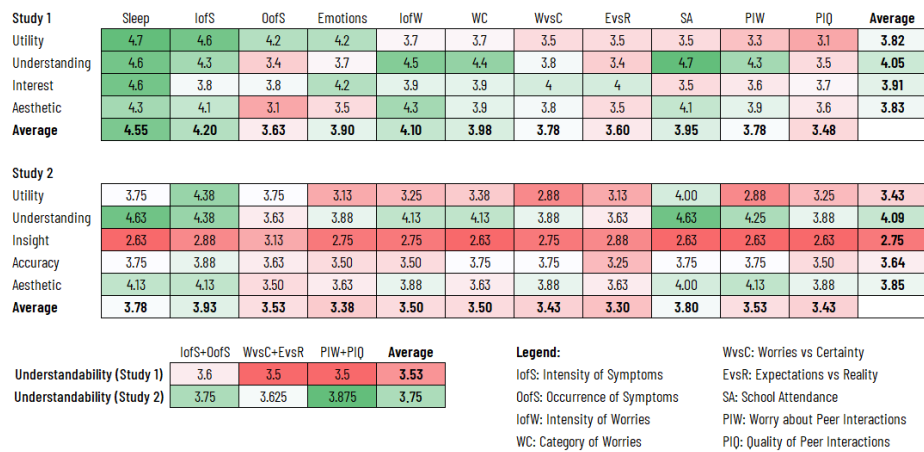
Finally, for **accuracy**, *Intensity of Symptoms* ranked the highest (3.875), with *Sleep*, *Category of Worries*, *Worries vs Certainty*, *School Attendance* and *Peer Interaction Worries* all ranking a close second (3.75). Most of the participants had mentioned in the interviews as well that the visualizations had been pretty accurately representative of their experiences, so the overall rating for accuracy (average 3.64) made sense. *Expectations vs Reality* ranked the lowest (3.25), which could also be attributed to their lower understandability - the complexity might have made them seem inaccurate as well. Accuracy could also well be enhanced by more complete data.

For the screens, cross-comparison across all the screens seemed to be at the same level, with all three screens rated 3.75, 3.625 and 3.875. This is still not very high, meaning we could redesign the screens to better facilitate cross-comparison across visualizations.

Overall, **Understandability** and **Aesthetic** for the graphs ranked pretty high (4.09 and 3.85), followed by **Utility** (3.43), **Accuracy** (3.63) and **Insight** (2.75). This could indicate that participants were able to understand most graphs and liked how they looked (corroborated by interview responses), but found some of them to be irrelevant or complex to extract insights from. We already see some visu-



alizations that could use significant redesign like *Emotions*, and other factors like consistent and simpler encodings that could help boost the **Accuracy** and **Insight** measures, along with more complete data points. We also heard from participants how certain aspects were more relevant to them than others, in which case we could also consider personalizing the experience to only track what they would like, which could increase the **Utility**.



**Figure 6.10:** Heatmap showing the ratings for the visualizations and the screens for both the design evaluation study (Study 1, top) and the visualization impact evaluation study (Study 2, bottom)

Compared to the phase 1 results, we saw some changes, while others remained the same, shown in Figure 6.10 as well:

- Overall, between phase 1 and phase 2, the **Understandability** and **Aesthetic** of the visualizations remained very similar. This is good as this shows we did not lose out on the comprehensibility and likeability of the visualizations as we transformed from our React prototype to the CareTeam integrated version. **Utility** decreased slightly (which could be attributed to irrelevant visualizations for some participants as well as incomplete data points).

For the screens, compared to Phase 1, **Understandability** increased for all in Phase 2, which could partly be attributed to participants being able to better relate to their own data instead of the mock data presented in Phase 1.

	Study 1	Study 2
Utility	3.82	3.43
Understanding	4.05	4.09
Aesthetic	3.83	3.85
Interest	3.91	
Insight		2.75
Accuracy		3.64

**Figure 6.11:** Heatmap showing the average ratings for the metrics for the first and second study in comparison

- Specifically looking at changes across metrics,
  - For **Utility**, *Intensity* and *Occurrence of Symptoms* and *Sleep* ranked high in both phases, while *Peer Interactions* ranked low in both. This is inline with our interview feedback, where the most commonly mentioned attributes participants would like to track were *Symptoms* and *Sleep*.
  - **Understandability** was high for *Sleep*, *School Attendance* and *Intensity of Symptoms* in both phases, and low for *Occurrence of Symptoms* and *Expectations vs Reality*. The *Quality of Peer Interactions* visualization that underwent significant redesign received higher **Understandability** ratings in phase 2 (3.88 in Phase 2 compared to 3.5 in Phase 1) whereas the *Category of Worries* **Understandability** decreased (4.13 in Phase 2 compared to 4.4 in Phase 1)
  - **Aesthetics** remained similar even on an individual visualization basis,

with *Sleep, Intensity of Symptoms and Worries*, and *Peer Interaction Worries* being rated the best. *Occurrence of Symptoms and Expectations vs Reality* remained the lowest, indicating the need for redesign.

- Overall, ratings were lower in Phase 2 as compared to Phase 1, with the ratings for **Insights** being concerningly low. Thus, we do need to consider redesign to improve the **Utility** and **Insights** of these visualizations which were considerably the lowest metrics.

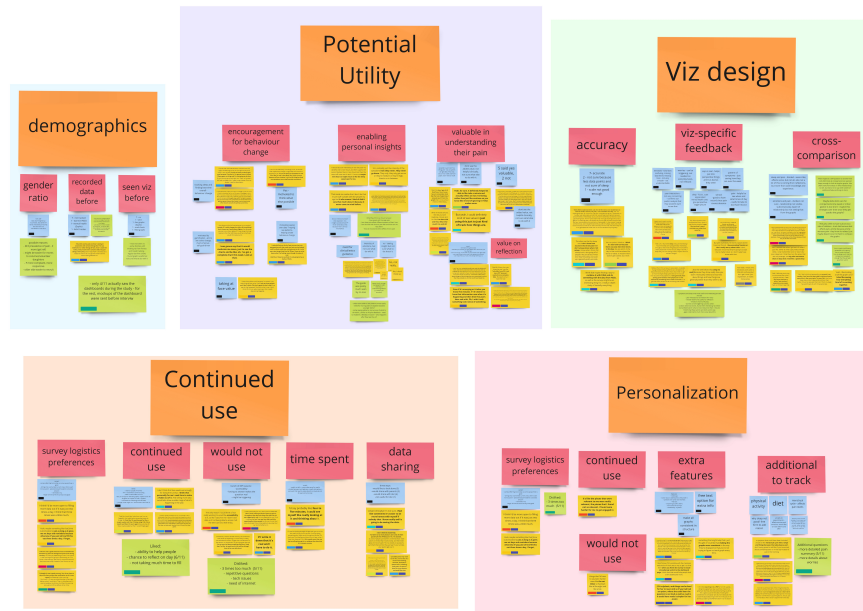
### 6.3.5 Qualitative Results

The interviews provided useful and actionable insights on which aspects of the visualizations appealed to the youth participants, and which aspects did not, along with insights on how they would like to continue the usage of the tool. Participants also provided detailed feedback on additional aspects and features they would like to see, in both the EMA and visualizations.

In addition, given the technical obstacles participants faced, we uncovered key insights on what was necessary technically to make such a data tracking and reflecting experience workable and positive, which was also the purpose of this clinical feasibility pilot.

Although we had originally hoped to learn about the engagement aspect of the visualizations, due to the inconsistency of participant experience for this initial deployment, that was not possible. We did however learn about utility, interest and potential long-term usage, which we focus on in the rest of this section.

Below, we present the categories formed as a result of the affinity diagramming, also shown in Figure 6.12;



**Figure 6.12:** Affinity diagram of feedback from the evaluation interviews, grouped by categories. Orange notes represent categories, pink notes represent sub-categories, blue and green notes are researcher notes on categories, and yellow notes represent direct quotes from participants

### Utility of the Visualizations

Participants spoke of the value they found in the visualizations, including patterns they discovered in their data, encouragement and motivation for better managing aspects of their lives, and how they felt the visualizations reflected their experiences. Overall, we received many interesting insights from participants on how they could see themselves using the visualizations and what value the experience brought to their existing management techniques.

A majority of the participants (7/11) reported finding the experience valuable and useful, and felt it was encouraging in a variety of ways.

We further subcategorize their answers and expand on them below.

#### ***1. Enabling insights through the visualizations***

P7 reported seeing what their ideal sleep length would be: *“It would also be inter-*

*esting to see because my darkest one [colour of the sleep bar] is nine hours and then I guess the second darkest two are nine hours but then the worst off ones are six and 11 hours so **maybe nine hours or eight hours is like the sleep sweet spot for me.***

P7 noted how the *Expectations vs Reality* graph helped them look at their experiences through a more realistic perspective: *“It also helped the little questions of how bad do you think it would be, because **I guess I build it up in my head and then if I think about it for more than like two seconds I realize it actually probably isn’t going to be that bad. If that happens like the world’s not going to end.**”*

P4 noted how, for them, the intensity of their symptoms seemed to stay consistent, *“Probably just the intensity of the symptoms how **they never, they never go down.** They only get worse or they’re medium or they’re high, there’s no in between.”*

P7 had found the sleep and mental health graphs particularly useful to track, while P4 found tracking their symptoms to be the most useful, showing a possible correlation between visualizations that were the most useful and visualizations that showed them new knowledge. While it is possible that participants found patterns specifically in charts they were most interested to track because they paid more attention to them, it could also be possible that seeing patterns in certain visualizations made them more useful than others. We do not have sufficient data to confirm which of these perspectives might be more accurate, but we do know that participants did find new insights about different aspects of their lives through the visualizations, and found them interesting.

Participants also found insights about their thought process that they subconsciously had been aware of but never realized. For instance, on seeing ‘No interactions’ through most of the tracked week, P7 acknowledged, *“That made me realize that I don’t do that much stuff outside with like people my age but **it also means I kind of didn’t care that much about it because it never came to mind before.**”* P7 also noted that learning they did not have many interactions did not stress them out, but merely confirmed what they already presumed their interactions were like, and it was interesting to see recorded. This highlights that the insights need not be actionable, or present brand new information each time to engage youth, but in

cases supporting or confirming their existing beliefs can be just as interesting and useful.

Some participants were able to recognize patterns but were not sure what to do with the information they were seeing (3/11). Others were unable to see patterns in their data (3/11). P11 mentioned how they could see the intensity of their emotions peaking on some days, but were unsure on what to do with that information: “*Um, mostly, it looks like on Wednesday and Thursday I had more intense emotions but yeah, I don’t, I didn’t really know what to do with it*”. This shows the need for more supported interactions with the application, rather than stand-alone use for independent self-management of symptoms.

## ***2. Valuable in understanding their pain***

Participants noted how they felt the experience of recording their data and looking at the visualizations could be valuable or not through different perspectives. 4 participants felt the experience was valuable in understanding and managing their pain, while 2 felt the experience was not particularly valuable.

P7 noted “*How I get all of that from, I don’t even have to remember what day that was happening, I can just see it from the graph that I know school ended on Wednesday*”. They saw value in being able to reconstruct important events simply by looking at the visualizations.

For P3, it was simply the ability to track different things in one place, “*But yeah, I could definitely kind of see value in just using this to kind of track how things are.*” Similarly, for P6, it was recording multiple aspects that was most valuable - “*Yeah, for sure. It definitely helped to be able to take a minute and actually reflect on how I’m feeling rather than just like continue on kind of ignoring it if that makes sense.*”

P1 said answering the questions about medications helped them think of other ways to manage their pain, “*When it would ask you like did you take medicine, I’d look at it, I’m like, I’ve done this and this. What else could I try and do?*”

For P2, the visualizations offered a way to record data for future clinical reference, which they felt was valuable, “*Not just like knowing but being able to be like, this is what I said at this time and bringing that to the doctor, that kind of stuff would be useful, because like, half the time I go to the doctor I’m like I forgot.*”

Thus, each of these 4 participants found the application useful in understanding their pain and their experiences around their pain, but in different ways, from helping them think of alternate strategies to try to being used as a health record during clinical visits.

However, for P4, they were not sure of the value, from a clinical perspective, given their experience with the healthcare system, saying *“A lot of people just blame it on the fact that I have autism or the fact that I have anxiety, if it’s my anxiety that is causing my pain that’s fine but then they just say it’s your anxiety, you need to get over it. but, like, help me.”* This emphasizes the potential for this tool to be used in combination with ongoing clinical care as a communication tool between patients and clinicians. Given the complexity of chronic pain and the young age of this demographic, clinical guidance and collaboration in understanding and engaging with the visualizations could help make the experience valuable. To this end, it would be important to study the use of *myWeekInSight* in bridging the gap between clinician and patient and how this application could help patients and clinicians better communicate with each other.

### **3. Potential value in retrospect:**

Participants commented on the value of the visualization dashboard as they reflected on how things might have been if they had been able to see the dashboard during the week of the study itself as opposed to just before the interviews. P3 mentioned *“I really feel that I probably should have used the dashboard more, and that it would have been nice to have seen my progress or not progress but like, what was going on with the surveys and relating it to there”*, while P7 said *“I liked all of them, the main thing was that I was like ”Why didn’t you fill it out more [own name]” because I wanted more complete data”*. This shows the value of the visualizations as being a motivation for the data collection process, something expanded on later as well.

P4 mentioned how looking at their data made them realize that *“even if it’s annoying or takes five minutes, it’s better to have that information now when it’s happening rather than five years later wish, Oh, I wish I took notice of something.”* P5 commented on the value of collecting data not simply on their physical symptoms but other aspects of their life as well, *“I really appreciated the oppor-*

tunity to do this kind of survey because, at least in with me going through my experience in the healthcare system, especially the pediatric healthcare system. There's not a lot of opportunities for me to give feedback or for me to kind of offer insight into how it affects me like as **most of the time just oh how do you feel, not how is this affecting you.**" Thus, for P4 and P5, the value lay in recording data for future use, and recording data from a holistic perspective.

#### **4. Motivating behaviour change**

Part of the hypothesis for this study was whether looking at their own data and reflecting on it could enable youth to better manage their pain. This could be in different ways - while the visualizations could offer actionable insights, participants could interpret the visualizations as reference for clinical visits, motivation for behaviour change, or simply informational sources about their own behaviour. We were interested in seeing if the visualizations were encouraging or motivating for youth, and asked them specifically if there were aspects about the experience they found motivating.

P7 mentioned how the colours of the visualization scales could be motivating, saying "*The colors are kind of motivating to try to maybe, **I wonder if I could change the colors of everything, I don't know, can I make them lighter***". Gamifying the experience to an extent by aiming to get 'lighter' colours of pain and worries was what P7 thought would engage them and motivate them to stay consistent with the data collection. This shows the ability of the visualizations to motivate users through a gamification perspective depending on how it is presented.

P7 also noted how recording their sleep time gave them accountability, and so encouraged them to stick to a better schedule, stating "*I found that I did that because I would fill out the night survey and when I went to bed I'd be like we have to sleep right now because if we don't, I'm gonna have to check 12am again on that thing and I'm not going to do that. So you have to go to bed right now. Yeah, so **I guess it did help me sleep a bit. I need to see a better chart so please I need to sleep better.***" Interestingly, P7 had also discussed their previous use of habit tracking applications, where seeing the habits continuously recorded when followed had encouraged them to be consistent. Accountability, and rewarding participation, could be a source of motivation for consistent data collection in the



long run for some participants. Along the same lines, P7 noted *“I was gonna say that it would motivate me more, just to see the charts and be like, oh, I’ve got a complete chart this week. Look at that”*.

Participants were able to see the connections other aspects of their lives had on their symptoms which motivated them to improve in those aspects. P5 noted how seeing their symptoms became worse when they got less sleep motivated them to get better sleep - *“You know some of my symptoms are worse when I don’t get that great of sleep, then maybe I can put some more effort towards actually like getting a good sleep”*.

For some participants, seeing the visualizations was motivating in the sense that it helped put their symptoms or worries into a larger perspective where they could see things being not as bad as they thought they were. P1 found their symptoms were not as bad as they believed them to be, saying *“I think it was definitely motivating to me, to see like that maybe even though it might feel like I have this symptom a lot, it’s not as much as I feel it, and it just feels like I have it more because of how intense it is but that my symptoms are actually pretty consistent.”* For P7, it was the act of recording what they were worried about that helped them reflect and realize things probably would not be that bad - *“It also did help to kind of put my worries into perspective and that made me less worried about stuff, so that could also motivate me”*.

Interestingly, P4 mentioned how the graphs neither encouraged nor discouraged them - *“I have this problem where because I’m autistic I just take things at face value. Like I look at those graphs and I don’t think, Oh that’s good oh that’s bad I just say oh that happened, like that’s what it was, I don’t think, Oh, this is really inspiring or this is really depressing. It just is.”* This reveals how *WeekInSight* might simply be a record-keeping tool for some users, which would be an interesting use-case.

Thus, overall, different participants found different aspects of the experience to be motivating, with some believing the experience could motivate them to be more consistent with the data collection, while for some the experience could motivate them to improve aspects of their lives that affected their physical symptoms. For others, the experience was simply what it appeared to be, a record-keeping experience, akin to maintaining a diary or a journal.

### ***5. Accurate reflection of lived experience***

7 out of 11 participants felt the visualizations accurately reflected their lived experiences at the time. For instance, P7 reported, “*Yeah. When I looked at them, like, for the first time, and I looked back to that last week I was like, **oh yeah, I can remember that day.***” P7 also noted how looking at the visualizations they could recap their entire week, for instance looking at their worries they were able to remember why they were worried about that thing and how it panned out, which further helped them reconstruct the rest of the day and week. This was particularly useful as a major drawback of existing self-tracking methods for chronic pain is recall bias. By finding themselves able to reflect on their past week simply by looking at the visualizations, patients could reduce the magnitude of recall bias to an extent, leading to more accurate records, diagnosis and treatment.

However, 2 participants felt the number of data points we had was insufficient to accurately record their experience, and further that certain questions just could not be recorded accurately, for instance, the question asking when exactly did the participants go to sleep. P6 mentioned “*I think it’s also hard because there were only like three times in the day, like **any other points in the day could have been like worse or better, it wouldn’t get tracked***”. For the accuracy of their sleep time, P3 noted “*I don’t know how accurate that is because **I don’t always know when I fall asleep***”. P3 also noted how it could be useful if we could combine this method with Fitbit, “*I think that **maybe finding a way to combine it with Fitbit and do something with the data from Fitbit**, as well as the surveys might be an interesting thing for a really in depth study of basically everything*”. These are both valid points. In the future, it could be worthwhile integrating the EMA surveys with existing technology already in use by users, for instance incorporating wearable sleep monitor data to get accurate records of when users fall asleep vs when they go to bed/fill out the survey. It could also be beneficial to allow users to add additional data points throughout the day at times they wished to, for more accurate data capture.

## Individual Visualization Preferences and Design

While our questions were mostly based on the overall experience, we also asked for specific feedback on visualizations that might have particularly appealed to each participant. This was to get specific feedback on the visualization design, while also gain information on whether participants had been able to cross-compare the visualizations and if the visualizations had represented their lived experiences accurately.

Most participants found the graphs to be an accurate reflection of their actual experience (7 out of 11). In terms of visualizations they liked, different participants responded with different answers, based on aspects they were partial to tracking in the first place. Overall however, participants favoured the *Symptoms* and *Sleep* visualizations, and found the *Peer Interactions* one the least relevant for them. In terms of cross-comparison, while many participants subconsciously were aware of the connections between different aspects of their lives, the visualizations in particular did not help draw those out.

Below, we describe each of these subcategories in detail.

### 1. Visualization design feedback

Different visualizations appealed to different people, for instance for P1, the *Intensity of Symptoms* visualization was the one they liked the most, noting “*For me like, definitely being able to track what time of day it was worse. And then, also being able to see when like what days like if towards the end of the week it was worse compared to the beginning of the week kind of thing.*” P7 found their *Sleep* visualization the most useful, stating “*I found the sleep one quite generally interesting throughout the entire thing because I know before when people ask me how do you sleep I was like, I sleep okay, but um looking at that, maybe I don’t as well as I thought.*” They felt the visualizations helped them understand their sleep patterns better. P3 appreciated the *Expectations vs Reality* visualization, saying “*Because they show really how you don’t necessarily need to be worried about things and how things are generally better than they seem to be.*” They liked how the visualization showed a better real outcome than they believed. Thus, people had generally different views on which visualizations were the best, mostly

driven by relevance to them.

The visualization that most people found confusing was *Emotions*, with 6/11 participants stating that the overlaid bubble chart on the line graphs made it difficult for them to comprehend what information was being shown. As P6 noted, “*Um, the only part I was a bit confused, I think it was like the emotions, it was like two dots I wasn’t entirely sure what they were for.*” However, as we went through the dashboard as we asked the questions and we explained how to interpret the emotions visualization, things became a lot more clearer. P8 noted, post explanation, “*I mean, the emotions ones were a little bit confusing but I get it now, you explained it, it makes more sense.*” While we did include the guide on how to interpret the visualizations, no participant reported finding or reading it. This could be attributed to a combination of the platform complexity and the lack of explicit instructions for reading the guide. However, the complexity of the *Emotions* visualization despite our efforts to simplify the design revealed further opportunities to improve the design, as well as include a more integrated, shorted version of the guide, perhaps a short video for each visualization showing what and how the information is presented. Some visualizations did not find relevance for any participant – 5/11 mentioned that they would not look at the *Peer Interactions* visualization themselves, because it was not a major factor in their lives they thought about a lot or felt influenced their physical symptoms. For P2, a lack of social interactions made the visualization less meaningful - “*Like me personally, I have no friends, so the social interaction, I basically based on random conversations with my classmates about school*”. For P4, friends just were not something they were worried about - “*But with my friends, I have amazing friends so I don’t really worry about that because I know that they’re going to accept me no matter what. So I don’t really have issues with that*”, and for P3, the lack of peers around them led to them modifying what they were tracking – “*I did base a lot about that around my sister who’s very similar in age to me, and we get along quite well. So I’m not sure how accurate those graphs are.*” These responses mostly reflect what the Phase 1 interviews informed us – most of the teens we spoke

to do not seem interested in tracking their peer interactions as they seem to be on either of two extremes - extremely good interactions, or no interactions at all. Based on the Phase 1 interviews, we had placed these visualization at the end of the dashboard, but given this feedback, it might also be worth reconsidering the need to record that data and visualize it at all in the first place.

Overall, outside of the *Peer Interactions* and *Emotions*, participants found all the visualizations interesting, with different participants preferring the *Symptoms* or *Mental Health* or *Sleep* visualization. Participants were confident in their preferences for tracking, versus aspects they already had under control. This highlights the potential for a personalized tracking option, where users could ideally select and track only those aspects they felt most relevant to them, with the ability to add/subtract more aspects as they progressed in their lives.

## 2. Cross-comparing visualizations and challenges

An important aspect of the EMA+visualization experience was enabling youth in reflecting how different aspects of their lives connected and affected each other. We made many efforts to make cross-comparisons cognitively accessible. Key measures included vertically aligning and compactly encoding each of the visualizations, re-using encodings across visualizations, and color-coding categories.

Nearly half of the participants (5/11) reported that looking at the graphs together was useful. P5 felt all the different aspects of their life were connected, and stated “*So, I appreciate it that it wasn’t just focused on one section of my life like it wasn’t just focused on pain or just on sleep or just on emotions, it was a combination of all of them because I think they do all affect each other.*” For P6, it mainly their worries and their pain, “*I think the one about like being worried about things and then also the level of pain and when it occurred and I think those three were important because I kind of looked at them all together.*” The other participants did not have concrete answers on whether looking at the graphs together provided any additional information or value.

6/11 were unable to find any such patterns, or thought the different aspects were not really related. However, when we probed all the participants with more specific questions, like did they think their sleep was related to their symptoms or were their emotions and pain connected, participants did have opinions. For instance, when asked if they thought their emotions and pain were connected, P11 noted, “*Yeah, I definitely think they are connected when I experience pain. I can feel more anxious or when I am anxious I experience more pain. Yeah, so I’d like to see that*”. For P4 as well, “*Oh they definitely are, because I know I feel less pain when I’m at home with my cat*”. When asked about sleep and pain, P1 responded “*I definitely think if you were to combine them like I found like the days my symptoms were not quite as bad I slept much better. And then if they were worse I didn’t sleep very well*” while P5 said “*I know that my headaches were worse on days when I didn’t get enough sleep or I didn’t get as great of sleep, and my anxiety was worse when I didn’t get as great of sleep.*” This shows that the teens did know how aspects of their lives might be connected to their pain, but were unable to see those connections across the visualizations. This raises an important question – were our designs good from an individual visualization perspective, but failed when it came to highlighting connections? It is also possible given the higher cognitive task of comparing two different graphs, the connections, even if present, were not as apparent given the insufficiently detailed data, or were too complex to decipher. As P11 and P1 mentioned, they did think that connection existed, they just did not look at that connection across the visualizations, and instead felt it would be better if presented explicitly. One of the participants in Phase 1 had suggested perhaps overlaying charts to enable cross-comparisons, which while also high cognitive load and development effort, could be a more explicit way of showing the connections between visualizations.

Some participants, on the other hand, were quite certain there were no connections between certain aspects. P11 was quite sure their pain did not affect their sleep, and P4 too mentioned from her experience, “*Um, I don’t think so, because for me my pain is so random I can have the best night’s sleep*”

*and wake up and be in the worst pain I've ever felt, then have days where I don't sleep at all and then I feel better. It's just so sporadic that I don't think my sleep has anything to do with mine personally*". These valid perspectives would be represented in their visualizations as well, but it does raise the question of explicitly combining visualizations at the risk of showing misleading connections that might not apply to some of the users. Perhaps a middle-ground in this case is giving the user agency to compare attributes they wish to, for instance keeping our current modular layout of the visualizations, but encoding them in more consistent formats and allowing users to overlay them over one another to see possible connections. Thus, our takeaway here is that while some participants acknowledged the complex relationships between their physical symptoms and other attributes of their life, they were unable to see these in our visualizations, owing perhaps to the encoding and cognitive effort. This definitely highlights the need to redesign the visualizations to enable easier cross-comparison. For some participants, attributes might just not be related, and in this case it is then important to give users the ability to choose what they'd like to compare.

### **Insights for Longitudinal Continued Use**

A key motive of the interviews was to collect data on how the tool might fit into the youths' daily lives. We asked questions regarding if and how they would continue using this tool, and reasons they might not want to use it. We also asked their feedback on the time and effort it took in the data collection process and what changes they might want to that. Finally, we asked them how did they see themselves sharing these visualizations and with whom.

Most participants said they would want to continue to use the tool, with changes to personalize the tool to them. However, there were minor concerns regarding the accessibility of the tool, and the ability of certain questions to be triggering in certain cases. Overall, participants felt the effort and time for the data collection process was reasonable, and there were divided opinions on whether they would want to share the visualizations with their caregivers and clinicians versus use it as a personal reflection and monitoring tool.

We expand on these thoughts below:

### 1. **Time and effort in data collection and reflection**

We asked participants how they felt about the amount of time the surveys took to fill, and how long did they see themselves interacting with the visualization dashboard for at a time.

For the surveys, all participants said the effort and time was fair enough, with P3 stating *“It doesn’t take very long, it takes two minutes, maybe four or five if you are really thinking about something, so it’s pretty quick and easy.”* P6 echoed those sentiments while also stating they’d be happy to answer additional questions, *“Um, I think having the option to give more detailed information would be good, but I didn’t mind the time I thought it was pretty easy to fill out pretty quickly.”* We seem to have hit the jackpot on the amount of time and effort each survey took to fill out and the amount of data we were collecting.

For the visualizations, 7 out of 11 participants said they would come back and reflect on the visualization dashboard at the end of every week for 4-5 minutes, preferring if they could just receive a report of the same while 3 participants said they would like to look at the visualization every day.

Overall, participants were happy with the amount of time and effort the data collection process took, and majority of the participants felt they would like to check in on the visualization dashboard at the end of each week for a couple of minutes at a stretch instead of daily glances.

### 2. **Use of the visualizations for communicating with caregivers and clinicians**

We were curious to see how youth saw themselves using the visualization dashboard - would they want to share this with their clinicians and use it as an aid in clinical visits? Would they share it with their caregivers to better explain their lived experiences? Or would they see it as a personal self-management tool, to be used and seen only by themselves?

To answer this, we asked them if they saw themselves sharing this with others around them including their clinicians and caregivers, and what value they



might see in sharing this data with those individuals.

The answers were quite divided - 3 participants said they would like to reflect on the data alone, 2 said they would additionally share it with their parents, and 4 said they would want to share it with their clinicians, while 1 mentioned how they did not think this would help clinically even though they would like to share it with their clinicians if it could help.

P3 mentions how looking at the dashboard by themselves would allow them to be more honest in their answers, knowing no one else would be seeing them. They mention *“I’m not sure. I feel like sometimes it’s easier to be more honest with myself if nobody that I know really well is going to be seeing the data.”* This is a valid concern that many teens could possibly have - given the many questions and detailed information the survey would collect, it is possible a teen user would be apprehensive of their parents or clinicians seeing all their responses, especially if they felt it might bias the caregiver or clinician in their care.

P2 discussed how they would want to share the dashboard with their clinicians, because *“I have the worst memory ever. So, being able to be like, this is what I said at this time and bringing that to the doctor, that kind of stuff would be useful, because like, half the time I go to the doctor I forget.”* For them, the value of the dashboard lay in its ability to present a near-real-time record of their lived experience at the time, which they felt could aid in their clinical care.

For P7, the value of sharing the dashboard lay in showing what their experiences were like, not necessarily from a clinical standpoint, but simply from a point of showing how P7 felt. They said *“I’d probably show my mom to be like, look at this. It’s kind of cool looking and also it shows how I’m feeling.”*

However, for P4, while they saw value in the dashboard, they were not sure if sharing it would help, especially with clinicians, based on their previous experiences with the healthcare system. They mentioned *“I don’t think it would help. I’ve been to so many doctors and a lot of them just brush me off because I’m autistic.”*

Overall, depending on how they thought sharing the visualization dashboard could be useful, the participants had differing thoughts on who they'd want to share their data with. Ancker *et al.* [32] discuss adolescent opinions on data sharing when considering parental access, with mostly positive opinions on allowing parental access to health records but having that influence the data they share with their clinicians, while Vaala *et al.* [89] discuss adolescents' tendencies to be willing to share personal health data more freely when they seem to be doing well. This is inline with our responses, where participants are divided on who they would want to share the data with based on what possible value they see arising from it.

### 3. Reasons and patterns for continuing use of the tool

9 out of 11 participants said they would want to continue using the tool for a longer period of time, however the period varied between a couple of weeks to a couple of months.

P3, for instance, said while they saw themselves using it for a long time, two weeks were insufficient and they would need to make a habit out of it to be able to use it consistently, stating *"I don't think that two weeks was enough for doing the surveys. I think that personally for me I need time to make a habit out of it. And seeing more data would also show a wider range of what's happening in the year."* P2 mentioned something similar about forgetting unless a habit was made, but said they were fine with using the tool in phases, *"Feel like I would but I also know me, I am so forgetful. And really bad at remembering to do things. So I feel like I'd used it great for like a couple weeks and then I'd stop using it for like a month and then I'd use it again like every day for like a couple weeks but then I would forget again"*. For P7, the quality of information the visualizations provided made the tool important enough for them to use consistently, saying *"I'd like to, I guess, compare it to my, my Duolingo [19]. I don't deliberately check like my little charts that they give me, but often I'll just click over and look at them be like, Oh, that's cool. But I think for this I would probably be much more inclined to check because obviously I get cool insights like this into oh I guess that's how I was feeling or that's how the pain was that day, not*

*just yeah I learned a lot of French that day I guess*". Overall, the participants liked the experience, and saw themselves continuing with it for a long time if they were able to form a habit.

Based on the feedback questionnaires sent out at the end of each week, 6 out of 11 participants mentioned how they liked the opportunity to reflect on their day, which made them like the experience. For instance, P6 mentioned *"It really made me slow down and think about how I was feeling both physically and mentally. I liked being able to have a better sense of how I was doing"*, and P1 said *"I am able to think more about how I feel each day. Normally I don't think of checking up on myself"*. These reflections show not only did youth like the visualizations but also the act of recording their data through the EMA surveys.

Thus, we overall saw positive feedback for both the data collection process as well as the visualization process, with participants motivated to continue for longer periods of time.

#### 4. **Reasons for not continuing use of the tool**

However, we also heard reasons participants would not want to use this tool.

For P1, accessibility of the tool was a concern, as the tool relied on an active Internet connection to load the surveys and visualizations, and P1 had missed certain surveys due to lack of access to the Internet. They mentioned *"The only reason I could think of not really wanting to would be accessibility to it, so like I said, for me I don't have data so not being able to access it all the time can be a little tricky."*

Participants also mentioned how they felt the tool would be more user-friendly and accessible as a standalone smartphone application that would not need Internet for data collection and visualization. As P7 detailed, *"It would be nice if it was an actual app app. Because every single time I have to fill out a survey I have to log in to the website which isn't annoying because my browser remembered the password. But it was kind of annoying when it didn't remember this, because I had to go and find the little piece of paper I wrote it down on and then go okay it's this. And it also opened a brand new*

*tab every single time I did it. So I had to like go and delete like three tabs a day or they could build up and fill my browser.”*

For P5 and P4, there were concerns about the questions being potentially triggering or upsetting. P5 mentioned *“I mean personally for me, I don’t think so because I don’t mind, looking at kind of how my pain is throughout the day and things like that like it’s not triggering for me it’s not upsetting for me. I find it interesting, but I can see how that could be upsetting for other people.”* P4 also mentioned *“Sometimes what ends up happening is I write what I’m really worried about and then I forget what it is because I’m that person, or sometimes I’m having a great day and I’m not worried about anything and then I read that I’m like, oh yeah here’s the million things I have to be worried about.”* P7 also mentioned how writing down her worries meant they had to acknowledge them (*“if I write it down that it’s real and I have to do it.”*). While all three said these were not reasons that would stop them from using the tool, they could see how it might affect others.

Thus, overall, we needed the tool to be more accessible and personalizable, allowing users to choose what they wanted to track and how frequently, which could offset these concerns to an extent.

Based on these responses, while participants definitely saw value in the longitudinal use of the tool, it became clear there were several aspects of personalization that could enhance this experience significantly.

### **Personalization of the myWeekInSight Application**

Participants mentioned how they would like to be able to personalize various aspects of myWeekInSight, from the frequency of the EMA surveys to the visualizations they would like to see on their dashboards. This was stated as an important factor for their engagement and compliance, with a diverse range of feedback from all the participants.

Participants were divided regarding the frequency of the EMA surveys, with almost half stating they’d like fewer surveys to fill out. Participants noted that they

would have liked to be able to track aspects other than the ones the EMA captured, like physical activity or menstrual cramps. They also mentioned how some of the visualizations were irrelevant to them, so they would like to be able to choose which visualizations they wished to interact with instead of all of them. We discuss these subcategories more in detail:

### 1. EMA survey preferences

While half the participants (5 out of 11) felt the three time frequency of the EMA surveys was more than what they would have liked, others (5 out of 11) felt the frequency was just right.

P1, mentioned they were more likely to be compliant with the surveys if they only fill them out twice a day, *“I think I’d be more open to filling more data out if it was just two times a day, I think that three times was a little much.”*

However, P5 thought thrice a day was a good frequency, as they felt their pain could change a lot during the day, stating *“I think it was a good amount of sort of timeframes because my pain can change like quite a lot during the day”*. For P11 as well, the timings fit right in their schedule, and so they felt thrice a day was a good amount, stating *“I thought it was a good amount. Yes, three times a day and when you got the notification to do it was a good time because in the morning if I went to school that day, it was right before school I could do it. Then, in the afternoon it was during about lunchtime. And then the evening one was kind of like before dinner time.”*

For P1, the set times further constrained their compliance, *“Things that I’d have to say were harder were like the set times so having it like at like eight and like at six.”*

This shows participants would be more compliant with the data collection if they were able to customize the timings and frequency to ones that best fit into their schedules and preferences on how often and when they wanted to track their experiences.

### 2. Personalizing what data is tracked (the EMA survey)

Participants mentioned how they would have liked to track additional as-

pects through the EMA surveys which they felt influenced their physical symptoms.

Multiple participants reported tracking physical activity and diet as well, and linking them to the symptoms visualizations. Some also noted how menstrual cramps affected their symptoms and how they'd like to be able to record that - as P6 mentioned, ***“a symptom that could have been included would be like menstrual cycle like cramps and things because that also plays a part.”*** P5 mentioned how they would have liked to be able to record appointments and how that affected their mental health, saying ***“I guess the only sort of thing, I would maybe like a little more in the survey is if there was an option to enter do you have an appointment today yes or no. And then if it clicks yes like it asks, How are you feeling about this. How did it go like, how did you feel after the appointment, did you feel like you got to speak how you were feeling. Just because, at least for me, if I have an appointment, my anxiety is definitely like higher in the day, and how that appointment goes really affects how I'm feeling.”***

From the questions we already had in the EMA surveys, participants wished they could expand on some as free-text options. For instance P7 would have liked to be able to additionally detail long-term vs short-term worries, while P6 wished they could record what they were worried about in other surveys as well instead of just the morning surveys. 5 out of 11 participants also mentioned how they would like to be able to add more detailed pain summaries for days when they experienced symptoms. P7 also mentioned how they would like to be able to detail why their sleep might have been of a certain quality on a certain day, in the morning survey. Incorporating free-text options and adding them to the visualizations as notes or pop-ups could help integrate such detailed information that could be important when recalling events.

While as of now we are not sure on which of these attributes we might like to additionally track, these comments do give us feedback on what might appeal to a majority of the target demographic and how we could incorporate them.

### 3. Personalizing the visualization dashboard

P1 also mentioned how they found certain visualization that were extremely relevant for them that they'd be much more interested in tracking, as compared to all of them, saying "***It's like the pieces that were relevant to me were really relevant, the pieces that I found not so relevant, I found were harder for me to get engaged in***". This resonates with participants finding visualization relevant to them more useful and interesting as compared to the whole dashboard. Allowing participants to select which aspects of their life they wanted to track and which visualization they wanted to see would reduce not only the visualization cognitive load but also the data collection effort and time, which was something participants reported on earlier as well.

Interestingly, while we had spent significant time and effort in designing the visualizations so they would all be unique to an extent, we received feedback from P3 on how that might actually have been contradictory to our aim of making them comprehensible. P3 mentioned "***Something that might help that I just thought of could be that making the graphs more consistent in the way they're displayed so that you're not trying to figure out each graph every time***" to the extent that they would even appreciate the entire dashboard just being bar graphs for consistency. This is important feedback because we heard from several participants how the emotions and peer interaction quality charts were not the easiest to comprehend. Thus, it might be a good idea for a next design iteration to bring more consistency in the encoding of these visualizations which could help make them more comprehensible and perhaps even enable easier cross-comparison across visualizations.

We also received feedback from P10's mother on how we could make the experience more accessible by adding a feature to hear the question instead of reading it, given P10 was dyslexic - "***P10 is dyslexic, and things can be hard for her to read. And so if you had had an option, where she could hear the question out loud as well as read it, it would have made it simpler for her.***"

### 6.3.6 Summary and Design Recommendations

Overall, the feedback interviews to evaluate the impact of the visualizations coupled with the questionnaires revealed many things, which we discuss under Section 6.3.4 and 6.3.5. Here, we summarize those key findings, as well as suggest design recommendations for certain findings:

#### 1. Participant demographics:

- (a) *Female overrepresentation in participant pool is representative of the target demographic:* The completely female participant pool can be considered generally representative of the target demographic given the higher number of adolescent females with chronic pain due to higher prevalence, as well as the higher number of adolescent females seen at the pain clinic at the pediatric hospital.

#### 2. Personalization of the *myWeekInSight* application:

- (a) *Allow for custom survey frequencies and timings:* Participants mentioned they would be more compliant if they could customize the frequency of the surveys as well as the timings to fit them in their daily schedule.
- (b) *Allow users to personalize tracking and level of detail:* Some users mentioned wanting to track additional aspects like physical activity and menstrual cycle, as well as wanting to add more details for their symptoms and sleep. From a development perspective, this means allowing users to add custom items to track, as well as embedding free-text responses in the visualizations.

#### 3. Insights for continued use:

- (a) *Need for an Internet-independent smartphone application:* Participants mentioned how an independent smartphone application would work better, especially one that would not require the Internet to administer the surveys or show the visualizations.



- (b) *Need for guided interactions:* While some participants could find actionable insights, there remains a need to create guided reflections for the majority, perhaps supported by clinicians, that can enable users to interpret the graphs and extract insights independently.
- (c) *Preferences for continued use:* The majority of the participants said they would want to continue using myWeekInSight for at least more weeks, if not months. All of the participants said the amount of time and effort spent in the data collection process was reasonable, and the majority of the participants said they would reflect on the visualization dashboard at the end of each week for 4-5 minutes.

#### 4. Utility of the *myWeekInSight* application:

- (a) *Need to design for kids:* While some participants had experience with other visualizations of health data, they were unsure of what to do with the information they had seen there. Existing methods, while understandable, do not bring value to youths' lives, and hence there is potential for designing for this specific demographic taking their unique needs into account.
- (b) *Diverse use-cases for myWeekInSight:* Participants found value in several aspects of the application, from reflecting during the data collection process, to helping them think of alternative treatment strategies, to using the application as a health record.
- (c) *Visualizations may drive behavior change:* Participants shared how the visualizations themselves could be a motivation for the data collection process, as well as other factors like gamification and accountability that could increase compliance.
- (d) *Accurate reflection of lived experience may be clinically useful:* Majority of the participants felt the visualizations accurately reflected their experience at the time, which enabled them to use it for recollection in the future, with the potential of reducing recall bias. Some also stated how they would share it with their clinicians, to show accurate records of their experiences.

## 5. Individual visualization preferences and design:

- (a) *Account for individual visualization preferences:* Participants were drawn towards visualizations they felt were the most relevant to their lives and wanted to track the most, with *Sleep* and *Intensity of Symptoms* being top favorites, and *Peer Interactions* being generally unnecessary. Overall, **Understandability** and **Aesthetics** were high for all visualizations. Participants mentioned how they would like to track and engage with only those aspects that were relevant to them, as well as the need for consistent encodings for easier understanding and cross-comparison.
- (b) *Redesign for comprehensibility:* Some visualizations like *Emotions* and *Expectations vs Reality* need to be redesigned and made simpler for better comprehensibility.
- (c) *Redesign for cross-comparison:* The majority of the participants were unable to compare different visualizations and extract insights, both through the interviews and questionnaire. However, some of them were aware of implicit connections between aspects, while some were certain there was no relation between certain aspects. A solution to this would be to redesign the visualizations in a way that allows users to easily choose what visualizations they might want to compare and see connections only between those.
- (d) *Individual preferences for data sharing:* Participants were divided on who to share data with, depending on what value they saw in sharing their data. Some wanted to share it with their parents to show them how their life was, others felt sharing it with clinicians would help in more accurate reflections and diagnoses, and others felt they would best use it alone so they could be honest with their answers.

## Chapter 7

# Discussion

In this chapter, we revisit our research questions to highlight the information gained through the thesis. We then discuss the limitations of this thesis, while also commenting on how that fits into existing research and suggestions for improvements to current research methodologies based on our learnings.

### 7.1 Revisiting our Research Questions

In this section, we revisit our research questions, and expand on them based on our findings through the studies conducted and our design process:

#### 7.1.1 Visualization as a Tool to Understand Pain

**How does enabling youth to reflect and interact with their own data affect their understanding of their pain and its connection with other aspects of their lives?**

*(a) How can data visualization be leveraged to reflect a holistic view of users' lives and their daily experiences in an accurate and youth-focused manner?*

Through initial interviews with clinicians, the questions from the EMA surveys and based on our literature review, we formed a preliminary assessment of what youth would be most interested in tracking and seeing. We focused on designing visualizations that would invite users to reflect on their data, as opposed to present-

ing patterns or trends explicitly. Hence, we tried to use encodings that would be familiar and thus potentially engaging for our audience. We chose simple graphs, and a modular arrangement that would allow youth to focus on specific visualizations if they wanted to. We integrated colours in a way to create color-codings for categories, and choosing color scales per visualization in a way to highlight changes and patterns, but not explicitly mark them. We used icons and a variety of encodings like bar charts, line charts and heatmaps, to increase the appeal of the visualizations, while still maintaining consistency for better comprehensibility. We chose the type of graphs and ticks within graphs to be as reflective of the EMA responses as possible, to maintain accuracy of the visualizations compared to the youths' actual lived experiences.

To assess if we had indeed managed to create visualizations that accurately reflected youths' daily lives, we measured accuracy in our second evaluation study questionnaire, as well as asked participants in the semi-structured interviews. 7 out of 11 participants in the interviews reported finding the visualizations to be an accurate representation, while 2 reported needing more data points through the week.

In the questionnaires, **Accuracy** was rated 3.64/5 on average, with ratings higher than 3.5 for all of them. On our 1-5 diverging Likert scale, this indicates that participants mostly agreed that the visualizations were accurate. Visualizations such as *Expectations vs. Reality* and *Emotions* scored lower, while *Intensity of Symptoms* was the highest.

To an extent, this could be attributed to missing data points, which led to incomplete visualizations which might have seemed inaccurate. Two participants had also noted how they felt the number of data points was insufficient to accurately track their experience, which might indicate the potential of allowing personalization of the EMA survey frequency to gather more data.

*(b) How can visualization be used to empower users to extract actionable insights from their data?*

To evaluate if the visualizations had enabled youth to extract actionable insights from their data, we asked them if the visualizations had been insightful or if they could see connections between different aspects of their lives in the second study

interviews. Participants acknowledged learning new patterns about their behaviours that they might not have seen otherwise, but a majority of the participants were unable to see any connections between the different aspects of their lives in the visualizations. Overall, **Insightfulness** was also rated 2.75/5 on the questionnaire, tending towards disagreeing that the visualizations were insightful on the diverging Likert scale. This means while the visualizations hold the potential to be insightful and engaging, we need to revisit and redesign some of them to highlight those aspects.

On the measure of **Utility** of the visualizations however, the visualizations were rated 3.82 in the first study and 3.43 in the second on average, meaning participants agreed that the visualizations were definitely useful even as the uses differed from personal reflection to sharing accurate records with clinicians. Multiple participants noted how the visualizations were valuable in understanding their pain, and how the visualizations motivated behavioral changes as well. The visualizations were rated highly **Understandable** as well, except for a couple of them which would need minor revisions to the design, with the rating being 4.05/5 in the first study and 4.09/5 in the second.

Ratings of high **Utility** and **Understandability** combined with low **Insights** could mean participants were able to understand the visualizations and see their experiences reflected in them, but were unable to extract any new information they did not already know about themselves. **Utility** was also described in different ways, like using the visualizations to change behaviour, or using them for clinical reference, which need not be directly related to extracting actionable insights.

**Insights** would also be more apparent through more complete visualizations, which were few in our case owing to missing data. Thus while the visualizations could potentially be insightful (as mentioned by some participants in the interviews), they did not offer much in this way in this first deployment.

*(c) How can such visualization methods engage youth in self-reflection and interactions with their data?*

Participants liked interacting with the visualizations, and all of them mentioned how they would like to continue tracking their symptoms and other aspects for extended periods of time through the *myWeekInSight* application. They found the

visualizations insightful to an extent, and were able to see patterns in their data that they felt would be helpful, from a self-management as well as clinical perspective. Most participants felt the designs were accurate and reflective of their experiences, and most of the visualizations were understandable as well. While some redesigning needs to be done to present insights and connections across visualizations in a more straightforward manner, there is no denying the potential of this application on youth and their understanding of pain and its impact on their lives.

### **7.1.2 Design Guidelines for Youth with Chronic Pain**

#### **What design guidelines can be followed when designing data visualizations for youth with chronic pain?**

*(a) What are the differences between existing guidelines for visualizations and designing visualizations for younger populations?*

General design guidelines for data visualization often involve compressing as much information as possible into a single visualization. This makes sense when we consider screen sizes for a lot of visualization use cases - for instance, mobile and wearable screens for showing health data - the smaller the screen, the more the visualization needs to be compressed. This often results in visualizations that appear cluttered, require heavy cognitive effort to understand, and use multiple encodings like overlapping lines and bars or multiple marks and channels in one visualization. However, when designing for a younger demographic like teens, it is necessary to keep in mind the amount of cognitive effort that can be demanded from them. Younger demographics have lesser familiarity with complex graphs, and shorter attention spans, which makes it tougher to design visualizations that are engaging and captivating for this demographic [41, 90]. If we consider a similar application designed for adults, the visualizations would potentially be more concise, and use multiple encodings like overlaid line and bar charts, utilizing existing visualization design guidelines, and while that could work for an audience with higher cognitive capacities, it would not work for youth. Thus, the convergence or divergence of design guidelines for youth compared to existing guidelines would be an important consideration for visualization designers.

*(b) What additional guidelines are required for this specific demographic of youth with chronic pain?*

In our designs, we tried to cater to this young demographic by making specific design decisions:

- Using simple, familiar graphs to encode data, like bar charts, line charts, heatmaps, as opposed to including multiple creative encodings. While multiple creative encodings for adult populations can help drive engagement and interest, it increases the cognitive effort required, and hence is best avoided for younger demographics.
- Modular breakup of the EMA data into categories, with each visualization showing data from one or two EMA questions only - this helped reduce the amount of data per visualization, which lessens the cognitive load per visualization. While overlaying charts or integrating more data into a singular visualization is compact and useful from a visualization designer's perspective, that is better suited to adult populations given their higher cognitive processing capacities. For younger demographics, breaking up the visualization into simpler, modular sections can make it easier to understand.
- Using colors judiciously to mark categories in the visualizations to logically group them, which increases familiarity. Colors within visualizations were restricted to color scale in a single hue, with multiple hues used only for the *Emotions* visualization for the different emotions. This also applies to adult populations, but needs higher consideration in this case given the multiple categories we visualized where careful use of colours to avoid visually overloading users was necessary.
- Vertical alignment of visualizations to enable easy cross-comparison of visualizations, instead of overlaying them.

These decisions were informed by our literature review and interviews with people with previous chronic pain experience as well as a high school teacher, who stressed the use of familiar encodings and judicious use of colours.

*(c) How can we design to show huge amounts of chronological data in a way that enables quick reflection and engagement?*

Given the timescale of the data collected through the EMA surveys, we decided weekly segments were an appropriate time period to design for. Ideally, the visualizations would need to be scalable to be able to integrate larger periods of time extending to months and years. However for the scope of this thesis, we focused on designing for weekly segments as that allowed us to segment the EMA data into sizeable chunks that could show some progression or patterns. A one week period would also be an appropriate amount of time for users to reflect on in terms of cognitive load.

Our vertical alignment encapsulates this chronological aspect by allowing users to get an idea of their complete day if they look at the visualizations from top to bottom, while looking at each viz horizontally gives an idea of weekly progressions. The visualizations could be scaled to larger time periods by averaging values but retaining the same encodings.

*(d) How can we design visualizations that enable cross-comparison and highlight connections between them?*

To facilitate cross-comparisons and highlight connections across visualizations, we created a modular vertically-aligned layout. We also hoped that the fairly consistent encodings would help create a familiarity across visualizations which would enable viewers to extract insights. The vertical alignment also made it easier to track aspects across a single day, further facilitating cross-comparison. We also arranged the visualizations in an order that we thought made most sense to seek patterns across - for instance, aligning symptoms with sleep and emotions. The visualizations were also logically colour-coded, to enable quicker cross-comparison within and across groups like *Symptoms* and *Worries* or *Symptoms* and *Peer Interactions*.

Finally, over the course of our two evaluation studies, we saw design guidelines emerge that can be used when designing visualizations for this specific demographic, which are different from the ones used when designing for adult populations, which we detail in Section 7.2.



### 7.1.3 Evaluation Metrics for Qualitative Assessment of Visualizations

**How can we best evaluate visualizations for this specific demographic?**

*(a) What current metrics exist to measure the efficacy of data visualizations?*

In Section 5.1.2 we briefly discuss evaluation metrics currently in place to measure the efficacy of data visualizations as well as personal tracking applications. While visualization systems and personal tracking applications usually rely on quantitative metrics like system and viz performance based on response rate, accuracy and engagement metrics, design studies usually rely on qualitative methods like interviews and observations. Both have advantages and drawbacks - while quantitative measures give evidence for efficacy, accuracy and other measures related to performance, qualitative methods allow designers to get user feedback on the application or visualization. Evaluation of tracking applications in research is usually through combining qualitative and quantitative methods, usually a mix of semi-structured interviews and questionnaires. In recent years, Saket *et al.* [78] also discussed the qualitative evaluation of visualizations in addition to quantitative analyses.

*(b) How can we best evaluate the efficacy of our designed visualizations and how might that be different from existing evaluation methods?*

We believe a similar combination of qualitative and quantitative analysis can provide the best evaluation metrics for visualizations for this demographic as well. As in our evaluation studies, evaluation would ideally be of two forms - one evaluating the design of the visualizations, and the other evaluating the use of the application. Given limited access to specific high-risk demographics like youth with chronic pain, it might be worthwhile splitting the evaluation into phases, to get actionable feedback and be able to turn that around before another evaluation. A combination of interviews with questionnaires can be a comprehensive design for an evaluation study, as that allows the designers to get in-depth feedback from participants through interviews, while also receiving more structured quantitative data through the questionnaires.

Interviews can be centered around themes designers would like input on, for instance in our second evaluation study we focus our questions on continued use, motivational impact and design feedback as some of the categories, as those were the aspects we felt we most needed feedback on. Questionnaires can be structured based on metrics deemed most valuable for gauging the efficacy of the visualizations, for instance in our second evaluation study we chose the metrics utility, understandability, aesthetic, insightfulness and accuracy, as those were the aspects of the visualizations we most wanted user feedback on. Designers do need to consider the effort required for interviews and filling questionnaires while designing the metrics - we found our interviews lasted 30-40 minutes which seemed to be an appropriate length of time to the youth, and the number of metrics was not too less or too many. A careful balanced combination of interview questions and questionnaire metrics can ensure designers get qualitative and quantitative feedback encompassing all aspects of the visualizations, from their usability to impact.

*(c) What are the most suited metrics to evaluate our designed visualizations?*

In Sections 5.1.2 and 6.3, we discuss the evaluation metrics used for both the phases of our evaluations, which we summarize below:

We converged on three common metrics [Utility, Understandability and Aesthetic] for evaluating both the design and impact, with an Interest metric while evaluating the design and an Insight and Accuracy metric while evaluating the impact which we felt best met our goals, shown below:

- **Utility:** Assessing if the information shown in the visualization would be useful to the user personally
- **Understandability:** Assessing if the information shown through the visualization was easy to comprehend
- **Interest** (Phase 1 only): Assessing if the visualization seemed interesting or motivated them to interact with it
- **Insightfulness** (Phase 2 only): Assessing if users could see new patterns or knowledge in their data through the visualizations
- **Accuracy** (Phase 2 only): Assessing if the visualizations accurately represented the user's lived experience

- *Aesthetic*: Assessing if the users liked how the visualizations looked

## 7.2 Guidelines for Designing Visualizations for Youth with Chronic Pain

There are many guidelines for visualization design that exist, for instance, those noted in Munzner's Visualization Analysis and Design [27]. These guidelines are for general audiences, and include principles like *careful use of colours* or *visualizing temporally*. However, for a specific demographic, guidelines may need to be modified or different guidelines required to design visualizations that can cater specifically to them. In our case, when considering youth with chronic pain, some existing design guidelines like *overlaying graphs* or *using multiple creative encodings to engage users* might not work best, given younger demographics' different cognitive capacities and needs. Through our visualization design process and evaluations, we followed some basic design principles, while others emerged through the process or were told by participants.

Below, we list a number of relevant guidelines, most of which will be familiar from other sources, which our design experience has allowed to either confirm fully for this demographic and purpose, or suggest modifications or caveats.

1. **Use simple graphs:** While using newer, creative graphs like ribbon or combo charts can be a concise and compact way of reflecting information to adult users, for teenagers we propose using simple and familiar graphs like bar or line charts that youth will be familiar with. Complex charts require more cognitive effort and can lead to less comprehensibility and less engagement. Existing design guidelines stress the importance of simplicity for younger demographics, which we confirm through our designs.
2. **Don't overlay graphs:** This is an interesting divergence from existing principles which would recommend overlaying graphs to showcase more information through limited screen sizes. However, in our case, the cost of increasing cognitive effort outweighs the benefits from overlaying the graphs, hence for this population we would recommend not overlaying graphs to ensure simplicity and understandability.

While overlaying graphs also allows designers to keep designs compact, we recommend for younger demographics, stick to single charts or graphs. Given younger demographics familiarity with graphs, it is best to use only one type of a chart at a time for a visualization.

3. **Account for missing data:** Over our three-week study, we saw many participants miss filling out surveys. While this could happen due to a multitude of reasons, accounting for missing data in the visualization design is necessary to ensure accuracy of the users' experiences is maintained. There is also a need to demarcate the difference between 'zero' or 'low' values in visualizations like no symptoms or no medications taken, versus 'null' values where the data point is missing like if the symptoms question was skipped on a particular day. Distinguishing these marks in the visualizations is important as they both mean significantly different things, and in a real-world scenario, missing data is more than likely to happen given user engagement with tracking applications is never 100%.

While this might not be a consideration in most designs, in our case owing to the nature of the data collection process, missing data was inevitable, and hence needed to be considered in the design. Given the technical difficulties we ran into discussed in Sections 6.1.3 and 6.2.3, accounting for missing data in our case was also particularly helpful - participants were able to report when they saw missing data on days they knew they had filled the surveys out, which helped us debug technical issues and track compliance.

4. **Visualize temporally:** If recording chronological data, visualize the same retaining the chronological aspect, and allow users to see changes over time. In terms of health-tracking applications, especially ones that track physical symptoms and can be used for self-management of the same, it is crucial to maintain the chronological aspect to show improvement or deterioration over time.

This is an existing design guideline for general demographics as well, and applies to younger populations too, including youth with chronic pain.

5. **Use colours carefully:** While it can be tempting to use different colours in

every visualization and make use of aesthetic palettes, colour is a powerful visual medium, and so should be leveraged only where needed. Use colour to encode information that should stand out, like using contrasts to show outliers, or similar hues to logically group similar visualizations together. When used correctly, colour can be an asset to the comprehensibility of visualizations, but too many colours or incorrect use of colours can make visualizations unappealing and complicated.

Existing guidelines state the same, and we highlight this further in cases of multiple visualizations, where colour can serve as an attribute to distinguish between visualization groups.

6. **Allow personalization:** When trying to present a multitude of things, like sleep, physical symptoms, mental health, and emotions, all at once, it is possible the target demographic will be interested in only a subset of them. Different visualizations will appeal to different users, in which case the other visualizations will simply be unnecessary to them. Allow users to hide things they don't want to see, and allow them to only retain or prioritize what is important to them. Yet, in a real-world deployment of a design, it is also crucial to note the technical feasibility of such personalizations, and whether the user effort in personalizing will be justified by the enhancement in the user experience.

Many existing design principles state the need to allow users to personalize applications to increase engagement, and we stress the same, however also highlighting the delicate trade-off between what users want to do *vs.* what they should be able to *vs.* what is technically feasible, which applies not only to this demographic, but also to the general audience.

7. **Allow details:** Visualize the minimum required to make the visualizations valuable while keeping them simple, yet allow users to add more details to events if they wish to. Methods for doing this can be keeping free-form text boxes that show as pop-ups on the visualizations if filled, which allows designers to maintain the encoding of the viz yet integrate sporadic details filled.

8. **Represent accurately:** Confirm if the visual representation of the users' data reflects their lived experience. Misrepresentations can appear optimistic or pessimistic to users, affecting their management of their symptoms and treatment, while also creating an inaccurate record of their data. Accurate representations allow users to use the visualizations for future reference clinically as well, increasing their utility.
9. **Consistency over variety:** Existing visualization principles encourage variety in visual encodings to increase user engagement. While this works for adult demographics, younger demographics prefer consistency as mentioned in our feedback interviews.

We recommend keeping the visualization encodings as consistent as possible, even if that means using the same type of graph throughout. Instead, use other marks and channels like size and colour to differentiate between visualizations. Consistency in structure makes visualizations easier to understand, and reduces cognitive effort.

## 7.3 Limitations

In the course of this project, while we were able to create a fully-functional web application partnering with a health tech firm and run two evaluation studies, our results are still influenced by certain factors. In this section, we briefly summarize the limitations faced in the course of this project and how that impacts our results, as well as how such limitations might affect research in the field:

### 7.3.1 Restricted Access to Target Population

As opposed to non-clinical design studies, which can have multiple rounds of interviews and iterations with target users, we would only be able to interact with our target users a limited number of times excluding the clinical study, since youth with chronic pain is a high-risk population for two reasons - a) being that they are under the age of 18 years and b) they are a clinical population which requires careful consideration before participation in studies. We were fortunate to be able to recruit participants through our clinician collaborators at the chronic pain clinic at

a tertiary-level pediatric hospital, but we still had limited access. Given the restricted demographic we could recruit from (only current patients at the pain clinic), this meant we had a limited number of potential participants as well.

Our interactions with the youth were crucial for our understanding of whether our designs met their requirements. We were able to recruit our target numbers, but it took longer than we had anticipated, although it was most certainly fruitful. Easier or more frequent access would enable faster design iterations, but at the same time, we would need to be mindful of the cost of these interactions on the youth themselves. Thus, we wanted to ensure our interactions were not distressing and make the most out of them, and hence we chose to conduct only two evaluation studies with a limited number of participants, while also keeping in mind there was no overlap between the two participant pools. This meant we had to break down our evaluation carefully into the two phases, as well as test out the designs and application with other participants before taking it to our target users, resulting in us piloting our designs with populations close to, but not the same as, our target users, for instance adults with previous chronic pain experience. This led to more uncertain design iterations, as we could not get substantial feedback from the target demographic before the first evaluation study, and most of our decisions were based on previous work or interviews with other demographics and clinical experts. However, even through our limited interactions with the youth, we were able to obtain significant feedback and insights from them, proving that despite this population being inherently limited and hard to reach, the need to hear their opinions is crucial to designing for them.

Limited access to clinical populations is often a reason why designs for such demographics don't end up being evaluated with the populations themselves, but it is essential to get feedback from the target users to get an idea of how efficient and accurate the designs are and whether or not they meet the users' requirements. There is considerable effort required to gain access to this population, but when designing for such specific demographics with unique needs, it is important to take their feedback into account during the design process.

A key aspect that helped us gain access to this population as well as gave us meaningful context for our designs and interactions were our clinical experts. Our collaboration with the clinical team leading the clinical study has been an integ-

ral factor in keeping our designs patient-centered and incorporating patient and clinician requirements. Their continuous participation in the design iterations, interviews to provide context, access to patient populations and guidance in analyses of the patient feedback has been pivotal to our design process. In Chapter 2, where we discuss existing patient-centered applications, we mention the lack of clinical co-design or validation. Our collaboration with the clinical experts highlights the benefits of such co-designed work, and showcases the need to integrate key stakeholders in the design process.

### **7.3.2 Technical Constraints of Deployment Platform**

While we were able to integrate the visualizations on the deployment platform and visualize real-time data on a fully functional platform during the course of the study, the platform was constrained in many ways due to our restricted timeline. We detail some of these constraints in Sections 6.1.3 and 6.2.3.

While these constraints affected the usability of the platform, we still had a fully functioning application to deploy. This is significant, given many design studies do not reach this stage. Functional prototypes are still different from fully-deployable applications, which can be used for longer periods of time, are robust and responsive, and allow evaluation of functionalities other than just design. Our *myWeekInSight* application also allowed us to run the second evaluation study in the wild, where users could integrate the application into their daily lives. This allowed us to evaluate not just the design and accuracy of the visualizations but also their usage, engagement and impact on the users' daily lives. This is significant when considering personal tracking applications need to be able to seamlessly blend into users' lives for maximum engagement - requiring users to focus on just the application at fixed times or for fixed periods of time can be distracting and lead to lower user engagement.

However, within the technical obstacles we did face, most of them were fixable given a more flexible timeline. Issues like inconsistent surveys and a non-intuitive user interface impacted the user experience, with some users unsure of their compliance with survey completion, which left them confused. Yet, these issues could be refined post a round of design iterations and testing, and an in-the-wild deploy-



ment with the target demographic was key to understanding such conditions that did not arise during piloting the application.

Furthermore, while we created a deployable application for youth to use, there were aspects of the user experience that potentially distracted the youth from just the visualizations themselves. This meant even though our focus was the visualizations and their impact, the obstacles faced by users impacted their experience with the visualizations as well and hence we were unable to isolate just the visualizations for impact evaluation in the clinical study. Our feedback interviews, however, mitigated this to an extent as we were able to obtain feedback specifically from a visualization standpoint.

When assessing the impact of such tracking applications, it is also necessary to consider long-term use, to factor in the *'novelty effect'* - a one-time use and evaluation can often be biased as compared to usage over a longer period of time. In-the-wild use also allows designers to track usage patterns and engagement, and can lead to deeper, more useful feedback from users as well. Thus, despite our constraints, our in-the-wild functional deployment was useful in many ways to obtain feedback on a long-term solution for youth with chronic pain, and we advocate for the same to be a part of more design studies.

### **7.3.3 Lack of Evidence for Impact of Visualizations**

Given the non-ideal study experience participants faced, few of them at the start were able to interact with the dashboard during the study (explained in Section 6.2.3). A major part of the study for us was exploring the impact of the dashboard and visualizations, and exploring user engagement with the same. However, most of our participants were only able to interact with static versions of their dashboard or saw it post the data collection period, which was not our ideal scenario. The timing of study participation also affected their engagement with the application. This consequently affected the questions we were asking as user responses changed based on the experience they had.

In a future iteration, we would like to test out the application once again over a long period of time like a week or so, after fixing technical glitches and improving the user interface. We did, however, get many good insights from the participants

we interviewed on the design and possible long-term use of the application, but failed to get more in-depth feedback on the impact of their interactions with the visualizations.

## **Chapter 8**

# **Conclusion**

In this thesis, we explored the design and evaluation of a data visualization-based web application for self-management of symptoms for youth with chronic pain. We presented a summary of current research in the field to ground our work, and then spoke of our design process. We detailed our iterative approach to designing the visualizations, with clinical and expert guidance, as well as the design evaluation of the same. We also detailed our collaboration with healthtech firm CareTeam to develop a deployable application, and discussed the clinical study and our second evaluation of the impact of the visualizations. We concluded with a discussion of our findings and how they answered our research questions, as well as highlighting the limitations and learnings of our approach. Finally, in this chapter, we draw the thesis to a close by summarizing the work discussed in each chapter, discussing the contributions arising from this work, and a short note on the implications of this work for future research.

### **8.1 Summary of Work Done**

#### **8.1.1 Motivation and Approach**

In Chapter 1, we showed the motivation for this work, and the potential for personal health data to be used as a treatment intervention for youth with chronic pain. We laid forth our research questions and discussed our approach to answering them, as

well as briefly laying forth our contributions.

### **8.1.2 Context and Existing Research**

We provided a concise background on chronic pain and its impact on the young demographic of teens 12-18 years old in Chapter 2. We discussed existing tracking techniques and their shortcomings, as well as research done in the field for newer, better solutions. We also discussed existing applications for personal health informatics, the scope of data visualization in the same, and the need to build a solution catered to younger demographics.

### **8.1.3 Designing the Visualizations**

In Chapter 3, we laid the foundation for visualizing personal health data for youth with chronic pain, through a brief series of design interviews and prototyping iterations, concluding with some preliminary guidelines for designing visualizations for this demographic. We also presented a brief overview of the EMA survey that would be used for this project, designed by our clinical experts. In Chapter 4, we started designing the visualizations from scratch, keeping these guidelines in mind. We went through the visualization design process suggested by Munzner *et al.* [68], starting with a data and task abstraction, moving on to designing views, and finally prototyping. We showed our low, high and final deployable prototypes, going through a constant iterative process with HCI and visualization experts and continuously consulting with our clinical experts.

### **8.1.4 Evaluation of the Visualization Design**

We evaluated our visualizations in two stages - first, evaluating the design of the visualizations by themselves, and second, evaluating the impact of these visualizations over a continuous prolonged period of use. In Chapter 5, we discussed this first study, evaluating the design of the visualizations. We explained our pilot and findings, resulting design decisions and iteration, and then the full study. The study was conducted with 10 youth, through semi-structured interviews and Likert-scale based questionnaires, evaluating the understandability, utility and appeal of the visualizations. We analyzed the interviews and presented our findings through

an affinity diagramming approach.

### **8.1.5 Evaluation of the Visualization Impact**

Based on the findings from the analysis in Chapter 5, we fixed minor issues and enhancements to the visualization designs. In Chapter 6, prior to conducting the longitudinal study to assess the impact of the visualizations, we discussed our collaboration with CareTeam, to integrate our visualizations into their scalable, robust, responsive platform through several design iterations. Post the integration of the visualizations and EMA surveys into the CareTeam platform, we conducted a three-week study with 50 youth with chronic pain aged 12-18 years old where we followed an A/B approach with participants seeing the visualization dashboard in one week and not in the next, with a one-week break in between. This was followed by semi-structured interviews with a subset of 11 youth, to gather more feedback on the impact of the visualizations with respect to their understanding of their pain. We presented the findings from those interviews through an affinity diagramming approach.

## **8.2 Contributions Emerging from this Work**

As we come to close our discussion, having revisited our research questions and detailed our learnings, we revisit our proposed contributions mentioned in Section 1.4:

### **Design guidelines for creating engaging visualizations of personal health data for youth with chronic pain**

In Section 7.2, we discuss the design guidelines that we followed through this thesis and those that have emerged through a combined process of designing and evaluating, with constant guidance from experts and clinicians, and crucial feedback from youth. These guidelines are preceded by preliminary findings and discussions in Chapters 3 and 4 (Section 3.4 and Section 4.4), as well as the discussion of study results in Chapters 5 and 6 (Sections 5.3.3 and 6.3.5).

While these guidelines are not a novel contribution, our approach to evaluating them for this demographic and discussing specific modifications needed to be

able to apply them when designing for this demographic is in some respects a significant departure from conventional practices. These revised guidelines for this demographic can aid future researchers when designing for them.

### **Metrics for evaluating the efficacy of visualizations designed to reflect personal data for self-management of health**

In Section 5.1.2, we discuss evaluation metrics currently existing, as well as our rationale and basis for the metrics we used in our evaluations. In Section 5.1.2 and Section 6.3 in particular, we detail the metrics that can be used for evaluating the efficacy of personal health data visualizations, particularly for assessing qualitative attributes like engagement and comprehensibility. We also discuss the importance of qualitatively evaluating visualizations, especially when they might be directed at improving users' understanding of their own health. Thus, while these are not novel metrics in HCI research, we propose their use in qualitative analysis in visualization research to evaluate user experiences, in addition to quantitative metrics.

In future research, we hope to see visualizations evaluated on user-centered attributes like engagement and insightfulness, in addition to existing quantitative measures like system performance, and our discussions could help designers in finding similar metrics for their evaluations.

### **Insights on the use of a visualization-based web application for youth to self-manage their symptoms and explore their personal health data**

In our feedback interviews at the end of the clinical study, we received many critical insights and feedback on the potential of a visualization-based tool for youth to self-manage their symptoms and gain a better understanding of their general functioning. These insights are detailed in Section 6.3.5, and further expanded on in Section 7.1.1, while we also discuss our limitations in Section 7.3. We discuss aspects youth liked and disliked about our application, and the overall experience, while also noting the challenges and considerations that arise when working with a clinically vulnerable population.

Overall, the approach of enabling youth to track their personal health using data visualizations looks promising, and we hope our discussions and insights can help other researchers in the field in more engaging and accessible designs and

deployments.

## **8.3 Next Steps**

In this section, we briefly discuss future directions for the research detailed in this thesis, mostly directed by the results discussed in Section 6.3.5.

### **8.3.1 Upgrading Visualization Design**

Based on the feedback we received, an initial next step would be to modify the visualizations to incorporate the feedback, as well as improve the *myWeekInSight* application to accommodate personalization and individual preferences.

#### **Redesign of Certain Visualizations**

Firstly, based on the feedback on the visualization designs from both the evaluation studies, there are certain specific visualizations that need to be redesigned for better comprehensibility. Furthermore, based on insights like favoured consistency across visual encodings, other visualizations could also be redesigned to facilitate familiarity and lower cognitive effort.

#### **Enable Insights and Cross-comparisons**

We received general feedback that extracting insights from the visualizations was not as easy as we had intended. The low **Insight** ratings on the questionnaires also support the same. Participants however did indicate a subconscious knowledge of connections between different aspects of their lives and their pain, and so we would like to revisit the visualizations to ascertain how we could highlight these connections in a youth-centered approach. The partial data set and lower compliance due to mistimed study participation could also be a factor, hence we would like to re-evaluate our visualizations for enabling the extraction of actionable insights post a design iteration.

### **Accommodate Personalization and Individual Preferences**

Based on the feedback on individual preferences and features participants would have liked, we would like to ensure a future deployment is more personalizable and accessible. This could entail deploying an offline version of the surveys and visualizations, allowing participants to select custom frequencies and timings for the surveys, as well as allowing them to select which attributes they would want to track. This was stated as an important factor for compliance and engagement, so it would be interesting to review the same.

Overall, our research has shown the feasibility of visualizing personal health data for youth with chronic pain. While there were significant barriers to the research and deployment of the application, we were able to gain decisive feedback from the target users which highlighted the many possible future directions this research could take. A future more robust deployment with improved visualizations could offer further insights into the potential of self-tracking applications in engaging youth with chronic pain and enabling them in better understanding connections between different aspects of their lives.

### **8.3.2 Towards Understanding the Value of Visualizing Chronic Pain**

This work is also a first step in understanding the value in visualizing chronic pain, and how this concept might apply to other populations. While we received useful feedback on the feasibility of this approach, the results also open up other avenues for future research:

#### **Need for a Second Deployment**

Given the nature of the technical issues we faced, and the consequent lack of validated data, we would need a second iteration and long-term deployment to effectively gauge the accuracy of this approach. A second clinical trial, on a robust, validated platform, with the enhanced visualizations, would be one possibility to gather evidence for the effectiveness and feasibility of the *myWeekInSight* application. We also note the valuable feedback received from the in-depth interviews conducted post the study with the participants, and hence would like to include such open-ended feedback sessions in any subsequent iterations.



### **Need to Test with a Diverse Population**

Our current demographic included teens in a first-world country, with access to their own smartphones and constant Internet. Our demographic was also majorly female, and towards the older end of 12-18 years. This raises the question of how generalizable our results might be, given this very specific subset of the population. Thus, an interesting next step would be to conduct this same study, but with a more diverse population, sampling more uniformly through the age range, and also considering other factors like access to smartphones and Internet. This also highlights the need to modify *myWeekInSight* to make it more accessible - for instance, having an offline version of the application to reduce dependency on the Internet, and reducing the frequency of the EMA surveys to accommodate participants with limited access to smartphones.

### **Empowering Teens with Data Access Control**

Through the feedback interviews, participants noted how they saw different sharing strategies for their data and visualizations - some wanted to share the information with their parents, others with clinicians, while some felt they would like to keep the information private which would encourage openness and veracity in their EMA survey responses. This shows the potential of *myWeekInSight* as a possible data source for clinicians and caregivers. Could the data provided by the youth and the visualizations be a part of their health records? Furthermore, CareTeam's platform included a feature allowing youth to select who could access their data, which empowered teens in tracking and enabling who could access their information. Giving youth the agency and control of their own data, while allowing them to share it with others to improve their lived experiences, could be an important factor in their willingness to engage with such an application, and this would be an aspect that could be further researched.

### **Potential Mental and Emotional Toll**

While *myWeekInSight* received positive responses from most participants, some participants did highlight the possible mental and emotional toll of the application. This includes the potential cognitive overload from the visualizations, ex-

haustion from having to fill the 3x EMA surveys for a prolonged time, and the emotional and cognitive effort of reflecting on one's own data. While we intend for the self-reflection experience to be positive and insightful, it could also appear demoralizing and pessimistic at times, which could be detrimental to how youth felt about their pain. Thus, we would like to further evaluate the mental and emotional cost of using *myWeekInSight* for a prolonged time, to assess possible negative consequences.

### **Potential for Other Populations**

Through this work, we discovered the feasibility of this approach for youth with chronic pain, but could this approach also be leveraged for other youth demographics involved in the self-management of their health? For instance, could such an approach of surveys and visualizations to enable self-reflection and improvement be useful for teens undergoing therapy, in tracking their emotions and mental state, or for teens undergoing physiotherapy to track their physical progress? Thus, we believe segments of the EMA classes (Sleep/Symptoms/Emotions/Mental Health/Peer Interactions) could be useful to other demographics as well, with particular configurations for each demographic, following the guidelines we mention in Section 7.2.

## **8.4 Design Recommendations for Research in this Domain**

### **Include Stakeholders through Collaborative Design**

This thesis has encompassed work done at the intersection of HCI and healthcare. It has been a unique opportunity to co-design with clinicians, visualization experts, HCI researchers, and be able to evaluate the same with patients. We acknowledge that such design cycles are rare in the HCI community, reasonably owing to the lack of access to such expertise, collaborations, and patient groups. However, our work has shown the great benefits such collaborations bring to the research; the different perspectives, understandings of different processes, and finally the importance of end-user feedback on the designs. Thus, we recommend including key stakeholders

in the design process, designing from patient-centered perspectives, and evaluating such applications in-the-wild over time.

### **Leverage Patient Data through Patient-Centered Design**

Opportunities for more applications at this intersection of HCI and healthcare continue to expand. Personal informatics is a growing field, and with technology moving forward towards smaller and more invasive form factors, this is a field that will only be more incorporated into our lives. Simple tools like wearables and smartphone applications provide a medium to obtain data on physical and psychological events throughout the day. When we consider chronic pain patients, especially a younger demographic, these tools offer a way for clinicians and care providers to obtain data on the health of their patients and loved ones in a consistent, accurate manner. Yet, the challenge remains to design in a way that places patients the center of this process. People with chronic pain experience will tell you, no one knows them better than themselves [6], and this knowledge is important and worth leveraging, not just for clinicians, but for patients themselves. Simply allowing patients to track their data in a format that is relevant and understandable for them, yet useful for clinicians and care providers as well, provides a data collection medium that can be insightful and helpful for patients and clinicians alike.

### **Teenagers Know What They Want - Design with Them**

Finally, considering our specific target demographic over the course of this thesis - as we have evaluated the visualizations and the *myWeekInSight* application, we have had the opportunity to interact with teens directly, and we have seen the application's potential in being a self-management tool for youth with chronic pain. Most teens spoke how the visualizations could be helpful, how they could use it, what information they could see in them. They were sure of what they wanted track, they knew what was relevant to them, they subconsciously knew what affected their pain and how, and they were also motivated to continue tracking those aspects for a long time. While there is a difference in the cognitive capacity of an adult versus a teenager when it comes to processing visualized data, the use and potential remains the same for both. Designing for younger audiences does not

necessarily mean ‘dumbing down’ the design, but designing carefully to highlight what is most relevant to them, which might be different from what would be relevant to an adult population. It also means designing for a group that has different priorities and understanding of their health and daily lives, and needs guidance from caregivers and healthcare providers. The best way to design for such audiences is to incorporate their feedback into the design - while feedback sessions can be limited, there are valuable insights the end user brings to the table in any design process, and that remains the same for this population as well.

## **8.5 In Closing**

We began this thesis by talking about Eleanor – her daily experiences, and how her pain impacted her life. In the course of the thesis, we made an application that would visualize Eleanor’s daily lived experiences and enable her to reflect on them and learn more about herself. We incorporated Eleanor in the design process, took her feedback on the designs, and ended up with a tool she would want to continue using for a long time, and saw as significantly valuable in the management of her pain. Eleanor is a persona we built based on our conversations with the youth in our second round of evaluation interviews. We urge designers to think of an ‘Eleanor’ for their applications, and include her and her perspective in the design process, to ensure they end up with a product that is useful, engaging and relevant to her.

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## **Appendix A**

# **Supporting Materials**

### **A.1 EMA Survey Items**

**Child EMA Items**

**\*\*THE FOLLOWING ITEMS ARE INCLUDED AT EACH PROMPT (morning, afternoon, and evening)**

**Instructions: Please answer all of the questions below. In these questions, “survey” means the last time you filled out questions for this study.**

Item	Response Type	Response Options
1. Since the last survey, I felt <i>worried about experiencing physical symptoms</i> .	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)
2. Since the last survey, did you experience any physical symptoms?	Check box	- Yes - No
If “Yes” was endorsed from Question 8		-
2a. Since the last survey, I felt these <i>physical symptoms</i> :	Nominal check box (choose all that apply)	- Stomach ache - Headache - Pain in my lower back - Faintness or dizziness - Pain in my arms or legs - My heart was beating too fast - Nausea or upset stomach - Weakness in parts of my body - Other: [free response box]
2b. Since the last survey, how <i>intense</i> were your physical symptoms?	Slider visual analogue scale	0 (No symptoms) to 10 (Worst I can think of)
2c. Since the last survey, did you <i>do anything about your physical symptoms?</i> (e.g., take medication, rest, use a coping strategy, etc.)	Check box	- Yes: [free response box] - No
END SECTION HERE		-
3. Since the last survey, I felt <i>worried or scared</i> .	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)
4. Since the last survey, I felt <i>happy</i> .	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)
5. Since the last survey, I felt <i>annoyed or angry</i> .	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)

6. Since the last survey, I felt <i>unhappy, sad, or miserable</i> .	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)
END SECTION HERE		
7. Since the last survey, <i>my interactions with other people my age have been:</i>	Nominal check box	- Very positive - Somewhat positive - Neutral - Somewhat negative - Very negative - I haven't had any interactions with other people my age since the last survey
8. Since the last survey, I felt <i>worried about my interactions with other people my age</i> .	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)
END SECTION HERE		

MORNING-SPECIFIC PROMPTS (these come before the items listed above)

Item	Response Type	Response Options
1. Last night, I <i>fell asleep at:</i>	Drop down menu	[Drop-down menu: 1:00 am-12:00am allowed]
2. This morning, I <i>woke up at:</i>	Drop down menu	[Drop-down menu: 1:00 am-12:00pm allowed]
3. How well did you sleep last night?	Interval check box	- I had a great night of sleep - I had a good night of sleep - I had an okay night of sleep - I had a poor night of sleep
4. What are you <b>most</b> worried about happening today?	Free Response	
5. The thing I am <b>MOST</b> worried about today involves...	Nominal check box (select all that apply)	- My family - My friends or peers - People I don't know well - School - Sports or extracurricular activities

		- My health and safety - Nothing in particular - Other [free response box]
6. How <b>worried</b> are you about this?	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)
7. How <b>certain</b> are you that it will happen?	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)
8. How <b>bad</b> do you expect it to be?	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)

PM-SPECIFIC PROMPTS (these come AFTER the items listed above during the Afternoon and Evening Prompts)

Item	Response Type	Response Options
1. Did the thing you were worried about earlier happen?	Nominal check box	-Yes -No
<i>If "Yes" was endorsed from Question 1</i>		
1a. How bad was it?	Slider visual analogue scale	0 (Not at all) to 10 (Extremely)
2. Did you do anything to try and avoid the situation?	Nominal check box	-Yes: [free response box] -No
END SECTION HERE		
3. Did you go to school today? ( <i>afternoon only</i> )	Nominal check box	-Yes -No
<i>If "No" was endorsed from Question 3</i>		

3a. Why not?	Nominal check box (check one)	<ul style="list-style-type: none"> <li>- weekend</li> <li>- school holiday</li> <li>- chronic pain</li> <li>- home sick</li> <li>- doctor's appointment</li> <li>- summer vacation</li> <li>- home-schooled</li> <li>- online learning</li> <li>- other: [free response box]</li> </ul>
END SECTION HERE		

## **A.2 CPSC 554K Application Prototype**



**DataViz**

**Helping you  
manage your pain**



Loading...







**DataViz**

## Welcome

Sign in to continue

Sign in with mobile number

or

Register as new user

By signing in, you accept our [Terms and Conditions](#)



**Abigail Watson**  
Vancouver



 Daily Log

 Daily Summary

 Statistics

 Get Reports

 Chat

 Account Settings

 Help

 Logout





## March 2021



Wed, Mar 24

Worried about homework  
Online classes  
Played basketball

Minor back pain

09:30 PM - 08:00 AM



Tues, Mar 23

No worries  
School holiday  
Hung out with friends

No pain

11:30 PM - 06:00 AM

Mon, Mar 22

Data missing, tap to add



Sun, Mar 21

Worried about school, health  
Doctor appointment  
No peer interaction

Major headache, back pain

01:30 AM - 06:00 AM



Home



Daily



Statistics



Share



## Daily Summary

< 24 March 2021 >

09:00 AM 

Minor back pain  
Took medicines  
Had online classes  
No peer interaction  
Got up at 8 AM  
Slept at 10 PM



01:00 PM

No back pain  
No medicines  
Had online classes  
Video call with friends  
Worried about school  
Took a nap  
Happy, little anxious

07:00 PM 

Severe back pain  
Took medicines  
Worried about school  
No peer interaction  
Played basketball  
Anxious, sad



Home



Daily



Statistics



Share

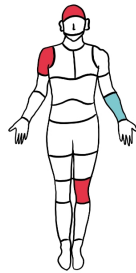


## Detailed Summary

< 24 March 2021 >

09:00 AM

### PAIN:

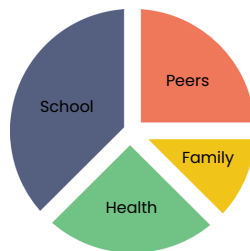


Severe back pain  
Severe headache  
Mild pain in right arm  
Took medicines

**Overall pain level: 5/10**

Share

### MENTAL HEALTH:



#### Worried about:

School: 40%  
Peers : 20%  
Feeling anxious  
Feeling miserable

Share



Good sleep



Met friends



Online classes

Weekly Stats

Back



Home



Daily



Statistics



Share



## Share Data

### Include Data:

- Sleep Data
- Mental Health Data
- Pain data
- Peer interaction Data

### Time Period:

 Select Date

OR

- Today
- This Week

Next



Home



Daily



Statistics



Share



## Share Data

Export as:

- PDF
- PNG Image
- DOC
- JPEG Image

OR

Share via:



Email



Message



WhatsApp

Export

Cancel



Home



Daily



Statistics



Share



## Share Data

Export as:

- PDF
- PNG Image
- DOC
- JPEG Image

OR

Share via:



Email



Message



WhatsApp



Exporting...

Home

Cancel



Home



Daily



Statistics



Share





## Sleep Data

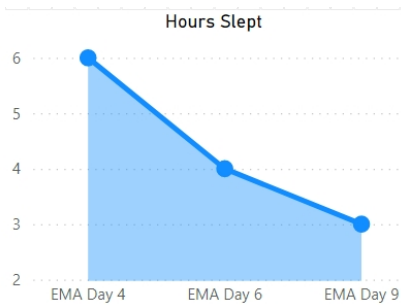
Developed by: Ummi Danni, Dhanish Shreya,  
Himanshu Chugh, Ashish Kumar, Pooja Gupta



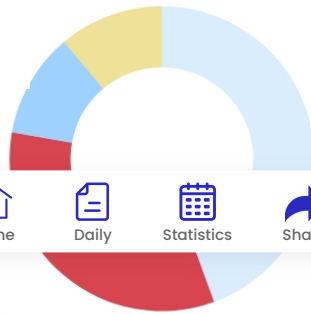
< 21 - 27 March 2021 >

### 6.5

Average Hours of Sleep



### Sleep Quality



Home



Daily



Statistics



Share

- Great quality sleep (12%)
- Good quality sleep (45%)
- Average quality sleep (11%)
- Poor quality sleep (32%)

Share

Back



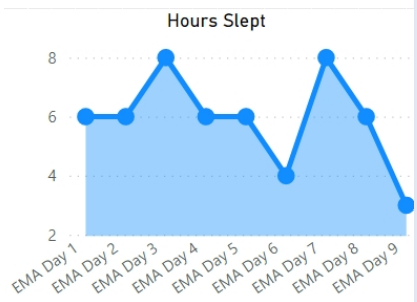
# Sleep Data



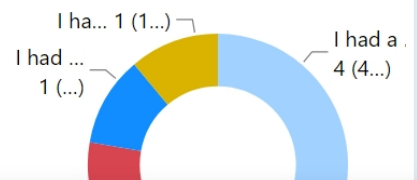
< 21 - 27 March 2021 >

## 6.5

Average Hours of Sleep



### Sleep Quality



- Home
- Daily
- Statistics
- Share

I had a poor ni...  
3 (33.3...)

- Great quality sleep (12%)
- Good quality sleep (45%)
- Average quality sleep (11%)
- Poor quality sleep (32%)

Share Back



## Weekly Statistics

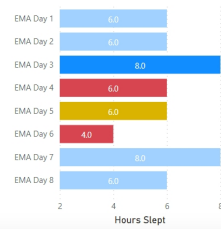
< 21 - 27 March 2021 >

### MENTAL HEALTH:

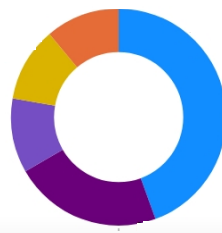


Share

### SLEEP:



### WORRY:



Home



Daily



Statistics



Share



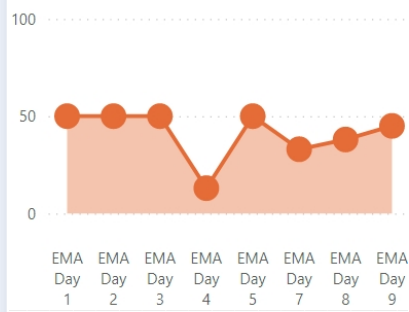
## Worry Data

< 21 - 27 March 2021 >

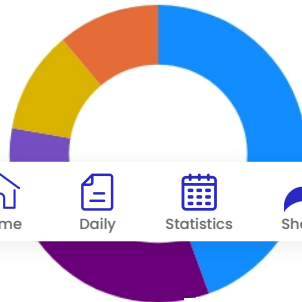
# 61.5

Worry Score

### Your Worry levels



### Worried about



Home



Daily



Statistics



Share

- School (45%)
- People I don't know well (22%)
- Nothing in particular (10%)
- My health and safety (12%)
- My friends or peers (13%)

Share

Back



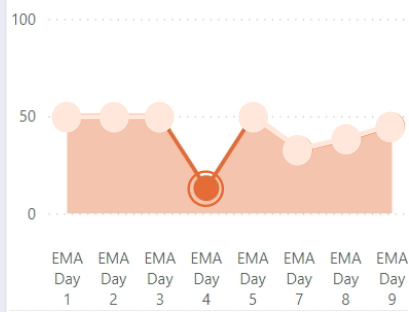
## Worry Data

< 23 March 2021 >

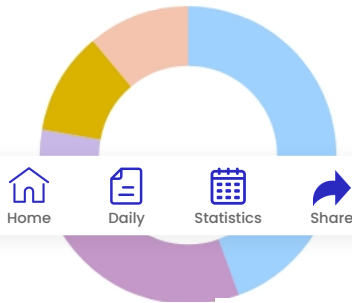
# 61.5

Worry Score

### Your Worry levels



### Worried about



- Home
- Daily
- Statistics
- Share

- School (45%)
- People I don't know well (22%)
- Nothing in particular (10%)
- My health and safety (12%)
- My friends or peers (13%)

Share

Back

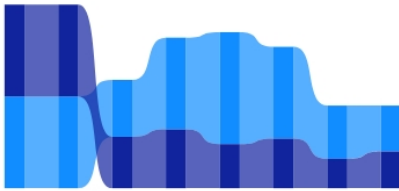


# Mental Health Data



< 21 -27 March 2021 >

## Positive



EMA Day 1 Day 2 Day 3 Day 4 Day 5 Day 6 Day 7 Day 8

- Happy
- Giddy, silly, happier than usual

## Negative



EMA Day 1 Day 2 Day 3 Day 4 Day 5 Day 6 Day 7 Day 8

- Worried or scared
- Annoyed or angry
- Unhappy, sad or miserable
- Frustrated



Home



Daily



Statistics



Share

View 2

Back



## Mental Health Data

< 21 -27 March 2021 >

### Emotion Distribution



Details

Back



Home



Daily



Statistics



Share

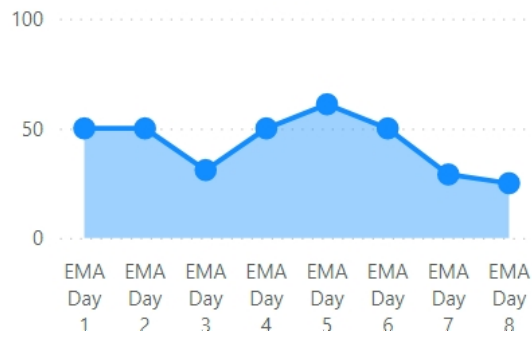


## Mental Health Data

< 21 -27 March 2021 >

### Emotion Distribution

Happy



### Add emotion:

- Frustrated
- Annoyed or Angry
- Unhappy, sad or miserable
- Giddy, silly or happier than usual

OR

View All

Back



Home



Daily



Statistics



Share



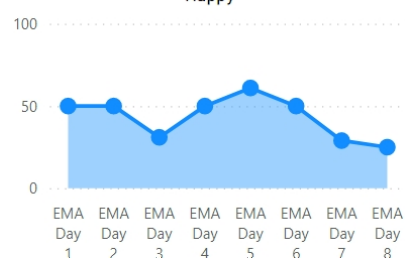


## Mental Health Data

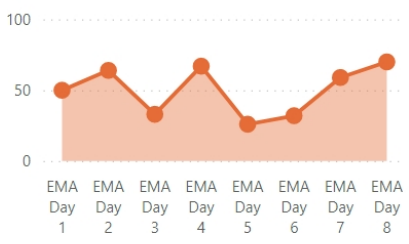
< 21 -27 March 2021 >

### Emotion Distribution

Happy



Frustrated



Add emotion:

- Home
- Daily
- Statistics
- Share

- Annoyed or angry
- Unhappy, sad or miserable
- Giddy, silly or happier than usual

OR

[View All](#) [Back](#)



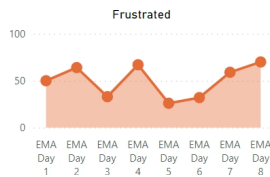
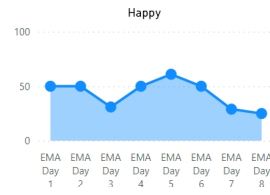
Download My EMA Data Report Here



## Mental Health Data

< 21 -27 March 2021 >

### Emotion Distribution



Home



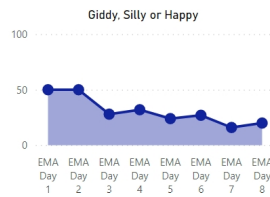
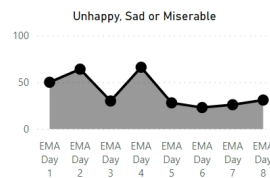
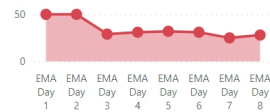
Daily



Statistics



Share



Back

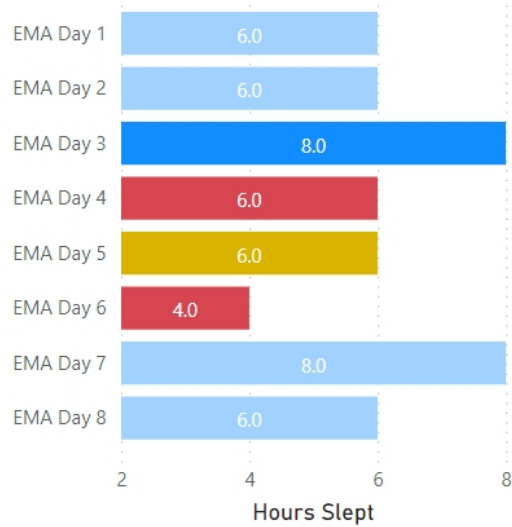


## Sleep Data

< 21 - 27 March 2021 >

# 6.5

Average Hours of Sleep



- Great quality sleep
- Good quality sleep
- Average quality sleep
- Poor quality sleep

View 2

Back



Home



Daily



Statistics



Share

## **A.3 Invitation Letters, Consent And Assent Forms**

### **A.3.1 Phase 1 Design Evaluation Invitation Letter**



Dear Patient/Parent,

The Provincial Health Services Authority (PHSA) wants to let you know about the following opportunity. The Complex Pain Service at BC Children's Hospital is conducting a research study. You are being invited to participate because you live in Canada and are either aged 12-18 and living with complex ongoing pain; or you are the parent of a young person living with chronic pain. If you have already been invited to this study or this study does not apply to you, please ignore this invitation.

The purpose of this study is to gather feedback on a proposed system of representing health data graphically, including the pain, sleep and interaction experiences of youth with chronic pain. This will help us improve our design of a data visualization-based smartphone application for better pain management.

In this study, the young person will participate in a one-time remote online interview. It will take around 30-60 minutes, and will ask questions related to their experience with data visualization or mobile health applications. They will then be shown a number of images and asked for open feedback about each. The young person will fill out a questionnaire online simultaneously as they are being shown the visualizations. The questionnaire will ask them to rate each visualization on parameters like creativity, ease of use, motivation and interest.

Your participation can help us make future decisions and improve services delivered to you and other patients/families.

For more information or if you want to join the study, please contact Unma Desai (Graduate Student at UBC; [REDACTED]) or the study coordinator (Jane Shen at [REDACTED]).

If you choose not to participate, any care you receive now or in the future will not be affected in any way.

We try our very best not to send these letters to loved ones of patients who have passed away. If your loved one has passed away, please accept our heartfelt condolences and our sincere apologies.

Everyone who joins this study will receive a \$20 gift card.

We have attached the consent form here which provides more information about the study. A representative may contact you about this study in the next 2 weeks. If you do not want us to contact you about this study again, please contact *[insert e-mail and/or telephone number]*.

Thank you for your time.

Sincerely,

Tim Oberlander, MD, FRCP  
Physician, Complex Pain Service, BC Children's Hospital

Version 1: July 12, 2021

Phase 1 Invitation Letter

Professor, Department of Pediatrics, University of British Columbia

Version 1: July 12, 2021

Phase 1 Invitation Letter

### **A.3.2 Phase 1 Design Evaluation Consent Form**



## Participant Information and Consent Form



### Remotely delivered data collection in youth with chronic pain: A pilot study (Phase 1 – Data Visualization Feedback)

**Principal Investigator:** Tim Oberlander, MD, FRCPC  
Physician, Complex Pain Service, BC Children's Hospital  
Professor, Department of Pediatrics, UBC  
[REDACTED]

If you are a parent or legal guardian of a child who may take part in this study, permission from you and the assent (agreement) of your child is required. When we say “you” or “your” in this consent form, we mean you and/or your child; “we” means the researchers and the research team.

#### 1. Invitation

Your child is being invited to take part in this research study because they have complex pain. We are doing this study to gather feedback on potential data visualization methods for the daily lived experiences of youth with chronic pain.

#### 2. Your participation is voluntary

Your child's participation is voluntary. Your child has the right to refuse to participate in this study. If your child decides to participate, they may still choose to withdraw from the study at any time without any negative consequences to the medical care, education, or other services to which they are entitled or are presently receiving.

You should be aware that there is a difference for both your child and their doctor between being a patient and being a research participant. As a patient, all medical procedures and treatments are carried out for the patient's benefit only according to standard accepted practice. As a research participant, your child and their doctor also must take into account the requirements for the research study. This consent form describes the procedures that are being carried out for research purposes. Please review the consent document carefully when deciding whether or not you wish for your child to be part of the research and sign this consent only if you accept your child being a research participant.

Please take time to read the following information carefully and to discuss it with your family, friends, and doctor before you decide.



### **3. Who is conducting this study?**

This study is being conducted by researchers at the University of British Columbia Department of Computer Science and Department of Pediatrics. This study is receiving funds from the BC Children's Hospital Brain, Behaviour & Development Theme and the Digital Health Research Accelerator Grant.

### **4. Background**

Complex pain affects 3-5% of youth. Youth with complex pain often experience additional challenges such as functional difficulties (e.g., having a hard time attending school, missing out on social or recreational activities), mental health concerns, and other types of physical symptoms.

Most of what is known about complex pain comes from research studies that ask youth to fill out questionnaires about how they think and feel. Researchers believe that allowing youth to observe and interact with this self-reported health data through accessible and youth-focused visualizations will provide them with better agency over their pain. It will also allow them to reflect on and incorporate behavioral changes in their daily lives, and aid clinicians in providing better medical treatments.

Researchers are carrying out this study to gather feedback on initial designs for visualizing health data collected through an EMA approach. The EMA or Ecological Momentary Assessment approach involves youth filling out a few short questions multiple times a day for a certain time period. This allows researchers to learn more about the experiences of the youth as they happen in real life. However, in this study, participants will not have to fill out the EMA questions. Instead, similar sample data will be used to create the visualizations. These designs include graphical representations of the recorded pain, sleep and interaction experiences of youth with chronic pain. This will guide their future work as they develop a data visualization-based mobile application for better pain management.

### **5. What is the purpose of this study?**

Your child is being invited to be in the study to provide feedback on data visualizations of sample health data gathered using an EMA approach. This research study is planning to ask 10 youth with complex pain to participate in a one-time remote online interview and fill out a questionnaire that will help evaluate the design of these visualizations.

This type of study is called a “usability study”. These studies are done to test the design of an application and find out how users might respond to it. This type of study involves a small number of participants and the data will be used to help improve on the design of the application.

#### **6. Who can participate in this study?**

Your child may be able to participate in this study if:

- They are between the ages of 12 and 18 years old and have been seen by the Complex Pain Service at BC Children’s Hospital
- Your child can read and write enough English to answer written questions
- Your child can speak enough English to answer verbal questions

#### **7. Who should not participate in this study?**

Your child will not be eligible to participate in this study if:

- They have a significant developmental delay or disability that would interfere with their ability to complete the tasks required in this study

#### **8. What does the study involve?**

If your child chooses to be in the study, they will be asked to do a few different things:

(1) Your child will participate in a one-time remote online interview. It will take around 30-60 minutes, and they will be asked questions related to their previous experiences with data visualization or mobile health applications. They will then be shown a number of data visualizations and asked for open feedback about each.

(2) Your child will fill out a questionnaire online simultaneously as they are being shown the visualizations. The questionnaire will ask them to rate each visualization on parameters like creativity, ease of use, motivation and interest.

In all of these different tasks, your child will be free to skip any questions they do not want to answer. Your family is free to withdraw from the research at any time.

#### **9. What are the possible harms and discomforts?**

Participation in this study is low risk. Some questions in the interview may seem confusing or irrelevant. Your child can skip any question they do not want to answer.

If you or your child are upset by any feelings that come up as a result of participating in this study, you can contact the study doctor (Dr. Oberlander at [REDACTED]) or researcher (Unma Desai at [REDACTED]).

If you are in crisis, you can call the Crisis Line Association of BC ([REDACTED]). Your child can call for help at Kids Help Phone ([REDACTED]). You can also receive resources about mental health services in British Columbia by calling [REDACTED] (no area code, available 24/7). If you or your child are having an emergency, please go to your local emergency department for help.

This study requires your child to have access to a computer with access to the internet and a video-conferencing software such as Zoom installed. This is necessary to complete the remote online interview and online questionnaire.

#### **10. What are the potential benefits of participating?**

Participating in this study may not benefit your child.

We hope that the information learned from this study can be used in the future to benefit other youth with complex pain. If you wish, you have the option of being informed of the results of this study after its completion (i.e., what we develop overall, not individualized feedback on your child's responses).

#### **11. What happens if I decide to withdraw my consent to participate?**

Your child may withdraw from this study at any time without giving reasons. If you choose to have your child enter the study and then decide to withdraw at a later time, the study team will have a discussion with you and your child about what will happen to the information already collected. You have the right to request the destruction of your information collected during the study, or you may choose to leave the study and allow the investigators to keep the information already collected from your child until that point.

If you choose to have the data collected about your child destroyed, this request will be respected to the extent possible. Please note however that there may be exceptions where the data will not be able to be withdrawn for example where the data is no longer identifiable (meaning it cannot be linked in any way back to your child's identity) or where the data has been merged with other data. If you would like to request the withdrawal of your child's data, please let the researcher know.

#### **12. How will my taking part in the study be kept confidential?**

Your child's confidentiality will be respected. However, research records or other source records identifying your child may be inspected in the presence of the Investigator or his or her designate by representatives of the UBC C&W Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your child's identity will be published without you and your child's consent, nor will any information or records that disclose your child's identity be removed or released without you and your child's consent unless required by law.

Please note that your child's responses to questionnaires and other study data will not be released to you unless there is a significant concern related to health/safety (i.e., where the investigators have a legal obligation to break confidentiality for the child's safety).

Your child will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify them (e.g., it will not include Personal Health Number, SIN, initials, etc.). Only this number will be used on any research-related information collected about your child during the course of this study, so that your child's identity will be kept confidential. Information that contains your child's identity will remain only with the Principal Investigator and/or designate. The list that matches your child's name to the unique study number that is used on your child's research-related information will not be removed or released without you and your child's consent unless required by law.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected. You also have the legal right of access to the information about you, and if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor.

**Disclosure of Race/Ethnicity:** Studies involving humans now routinely collect information on race and ethnic origin as well as other characteristics of individuals because these characteristics may influence how people respond. You should be aware that providing this information is not mandatory.

**Use of websites and/or third-party applications:** This study collects email addresses for the purposes of sending the link to this consent form and sending the link for the remote online interview and questionnaire. This information will be collected and stored using the Research Electronic Data Capture (REDCap) system. All data collected in the questionnaire will be captured and recorded on the BC Children's Hospital REDCap server, and will not be stored on participants' computers. This study will also use the video conferencing platform Zoom, for remote online interviews. Interviews may be recorded (audio only) with the consent/assent of the participant, in which case recorded data will be stored securely on a UBC server, and not on the participants' computers.

We are asking to collect your email address for sending the link to this consent form and sending the link for the remote online interview and questionnaire. Although you may not be

aware of this fact, emails sent to some webmail services (e.g., Gmail, Hotmail, etc.), may be stored/routed outside of Canada (for example, in the United States). Due to the fact that future emails will contain personal information about you, including your name, the Freedom of Information and Protection of Privacy Act requires that we obtain your consent before we continue. We will only send your personal information to the email address you have provided to us. All of the information which you provide to us will be kept completely confidential. Providing your email address means that you voluntarily agree and give your consent for the study team to email your personal information to you.

The information collected by the research team will be stored in a secured electronic REDCap database in the BC Children's Hospital Research Institute Clinical Research Support Unit (BCCHRI CRSU) located on-site in Vancouver, BC. Your child's personal identifying information (i.e., email address, name, phone number) will be stored separately from their other data (responses to questionnaires). De-identified data entered into REDCap can only be accessed by limited, authorized members of the research team with appropriate electronic signatures. BCCHRI CRSU stores the data in a secure, firewall-protected server; the web-server uses Secure Socket Layer (SSL) technology for the transfer of data between the participating computer and the server. The actual data center at BCCHRI CRSU is a physically secured and protected area, with very limited access. BCCHRI information technology and security personnel control and record authorization and access linked to identification cards in this area. The data center is patrolled by onsite security personnel, monitored by surveillance cameras, and protected by a fire-suppression system.

Any interview recordings will be de-identified, and your child's personal identifying information (i.e., name) will be stored separately from their other data (interview recordings). De-identified recordings will be stored on a secure UBC server, with restricted access only to Dr. Oberlander and the research team.

Your electronic consent form will be stored in BC Children's Hospital Research Institute's secured network in Vancouver, BC. Only authorized personnel will be able to access it.

### **13. What happens if something goes wrong?**

By signing this form, you do not give up any of your or your child's legal rights and you do not release the researchers, participating institutions, or anyone else from their legal and professional duties. If your child becomes ill or physically injured as a result of participation in this study, medical treatment will be provided at no additional cost to you. The costs of medical treatment will be paid by your provincial medical plan.

### **14. What will the study cost me?**

Your child will need to have access to a laptop with internet access for the duration of the interview. There are no other costs incurred by your participation in the study.

Your child will receive a 20 CAD gift card for participating in this study.

**15. If I have questions about the study procedures during my participation, who should I speak to?**

If you have any questions or desire further information about this study before or during participation, you can contact Jane Shen (Research Coordinator) at [REDACTED].

**16. Who do I contact if I have any questions or concerns about my rights as a participant?**

If you have any concerns or complaints about your child's rights as a research participant and/or your child's experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at [REDACTED] or by phone at [REDACTED]. Please reference the study number (H20-02965) when calling so the Complaint Line staff can better assist you.

**Remotely delivered data collection and intervention for anxiety and somatic symptoms in youth with chronic pain: A pilot study**

**Participant Consent**

My signature on this consent form means:

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided.
- I have been able to ask for advice if needed.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes.
- I understand that my child's participation in this study is voluntary.
- I understand that me and my child are completely free to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care that I/they receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me or my child.

I will print or save a copy of the signed consent form for my own records. If I do not wish to have my child participate in this study, I will close my web browser now without completing the information below.

**Parent/Guardian and/or Substitute Decision Maker Consent**

This consent form was read by the parent(s)/guardian(s)/substitute decision-maker (legally authorized representative), who is satisfied that:

- The study information was accurately explained to, and apparently understood by, the child/participant.
- The child/participant was given an opportunity to ask questions, and all questions have been answered.
- The child/participant assents to participating in the research.

Participant Name (Child): \_\_\_\_\_

Parent/Guardian or Substitute Decision Maker Name: \_\_\_\_\_

Date: \_\_\_\_\_

**Optional Consent**

Option to be contacted for future related studies (please select one):

- I give permission to be contacted for future related studies.
- I do NOT give permission to be contacted for future related studies.

Option to receive a summary of study results (please select one):

- I would like to receive a summary of the results of this study once the study is completed.
- I would NOT like to receive a summary of the results of this study.



**Resources for mental health and pain management**

Kids Help Phone: [REDACTED]

Solutions for Kids in Pain: [kidsinpain.ca](http://kidsinpain.ca)

### **A.3.3 Phase 1 Design Evaluation Assent Form**



## Adolescent Information and Assent Form

### Complex pain smartphone study (Phase 1 – Data Visualization Feedback)

#### WHO IS IN CHARGE OF THE STUDY?

The doctor in charge of the study is Dr. Oberlander. He is being helped by Jane Shen (Research Coordinator). The research will be conducted by Unma Desai (a Graduate student at UBC). They will answer any questions I have about the study. If I am having an emergency and cannot talk to my parents or legal guardians, or if I am having any problems, I can call them at [REDACTED] (Dr. Oberlander) or [REDACTED] (Jane Shen) or [REDACTED] (Unma Desai) for help.

#### INVITATION

I am being invited to take part in this research study because I have been diagnosed with complex pain. The following pages explain the study so that I can decide if I want to take part or not. It is up to me if I want to be in this study. No one will make me be part of the study and no one will get mad at me if I don't want to be a part of this study.

#### DO I HAVE TO BE IN THIS STUDY?

I do not have to participate in this study if I don't want to. If I choose to participate, I can stop at any time. The doctors and nurses will take care of me as they have in the past, regardless of whether I am in the study or not.

If I want to participate in this study, I will be asked to sign this form. My parent/guardian will need to sign a consent form before I start the study; but I do not have to participate even if they sign the consent form. The researchers will not include me into the study unless I agree to do so.

I should take time to read the following information carefully and to talk it over with my family, and if I wish, my doctor, before I decide. I understand that I should feel free to talk to the study

researchers if anything below is not clear. I can choose to be in the study, not be in the study, or take more time to decide. Even if I agree now to be part of the study, I can change my mind later. I can ask the study researcher or study coordinator any questions I may have at any time during my study participation.

#### **WHY ARE WE DOING THIS STUDY?**

Researchers believe that allowing youth to observe and interact with their self-reported health data will give them better control over their pain. It will also aid clinicians in providing better medical treatments.

Researchers are developing different ways of showing this health data by using graphs or other types of pictures so it is easier to understand the relationships between different experiences (like pain and sleep). This study is asking youth to give feedback on these different types of graphs and pictures, so that they can be designed in a way that they are most useful.

#### **WHY ARE YOU INVITING ME TO BE IN THIS STUDY?**

I am being invited to be in the study to provide feedback on graphical representations of sample health data gathered using an EMA approach. The EMA or Ecological Momentary Assessment approach involves youth filling out a few short questions multiple times a day for a certain time period. This allows researchers to learn more about the experiences of the youth as they happen in real life. However, in this study, participants will not have to fill out the EMA questions. Instead, similar sample data will be used to create the graphical representations. This research study is planning to ask 10 youth with complex pain to participate in a one-time remote online interview and fill out a questionnaire that will help evaluate the design of these visualizations.

#### **WHAT WILL HAPPEN TO ME IN THIS STUDY?**

If I choose to be in the study, I will be asked to do a few different things:

- (1) I will participate in a one-time online interview using Zoom or another video conferencing software. It will take around 30-60 minutes, and I will be asked questions related to my previous experiences with data visualization or mobile health applications. I will then be shown a number of images and asked to share what I think about each.
- (2) I will answer some questions online as I am being shown the visualizations. The questions will ask me to rate each image on parameters like creativity, ease of use, motivation and interest.

### **CAN ANYTHING BAD HAPPEN?**

There is nothing bad that is expected to happen to me by participating in this study. I might find some questions in the interview confusing or irrelevant.

The audio during the remote online interview might be recorded, but only if I am comfortable with it. At any point, I can ask the interviewer to stop recording, and also destroy any recorded portions of the interview I am uncomfortable with.

I do not have to answer every question. If I am upset by any feelings that come up as a result of participating in this study, I can talk to my parents or the study doctor (Dr. Oberlander at [REDACTED] or the researcher (Unma Desai at [REDACTED]). If I cannot reach these people, I can always call for help at Kids Help Phone ([REDACTED]). If I am having an emergency, I can go to my local emergency department for help.

### **WHO WILL KNOW I AM IN THIS STUDY?**

My privacy will be respected. Unless I allow them to, the study team will not tell anybody else I am or have been a part of this study. They will not release any information to anybody else that could be used to identify me unless they are required to do so by law. For example, researchers are required to report if a participant is believed to be at risk for harming him/herself or others. This also means that the researchers will not share my questionnaire answers with my parents unless there is a significant concern about my health/safety.

In order to protect my privacy, the study team will use a study code number instead of my name to identify my data. This means my identity as part of the study will be kept completely private. Only Dr. Oberlander and his research assistants will have the ability to link this code number with my personal information, and the linking information will be kept in a password-protected file on a secure server at BC Children's Hospital under the supervision of and control of Dr. Oberlander.

My electronic assent form (this form) will be stored in BC Children's Hospital Research Institute's secured network in Vancouver, BC. Only authorized personnel will be able to access it.

### **WHAT WILL THE STUDY COST ME?**

This study will not cost me anything.  
I will receive a 20 CAD gift card for participating in this study.

**WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?**

If I have any questions or desire further information about this study before or during participation, I can contact Jane Shen (Research Coordinator) at [REDACTED] [REDACTED] Unma Desai at [REDACTED].

**WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A PARTICIPANT?**

If I have any concerns or complaints about my rights as a research participant and/or my experiences while participating in this study, I should contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at [REDACTED] or by phone at [REDACTED] ([REDACTED]). I should reference the study number (H20-02965) when contacting the Complaint Line so the staff can better assist me.

**ASSENT TO PARTICIPATE**

My e-signature on this assent form means:

- I have read and understood this adolescent information and assent form.
- I have had enough time to consider the information provided and to ask for advice if necessary.
- I have had the opportunity to ask questions and have had acceptable answers to my questions.
- I agree to participate in this study.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific objectives.
- I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time without changing the quality of care that I receive.
- I understand that I can continue to ask questions, at any time, regarding my participation in the study.

I will print or save a copy of this assent form for my own records. If I do not wish to participate in this study, I will close my web browser now without completing the information below.

Participant Name: \_\_\_\_\_

Date: \_\_\_\_\_

Email to send questionnaire to: \_\_\_\_\_

## **FUTURE STUDIES**


There is a chance that during or after this study the study team will find other questions needing answers that require future studies. If I am willing to hear about these future studies, I will mark the "yes" box. This does not mean that I will have to take part in a new study, just that the study team will let me know about it. If I check this box, my contact information will be used only for the purpose of contacting me about future studies. If I do not want to be contacted about new studies, I will mark the "no" box."

Are you willing to be contacted by the researchers for future studies?

Yes

No

## **Resources for mental health and managing pain**

Kids Help Phone: 

Solutions for Kids in Pain: [kidsinpain.ca](http://kidsinpain.ca)



#### **A.3.4 Phase 2 Impact Evaluation Invitation Letter**



Dear Patient/Parent,

The Provincial Health Services Authority (PHSA) wants to let you know about the following opportunity: The Complex Pain Service at BC Children's Hospital is conducting a research study. You are being invited to participate because you live in Canada and are either aged 12-18 and living with complex ongoing pain; or you are the parent of a young person living with chronic pain. If you have already been invited to this study or this study does not apply to you, please ignore this invitation.

The purpose of this study is to test a new method of asking youth about their symptoms and emotions, using their smartphone. This will help us improve our ways of measuring and understanding how daily feelings of anxiety and other emotions are related to complex ongoing pain and other physical symptoms. We are also interested in looking at whether seeing your data dashboard (e.g., a place where you can view charts and graphs of your data over time) changes patient experiences.

This study involves 3 parts:

- (1) The young person complete a one-time online survey. It will take about 30 minutes and will ask questions about symptoms and pain, thoughts and feelings, daily function, and the impact of the COVID-19 pandemic on your health and overall quality of life.
- (2) The young person will fill out a short questionnaire, using their smartphone, 3 times a day for 14 days (7 days, followed by a one-week break, followed by 7 more days). The questionnaire will ask about feelings, thoughts, symptoms, and experiences. During one of the weeks, the young person will also have access to a dashboard to track their data (e.g., charts and graphs of symptoms and other experiences they are logging) over the course of the week. Which week is first (questions only or questions + dashboard access) will be assigned at random.
- (3) Halfway through and then at the end of the smartphone portion of the study, the young person will answer a few questions about their experience participating in the study.

Your participation can help us make future decisions and improve services delivered to you and other patients.

For more information or if you want to join the study, you can contact Dr. Katelynn Boerner (postdoctoral fellow at UBC [REDACTED]) or the study coordinator Jane Shen at [REDACTED].

If you choose not to participate, any care you receive now or in the future will not be affected in any way.

We try our very best not to send these letters to loved ones of patients who have passed away. If your loved one has passed away, please accept our heartfelt condolences and our sincere apologies.

Everyone who joins this study will receive a gift card for each phase of the study they complete. Reimbursement for out-of-pocket expenses such as internet access will also be available.

We have attached the consent form here which provides more information about the study.  
A representative may contact you about this study in the next 2 weeks. If you do not want us to contact you about this study again, please contact [*insert e-mail and/or telephone number*].

Thank you for your time.

Sincerely,

Tim Oberlander, MD, FRCP  
Physician, Complex Pain Service, BC Children's Hospital  
Professor, Department of Pediatrics, University of British Columbia

### **A.3.5 Phase 2 Design Evaluation Consent Form**



## Participant Information and Consent Form



### Remotely delivered data collection in youth with chronic pain: A pilot study (Phase 2 – EMA and data visualization trial)

**Principal Investigator:** Tim Oberlander, MD, FRCPC  
Physician, Complex Pain Service, BC Children's Hospital  
Professor, Department of Pediatrics, UBC  
[REDACTED]

If you are a parent or legal guardian of a child who may take part in this study, permission from you and the assent (agreement) of your child is required. When we say "you" or "your" in this consent form, we mean you and/or your child; "we" means the doctors and other staff.

#### 1. Invitation

Your child is being invited to take part in this research study because they have complex pain. We are doing this study to develop better ways of asking youth with complex pain about their symptoms and feelings in their daily lives.

#### 2. Your participation is voluntary

Your child's participation is voluntary. Your child has the right to refuse to participate in this study. If your child decides to participate, they may still choose to withdraw from the study at any time without any negative consequences to the medical care, education, or other services to which they are entitled or are presently receiving.

You should be aware that there is a difference for both your child and their doctor between being a patient and being a research participant. As a patient, all medical procedures and treatments are carried out for the patient's benefit only according to standard accepted practice. As a research participant, your child and their doctor also must take into account the requirements for the research study. This consent form describes the procedures that are being carried out for research purposes. Please review the consent document carefully when deciding whether or not you wish for your child to be part of the research and sign this consent only if you accept your child being a research participant.

Please take time to read the following information carefully and to discuss it with your family, friends, and doctor before you decide.

### **3. Who is conducting this study?**

This study is being conducted by doctors and staff at the BC Children's Hospital Complex Pain Service and University of British Columbia Department of Pediatrics. This study is receiving funds from the BC Children's Hospital Research Institute Digital Health Accelerator Grant.

### **4. Background**

Complex pain affects 3-5% of youth. Youth with complex pain often experience additional challenges such as functional difficulties (e.g., having a hard time attending school, missing out on social or recreational activities), mental health concerns, and other types of physical symptoms.

Most of what is known about complex pain comes from research studies that ask youth to come into a research lab or clinic to fill out questionnaires about how they think and feel. In this study, the researchers want to look at a new way of learning about the feelings and symptoms that youth experience in their daily lives. This approach is called "EMA" (Ecological Momentary Assessment). It involves youth filling out a few short questions 3 times a day for two 7-day periods using their smartphone. This way, the researchers can learn more about the experiences of youth as they happen without having to come in to the lab.

Researchers are doing this study to find out how youth feel about answering questions this way and to see if EMA gets new or different information than the usual way of collecting information. Researchers are also interested in looking at whether seeing one's own data dashboard (e.g., a place where they can see charts and graphs of their data over time) changes patient experiences.

### **5. What is the purpose of this study?**

Your child is being invited to be in the study to test a new way (EMA) of asking about symptoms and feelings for youth with complex pain. This research study is planning to ask 50 youth with complex pain to fill out some questions 3 times a day on their smartphone to see if this is a good way of learning about how youth with complex pain feel on a daily basis, and to see whether tracking their own data changes their experience.

This type of study is called a “pilot study” or “feasibility study”. These studies are done to test the study plan and find out how participants experience the study procedures. This type of study involves a small number of participants and the data will be used to help improve the study procedures. Knowledge gained from pilot or feasibility studies may be used to develop future studies that may benefit others.

#### **6. Who can participate in this study?**

Your child may be able to participate in this study if:

- They are between the ages of 12 and 18 years old and have been seen by the Complex Pain Service at BC Children’s Hospital
- Your child can read and write enough English to answer written questions

#### **7. Who should not participate in this study?**

Your child will not be eligible to participate in this study if:

- They have a significant developmental delay or disability that would interfere with their ability to complete the tasks required in this study
- Your child participated in Phase 1 of this study

#### **8. What does the study involve?**

If your child chooses to be in the study, they will be asked to do a few different things:

- (1) Your child will complete a one-time online survey. It will take about 30 minutes and will ask questions about your child’s symptoms and pain, thoughts and feelings, daily function, and the impact of the COVID-19 pandemic on their health and overall quality of life.
- (2) Your child will fill out a short questionnaire, using their smartphone, 3 times a day for 14 days (7 days, followed by a one-week break, followed by 7 more days). This is the “EMA” part of the study. The questionnaire will ask about feelings, thoughts, symptoms, and experiences. It should take your child less than 5 minutes each time to answer the questions. These will be reviewed on a weekly basis. If your child does not have a smartphone, they will be loaned one for use during the study. For one of the 7-day periods, your child will just answer the questionnaire. For the other 7-day period, your child will answer the questionnaire and be able to track their progress on the dashboard, which will show charts and graphs of their data. Which week happens first will be randomly assigned, and all children will have the opportunity to do both.

(3) Halfway through and then again at the end of the EMA part of the study, your child will answer a few online questions about their experience participating in the study. This will take about 15 minutes.

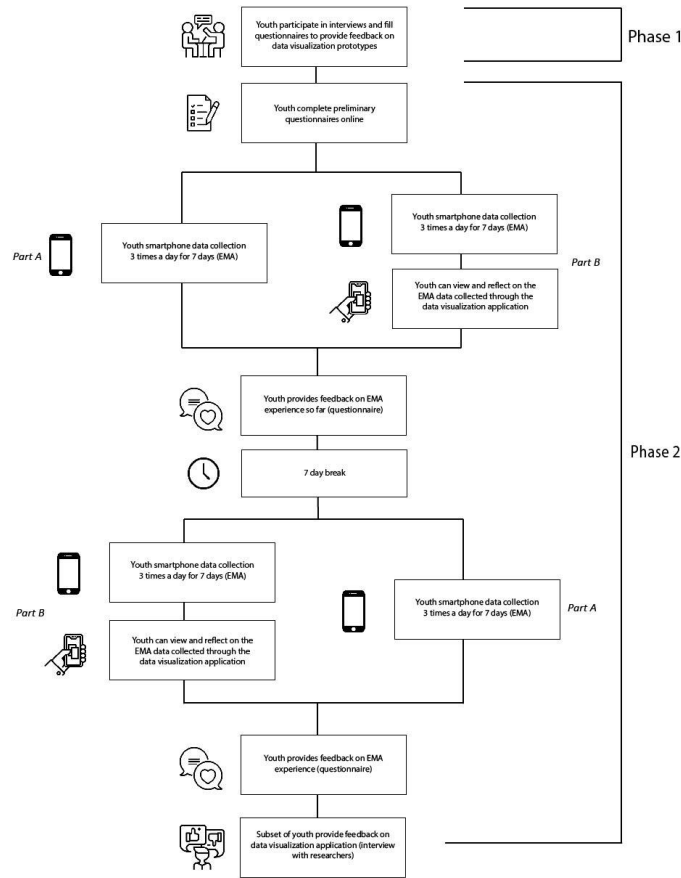
There is an optional, additional portion that your child can participate in to provide additional feedback on the dashboard, if they choose. This would involve the following: (1) Your child will participate in a one-time remote online interview. It will take around 30-60 minutes, and they will be asked questions about the data visualizations and asked for open feedback about each.

(2) Your child will fill out a questionnaire online simultaneously as they are being shown the visualizations. The questionnaire will ask them to rate each visualization on parameters like creativity, ease of use, motivation and interest.

In all of these different tasks, your child will be free to skip any questions you do not want to answer. Your family is free to withdraw from the research at any time.

Here is a flow chart to show all the steps of the study. By signing this consent form, you are agreeing for your child to participate in **Phase 2**. There is a space at the end of this form to indicate if you are interested in your child participating in the optional interview.





**9. What are the possible harms and discomforts?**

Participation in this study is low risk. Your child may be asked some questions that deal with personal or emotional matters. Some of these questions may be triggering and/or may make

your child feel uncomfortable, upset, or distressed. Your child can skip any question they do not want to answer.

If you or your child are upset by any feelings that come up as a result of participating in this study, you can contact the study doctor (Dr. Oberlander at [REDACTED]).

If you are in crisis, you can call the Crisis Line Association of BC [REDACTED]. Your child can call for help at Kids Help Phone [REDACTED]. You can also receive resources about mental health services in British Columbia by calling [REDACTED] (no area code, available 24/7). If you or your child are having an emergency, please go to your local emergency department for help.

This study requires your child to have access to a smartphone that can access the internet. This is necessary to complete the EMA portion of the research. If your child has access to such a smartphone, they can continue to use it as they normally do when they are not filling out study questionnaires. If your child does not have access to such a smartphone, we will loan one to them for the duration of the research. In these cases, we will take precautions to restrict usage of the phone, but we cannot guarantee that your child will not have access to internet content or that your child will not receive calls or texts from others while using this phone. Your child's use of the smartphone will be at your discretion.

#### **10. What are the potential benefits of participating?**

Participating in this study may not benefit your child.

We hope that the information learned from this study can be used in the future to benefit other youth with complex pain. If you wish, you have the option of being informed of the results of this study after its completion (i.e., what we found overall, not individualized feedback on your child's responses).

#### **11. What happens if I decide to withdraw my consent to participate?**

Your child may withdraw from this study at any time without giving reasons. If you choose to have your child enter the study and then decide to withdraw at a later time, the study team will have a discussion with you and your child about what will happen to the information already collected. You have the right to request the destruction of your information collected during the study, or you may choose to leave the study and allow the investigators to keep the information already collected about your child until that point.

If you choose to have the data collected about your child destroyed, this request will be respected to the extent possible. Please note however that there may be exceptions where the data will not be able to be withdrawn for example where the data is no longer

identifiable (meaning it cannot be linked in any way back to your child's identity) or where the data has been merged with other data. If you would like to request the withdrawal of your child's data, please let your study doctor know.

### **12. How will my taking part in the study be kept confidential?**

Your child's confidentiality will be respected. However, research records and health or other source records identifying your child may be inspected in the presence of the Investigator or his or her designate by representatives of the UBC C&W Research Ethics Board for the purpose of monitoring the research. No information or records that disclose your child's identity will be published without you and your child's consent, nor will any information or records that disclose your child's identity be removed or released without you and your child's consent unless required by law.

Please note that your child's responses to questionnaires and other study data will not be released to you unless there is a significant concern related to health/safety (i.e., where the investigators have a legal obligation to break confidentiality for the child's safety).

Your child will be assigned a unique study number as a participant in this study. This number will not include any personal information that could identify them (e.g., it will not include Personal Health Number, SIN, initials, etc.). Only this number will be used on any research-related information collected about your child during the course of this study, so that your child's identity will be kept confidential. Information that contains your child's identity will remain only with the Principal Investigator and/or designate. The list that matches your child's name to the unique study number that is used on your child's research-related information will not be removed or released without you and your child's consent unless required by law.

De-identified data from the EMA portion of the study may be saved in an electronic format and made publicly available online for use by the research community.

Your rights to privacy are legally protected by federal and provincial laws that require safeguards to ensure that your privacy is respected. You also have the legal right of access to the information about you, if need be, an opportunity to correct any errors in this information. Further details about these laws are available on request to your study doctor.

**Disclosure of Race/Ethnicity:** Studies involving humans now routinely collect information on race and ethnic origin as well as other characteristics of individuals because these characteristics may influence how people respond. You should be aware that providing this information is not mandatory.

**Use of websites and/or third party applications:** This study collects email addresses and phone numbers for the purposes of sending the link to this consent form/questionnaires and communicating about the study. This information will be collected and stored using the Research Electronic Data Capture (REDCap) system system.

A third party application called CareTeam will be used for collecting some of the questionnaire information. All questionnaire data will be stored in a HIPAA compliant database by CareTeam, and will not be stored on participant's computers or smartphones. All of the data collected by CareTeam is stored in Canada. CareTeam will only access your individual data if you are having a technical problem you need their help with. CareTeam will transfer your data to the research team for research purposes, and any transferred data will be stored securely on the servers at UBC/BC Children's Hospital.

If your child participates in the optional interview at the end of the study, all data collected in the questionnaire will be captured and recorded on the BC Children's Hospital REDCap server, and will not be stored on participant's computers. This study will also use the video conferencing platform Zoom, for remote online interviews. Interviews may be recorded (audio only) with the consent/assent of the participant, in which case recorded data will be stored securely on a UBC server, and not on the participant's computers.

The information collected by the research team will be stored in a secured electronic database REDCap in the BC Children's Hospital Research Institute Clinical Research Support Unit (BCCHRI CRSU) located on-site in Vancouver, BC. Your child's personal identifying information (i.e., email address, name, phone number) will be stored separately from their other data (responses to questionnaires). De-identified data entered into REDCap can only be accessed by limited, authorized members of the research team with appropriate electronic signatures. BCCHRI CRSU stores the data in a secure, firewall-protected server; the web-server uses Secure Socket Layer (SSL) technology for the transfer of data between the participating computer and the server. The actual data center at BCCHRI CRSU is a physically secured and protected area, with very limited access. BCCHRI information technology and security personnel control and record authorization and access linked to identification cards in this area. The data center is patrolled by onsite security personnel, monitored by surveillance cameras, and protected by a fire-suppression system.

We are asking to collect your email address to send e-consent forms and questionnaires, and to communicate with you about this study. Although you may not be aware of this fact, emails sent to some webmail services (e.g. Gmail, Hotmail, etc.), may be stored/routed outside of Canada (for example, in the United States). Due to the fact that future emails will contain personal information about you, including your name, the Freedom of Information and Protection of Privacy Act requires that we obtain your consent before we continue. We will only send your personal information to the email address you have provided to us. All of the information which you provide to us will be kept completely confidential. Providing your

email address means that you voluntarily agree and give your consent for the study team to email your personal information to you.

Your electronic consent form will be stored in BC Children's Hospital Research Institute's secured network in Vancouver, BC. Only authorized personnel will be able to access it.

### **13. What happens if something goes wrong?**

By signing this form, you do not give up any of your or your child's legal rights and you do not release the study doctor, participating institutions, or anyone else from their legal and professional duties. If your child becomes ill or physically injured as a result of participation in this study, medical treatment will be provided at no additional cost to you. The costs of medical treatment will be paid by your provincial medical plan.

### **14. What will the study cost me?**

All research-related materials will be provided at no cost to you. If your child does not have a smartphone, the researchers will loan them one to use for the EMA part of the study.

Your child will receive a gift card for participating in this study. The amount on the gift card will depend on how much of the study you complete. Every family that signs up for this study will receive \$20. Your child will then receive an extra \$10 after completing the first and second phase of the EMA (completing at least 2/3rds of the questionnaires) and feedback; up to \$40 total.

If your child participates in the optional interview at the end of the study, they will receive an additional \$20 gift card.

### **15. If I have questions about the study procedures during my participation, who should I speak to?**

If you have any questions or desire further information about this study before or during participation, you can contact [INSERT CONTACT INFORMATION FOR RESEARCH COORDINATOR].

### **16. Who do I contact if I have any questions or concerns about my rights as a participant?**

If you have any concerns or complaints about your child's rights as a research participant and/or your child's experiences while participating in this study, contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at [REDACTED] or by phone at [REDACTED]. Please reference the study number (H20-02965) when calling so the Complaint Line staff can better assist you.

**Remotely delivered data collection in youth with chronic pain: A pilot study**  
(Phase 2 – EMA and data visualization trial)

**Participant Consent**

My signature (i.e., typing my name below) on this consent form means:

- I have read and understood the information in this consent form.
- I have had enough time to think about the information provided.
- I have been able to ask for advice if needed.
- I have been able to ask questions and have had satisfactory responses to my questions.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific purposes.
- I understand that my child’s participation in this study is voluntary.
- I understand that I and my child are completely free at any time to refuse to participate or to withdraw from this study at any time, and that this will not change the quality of care that I/they receive.
- I understand that I am not waiving any of my legal rights as a result of signing this consent form.
- I understand that there is no guarantee that this study will provide any benefits to me or my child.

I will print or save a copy of the signed consent form for my own records. If I do not wish to have my child participate in this study, I will close my web browser now without completing the information below.

**Parent/Guardian and/or Substitute Decision Maker Consent**

This consent form was read by the parent(s)/guardian(s)/substitute decision-maker (legally authorized representative), who is satisfied that:

- The study information was accurately explained to, and apparently understood by, the child/participant.
- The child/participant was given an opportunity to ask questions, and all questions have been answered.
- The child/participant assents to participating in the research.

Participant Name (Child): \_\_\_\_\_

Parent/Guardian or Substitute Decision Maker Name: \_\_\_\_\_

Date: \_\_\_\_\_

Version 9: April 7, 2022  
02965

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### **Optional Consent**

Option for your child to participate in the optional interview at the end of the study (please select one; note that only a subset of participants will be asked to complete the interview, providing your consent does not guarantee your child will be asked to take part):

- I give permission for my child to participate in the optional interview at the end of the study.
- I do NOT give permission for my child to participate in the optional interview.

Option to be contacted for future related studies (please select one):

- I give permission to be contacted for future related studies.
- I do NOT give permission to be contacted for future related studies.

Option to receive a summary of study results (please select one):

- I would like to receive a summary of the results of this study once the study is completed.
- I would NOT like to receive a summary of the results of this study.



### Resources for mental health and pain management

Solutions for Kids in Pain: [kidsinpain.ca](http://kidsinpain.ca)

If you are in crisis or having an emergency, call 911 or go to your local emergency department. Here are some other resources that you might find helpful:

Kids Help Phone (available 24/7): [REDACTED]

KUU-US Youth Crisis Line (Indigenous-focused, available 24/7): [REDACTED]

Youth in BC crisis support: [REDACTED] (available 24/7) and online chat [youthinbc.com](http://youthinbc.com) (available noon-1am)

B.C. Child and Youth Mental Health

Services: <https://www2.gov.bc.ca/gov/content/health/managing-your-health/mental-health-substance-use/child-teen-mental-health> (visit the website to find contact information for your local clinic)

Online Mental Health Resources:

- [kelymentalhealth.ca](http://kelymentalhealth.ca)
- [foundrybc.ca](http://foundrybc.ca)
- [anxietycanada.ca](http://anxietycanada.ca)

Helpline for Children (to report child abuse or neglect in B.C., available 24/7): [REDACTED]

### **A.3.6 Phase 2 Impact Evaluation Assent Form**



## Adolescent Information and Assent Form

### Complex pain smartphone study (Phase 2 – EMA and data visualization trial)

#### WHO IS IN CHARGE OF THE STUDY?

The doctor in charge of the study is Dr. Oberlander. He is being helped by [INSERT NAME OF RESEARCH COORDINATOR]. They will answer any questions I have about the study. If I am having an emergency and cannot talk to my parents or legal guardians, or if I am having any problems, I can call them at [REDACTED] (Dr. Oberlander) or [INSERT NAME AND NUMBER OF RESEARCH COORDINATOR] for help.

#### INVITATION

I am being invited to take part in this research study because I have been diagnosed with complex pain. The following pages explain the study so that I can decide if I want to take part or not. It is up to me if I want to be in this study. No one will make me be part of the study and no one will get mad at me if I don't want to be a part of this study.

#### DO I HAVE TO BE IN THIS STUDY?

I do not have to participate in this study if I don't want to. If I choose to participate, I can stop at any time. The doctors and nurses will take care of me as they have in the past, regardless of whether I am in the study or not.

If I want to participate in this study, I will be asked to sign this form. My parent/guardian will need to sign a consent form before I start the study; but I do not have to participate even if they sign the consent form. The researchers will not include me into the study unless I agree to do so.

I should take time to read the following information carefully and to talk it over with my family, and if I wish, my doctor, before I decide. I understand that I should feel free to talk to the study doctors if anything below is not clear. I can choose to be in the study, not be in the study, or

take more time to decide. Even if I agree now to be part of the study, I can change my mind later. I can ask the study doctor or study coordinator any questions I may have at any time during my study participation.

### **WHY ARE WE DOING THIS STUDY?**

Most research studies of youth with complex pain ask youth to come into a research lab or clinic to fill out questionnaires. In this study, the researchers want to look at a new way of learning about the feelings and symptoms that youth experience in their daily lives. This approach is called "EMA" (Ecological Momentary Assessment). It involves youth filling out a few short questions 3 times a day for two 7-day periods using their smartphone. This way, the researchers can learn more about the experiences of youth as they happen in real life.

Researchers are doing this study to find out how youth feel about answering questions this way and to see if this gets new or different information than the usual way of collecting information. Researchers are also interested in looking at whether seeing your data dashboard (e.g., a place where you can see charts and graphs of your data over time) changes the way you feel.

### **WHY ARE YOU INVITING ME TO BE IN THIS STUDY?**

I am being invited to be in the study to test a new way (EMA) of asking about symptoms and feelings for youth with complex pain. This research study is planning to ask 50 youth with complex pain to fill out some questions 3 times a day on their smartphone to see if this is a good way of learning about how youth with complex pain feel on a daily basis, and whether being able to see their data dashboard changes the way they feel.

### **WHAT WILL HAPPEN TO ME IN THIS STUDY?**

If I choose to be in the study, I will be asked to do a few different things:

- (1) I will complete a one-time online survey. It will take about 30 minutes and will ask questions about symptoms and pain, thoughts and feelings, daily function, and how the COVID-19 pandemic has impacted me.
- (2) I will fill out a short questionnaire, using my smartphone, 3 times a day for 14 days (7 days, followed by a one-week break, followed by 7 more days). This is the "EMA" part of the study. The questionnaire will ask about feelings, thoughts, symptoms, and experiences. It should take me less than 5 minutes each time to answer the questions. For one of the weeks, I will just fill out the questionnaires. For the other week, I will fill out the questionnaires and have the opportunity to follow along with graphs and charts

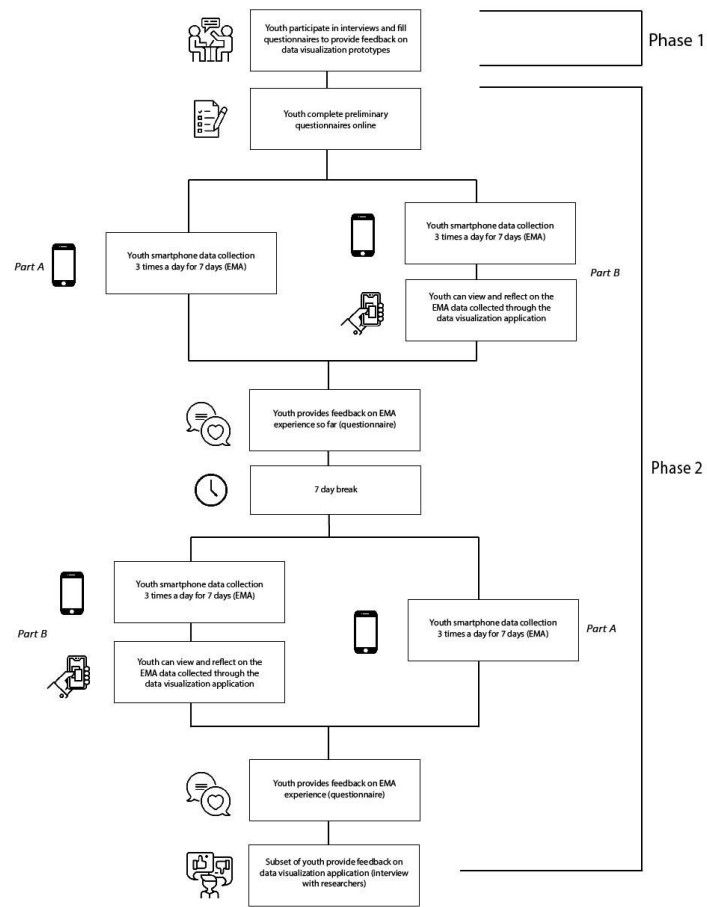
of my data throughout the week. Which week happens first will be decided at random (like flipping a coin).

- (3) Halfway through and then again at the end of the EMA part of the study, I will answer a few questions online about what I thought about being in the study. This will take about 15 minutes.

There is an optional (my choice) interview that I can do at the end of the study, if I want. If I do this, I will be asked to:

- (1) I will participate in a one-time online interview using Zoom or another video conferencing software. It will take around 30-60 minutes, and I will be asked questions about how I found the graphs and charts.
- (2) I will answer some questions online as I am being shown the graphs and charts. The questions will ask me to rate each image on things like creativity, ease of use, motivation and interest.

Here is a picture showing all the different steps of the study. I am being asked if I want to take part in **Phase 2**.



**CAN ANYTHING BAD HAPPEN?**

There is nothing bad that is expected to happen to me by participating in this study. I might find it annoying to answer questions on my smartphone 3 times a day. I also might find that some of the questions might make me think about how I'm feeling (my symptoms or emotions), which could make me feel uncomfortable or upset.

I do not have to answer every question. If I am upset by any feelings that come up as a result of participating in this study, I can talk to my parents or the study doctor (Dr. Oberlander at [REDACTED]). If I cannot reach these people, I can always call for help at Kids Help Phone ([REDACTED]). At the end of each day of EMA, I will receive a prompt inviting me to try a symptom self-management app that might help with symptoms or uncomfortable feelings. If I am having an emergency, I can go to my local emergency department for help.

#### **WHO WILL KNOW I AM IN THIS STUDY?**

My privacy will be respected. Unless I allow them to, the study team will not tell anybody else I am or have been a part of this study. They will not release any information to anybody else that could be used to identify me, unless they are required to do so by law. For example, researchers are required to report if a participant is believed to be at risk for harming him/herself or others. This also means that the researchers will not share my questionnaire answers with my parents unless there is a significant concern about my health/safety.

In order to protect my privacy, the study team will use a study code number instead of my name to identify my data. This means my identity as part of the study will be kept completely private. Only Dr. Oberlander and his research assistants will have the ability to link this code number with my personal information, and the linking information will be kept in a password-protected file on a secure server at BC Children's Hospital under the supervision and control of Dr. Oberlander.

De-identified data from the smartphone portion of the study may be shared online for other researchers to look at. This would not include my name or any other information that might identify me.

The study team will be using systems for collecting and storing information called CareTeam and REDCap. All of the data collected by CareTeam and REDCap is stored in Canada. CareTeam will only access my individual data if I am having a technical problem I need their help with.

My electronic assent form (this form) will be stored in BC Children's Hospital Research Institute's secured network in Vancouver, BC. Only authorized personnel will be able to access it.

#### **WHAT WILL THE STUDY COST ME?**

This study will not cost me anything. If I do not have a smartphone, the researchers will loan me one to use for that part of the study.

I will receive a gift card for participating in this study. The total amount I get will depend on how much of the study I complete. Every person that signs up for this study will receive \$20. I will then receive an extra \$10 after I finish each part of the EMA and feedback part of the study (up to \$40 total if I finish at least 2/3rds of the EMA). If I do the optional interview at the end of the study, I will get an extra \$20.

**WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?**

If I have any questions or desire further information about this study before or during participation, I can contact Jane Shen (Research Coordinator) at [REDACTED].

**WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A PARTICIPANT?**

If I have any concerns or complaints about my rights as a research participant and/or my experiences while participating in this study, I should contact the Research Participant Complaint Line in the University of British Columbia Office of Research Ethics by e-mail at [REDACTED] or by phone at [REDACTED]. I should reference the study number (H20-02965) when contacting the Complaint Line so the staff can better assist me.



**ASSENT TO PARTICIPATE**

My e-signature on this assent form means:

- I have read and understood this adolescent information and assent form.
- I have had enough time to consider the information provided and to ask for advice if necessary.
- I have had the opportunity to ask questions and have had acceptable answers to my questions.
- I agree to participate in this study.
- I understand that all of the information collected will be kept confidential and that the results will only be used for scientific objectives.
- I understand that my participation in this study is voluntary and that I am completely free to refuse to participate or to withdraw from this study at any time without changing the quality of care that I receive.
- I understand that I can continue to ask questions, at any time, regarding my participation in the study.

I will print or save a copy of this assent form for my own records. If I do not wish to participate in this study, I will close my web browser now without completing the information below.

Participant Name: \_\_\_\_\_

Date: \_\_\_\_\_

### **SMARTPHONE ACCESS**

To participate in this study, I will complete the questions on a smartphone. It does not matter what kind of smartphone I have; this should work on any smartphone.

First, the researchers need to know if I have access to my own smartphone where I can access the internet? (either with data or Wi-Fi)

- Yes, I have access to my own smartphone where I can access the internet.
- No, I do not have access to my own smartphone where I can access the internet. The research coordinator will contact me to arrange for me to borrow a smartphone while I am in the study.

### **OPTIONAL INTERVIEW**

At the end of the study, the researchers want to interview some of the people who did the study about how they found the graphs and charts. If I am willing to take part in this interview I will mark the "yes" box. This does not mean that I will definitely do the interview, just that the study team might ask me to do it. If I do not want to do the interview I will mark the "no" box."

Are you willing to do the optional interview at the end of the study?

Yes

No

### **FUTURE STUDIES**

There is a chance that during or after this study the study team will find other questions needing answers that require future studies. If I am willing to hear about these future studies I will mark the "yes" box. This does not mean that I will have to take part in a new study, just that the study team will let me know about it. If I check this box, my contact information will be used only for the purpose of contacting me about future studies. If I do not want to be contacted about new studies I will mark the "no" box."

Are you willing to be contacted by the researchers for future studies?

Yes

No

### **Resources for mental health and managing pain**

Solutions for Kids in Pain: [kidsinpain.ca](http://kidsinpain.ca)

If you are in crisis or having an emergency, call 911 or go to your local emergency department. Here are some other resources that you might find helpful:

Kids Help Phone (available 24/7): [REDACTED]

KUU-US Youth Crisis Line (Indigenous-focused, available 24/7): [REDACTED]

Youth in BC crisis support: [REDACTED] (available 24/7) and online chat youthinbc.com (available noon-1am)

B.C. Child and Youth Mental Health

Services: <https://www2.gov.bc.ca/gov/content/health/managing-your-health/mental-health-substance-use/child-teen-mental-health> (visit the website to find contact information for your local clinic)

Online Mental Health Resources:

- [keltymentalhealth.ca](http://keltymentalhealth.ca)
- [foundrybc.ca](http://foundrybc.ca)
- [anxietycanada.ca](http://anxietycanada.ca)

Helpline for Children (to report child abuse or neglect in B.C., available 24/7): [REDACTED]

## **A.4 Interview Guides and Questionnaires**

### **A.4.1 Phase 1 Design Evaluation Interview Guide**

## Phase 1 Interview Guide

*Note: Interviews will be conducted in a semi-structured manner, therefore the following questions and prompts may be modified in response to information provided by the participant.*

### 1. Before starting:

- Consent for recording
- Introduce yourself, ask for their introduction

### 2. Give an Introduction to our study

- Overview of project and aim of this interview (brief description of EMA survey)
- What will we be doing in this interview (open-ended questions + questionnaire)

### 3. Pre-test

- Have you collected your personal health data before?
- Have you seen visualizations of your personal health data before?

### 4. While showing prototypes:

4.1. Ask participants to provide feedback or walk us through their thought process as they look at each of the visualizations

*Detailed questions given below (4.1.1)*

4.2. Ask participants to rank each visualization/screen on the scale below, provided as a questionnaire, prototype visualizations will be labelled in sync with the questionnaire:

#### **Rating each visualization:**

On a scale of 1 to 5, how would you rate this graph on:

**Utility** - the way the information is shown here would be useful to me personally

**Understandability** - the information shown here is easy to comprehend

**Interestingness** - this graph looked interesting; I would want to spend time exploring it/ I like interacting with this graph

**Aesthetics** - I liked how this graph looks

#### **Rating each screen** (where you see multiple visualizations together):

On a scale of 1 to 5, how easy was it to understand relationships between what's shown in the top chart and the bottom chart? (Are you able to comprehend the meaning of that relationship?)

4.1.1 Questions for feedback while showing the prototype:

*Global Prompt:* Imagine Alice has filled the EMA survey for the past two weeks, and using her data we have created these graphs and pictures. You are now reviewing her data through these graphs and pictures.

*Intensity of symptoms: (Visualization 1)*

To gather data about how bad Alice's symptoms were, in the survey we asked this question:

Since the last survey, how intense were your physical symptoms? Worst I can think of

No symptom

(Place a mark on the scale above)

We asked it three times a day. Each time, Alice could mark how bad her symptoms were on the scale.

In the graph, notice how the square for the morning on the first Monday is a very different color than the square for the afternoon on the second Friday. What do you think that means?

Take a look at the full two weeks of data in this plot. Does anything stand out to you? For example, times where symptoms were particularly bad, or days where Alice started feeling a lot better.

*Occurrence of symptoms:*

To measure how often her symptoms occur, we asked (three times / day)

Since the last survey, I felt these physical symptoms:

- Stomach ache
  - Headache
  - Pain in my lower back
  - Faintness or dizziness
  - Pain in my arms or legs
  - My heart was beating too fast
  - Nausea or upset stomach
  - Other \_\_\_\_\_
  - No symptoms
- (Choose all that apply)

Where Alice could mark all the symptoms she was feeling in that time slot.

We also asked

Since the last survey, did you do anything about your physical symptoms? (e.g., take medication, rest, use a coping strategy, etc.)  Yes \_\_\_\_\_  
 No \_\_\_\_\_

In the graphs,

Do you see any patterns, like symptoms that happen many days in a row? Can you see which days Alice took medication?

Do you think that there are any connections between how bad Alice's symptoms are and how often they occur?

Imagine that you had the chance to see these same graphs, but using your data instead of Alice's. Would you be interested in seeing that? What would make it more interesting or relevant to you?

*Intensity of worries:*

In the morning, we asked Alice about which things she was most worried about, and also how worried she was about the things she selected:

The thing I am MOST worried about involves...

- My family
- My friends or peers
- People I don't know well
- School
- Sports or extracurricular activities
- My health and safety
- Nothing in particular
- Other \_\_\_\_\_

Alice could mark the scale above the same way she did with symptom intensity

We ask Alice more on her feelings about the thing she was most worried about:

How certain are you that it will happen? Not at all  Extremely  
(Place a mark on the scale above)

How bad do you expect it to be? Not at all  Extremely  
(Place a mark on the scale above)

In the afternoon and evening, we checked whether the thing she was worried about did happen, and if it did, how bad it was, and if she did anything to avoid it (e.g., procrastination):

Earlier, you said the thing you were most worried about happening today was: [ema\_worry\_qual]

- Yes
- No

Did the thing you were worried about earlier happen?

How bad was it? Not at all  Extremely  
(Place a mark on the scale above)

Did you do anything to try and avoid the situation?  Yes  
 No



Now, in the graphs,  
On which days do you think Alice was most worried AND using avoidance behaviors?

*Worries and certainty:*

Based on the information we collected from Alice in the morning about how worried & certain she was about something and the follow-up information on whether the event happened,  
Notice how the graphs are different for the first Monday and Wednesday. What do you think that means?

Take a look at the full two weeks of data. Is there anything that you can learn about Alice by looking at this graph? For example, do you think that Alice is a person that worries a lot? Does she feel like she always knows what is going to happen next?

*Expectation vs reality:*

We asked Alice how bad she expected an event to be in the morning, and then if it did happen, how bad it was, in the afternoon and evening. The light blue dot represents Alice's expectation of how bad an event would be while the dark blue dots represent how bad it actually was.

Notice how on the first Friday, the light blue dot is lower than both of the dark blue dots. What do you think that means?

When you look at how worried Alice was vs how bad she expected things to be, do you see any patterns?

*Occurrence of worries:*

Can you tell what worried Alice the most? Are there any patterns?

Imagine that you had the chance to see these same graphs, but using your data instead of Alice's. Would you be interested in seeing that? What would make it more interesting or relevant to you?

*School attendance:*

In the afternoon, we asked Alice

Did you go to school today?

- Yes
- No

Why not?

- Weekend
- School holiday
- Home sick
- Doctor's appointment
- Summer vacation
- Home-schooled
- Online learning

Over the two weeks, what were the reasons that Alice didn't go to school?

*Worry about interactions:*

In the afternoon and evening, we asked Alice about her interactions with her peers:

Since the last survey, my interactions with other teens have been:

- Very positive
- Somewhat positive
- Somewhat negative
- Very negative
- I haven't had any interactions with other kids since the last survey

Since the last survey, I felt worried about my interactions with other teens.

Not at all Extremely  
-----  
(Place a mark on the scale above)

How would you describe Alice's worry about her interactions with her peers in the first week compared to the second week?

*Quality of interactions:*

The purple squares represent the quality of Alice's interactions with her peers. The light purple ones are in the morning, the medium purple ones in the afternoon and the dark purple ones in the evening.

Notice how on the first Monday, the light purple dot is higher than both of the darker purple dots, while on Saturday, they are all at the same level. What do you think that means?





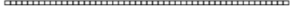
When you look at the quality of Alice's interactions with her peers and her school attendance graphs together, are there any patterns?

How would you describe Alice's overall peer interactions over the past two weeks? Does it seem like Alice is doing okay with her friends?

Imagine that you had the chance to see these same graphs, but using your data instead of Alice's. Would you be interested in seeing that? What would make it more interesting or relevant to you?

*Emotions:*

Three times a day, we asked Alice about various emotions she might be feeling:

Since the last survey, I felt worried or scared.	Not at all	Extremely
		
	(Place a mark on the scale above)	
<hr/>		
Since the last survey, I felt happy.	Not at all	Extremely
		
	(Place a mark on the scale above)	
<hr/>		
Since the last survey, I felt annoyed or angry.	Not at all	Extremely
		
	(Place a mark on the scale above)	
<hr/>		
Since the last survey, I felt unhappy, sad, or miserable.	Not at all	Extremely
		
	(Place a mark on the scale above)	
<hr/>		
Since the last survey, I felt frustrated.	Not at all	Extremely
		
	(Place a mark on the scale above)	

*Emotions summarized:*

Here, we summarize Alice's emotions over the two weeks.

How would you describe Alice's emotions over the past two weeks?

*Emotions individual:*

When you look at each of the emotions individually,  
When was Alice more angry than usual?

Imagine that you had the chance to see these same graphs, but using your data instead of Alice's. Would you be interested in seeing that? What would make it more interesting or relevant to you?

*Sleep:*

In the morning, we asked Alice when she fell asleep the night before and when she woke up, with all 24 hours as options.

Last night, I fell asleep at:	<input type="radio"/> 1:00am
	<input type="radio"/> 2:00am
	<input type="radio"/> 3:00am
	<input type="radio"/> 4:00am

This morning, I woke up at:

- 1:00am
- 2:00am
- 3:00am
- 4:00am

Now, looking at the charts:

When would you say Alice had the best sleep? The worst sleep? Why was that?

Do you see any connections between the amount of time she spent sleeping and the quality of her sleep? For example, did Alice have better quality sleep when she spent more time asleep?

Imagine that you had the chance to see this same graph, but using your data instead of Alice's. Would you be interested in seeing that? What would make it more interesting or relevant to you?

4.3 End

Was there anything about doing these tasks with these charts that you found difficult or confusing? What specifically did you have difficulty with?

## 5. Post-test

- Did any viz seem unnecessary or out of place?
- What improvements do you think could be made?
- Do you feel overall looking at these visualizations was helpful/useful/motivating?
- Would you want to engage/interact with such representations of your data often?
- Is there anything else you might want to share? About your experience with the visualizations/any other information that might be useful to us as we develop this further.

## 6. Conclude

Thank them for participating

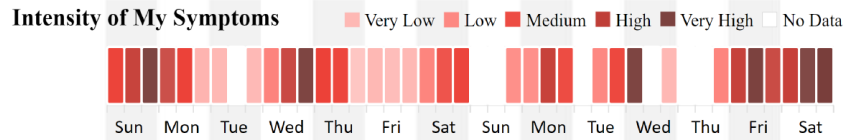
#### **A.4.2 Phase 1 Design Evaluation Visualization Questionnaire**

## Intro

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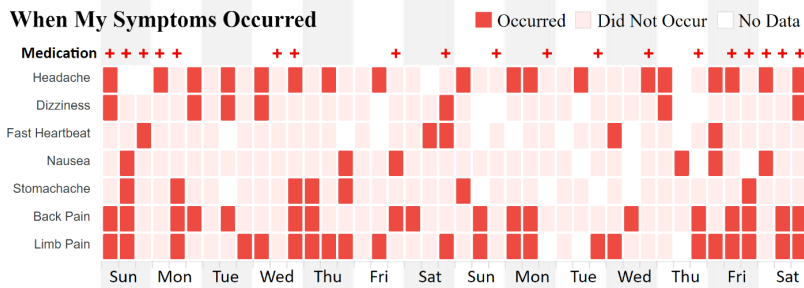
Please assess each of the visualizations which will be shown by selecting one circle per option, on a scale of 1 to 5, where 1 means you least agree and 5 means you most agree with the statement.

## Symptom Intensity



Rate "Intensity of symptoms"					
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/ like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Symptom Occurrence

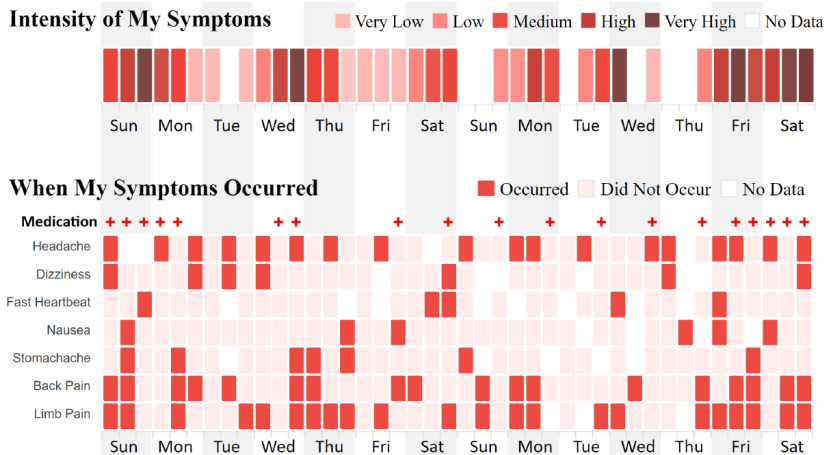


**Rate "When my symptoms occurred"**

	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/I like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

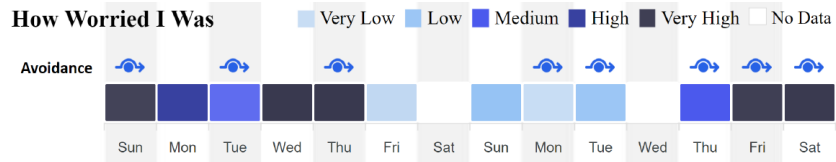


### Screen (Symptom Intensity + Occurrence)



- 1) It was easy to understand relationships between what's shown in the top chart and the bottom chart
- 1 (Highly Disagree)     2  
 3     4     5 (Highly Agree)

## Worry Intensity



Rate "How worried I was"					
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/I like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Worry Category

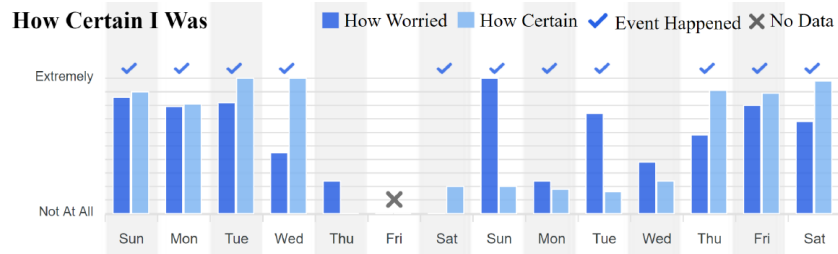
### What I Was Worried About

Family	✓	✓		✓	✓		✓			✓			✓	
Friends	✓					✓	✓				✓		✓	✓
Strangers								✓				✓		✓
School	✓	✓		✓	✓	✓		✓	✓	✓		✓	✓	✓
Sports		✓			✓		✓						✓	
Health	✓			✓	✓						✓	✓	✓	✓
	Sun	Mon	Tue	Wed	Thu	Fri	Sat	Sun	Mon	Tue	Wed	Thu	Fri	Sat

### Rate "What I was worried about"

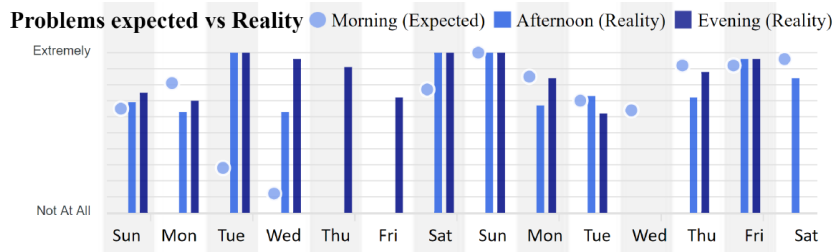
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/I like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Worry Vs Certainty



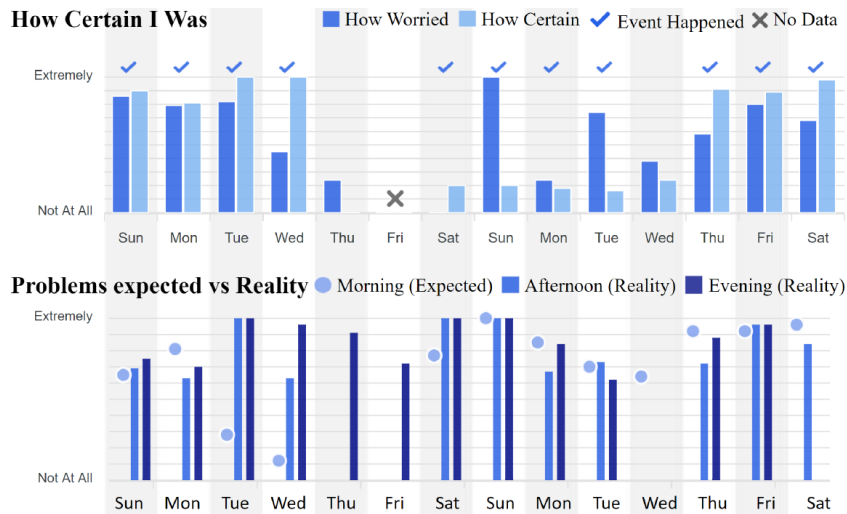
Rate "How certain I was"					
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/ like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Expectation Vs Reality



Rate "Expected problems vs reality"					
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/ like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

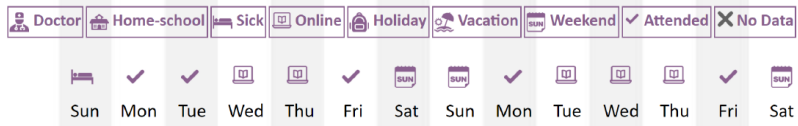
## Screen (Worry Certainty + Expectation Reality)



- 1) It was easy to understand relationships between what's shown in the top chart and the bottom chart
- 1 (Highly Disagree)    2  
 3    4    5 (Highly Agree)

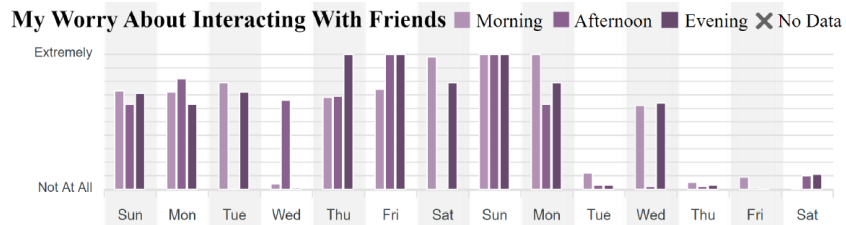
## School Attendance

### My Going to School



Rate "When I went to school"		1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1)	Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2)	Understandibility (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3)	Interest (This graph looks interesting, I would want to spend time exploring it/I like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4)	Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

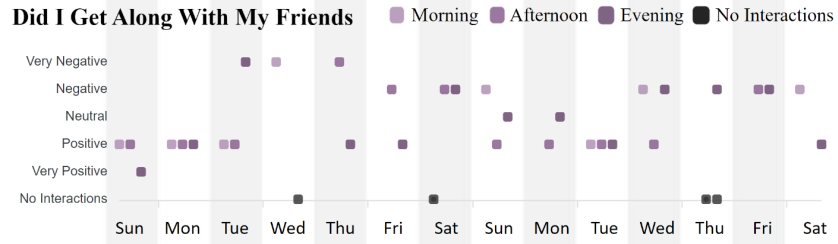
## Peer Interaction Worry



Rate "My worry about interacting with friends"					
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/I like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

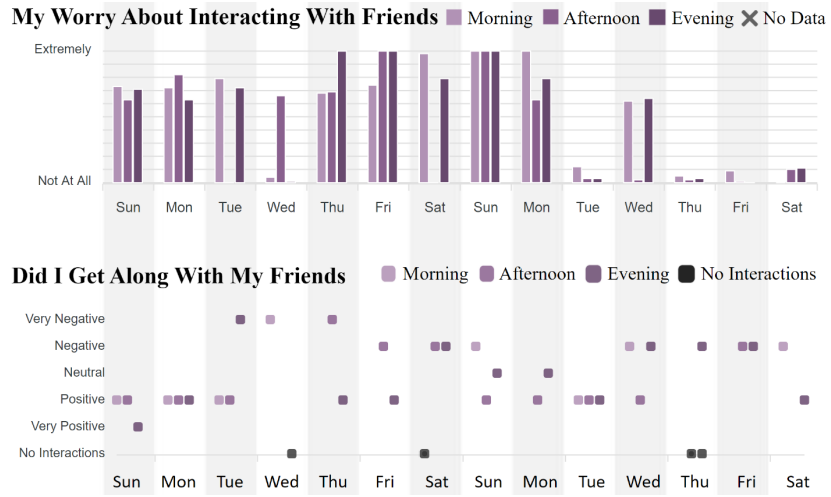


## Peer Interaction Quality



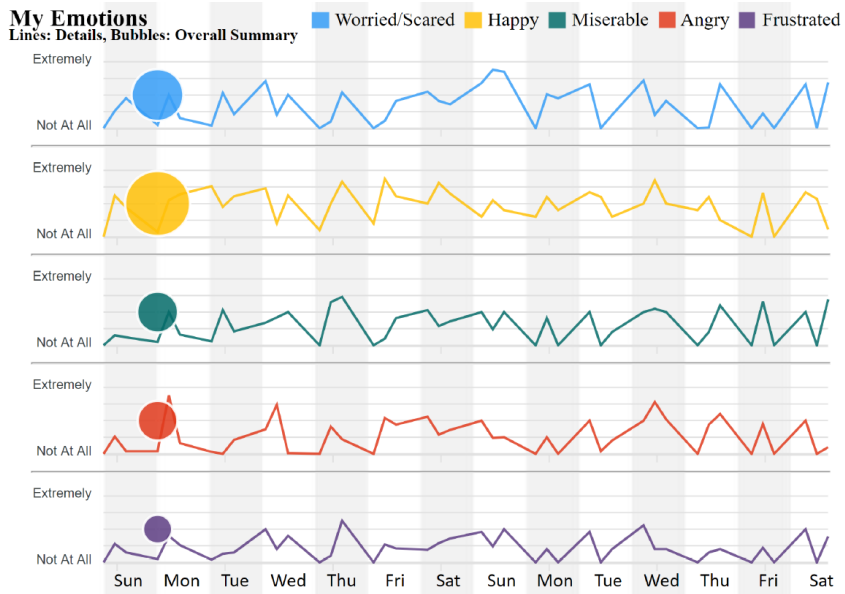
Rate "Did I get along with friends"					
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/I like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Screen (Peer Interaction Worry + Quality)



- 1) It was easy to understand relationships between what's shown in the top chart and the bottom charts
- 1 (Highly Disagree)     2  
 3     4     5 (Highly Agree)

## Emotions



Rate "My Emotions"		1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1)	Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2)	Understandibility (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3)	Interest (This graph looks interesting, I would want to spend time exploring it/I like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4)						

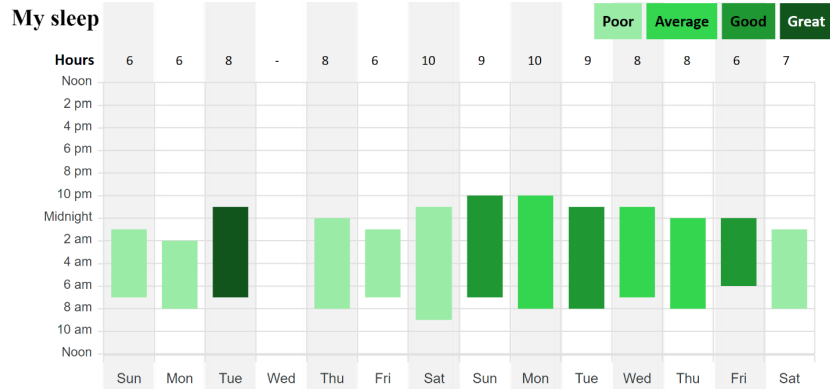
*Confidential*

Page 2

Aesthetic (I liked how this graph looks)



## Sleep



**Rate "My sleep"**

	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
1) Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2) Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3) Interest (This graph looks interesting, I would want to spend time exploring it/I like interacting with this graph)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4) Aesthetic (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*Confidential*

**End**

Page 1

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Thank you for participating in this study!

11/18/2021 2:27pm

projectredcap.org



### **A.4.3 EMA Follow-Up Feedback Questionnaire**

## Phase 2 follow-up satisfaction and feedback questions

*The following will be administered as a questionnaire via REDCap at the mid-point and endpoint of Phase 2:*

Thank you for completing 7 days of this study! We have a few questions to ask you about your experience doing this study **this week**. Your answers will help us understand how you are finding the study and what we can do to make it better in the future. As a reminder, “EMA” means “Ecological Momentary Assessment”, which is the type of study you are doing where you answer a couple of questions 3 times a day on your smartphone for several days.

1. What did you like about participating in the EMA study this week? **[free text box]**
2. What did you dislike about participating in the EMA study this week? **[free text box]**
3. Did you have any problems in doing the EMA study? If so, please describe them here (e.g., technical difficulties, not having access to your smartphone when the text messages arrived, questions too hard to understand, forgot to answer): **[free text box]**
4. How comfortable did you feel answering the questions on the EMA? **[choices: very uncomfortable, uncomfortable, neutral, comfortable, very comfortable]**
5. Did you find any part of participating in the EMA study emotionally distressing? **[choices: yes/no]** *\*Note: Researcher will follow-up with any participant that indicates “yes” to ensure appropriate debriefing is conducted and any necessary mental health supports are in place*
6. How was it filling out questions 3 times a day? **[choices: 3 times a day was too much, 3 times a day was just right, 3 times a day was too few times]**
7. How did you find the number of questions asked each time? **[choices: too many questions, just right, too few questions]**
8. What did you think of the timing of the reminders? **[free text box]**
9. What did you do when you received the reminder if you were in the middle of doing something else? **[choices: stopped what I was doing and answered the questions, finished the task I was working on and did the questions after, did the questions later, other: {please specify}]**
10. Is the amount that you got paid to participate in this study enough for what we are asking you to do? **[choices: yes/no]**
11. Was there anything that the EMA questions should have been asking about (e.g., different experiences, symptoms, emotions) that would have helped us better understand how your day was going? **[free text box]**



12. Is there anything else you would like to have been tracking with the EMA questions (e.g., weather, diet, menstrual cycle, other health conditions) that would have helped us to better understand your pain? **[free text box]**
13. *Asked only at the end of Phase B:* Did you look at the data visualization dashboard? (the place on the app where you could see charts and graphs of your data over time)
- a. [If yes:] Tell us what you thought about the data visualization dashboard.
    - i. What were the positives? (things you liked, found helpful or useful) **[free text box]**
    - ii. What were the negatives? (things you disliked, found unhelpful or confusing) **[free text box]**
    - iii. Please write any other thoughts you would like to share about the data visualization dashboard here: **[free text box]**
  - b. [If no:] Why not? **[free text box]**
14. At the end of each day, you received a prompt to try an app for managing symptoms called *Rootd*. Did you try the app? **[choices: yes/no]**
- a. [If yes:] Did you find the *Rootd* program useful? **[choices: yes/no]**
  - b. [If yes:] Would you recommend *Rootd* to a friend? **[choices: yes/no]**
15. During the past week of the study, did you use any of the following treatments for your pain?
- Over-the-counter medication (e.g., Advil, Tylenol)
  - Prescription medication
  - Physiotherapy
  - Psychology
  - Occupational therapy
  - Naturopathic treatments
  - Chiropractic treatments
  - Massage therapy
  - Acupuncture
  - Hot/cold treatments
  - Herbal remedies
  - Counselling or other mental health treatments
  - Other: \_\_\_\_\_

16. What kinds of questions should we be answering with this kind of research? **[free text box]**
17. Do you have any other questions or feedback you would like to give us about participating in this study?

#### **A.4.4 Phase 2 Impact Evaluation Interview Guide**

## Phase 2 Visualization Feedback Interview Guide

### 1. Before starting:

- Consent for recording
- Introduce yourself, ask for their introduction

### 2. Give an Introduction to our study

- Overview of project and aim of this interview (brief description of EMA survey)
- What will we be doing in this interview (open-ended questions + questionnaire)

### 3. Pre-test

- Have you collected your personal health data before in ways other than the EMA survey?
- Have you seen visualizations of your personal health data before other than the ones you saw during this study?

### 4. While showing dashboard:

- 4.1. Ask participants to reflect on their experiences while asking them open-ended questions about the visualizations and the EMA + visualization experience

*Note: Interviews will be conducted in a semi-structured manner, therefore the following are questions and prompts that may be modified in response to information provided by the participant.*

**Participants will be sent a copy of the visualizations they saw during the study, generated from their own data from the EMA surveys they filled over one week. The below questions will be based on those visualizations.**

#### **Category: Design Guidelines/Aesthetic**

1. Were there any specific charts you particularly liked or found relevant? *(If so)* Tell me more about that. *(ask for details)?*
2. Are there any features or things you would have liked to see that we missed? *(Prompt if needed – for example, rearranging the visualizations or adding something to a graph)?*

3. Did any of these graphs seem unnecessary or out of place?

**Category: Understandability**

1. Was there anything about these charts that you found difficult or confusing? What specifically did you have difficulty with?

**Category: Insightful**

1. Did you notice any interesting patterns about your experiences in these graphs? Tell me more about those/ What did you think of them?

**Category: Rewarding/Encouraging/Motivating/Usefulness**

1. Do you think these graphs helped you to think of ways to manage your pain?
2. If you're using any strategies to manage your pain, did this graph help you reflect on how those strategies might be working?
3. Were there any aspects of these visualizations that were motivating? Tell me more about that. Were there any aspects that were discouraging? Tell me more.
4. Do you feel overall looking at these visualizations was valuable? Tell me more about that? (*ask for details*)

**Category: Relatability/Authenticity**

1. Do you think these graphs accurately represented your experience at the time?
2. Do you have any ideas about what could be changed or added to make these graphs more interesting or relatable for you?

**Category: Screen usefulness and understandability**

1. Do you think comparing these graphs or looking at them together was useful?  
(*If yes*) Did you notice anything interesting by comparing these graphs or looking at them together? (*If no*) Why not?
2. Do you think your emotions and pain are connected? If so, did the graphs help you reflect on those connections?
3. Do you think your sleep and pain are connected? If so, did this graph help you see those connections?
4. Were there any other relationships that you were looking for in these graphs?

**Category: Negative consequences**

1. Are there any concerns you might have about using this tool? (*Prompt if needed - for instance, about the time it might take everyday, or what results it might show?*)
2. What might be a reason you would not want to use this tool?
3. Were there any particular graphs you disliked? (*If yes*) Why?

**Category: Open-ended**

1. If you could, would you keep using this tool? How could you imagine a tool like this fitting into your life, for instance, how often do you think would you use it?
2. Given the visualizations, how much time/effort would you be willing to put in to provide the data?
3. How much time/effort would you want to spend interacting with the visualizations?
4. Is there anything else that we could add to the survey or visualizations that would make it more valuable and make you more inclined to use it consistently?
5. Is there anything else you might want to share? About your experience with the visualizations/any other information that might be helpful to us?

4.2. Ask participants to rank each visualization/screen on the scale below, provided as a questionnaire link through REDCap (please see document Data Visualization Feedback Questionnaire Phase2 – V1.pdf):

*(The questionnaire will be revised for each participant to contain images of the visualizations they saw during the EMA study, made with their own data. No participant will be able to see another participant's visualizations and the link will be tested before being sent to each participant to ensure privacy. This is being done to retain consistency with respect to the visualizations the participants see throughout the course of the study. The document Data Visualization Feedback Questionnaire Phase2 – V1.pdf contains sample images of the visualizations.)*

Rating each visualization:

On a scale of 1 to 5, how would you rate this graph on:

Utility - the way the information is shown here would be useful to me personally

Understandability - the information shown here is easy to comprehend

Aesthetics - I liked how this graph looks

Insightful - This graph shows me something new I didn't already realize/know Accuracy - This graph reasonably reflects my experience

Rating each screen (where you see multiple visualizations together):

On a scale of 1 to 5, how easy was it to understand relationships between what's shown in the top chart and the bottom chart? (Are you able to comprehend the meaning of that relationship?)

## 5. Conclude

Thank them for participating



#### **A.4.5 Phase 2 Impact Evaluation Visualization Questionnaire**



## Phase 2C questionnaire

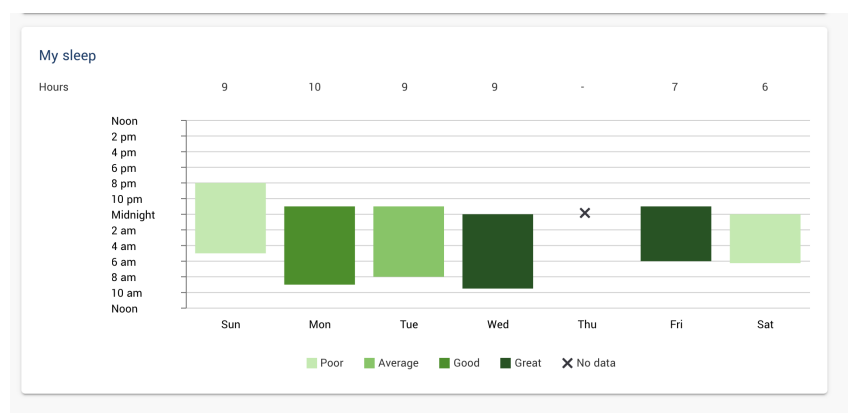
Please complete the survey below.

Thank you!

The images used in this survey have been taken from your CareTeam dashboard during the EMA study. This survey has been customized for you and no other participant will be seeing these same images.

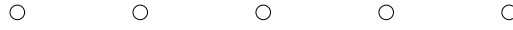
Please assess each of the visualizations which will be shown by selecting one circle per option, on a scale of 1 to 5, where 1 means you least agree and 5 means you most agree with the statement.

### My Sleep

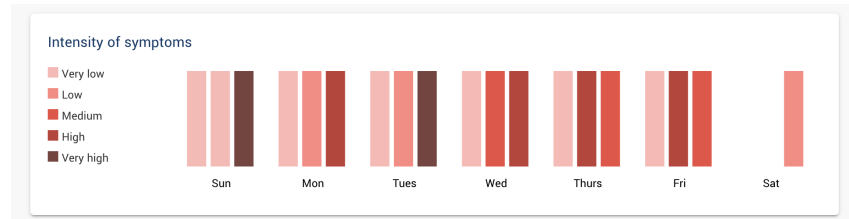


	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Accuracy (This graph reasonably reflects my experience)

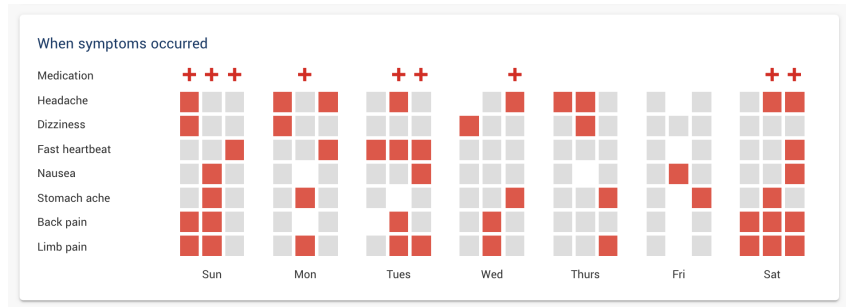


**Intensity of My Symptoms**



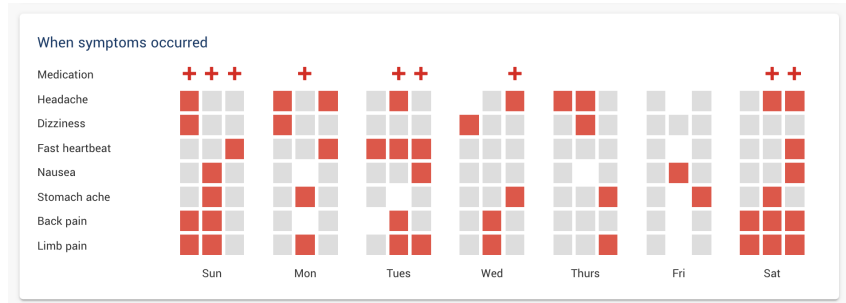
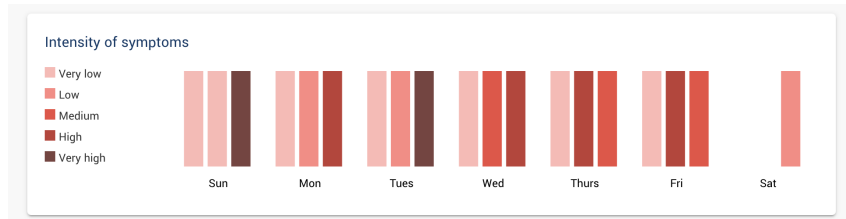
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**When My Symptoms Occurred**



	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

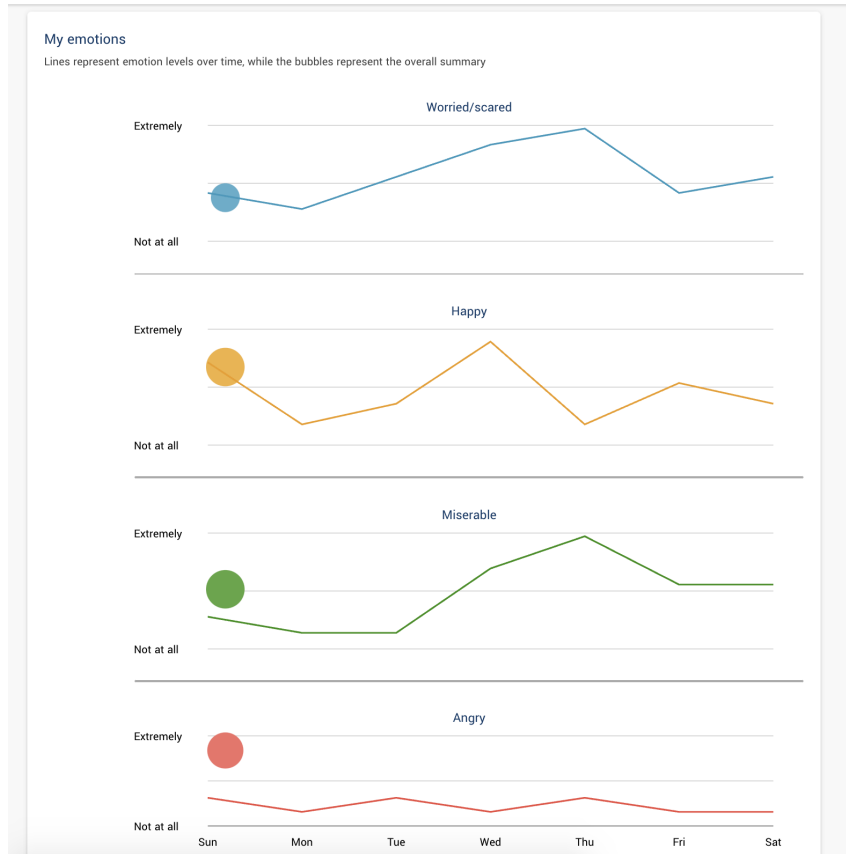
**Screen - Symptom Intensity + Occurrence**



It was easy to understand relationships between what's shown in the top chart and the bottom chart

- 1 (Highly Disagree)     2  
 3     4     5 (Highly Agree)

### My Emotions

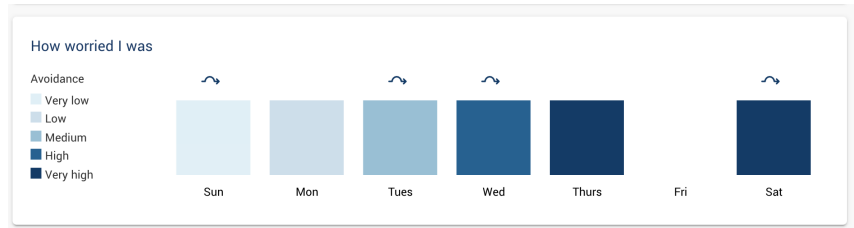


Utility (The way the information is shown here would be useful to me personally)

1 (Highly Disagree)    2    3    4    5 (Highly Agree)

Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

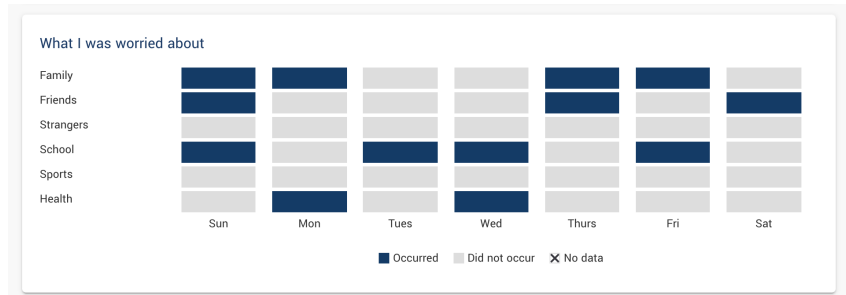
**How worried I was**



	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

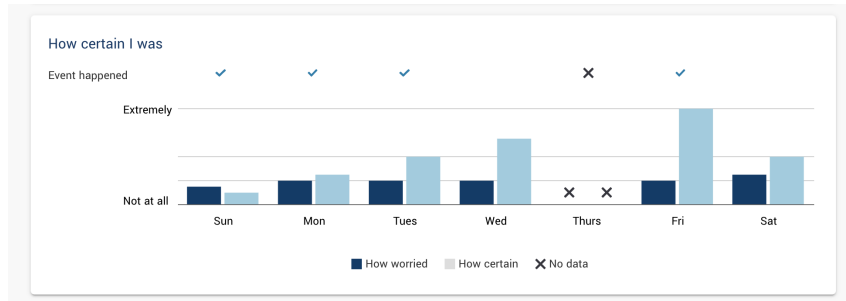


**What I was worried about**



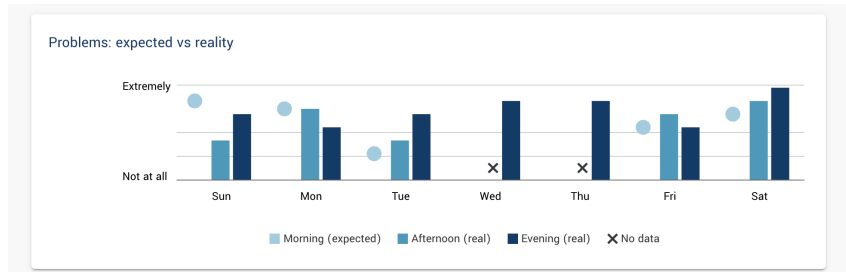
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**How certain I was**



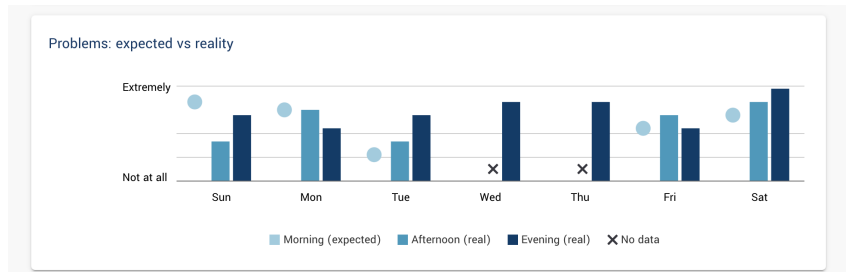
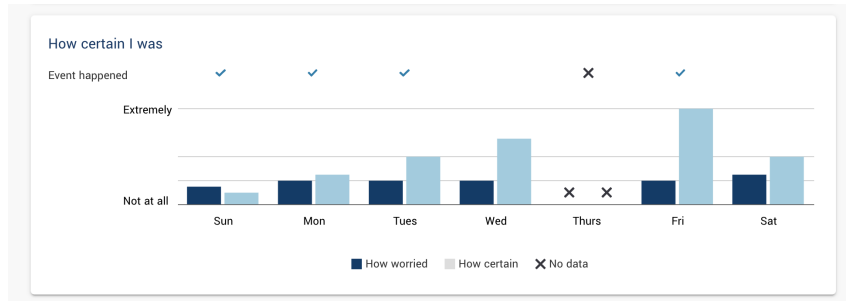
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Problems: Expected vs Reality**



	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Screen - How certain I was and Problems: Expected vs Reality**



It was easy to understand relationships between what's shown in the top chart and the bottom chart

- 1 (Highly Disagree)
- 2
- 3
- 4
- 5 (Highly Agree)

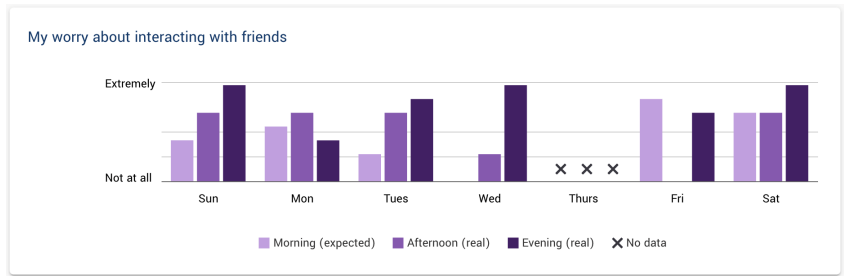
**My Going to School**

Going to school

No data	Attended	Vacation	Online	Doctor	Home school	Weekend
Sun	Mon	Tues	Wed	Thu	Fri	Sat

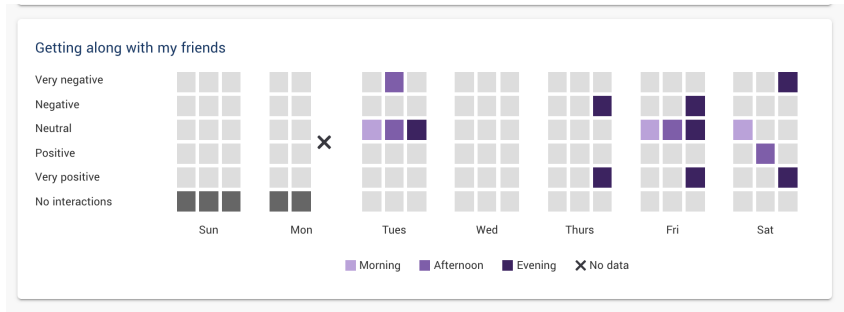
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**My worry about Interacting with Friends**



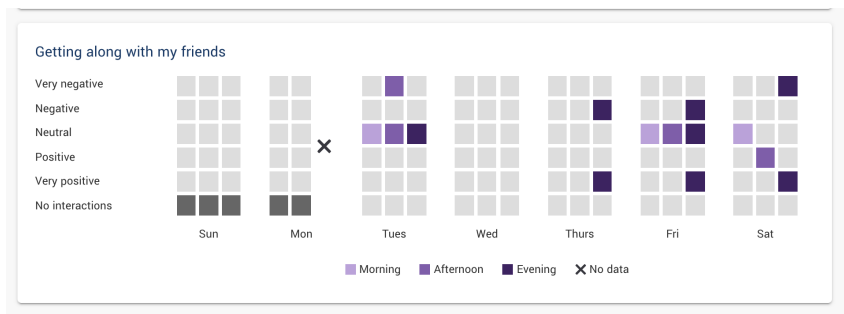
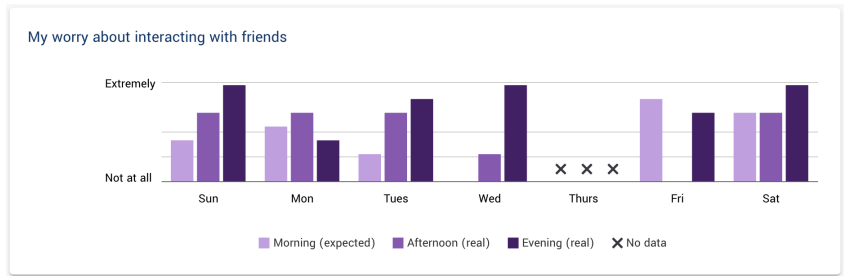
	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Getting along with my friends**



	1 (Highly Disagree)	2	3	4	5 (Highly Agree)
Utility (The way the information is shown here would be useful to me personally)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Understandability (The information shown here is easy to comprehend)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aesthetics (I liked how this graph looks)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Insightful (This graph shows me something new I didn't already realize/know)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Accuracy (This graph reasonably reflects my experience)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Screen - Peer Interactions**



It was easy to understand relationships between what's shown in the top chart and the bottom charts

- 1 (Highly Disagree)     2  
 3     4     5 (Highly Agree)





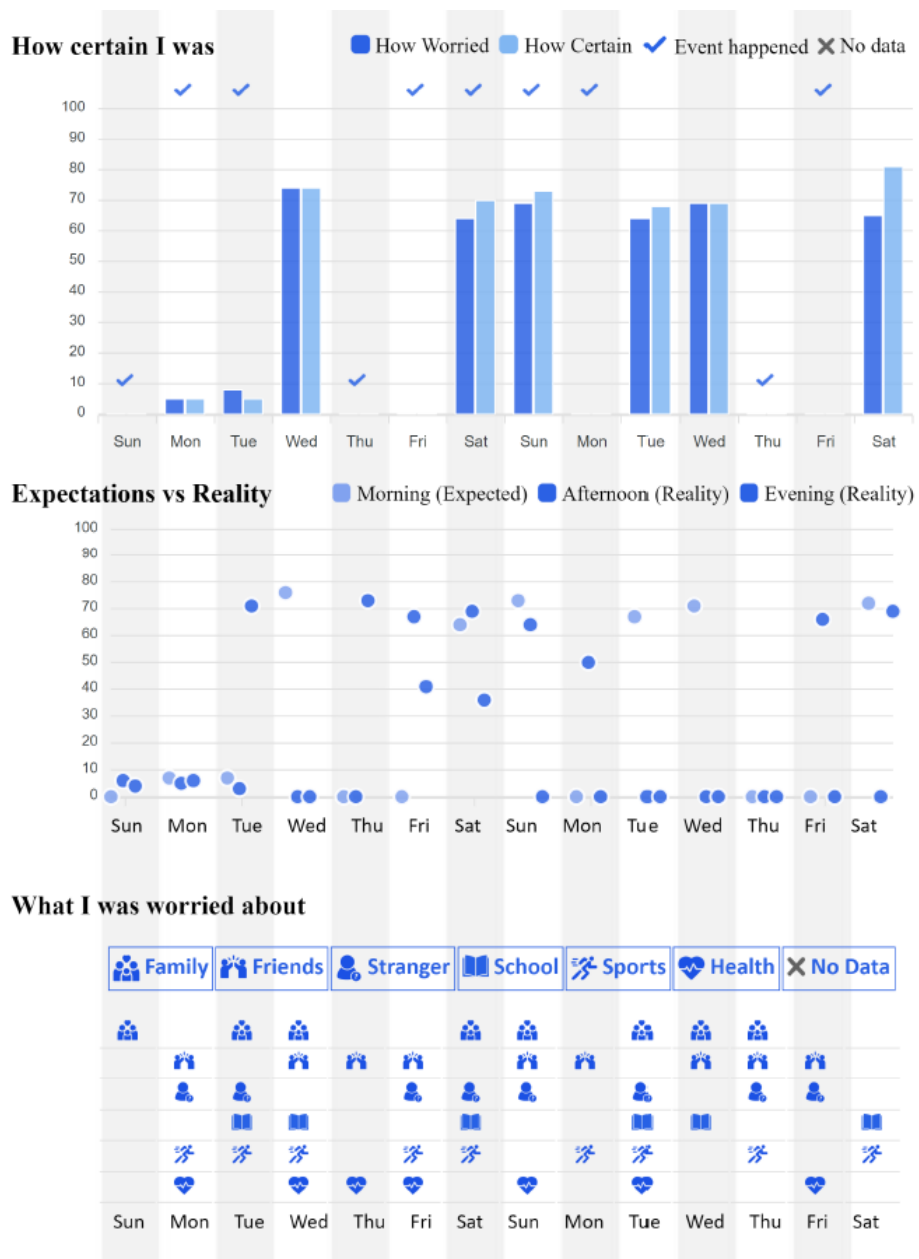
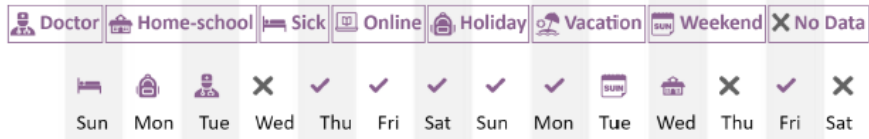
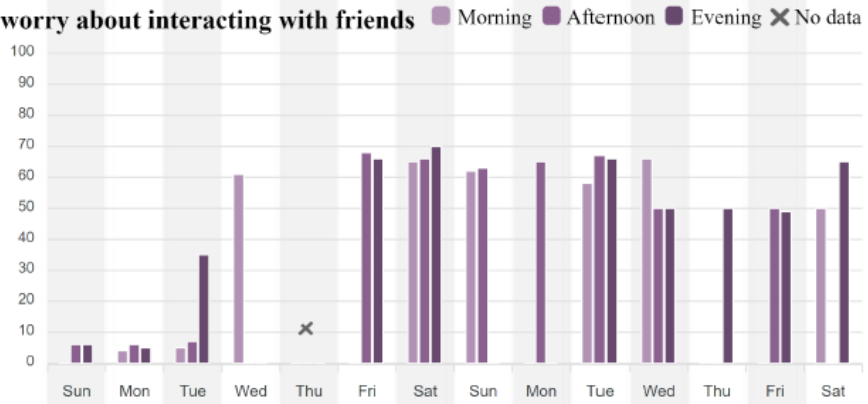


Figure A.2: Phase 1 Design Evaluation Pilot Visualization Dashboard (2/4)

### When I went to school



### My worry about interacting with friends



### Did I get along with friends

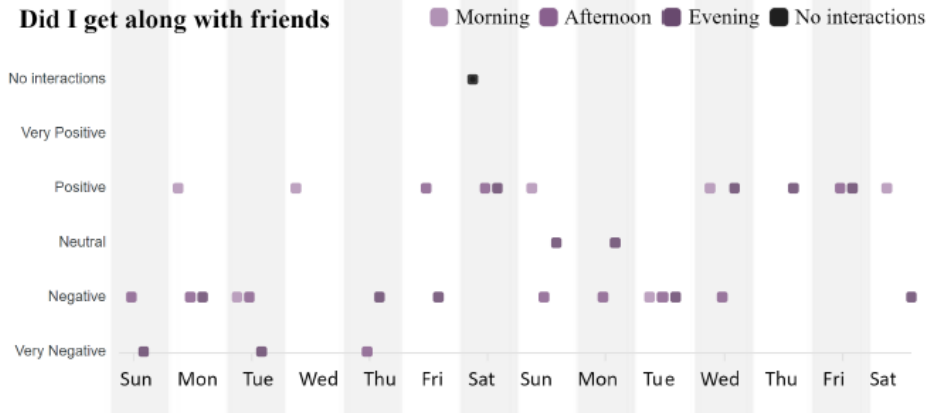


Figure A.3: Phase 1 Design Evaluation Pilot Visualization Dashboard (3/4)

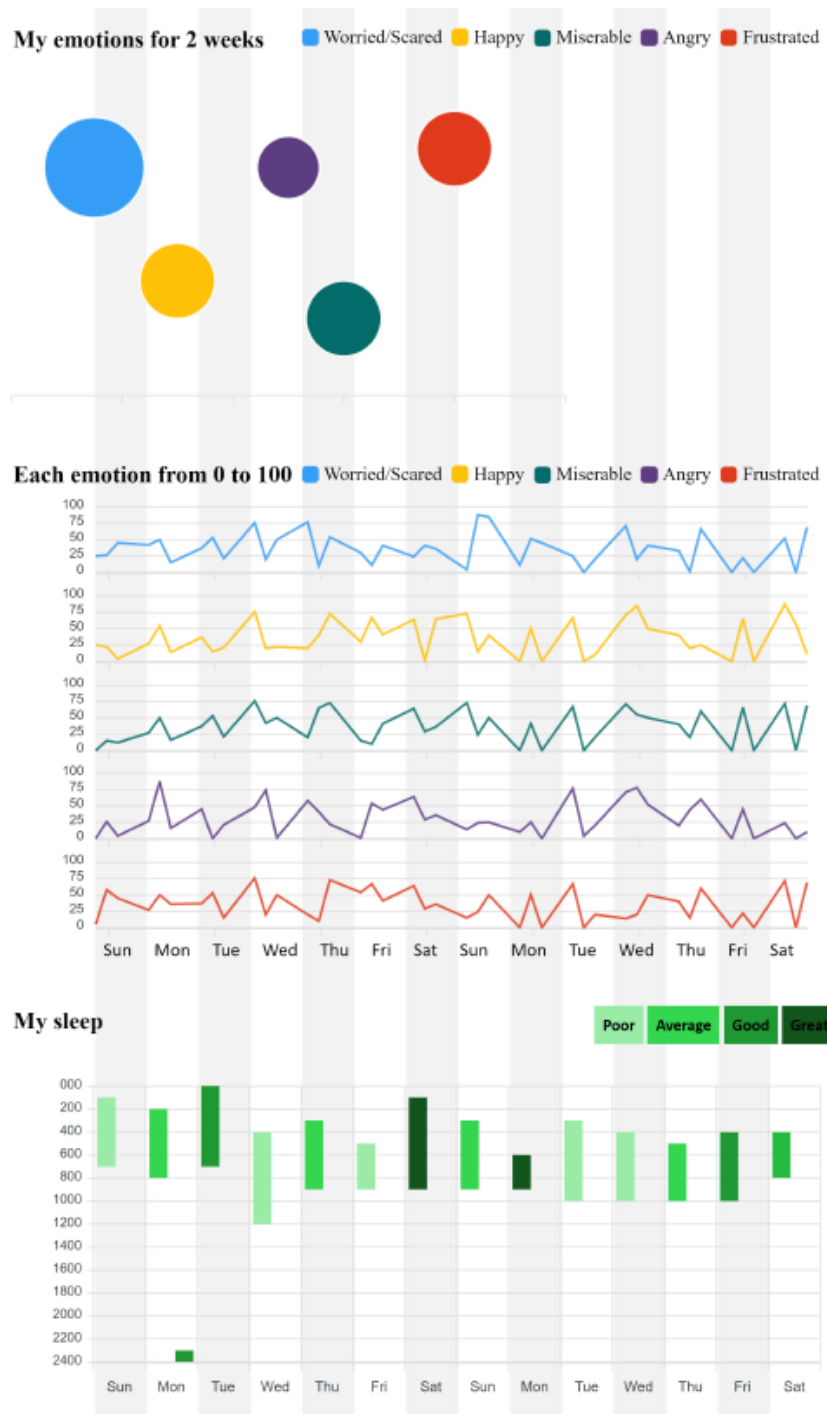


Figure A.4: Phase 1 Design Evaluation Pilot Visualization Dashboard (4/4)

## A.5.2 Phase 1 Design Evaluation Study Visualization Dashboard

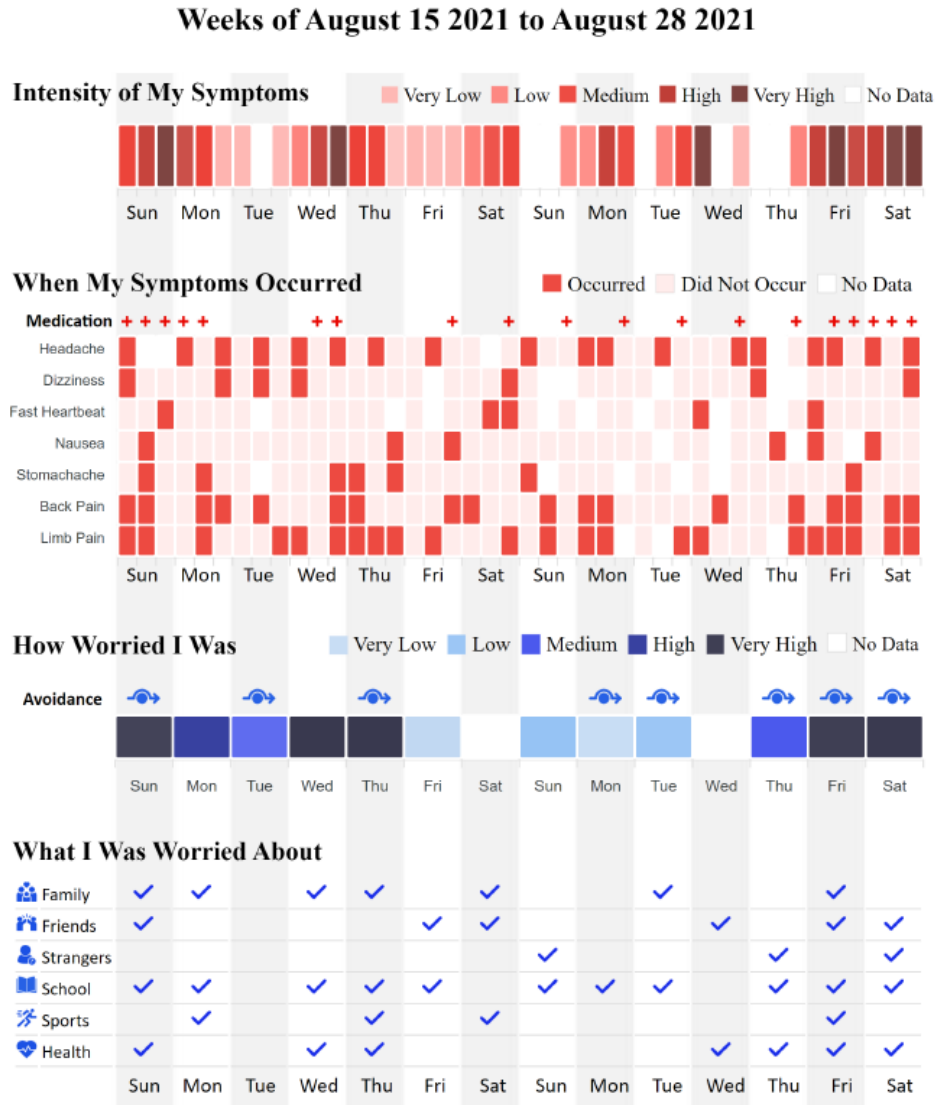


Figure A.5: Phase 1 Design Evaluation Study Visualization Dashboard (1/3)

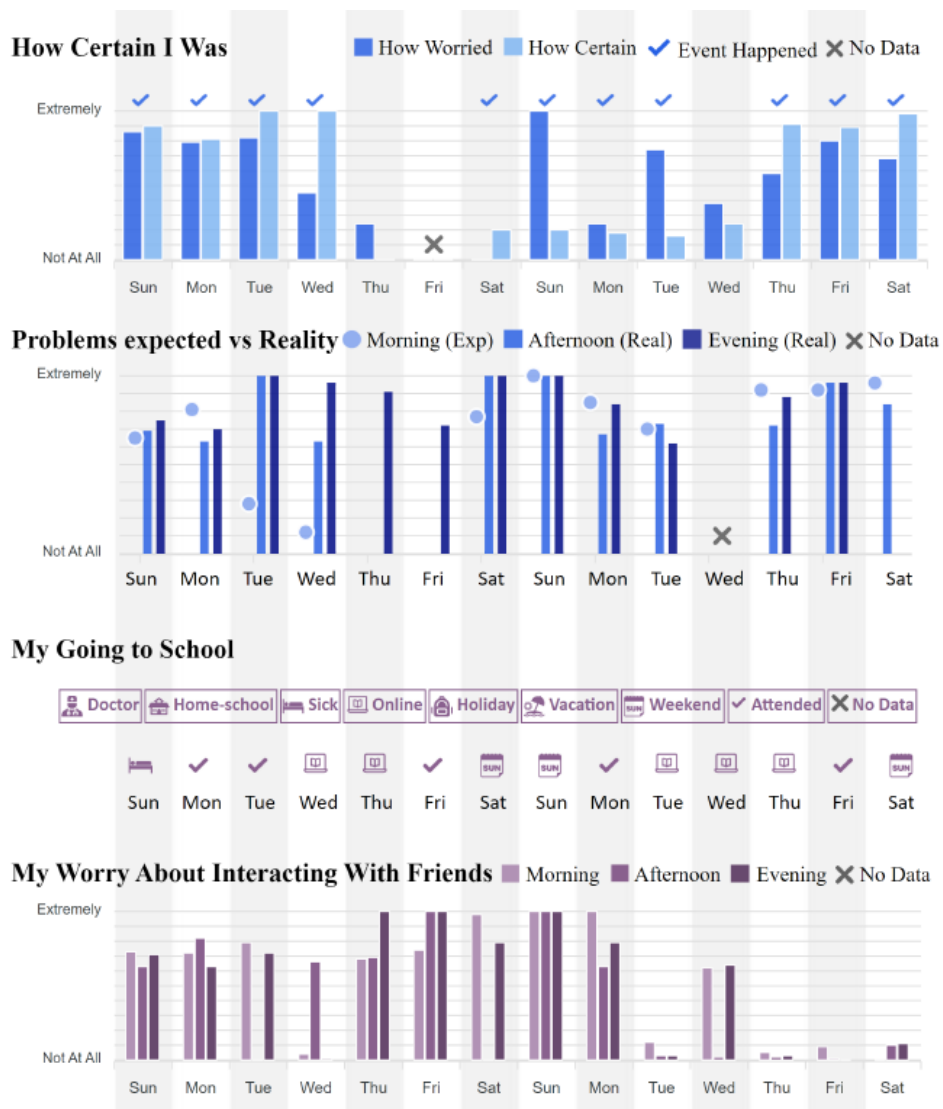


Figure A.6: Phase 1 Design Evaluation Study Visualization Dashboard (2/3)

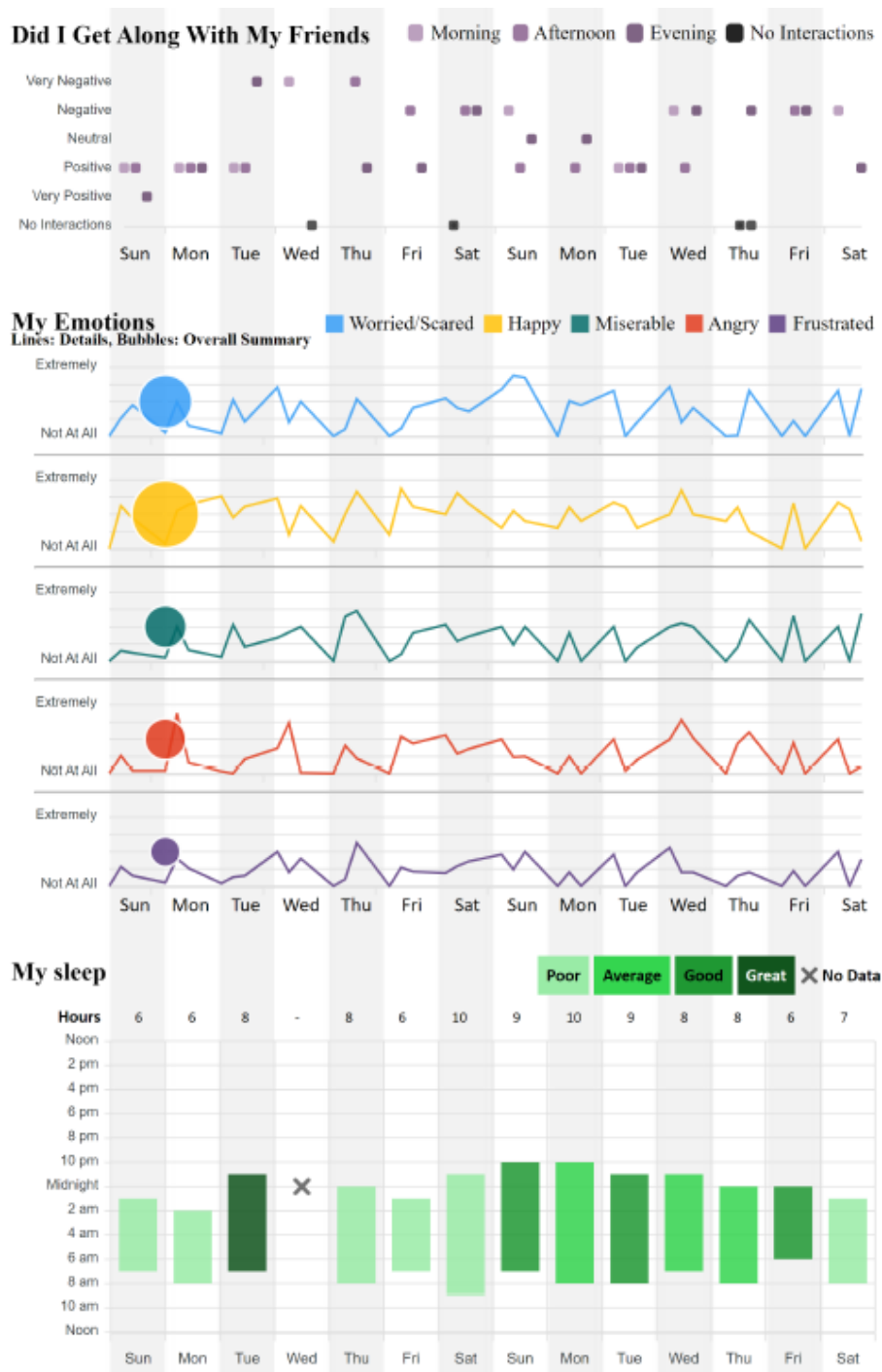


Figure A.7: Phase 1 Design Study Pilot Visualization Dashboard (3/3)

### A.5.3 CareTeam Visualization Dashboard Desktop Version



Figure A.8: CareTeam Visualization Dashboard Desktop Version (1/3)



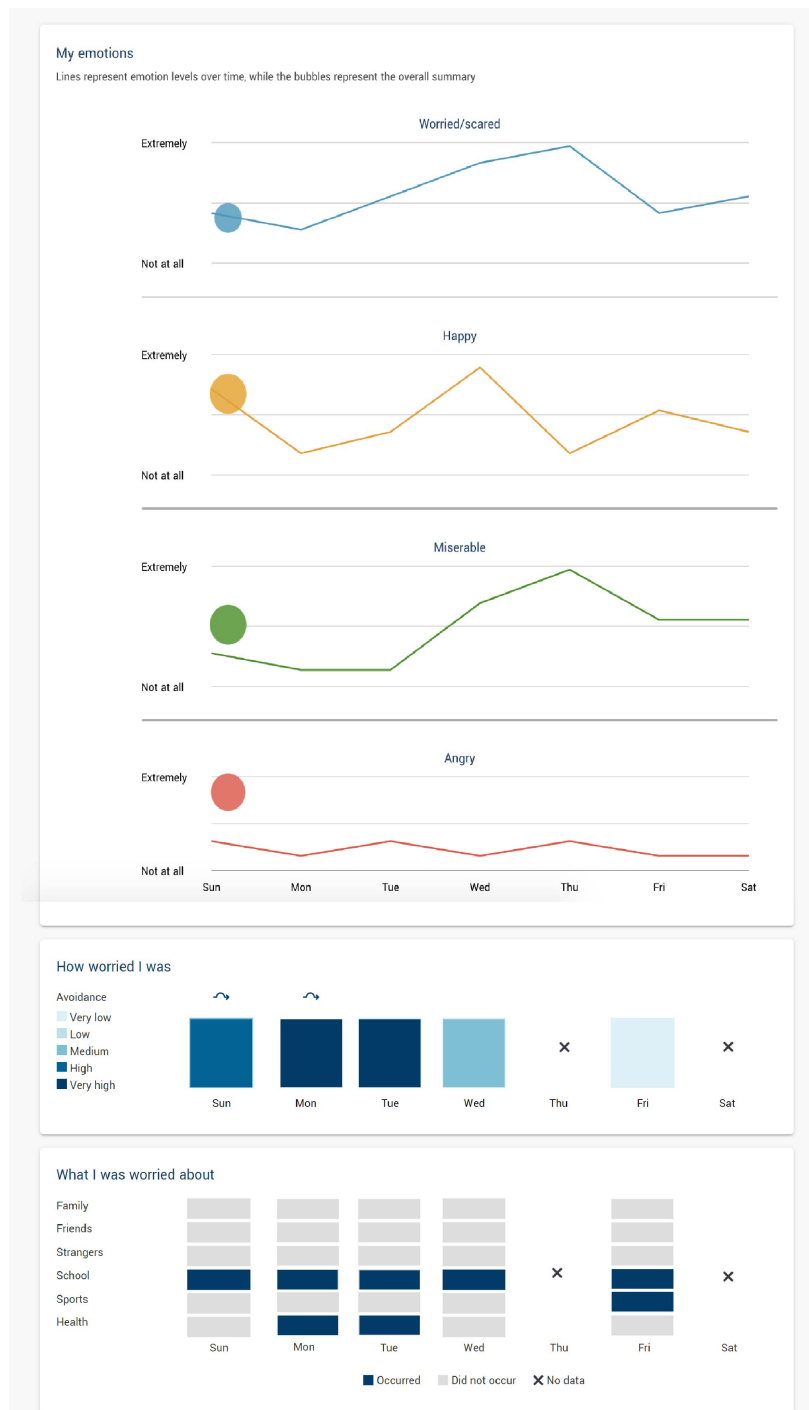


Figure A.9: CareTeam Visualization Dashboard Desktop Version (2/3)

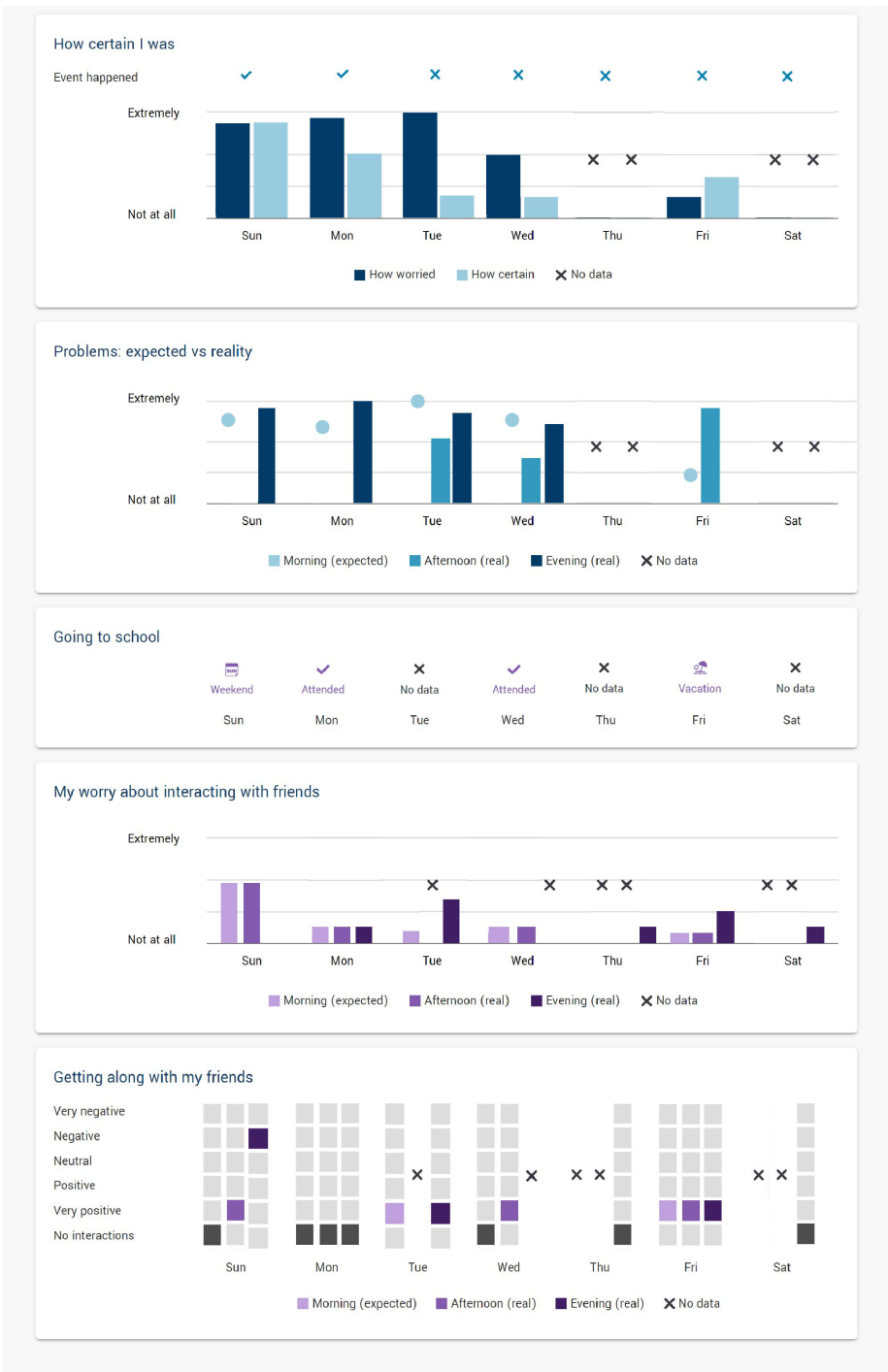


Figure A.10: CareTeam Visualization Dashboard Desktop Version (3/3)



### A.5.4 CareTeam Visualization Dashboard Mobile Version

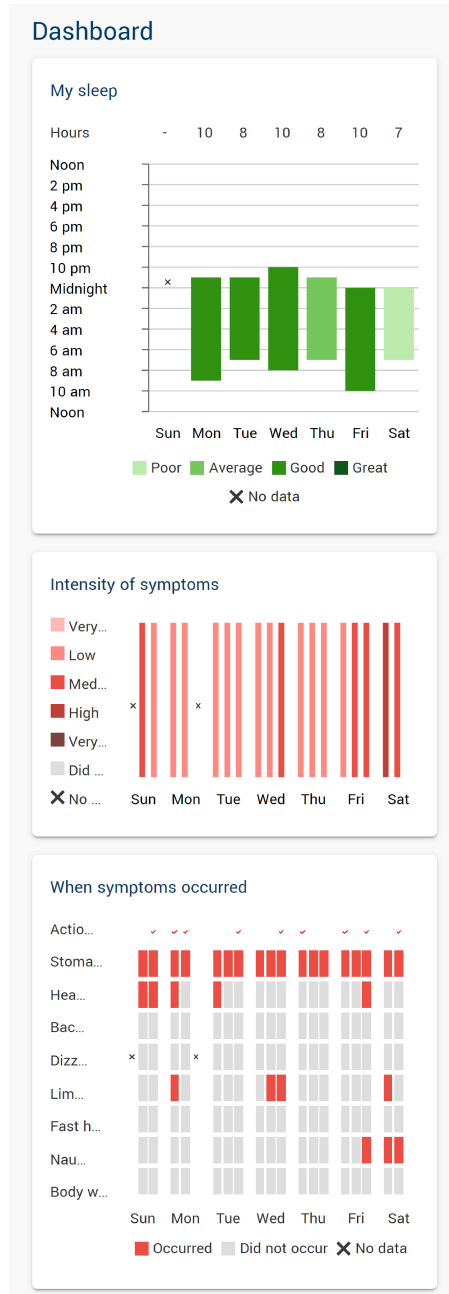


Figure A.11: CareTeam Visualization Dashboard Mobile Version (1/4)



**Figure A.12:** CareTeam Visualization Dashboard Mobile Version (2/4)

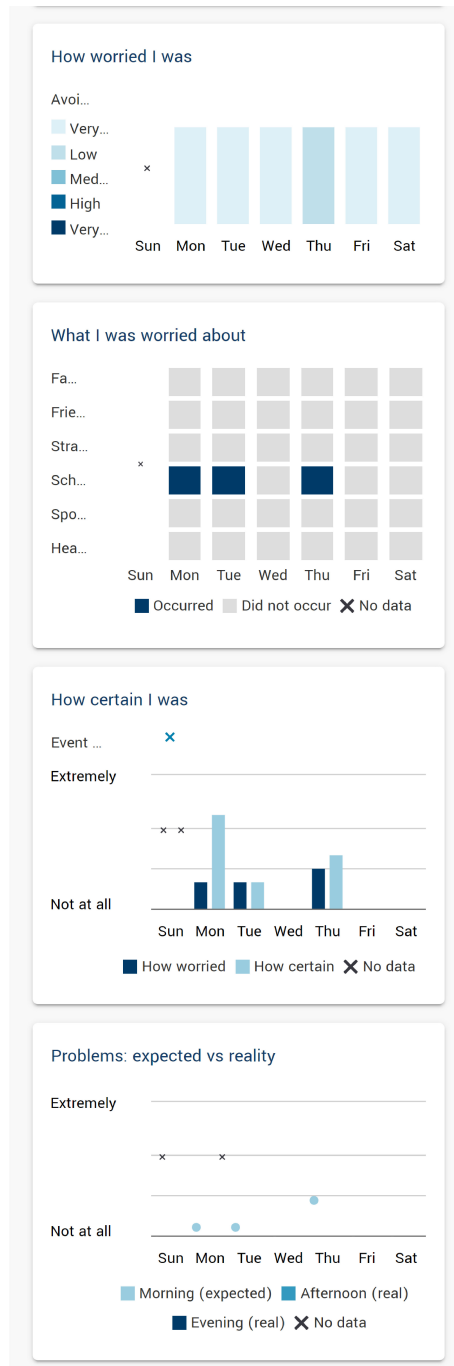
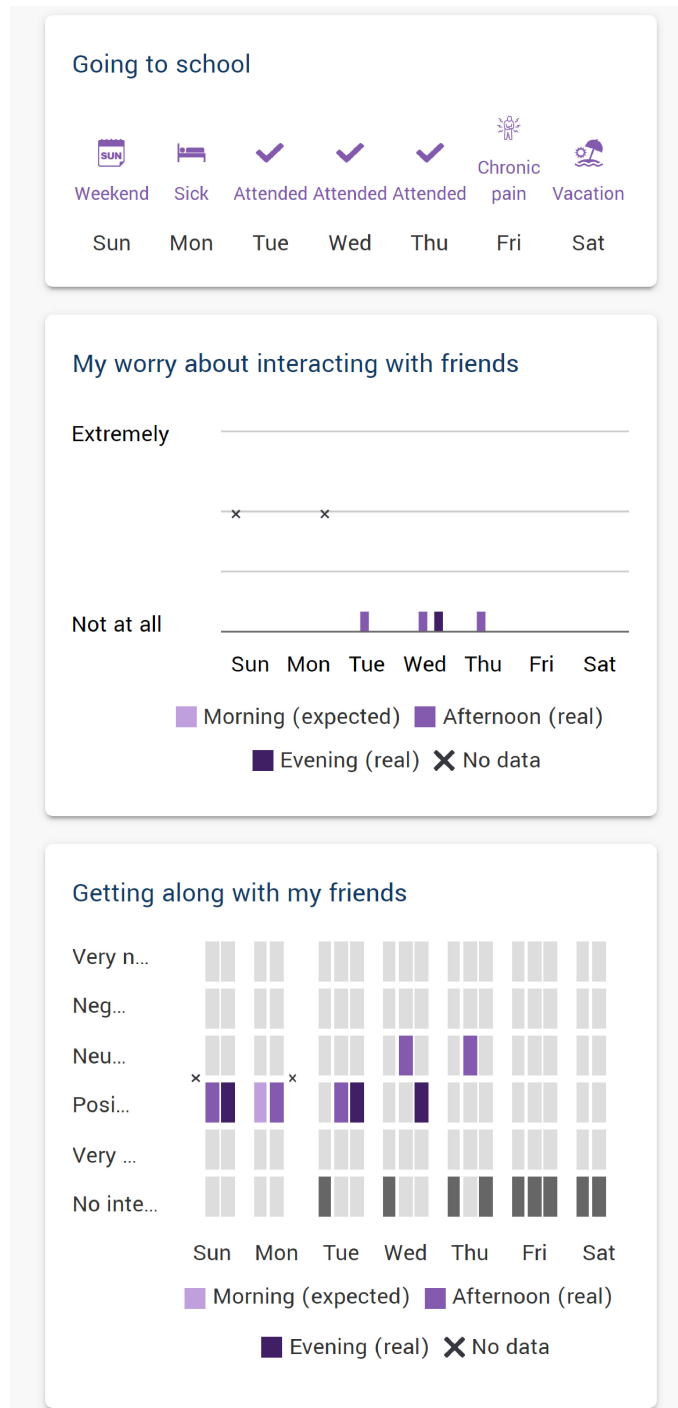


Figure A.13: CareTeam Visualization Dashboard Mobile Version (3/4)



**Figure A.14:** CareTeam Visualization Dashboard Mobile Version (4/4)

## **A.6 User Resources**

### **A.6.1 Orientation Document for Onboarding Participants (Clinical Study)**



## An Instruction Guide for participating in the Remotely delivered data collection in youth with chronic pain: A pilot study

Thank you for participating in this study.

Over the next three weeks, you will be using the CareTeam platform (<https://careteam.me/login>) to complete surveys and view visualizations.

**Please note:**

**This study will generate visualizations of your survey data, which are best begun on a Sunday, hence please start filling out the surveys on a Sunday morning!**

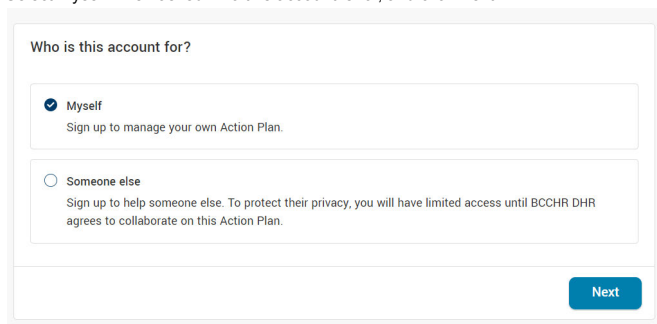
**While filling the surveys:**

- Please only fill the survey for the current date and time, eg please do not fill a Thursday night survey on a Wednesday or Friday night or even Thursday afternoon, even if you see links available for the same.
- If you forget to fill out a survey, no problem, please skip that and move on to the next one.
- You will see links for future surveys available beforehand, however, please do not fill them out before the appropriate time.

To begin, please sign up to the CareTeam platform after 6pm PDT on the Saturday before the Sunday you will begin the study by clicking this link:

[\[Redacted Link\]](#) and create your profile:

Select Myself when asked who this account is for, and click Next:



Who is this account for?

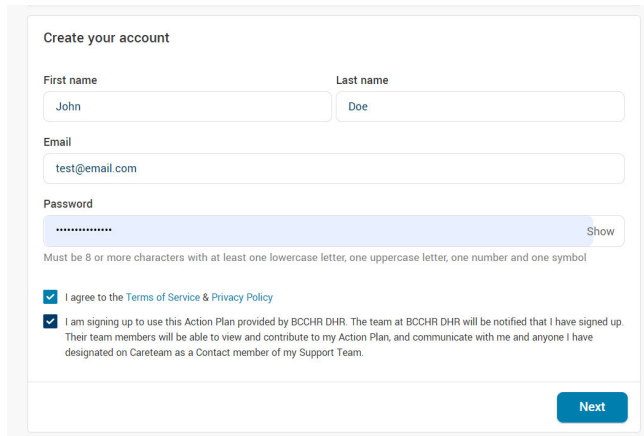
Myself  
Sign up to manage your own Action Plan.

Someone else  
Sign up to help someone else. To protect their privacy, you will have limited access until BCCHR DHR agrees to collaborate on this Action Plan.

Next

In the next step, put in your name, preferred email address (preferably one that you check most often since this is the email address that will be used to notify you of the surveys), and set up a password.

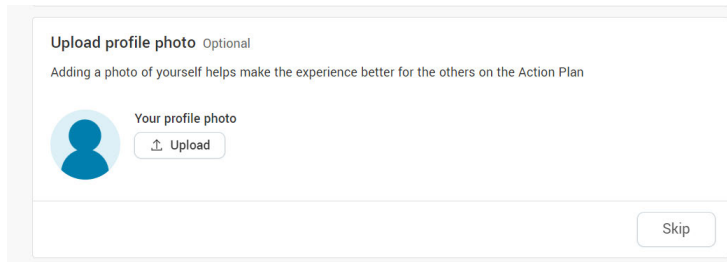
Agree to the Terms of Service and signing up points, and click Next



The screenshot shows a 'Create your account' form with the following fields and options:

- First name:** John
- Last name:** Doe
- Email:** test@email.com
- Password:** A masked password field with a 'Show' button. Below it, a note states: 'Must be 8 or more characters with at least one lowercase letter, one uppercase letter, one number and one symbol'.
- Agreements:** Two checked checkboxes:
  - I agree to the [Terms of Service & Privacy Policy](#)
  - I am signing up to use this Action Plan provided by BCCHR DHR. The team at BCCHR DHR will be notified that I have signed up. Their team members will be able to view and contribute to my Action Plan, and communicate with me and anyone I have designated on Careteam as a Contact member of my Support Team.
- Next:** A blue button at the bottom right.

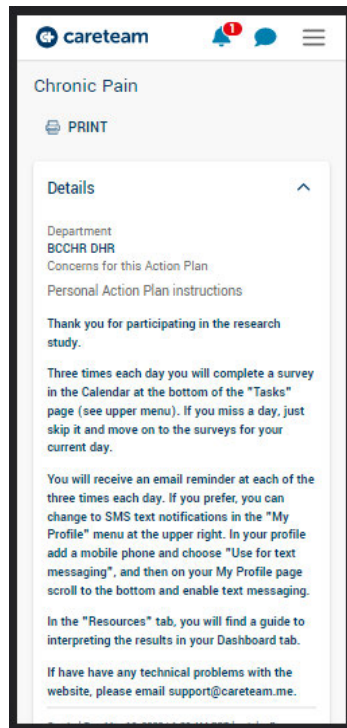
You can then optionally add your profile photo, or click Skip, and then Finish



The screenshot shows an optional step for uploading a profile photo:

- Section:** Upload profile photo Optional
- Description:** Adding a photo of yourself helps make the experience better for the others on the Action Plan
- Photo Placeholder:** A blue silhouette icon with the text 'Your profile photo' and an 'Upload' button.
- Skip:** A button at the bottom right.

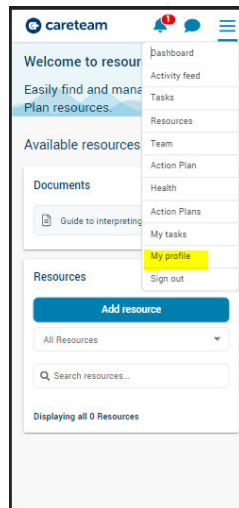
On signing up and logging in successfully for the first time, you should be directed to your **Action Plan**, which will look like:



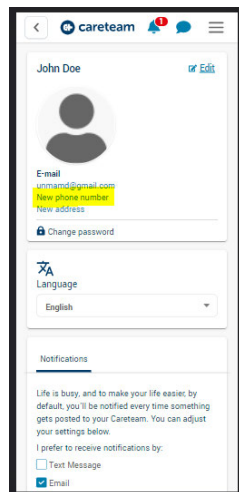
Please read these instructions, and we will explain them a bit more in detail below:

Signing up to receive text notifications:

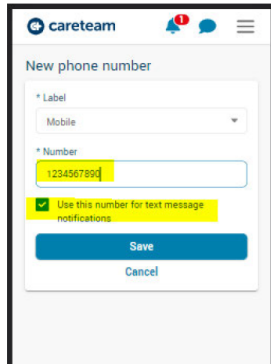
To receive notifications on your phone via text as well, please go to the **My Profile** tab in the menu in the upper right corner:



Click on **New phone number:**

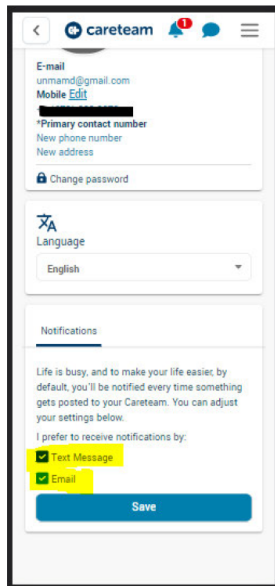


Enter your mobile number and check the "Use this number for text message notifications" box:



The screenshot shows the 'New phone number' form in the Careteam app. At the top, there is a header with the Careteam logo, a notification bell with a red '1', and a speech bubble icon. The form has a title 'New phone number'. Below the title, there is a 'Label' dropdown menu with 'Mobile' selected. Underneath is a 'Number' input field containing '1234567890'. A yellow highlight is placed over the input field. Below the number field is a checkbox labeled 'Use this number for text message notifications', which is checked. At the bottom of the form are two buttons: 'Save' and 'Cancel'.

On your **My Profile** page, at the bottom, scroll down and check the **Text Message** box (also keep the **Email** box checked) and click **Save**:

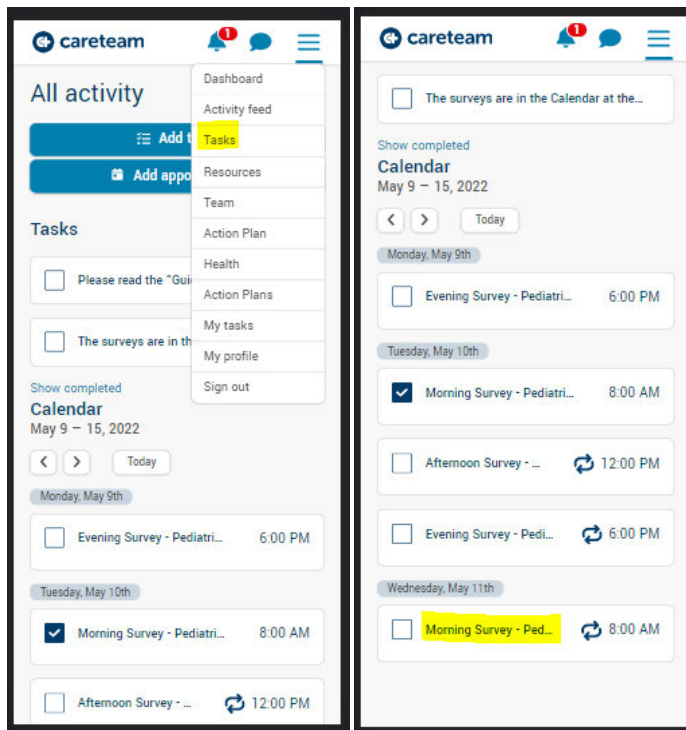


The screenshot shows the 'My Profile' page in the Careteam app. At the top, there is a header with the Careteam logo, a notification bell with a red '1', and a speech bubble icon. The page is divided into several sections. The first section is 'E-mail' with the address 'unmand@gmail.com' and a 'Mobile' field with a redacted number and an 'Edit' link. Below this is a 'Primary contact number' section with fields for 'New phone number' and 'New address'. The next section is 'Change password'. The 'Language' section shows 'English' selected in a dropdown menu. The 'Notifications' section contains a paragraph of text and a heading 'I prefer to receive notifications by:'. Below this heading are two checked checkboxes: 'Text Message' and 'Email'. A yellow highlight is placed over the 'Text Message' checkbox. At the bottom of the page is a 'Save' button.

Week 1:

- 1) Filling the daily EMA surveys:

In the first week, you will be filling out three EMA surveys per day. The surveys can be found under the **Tasks** tab, in the **Calendar** section. **The surveys for the latest day will appear at the bottom of the page.**



To fill out the survey, please click on the survey name and the corresponding survey should open in a new tab on your browser.

The survey should look like this (eg for the morning survey):

Morning Survey

Instructions: Please answer all of the questions below. In these questions, "survey" means the last time you filled out questions for this study.

Last night, I fell asleep at:

This morning, I woke up at:

How well did you sleep last night?

I had a great night of sleep

I had a good night of sleep

I had an okay night of sleep

I had a poor night of sleep

On filling out the survey, click **Finish** on the bottom of the form, and on successful submission, you should see this screen:

Questionnaire Complete

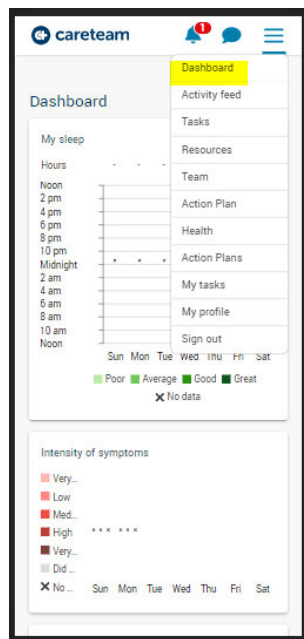
Thank you for completing this questionnaire. Your answers have been submitted successfully.

Please note that your healthcare provider will not routinely see your answers until the time of your next appointment.

If you have an urgent medical problem, you must contact your healthcare provider directly or proceed to the emergency department.

## 2) Understanding your visualizations:

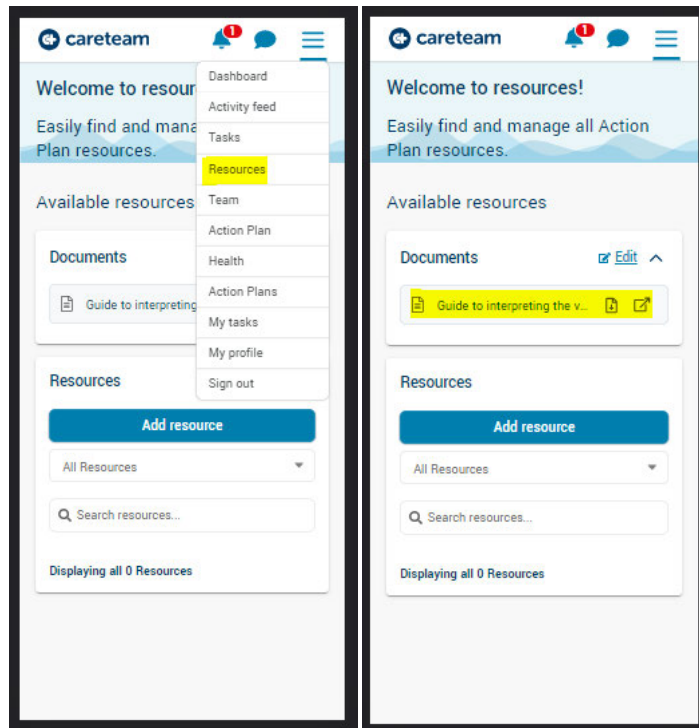
In the first week, you will also see the visualizations of your survey data under the **Dashboard** tab:



**The visualizations will update in real-time each time you successfully submit a survey, for one whole week.**

There is also a guide under the **Resources** section to help you interpret the visualizations:





In case of any difficulties or confusion regarding the visualizations, please feel free to email the study researcher at [REDACTED]

## Week 2:

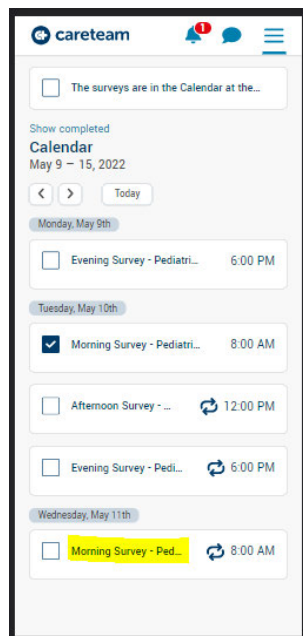
In the second week of the study, you will have a break. **There are no surveys to be filled out during this time, and no visualizations will be made!** Have a good break!

### Week 3:

Welcome to the last week of the study!

**In this week, you will again be filling out three EMA surveys per day, but you will not be seeing the visualizations of your data.**

The surveys will be under the same **Calendar** section under **Tasks** as before:



Please complete the surveys thrice a day for the last week!

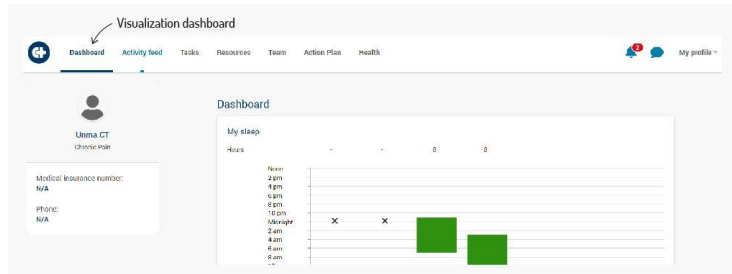
P.S. - The CareTeam platform has other tabs and sections as well, but they are not relevant for this study, and hence you can ignore them.

**In case of any queries or issues during the course of this study, please feel free to contact the study researcher at [REDACTED]**

## **A.6.2 Visualization Interpretation Guide**

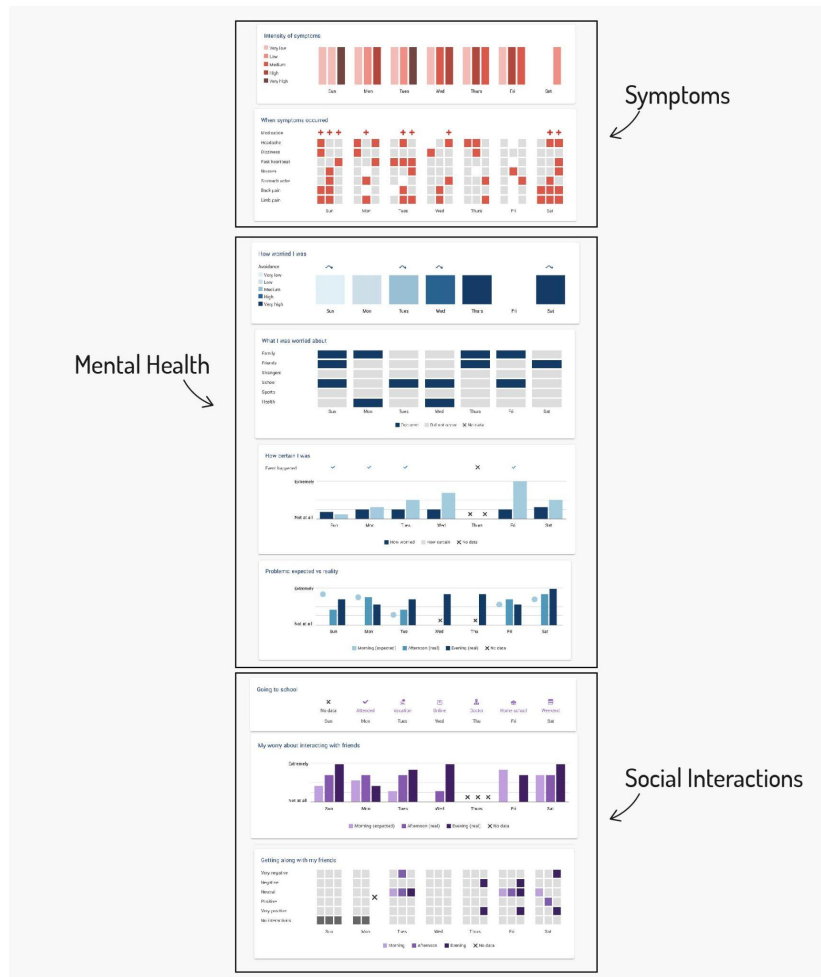
## Guide to interpreting the visualization dashboard

The visualization dashboard can be found under the **Dashboard** tab once you log in to your CareTeam account



The graphs have been grouped in various categories and color-coded accordingly:





The guide below shows how to read each of the graphs:

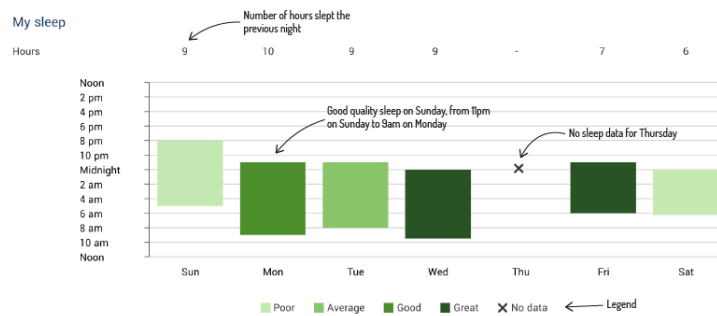
### Visualization 1 (My sleep):

This visualization shows your sleep schedule over the past week.

At the bottom, there is a legend for the graph, the green shades of the boxes correspond to the quality of your sleep, an X means there was no sleep data recorded for that night.

Above the graph, there is a row titled 'Hours' that shows the number of hours slept the night before.

The vertical axis on the left of the graph shows the time of day and the horizontal axis on the bottom shows each day of the week. The length of sleep is shown by the length of each column, for instance:



### Visualization 2 (Emotions):

This visualization shows your emotions over the past week.

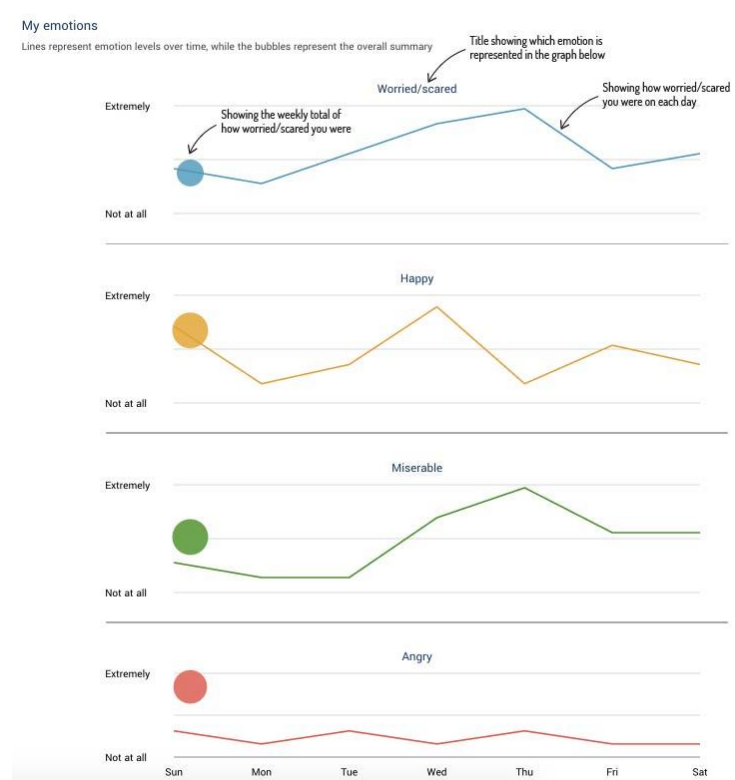
The area of the colored bubbles represents the weekly average of each of the emotions. The lines represent the more detailed daily emotions. The horizontal axis on the bottom shows each day of the week. The line is marked for each time of day, hence three points per day for morning, afternoon and evening.

The bubbles can be used to compare your emotions over the week - seeing which ones you felt more as compared to others, while the lines can help you see the fluctuation in each of the emotions across the day and week.

At the start or at points when previous surveys have not been filled out, you might see the individual data points as smaller points - these are not to be confused with the overall total bubble that will always be near the top left of the graph.

Each emotion is shown in a different colour: Blue = Worried/Scared; Yellow = Happy; Green = Miserable; Red = Angry.

For example:



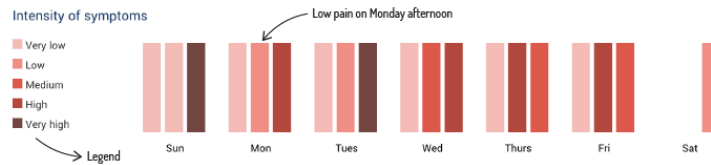
**Visualization 3 (Intensity of symptoms):**

This visualization shows the intensity of your symptoms over the past week.

On the left, there is a legend for the graph, the red shades correspond to different intensities of symptoms ranging from 'Very low' to 'Very high', an X means there was no data recorded for that time.

The horizontal axis on the bottom shows each day of the week. Each time of day is represented by one coloured bar, hence there are three bars per day for the morning, afternoon and evening.

For example:



**Visualization 4 (Occurrence of symptoms):**

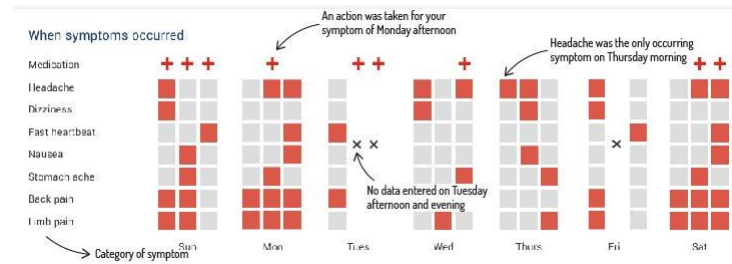
This visualization shows the occurrence of your symptoms over the past week.

On the left, there is a list of symptoms, each corresponding to a horizontal row of boxes alongside. If a symptom occurred, the box is filled red, else grey. If no data was entered, the .

On the top, there is a row labeled 'Action taken' where a '+' sign indicates an action was taken for the symptoms at that time.

At the bottom we show each day of the week horizontally. Each time of day is represented by one column of boxes, hence there are three columns per day for the morning, afternoon, and evening.

For instance:



**Visualization 5 (Intensity of Worries):**

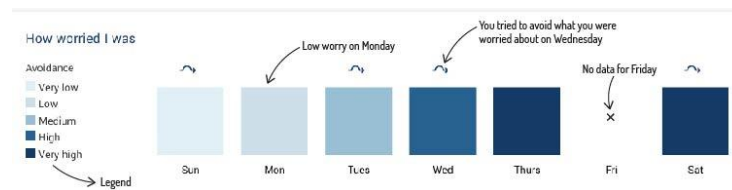
This visualization shows the intensity of your worries over the past week.



On the left, there is a legend for the graph, the blue shades of the boxes correspond to different intensities of worries ranging from 'Very low' to 'Very high', an X means there was no data recorded for that day. At the bottom, we have the days of the week.

Above the graph, there is a row titled 'Avoidance' where the presence of the arrow icon indicates if you tried to avoid what you were worried about that day.

An example of how the graph can be read:

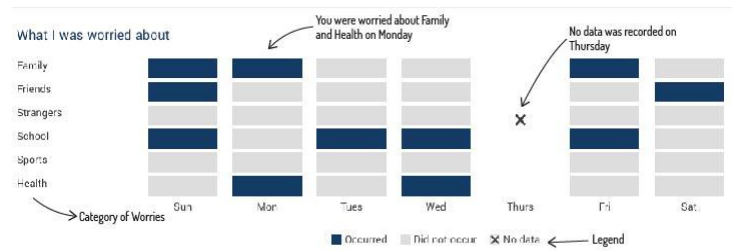


**Visualization 6 (Category of Worries):**

This visualization shows the categories of your worries over the past week.

On the left, there is a list of categories, each corresponding to a horizontal row of boxes. At the bottom, we have the days of the week. If you were worried about a particular thing that day, the corresponding box is colored blue, else grey. If no data was entered, the column is marked with an X. There is also a legend at the bottom.

For instance:



**Visualization 7 (Worry VS Certainty):**

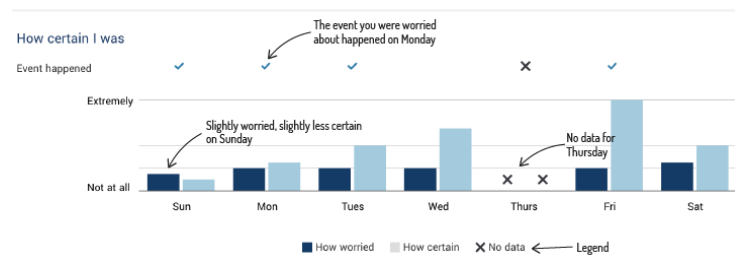
This visualization shows how worried you were about something and how certain you were about the event happening, as well as whether the event happened.

The dark blue bars indicate how worried you were about an event and the light blue bars indicate how certain you were that the event would happen. An 'X' represents no data was

logged. The horizontal axis at the bottom shows each day of the week. There is also a corresponding legend at the bottom of the chart.

Above the graph, there is a row titled 'Event happened', where the presence of a checkmark means the event you were worried about did occur on that day.

For example:

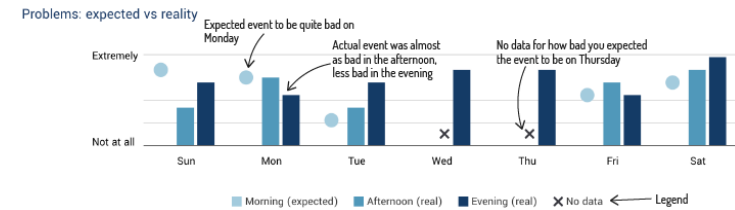


**Visualization 8 (Expectations VS Reality):**

This visualization shows how bad you expected things to be and how bad they were.

The light blue dots indicate how bad you expected the thing you were worried about to be, as recorded in the morning. The blue bar indicates how bad the thing was if it happened in the afternoon, and the dark blue bar indicates how bad it was if it happened in the evening. An 'X' represents no data was filled. If the event did not occur, there will be no bars, just the light blue dot for that day. There is also a legend at the bottom of the chart.

For instance:

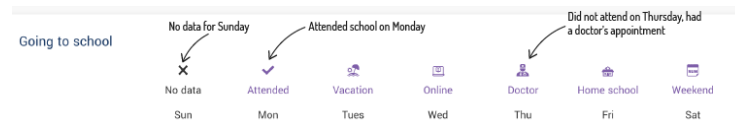


**Visualization 9 (School attendance):**

This visualization shows your school attendance over the past week.

Each icon corresponds to a reason written below the icon in the chart. An 'X' means no data was logged for that day. A checkmark means you attended school. Every reason for not attending school has a specific icon and label shown in the chart. The horizontal axis on the bottom shows each day of the week.

For instance:



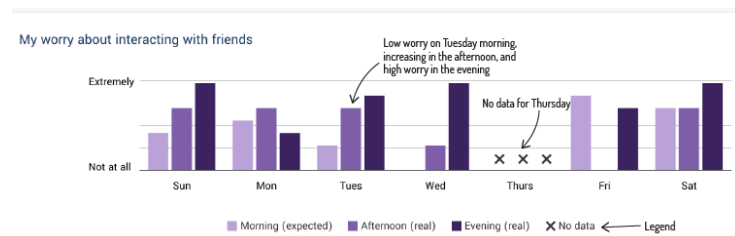
**Visualization 10 (Peer Interaction Worry):**

This visualization shows how worried you were about interacting with your peers over the past week.

The light purple bars indicate how worried you were in the morning, the medium purple bars are for the afternoon, and the dark purple bars for the evening. An 'X' represents no data was logged. The legend is at the bottom of the chart.

The horizontal axis at the bottom shows each day of the week. Each time of day is represented by one purple bar, hence there are three bars per day for the morning, afternoon and evening.

For instance:



**Visualization 11 (Peer Interaction Quality):**

This visualization shows the quality of your peer interactions over the past week.

On the left, there is a list of the qualities possible of an interaction, each corresponding to a horizontal row of boxes. The horizontal axis on the bottom shows each day of the week. Each time of day is represented by one column of boxes, hence there are three columns per day for the morning, afternoon, and evening.

Each interaction at any time of day can be one of the 6 qualities listed on the left (Very negative/Negative/Neutral/Positive/Very positive/No interactions), and the corresponding box will be coloured purple. There are three shades of purple to further help differentiate times of day - light purple in the morning, medium purple in the afternoon, and dark purple in the evening. There is also a corresponding legend at the bottom of the chart.

An example of the graph:

