

**Beyond the Bulging Binder: Family-Centered Design of an
Information Management System for Caregivers of
Children Living with Health Complexity**

by

Katayoun Sepehri

B.Sc, Biology, The University of British Columbia, 2016

B.Sc, Computing Science, Simon Fraser University, 2020

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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:

Beyond the Bulging Binder: Family-Centered Design of an Information Management System for Caregivers of Children Living with Health Complexity

submitted by **Katayoun Sepehri** in partial fulfillment of the requirements for the degree of **Master of Science in Computer Science**.

Examining Committee:

Karon MacLean, Computer Science, UBC
Co-Supervisor

Liisa Holsti, Occupational Science and Occupational Therapy, UBC
Co-Supervisor

DongWook Yoon, Computer Science, UBC
Supervisory Committee Member

Abstract

Children Living with Health Complexity (CLHC) require continuity of health and community care to improve their quality of life and decrease family care burden. Due to medical complexity and numerous chronic conditions, these children rely heavily on multiple care providers. However, a fragmented health system and the communication challenges between stakeholders poses many obstacles for their caregivers, and the result is non-optimal care in both hospital and community. This leads to an immense burden on families who take on dual roles and become responsible for care coordination. Parent caregivers must continually manage and share masses of paper documents and repeat their child's story for different stakeholders. A digital information management and care coordination solution to support these caregivers is long overdue.

Our goal was to engage with parent caregivers of CLHC through the user-centered design process to understand their needs in a digital solution. Twelve caregivers participated in three rounds of user studies which were followed by design phases. In the first phase of the study, we aimed to understand the caregiver challenges, pain-points and strategies for dealing with masses of paper and electronic data. By utilizing thematic analysis, we found a set of caregiver challenges which closely aligned with previous research: access to health records, navigating the care system, organizing and managing information, finding resources, repeating their story, and managing finances. We mapped these challenges to the caregiver strategies and devised a set of design principles to address these challenges. We also collected data on caregivers' feature preferences in a digital solution.

Our emergent design principles are: providing a holistic view of patient care, allowing customizability and flexibility, personalizing and humanizing, facilitating

communication and collaboration with care providers, avoiding jargon, capturing health history and providing insight, sharing and accessing confidentially, and integrating information.

Finally, we developed an extensive prototype blueprint through an iterative process of feedback and design to serve as an example for implementing these design principles in a caregiver-centered interface. The design principles and the prototype are intended to be a stepping stone for developing the content and features of a caregiver-centered information management system.

Lay Summary

Children living with health complexity are a small percentage of the pediatric population with immense costs. Due to numerous chronic conditions, these children rely heavily on multiple care providers; however, communication challenges between stakeholders and gaps in the care system poses many difficulties for parent caregivers. Parents are usually responsible for care coordination and must transmit information between stakeholders. Transformation to an electronic and cloud-based system (*e.g.*, smartphone application) can help this population with access to data, care coordination, information management and communication. We interviewed twelve parents to understand their challenges and strategies. Then, we prototyped a mobile phone application which we continuously re-designed based on additional rounds of feedback from parents. Our results suggest that parent caregivers highly value a system that is customizable and flexible, allows collaboration with care providers, provides a holistic view of their child, captures health history, provides insights, and humanizes their family.

Preface

All user studies referenced in this thesis were conducted with the approval of the UBC Behavioral Research Ethics Board (certificate number H21-02184).

This research topic was identified by my co-supervisor, Dr. Liisa Holsti, who also provided ongoing expert feedback. Dr. Karon MacLean provided project supervision and human-computer interaction knowledge and input. Dr. Karon MacLean and Dr. Liisa Holsti also provided supervisory assistance, helped to frame the research topic and guided the development of the prototype. I designed the user study, recruited participants, wrote the application for UBC Behavioral Research Ethics Board, collected all the qualitative data, conducted the data analysis and oversaw the development of the prototype.

The interview transcriptions were done by two undergraduate students at the SPIN lab, Sara Niasati and Vita Chan. They also assisted with affinity mapping and coding for thematic analysis. Sara built significant portions of the Child's Profile and the Calendar. Vita built significant portions of the Medical Timeline and the Care Team. Other sections of the prototype were built collaboratively as a team between Sara, Vita and myself.

Valuable feedback from colleagues of the UBC MUX group, SPIN lab, Dr. Hal Siden and Dr. Elodie Portales-Casamar was gratefully received throughout the project.

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Abbreviations

BC	British Columbia
CLHC	Children Living with Health Complexity
CMC	Children (and youth) with Medical Complexity
CST	Clinical and System Transformations
EA	Educational Assistants, a staff in the school who provides support for students with diverse learning challenges
ED	Emergency Departments
EHR	Electronic Health Records
ER	Emergency Room
ICU	Intensive Care Unit
IEP	Individual Education Plan
MVP	Minimum Viable Product
PFCC	Patient and family-centred care
VA	Voice-assistive

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Lastly, my thanks go to my parents (Kay and Dary) and family, whose support and encouragement has enabled me to pursue this research journey.

Dedication

To the parents and families who made this research possible

And to *Cameron*, who is no longer with us, but continues to inspire

Chapter 1

Introduction

Doctors diagnose, nurses heal, and caregivers make sense of it all.
— Brett H. Lewis

I¹ started this work by reading two memoirs from parents of children who live with health complexities. These memoirs, Brown and Kim, introduced me to the world of those living with a disability and complex chronic conditions [16, 40]; I began to understand the daily struggles (and joys) for parent caregivers, families and children. These stories shifted my perception about disability, and expanded my understanding of the complex care challenges which subsequently motivated me to push for a design solution. Therefore, I will begin with a story about a child with medical complexity (Jane) and her family who live in Greater Vancouver area, British Columbia (BC), Canada. While Jane does not exist as a single individual, her story is a composite based on conversations from actual parents (circa 2021-2022) as well as research studies about the challenges of parents, and can be considered fully realistic. The purpose of this story is to provide a snapshot of the challenges for parent caregivers who get pushed into additional unexpected roles (*e.g.*, care coordinators, document managers, administrators etc.) due to the diffi-

¹*Note:* In this thesis, “I” refers to myself, Kattie Sepehri. “We” refers to myself and my collaborators (*i.e.*, supervisors and sometimes undergraduate assistants). “Care providers” refers to individuals, health facilities, organizations, and teams who are licensed to provide care diagnosis and treatment services which are often paid. For the purposes of this thesis, “caregivers” refers to anyone who regularly provides unpaid care for the child. In this project, the terms “parent” and “caregiver” will be used interchangeably and are references to parent caregivers.

culties with communication in the care system which becomes highly amplified in the care of complex patients.

1.1 Jane's Story

Susan is a single mother of two children, Jane and Michael. Jane is twelve years old and Michael is nine. Jane was born with a complex and rare genetic disorder which took a few years to diagnose because the condition was very uncommon. The diagnosis provided hope and a direction for medical care, but it also meant that Jane would be highly dependent on at-home care for the rest of her life. Jane would have global developmental delay, frequent seizures, and require a G-tube². She would also need numerous surgeries and regular medications to help with her various health issues. It was unclear whether she would ever be able to verbally communicate or walk, but she would be enrolled in a number of therapies to help with developing these skills. Jane and Michael attended school together. Jane had a number of teachers and Educational Assistants (EA). Due to the complexity of her care, she would see her regular family doctor (and pediatrician), as well as numerous other care providers (*e.g.*, specialists, therapists, nurses, social workers). Her care team consisted of around 20 stakeholders (*e.g.*, care providers, social workers, school teachers, community service providers).

Susan is a very busy parent of two children and she also works part-time. There is home care assistance for the family but their services are sometimes difficult to get since staff with pediatric expertise are not always available. In addition to being a parent and a caregiver, Susan also manages all the doctor appointments and communications with care providers, handles the documents and planning for finances and insurance, and maintains the numerous binders full of important paper records that document Jane's health.

Table 1.1 provides an example of the type of documents that Susan needs to manage. Their breadth illustrate the extreme degree to which a parent in Susan's situation needs to wear multiple hats and is continually trying to balance her occupation, the caregiver and care coordinator duties, and the parental responsibilities.

²A tube that is used to provide liquid food directly into the stomach and is placed in children who can not eat orally

She is regularly stressed, tired, and interactions with care providers do not provide any comfort.

Table 1.1: A non-exhaustive list of documents and records that a parent may need to manage. Documents that parents might create is not included.

Category	Record type
Nursing and allied health documents	Respite care reports
	Care plans
	Palliative care report
	Mobility reports
	Occupational therapist reports
	Physical therapist reports
	Hospital or ER visit summaries
	Dietician/nutrition reports
	Assistive technology reports
	Speech language pathology reports
	Medical genetics consultations
	Nurse clinician reports
Lab/investigation documents	Lab test results
	Radiology/Imaging reports
	Surgical Planning Laboratory reports
Consultations and specialists referrals	Family physician reports
	Surgeon Reports
	Physician Specialist reports (eg. Neurology, Cardiology, Endocrinology, Audiology etc.)
	Pediatrician reports
	Prescriptions
	Social worker communications
	Psychology report
School documents	School reports
Legal documents	Lawyers/Hospital documents

When Jane was younger, there were many situations when Susan had to call emergency paramedics. The inherent stress of these incidents were greatly amplified by emergency responders not knowing her child’s health status, and certainly not having time to read the six inch binders that hold her medical records. Moreover, the hospital that Jane would be taken to was not able to access her recent information quickly because it is located in a different “health authority” from her regular children’s hospital. The emergency staff and doctors also did not know Jane and did not have time to read the binders. In these emergency situations it would

all depend on Susan to repeatedly tell each care providers about Jane's special condition, medications and allergies, the "sick protocol"³, the procedure required to connect her special equipment and so on. She also had to pack the "emergency" bag for Jane anytime that she needed to stay in the Emergency Room (ER) because many hospitals did not have the specialized equipment that she needed. Susan had to repeat Jane's story so many times that she had memorized everything, but still worried about forgetting something that would be life-critical; a part of the story, a piece of paper, a special document, a medication...

It wasn't only emergency situations that were stressful. Even visiting the children's hospital in which Jane was a regular patient could be a challenge. Initially, Susan didn't understand the medical terminology and had to actively learn how to talk with the doctors. After so many years, she had become an expert and in tune with her daughter and wanted to be Jane's advocate. But every so often, she could come across a new staff member who did not know Jane and did not read her information, so Susan was always updating and preparing summary care plans. Through the years, she learned about the specific information that each care provider or stakeholder would need. Susan found it difficult to understand why it should be so challenging for the specialists on the care team to connect with each other and provide Jane with a care that is collaborative and considers all aspects of her daughter's complex condition. Susan felt that she is always needed to be in the picture or there could be errors that can affect Jane's health and safety.

As for managing finances as a single parent, the family relied on charities for supplies, and insurances or government funding for medication or special equipment. Applying for these grants and submitting insurance claims and maintaining all the documents was basically a full-time job. But, it had to be done to ensure Jane had the supplies that she needed (*e.g.*, syringes) and could access specialized therapies or custom made equipment.

There have been times when Susan has wondered what will happen to Jane when she needs to transition out of the children's hospital as she becomes an adult. What would happen to all her records? How could she manage all the new staff on her care team? Since Susan is also a parent to Michael, she has had to grapple

³A plan/protocol which describes what needs to be done when Jane is sick

with the very difficult decision of having foster parents for Jane or finding a group-home. She wishes that she could spend time with her children as a parent without worrying about the duties and various roles of caregiving. These past 12 years have not been easy and no changes were made in the care system to help the process.

Susan has seen many rapid advances in technology, but all the while there seems to be no change or alleviation of her overwhelming day-to-day challenges as a caregiver.

1.2 Problem Definition

Figure 1.1 maps the complex and large care network comprised of entities that a child living with health complexity in BC could come in contact with. It demonstrates the potential for communication challenges at each point of contact (*i.e.*, internally within care centers or externally between stakeholders) and the complexity of the health records.

The main problem that we were trying to solve in this research is the complex communication and the record keeping/access challenges in the health care system for families like Jane's.

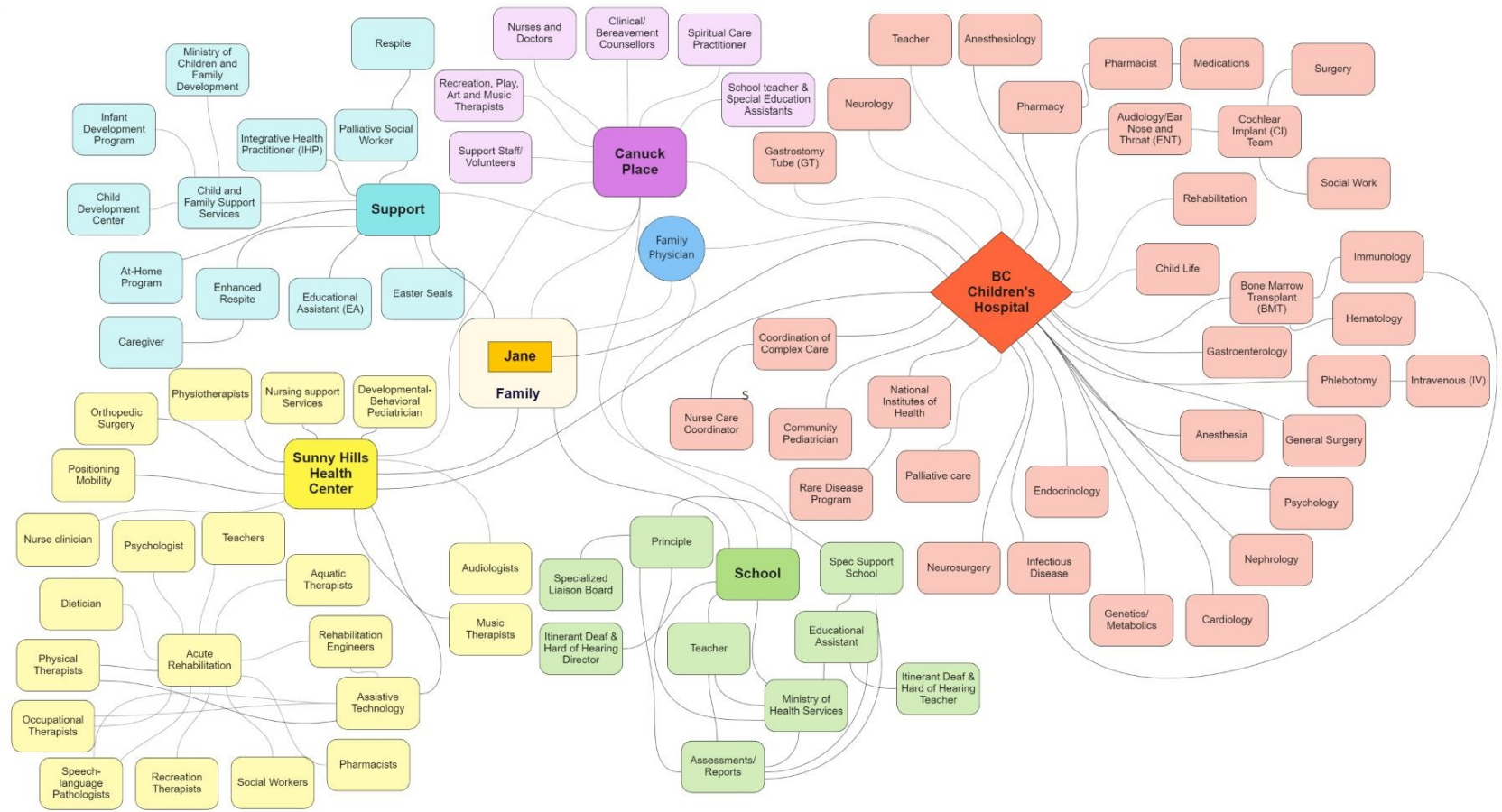


Figure 1.1: A map of care providers and stakeholders in BC that a child (Jane) with medical complexity may come in contact with. Each line indicates a possible communication bridge between the stakeholders. This figure is reprinted from the Ontario map in Dewan and Cohen and names of entities have been replaced with the ones that exist in BC [30].

Jane, and other children who live with health complexity often have multiple chronic conditions, severe functional limitations, visit numerous care providers and rely on technology assistance [25, 30]. Due to recent advances in pediatric care, Children Living with Health Complexity (CLHC) can survive for many years with complex care needs [30]. However, continuity of care is important to significantly improve their quality of life and build a positive experience for parents [48]. For many families and their children's care providers, lack of a centralized data storage creates a roadblock to flexible, timely and focused access to health information; this leads to disjointed care as care providers are unable to easily access all of the patient's data [5, 8, 30, 33, 55]. Moreover, due to the complexity and life-long duration of care, and the number of care providers involved, these children and their families become exposed to the fragmentation in the health care system [18, 44, 45]. Oftentimes, the parent caregivers need to wear multiple hats. They are burdened with care coordination as well as management and sharing of masses of paper documents which turn into numerous large binders throughout the life of the child [5, 33].

Much of this can be viewed as an information and communications challenge, and its solution will surely rely heavily on an overhauled and centralized data infrastructure. This database system is currently under development in our province (BC) through the Clinical and System Transformations (CST) project⁴ [24] and the Cerner software⁵ [23]. This project is a multi-year initiative and there will be a slow transfer of disjointed databases and paper documents to a centralized provincial database.

While the use of technology and the transition to integrated electronic records could be a solution that would reduce the parent caregiver burden, it requires some understanding of what a more digitally enabled system could look like as a user-facing interface (users could be parents, caregivers, care providers, and other stakeholders). Therefore, the goals of our research are futuristic and forward-looking: we target the time when the centralized database system is implemented and third

⁴The Clinical Systems Transformation project which aims to establish integrated plans of care and common electronic health records. The transformation will be accomplished by replacing existing systems with CST Cerner

⁵A cloud-based Electronic Health Records platform built by Cerner Corporation

party applications could access the patient health records without limitations. In essence, we wish to design for a scenario in which parents can access their family's health information at their finger tips, rather than provide a band-aid type interface to the current broken system, in which the burden of data fragmentation and care coordination falls on the parents.

It is not clear what this interface should be able to do, what aspects of care could it assist with, how parents could interact with it and what design guidelines should it follow to meet the needs of parent caregivers. These questions could be answered through user-centered design [37], scenario generation, prototyping and use of mock data. To achieve this futuristic goal, it is necessary to understand the pain-points for parents and how caregiver-centered technologies could facilitate the process.

1.2.1 Research Questions

Therefore, the aims of our project were to understand:

1. What parent caregivers need (*i.e.*, features, interactivity, content) in a digital tool solution?
2. To what extent are this group's health-coordination needs divergent from others? Where they are, can we identify principles to assist with designing tailored solutions?

1.3 Approach

To answer these questions, we utilized a caregiver-centered design process that began by seeking to understand the main challenges for parent caregivers, their strategies and the drawbacks (or advantages) to these strategies. We also wanted to understand their general feelings towards using technology and their design preferences. Our approach included multiple stages of interviews with parents of CLHC and domain experts; and iterative incorporating ideas and feedback into an evolving prototype.

Figure 1.2 provides an overview of the consecutive phases in our research.

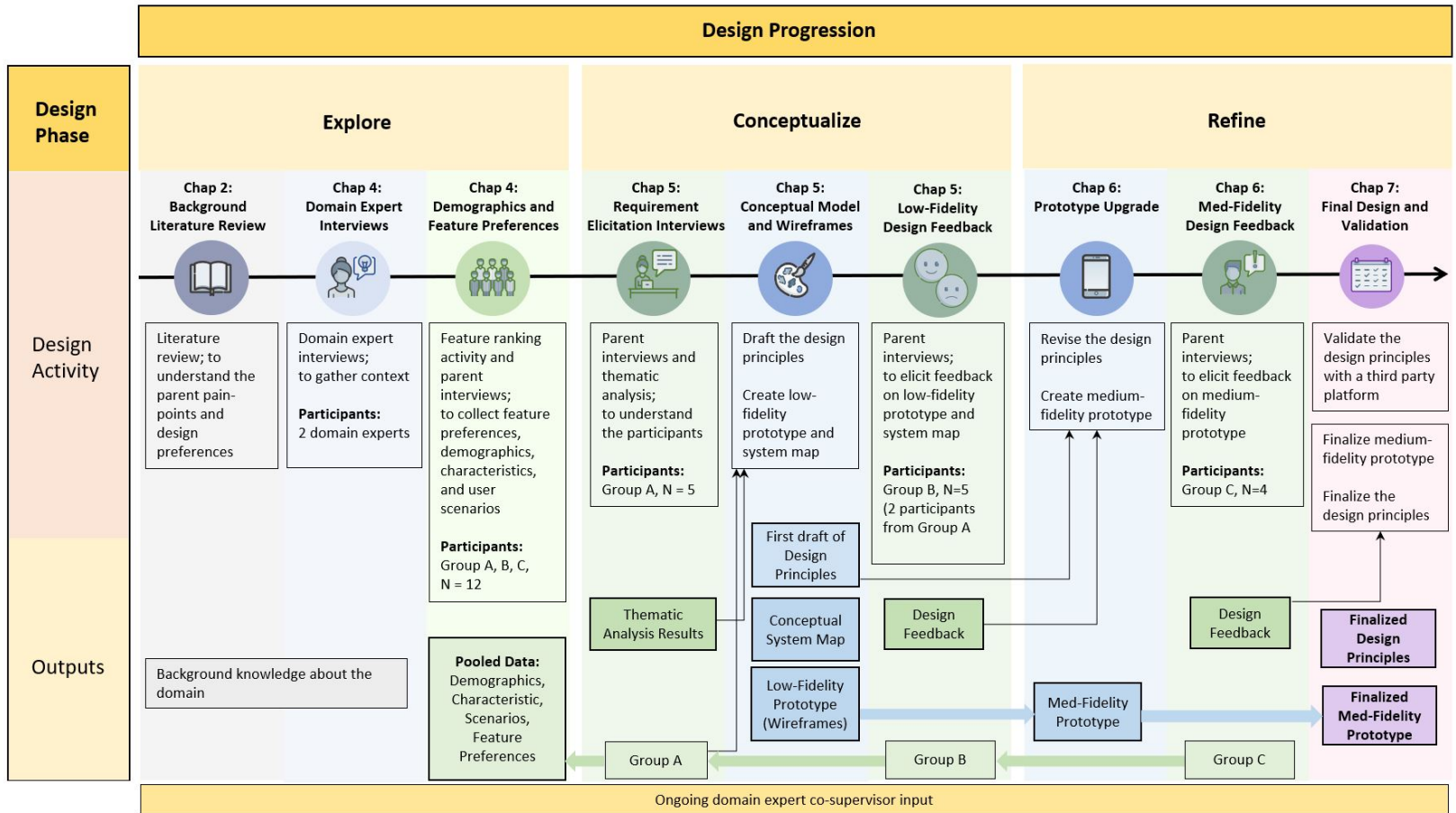


Figure 1.2: An illustration of the design phases and the corresponding thesis chapters. Outputs for each phase is indicated in the Outputs row. The Demographics and Feature Preferences column contains the “Pooled Data” box which indicates the data pooled from Group A, B, C parent participants from the multi-stage user studies.

1.3.1 Explore Phase

In the Explore phase (Chapter 2, and Chapter 4), to gain a better understanding of the electronic medical records in the care system, the problem space, and how things could evolve in the future, we interviewed two domain experts and reviewed the existing literature.

The domain experts were a pediatric physician who leads a community-based facility that cares for CLHC, and a senior researcher with expertise in health informatics. The expert input consisted of information about the centralization of Electronic Health Records (EHR) and the associated challenges, as well as the challenges for parents. In the hopes of finding areas of overlap, sharing resources and research methods, we began an ongoing engagement with another research project (TrustSphere) with similar research aims for a pediatric patient population whose care is less complex [31].

To add additional knowledge during this phase, a literature review was conducted. Through the literature review, we created the research questions and design goals, developed an understanding of what features have been preferred by caregivers and what design guidelines already exist.

1.3.2 Conceptualize and Refine Phases

In the Conceptualize phases, we conducted a Requirement Elicitation study with five parent participants (Group A) to identify the user requirements, understand their main challenges and strategies with regards to managing health information. We also wanted to understand their general feelings towards using technology and identify specific tasks that could be assisted with technology.

The data collected from this user study was used to develop a low-fidelity prototype (wireframe) and a conceptual system map. The purpose of this phase was to gain a high-level understanding of how the user interface should work. Then, in the Low-fidelity Design Feedback stage, we collected feedback on our designs through interviews with five parent participants (Group B).

This feedback was used to create a task-based medium-fidelity prototype in the Refine phase (Chapter 6). Then, during the Med-fidelity Design Feedback stage, we collected feedback on the prototype with four parent participants (Group C) and

finalized the prototype based on their feedback. During all of the user studies, we also collected data on the participant's feature preferences using a feature ranking activity. By combining the data from the user studies and the feature ranking, we devised a set of design principles to guide the design of digital health technologies for this population.

Lastly, in an effort to validate the utility and practicality of our design principles, we applied them to a third party platform to understand the gap between their platform and our findings about caregivers of children with complex chronic conditions.

1.4 Contributions

Building on previously published research, we contribute three new resources to aid the development and architecting of user-facing systems that support information management and care coordination for this population:

1. **A set of principles** to guide the design of health technologies in this space, derived from past works, in-depth engagement with parent caregivers, and ongoing expert guidance;
2. **A ranked list of caregiver feature preferences** to inform design priorities for task-based interfaces;
3. **A blueprint prototype** for caregiver-centered interface which illustrates a way to implement these emergent design principles and the caregiver-preferred features.

1.5 Overview

In this chapter we have laid out the problem definition and our approach. Chapter 2 explores the knowledge gaps from the literature review. Chapter 3 explains our data collection process with regards to parent caregiver interviews. Chapter 4 contains the takeaways from the domain expert interviews, the participant demographics and characteristics and the results for the feature preferences activity. Chapter 5 describes the results for Requirement Elicitation Interviews, the thematic analysis

findings, a first look at the emergent design principles (DPs) and the creation of the high-level conceptual system map and the low-fidelity prototype (wireframe). Chapter 6 discusses the prototype refinement process which includes Med-fidelity Design Feedback, more details about the finalized prototype and its important features. Chapter 7 dives deeper into the emergent design principles and our validation process with a third party platform. Chapter 8 contains discussion and Chapter 9 provides future directions and conclusion.

Chapter 2

Related Work

This chapter will summarize prior research related to this field. After surveying a range of definitions and important statistics about CLHC, we will review others' documentation of caregivers' burden and their strategies for handling their challenges. Finally, we will also discuss other closely related works that have offered design guidelines in this space which have taken the form of structure, design preferences and content priorities for a cloud-based care plan. In each section, we will identify the gaps that will be addressed with the present work.

2.1 Children Living with Health Complexity

The term “children and youth with special health care needs” (CYSHCN) represent a broad group of children who may have various conditions such as type 1 diabetes, cerebral palsy, asthma or attention-deficit hyperactivity disorder [30]. The most complex and medically fragile of these children have in the past been referred to as Children (and youth) with Medical Complexity (CMC); or more recently, Children Living with Health Complexity CLHC [39].

This group have been given many acronyms and definitions and they can have a wide range of incurable and life-long conditions. However, the most recent research usually defines CLHC as having four shared characteristics: high health care resource and/or community-based service utilization which necessitates involvement of multiple stakeholders (*e.g.*, nurses, specialists), severe functional limita-

tions which often requires technology assistance (*e.g.*, G-tubes), presence of one or more complex chronic conditions, and high need for home care or congregate care [25, 30]. CLHC could include children with severe neurological conditions, functional impairment, genetic diseases that affect multiple systems, cancer survivors with ongoing disability, and others [25].

Although CLHC make up a small percentage of the pediatric population (1%), they have the highest resource utilization [18, 26]. Furthermore, this population has been one of the fastest growing pediatric populations due to increased survival rates of infants born prematurely and/or born with chronic conditions [11, 25, 71]; recently, they make up 10% of hospital admissions in Canada [30]. A report on CLHC in Canada indicates that in 2016, 38% were younger than 5 years and 32% received medical technology assistance [18]. On average, CLHC had 6 primary health care visits in a year, which is double that of children without medical complexity, and visited an average of 13 distinct sub-speciality physicians [18, 26]. CLHC with multiple conditions were more likely to have “long stays” (60 or more days) in the hospital, usually including time in the Intensive Care Unit (ICU) and accounting for 41% of these stays [18]. They also experienced recurrent readmission and have a higher 30-day readmission rate (average %32) even though they may receive better discharge planning [9, 26]. CLHC disproportionately use the majority of ICU resources in children’s hospitals [19]. In Canada’s most populous province of Ontario, the hospital care costs for CLHC was approximately \$850 million over two years, which can make up one third of child health spending. [18].

Treatments for CLHC often involves numerous rare and expensive medications which frequently must be administered by the parents. Data from BC shows that many children used 5 or more drug classes in one year and 14% used 10 or more drug classes [18].

2.2 The Care Burden

Through time, numerous studies have discussed, explained and researched the burden of care and challenges for caregivers of CLHC with almost no changes in their narration, indicating the stagnant response in the health care system to accommodate these caregivers. The reality has always been that society and the health care

system greatly rely on families to provide at-home and unpaid care for chronic conditions [18]; hence, a significant portion of family resources are used to tend to the multifaceted challenges of caregiving. Initially, frightened by all the aspects of their child's care, parents soon become experts who are attuned with their child's care needs and in fact provide training to other stakeholders [5, 57].

2.2.1 Parents Have Dual Roles

Parents often have dual roles as a parent and a caregiver. Some additional roles that are undertaken by parents could include managing documents, chairing team meetings, sitting on advisory councils, attending conferences to learn the latest developments in medicine, engaging with researchers, writing letters to government officials, training or orienting nurses and other stakeholders, keeping time sheets, scheduling appointments, communicating with stakeholders and so on [5, 57]. These parents often feel trauma, fatigue, frustration, anger, distress, depression and inability to continue to provide care [18]. Parents are often distressed from the uncertainty of their child's future and health status, the traumatic experiences of interactions with the health care system, and the responsibilities of care coordination [18, 27, 33].

2.2.2 Large Financial Impact

Financial impact on these families is large, as one parent is often out of the workforce [18, 41]. Financial difficulties and employment loss are also very common. Obtaining expensive medications, therapies, supplies and equipment for CLHC often involves numerous hours spent on writing and contacting government grants, charities or insurance plans. Even with these resources, many parents may pay out of pocket [18, 41].

2.2.3 Difficulty with Obtaining Resources

Obtaining resources is often challenging for parent caregivers. For example, finding after-hours care can be challenging and Emergency Departments (ED) offer one of the few options. However, visits to ED is very complicated as the staff are not familiar with the child and/or may not have the experience to treat the condition

and/or may not have the right equipment [18]. Families may sometimes rely on home care or respite care services (where parents will always be on call) which may not be available at all times nor have the staff with pediatric expertise [18]. Publicly covered complex care programs which provide specialized care and family support are very limited. This is often due to long wait lists and strict acceptance criteria. Often, parents and their care providers need to advocate extensively for the child to gain access to these programs [18].

2.2.4 Navigating the System Requires Experience

Patient and family-centred care (PFCC) is a standard model that puts the family as expert in the care of their child and emphasizes on maintaining collaborative relationships between the family and care providers. The key elements of this model are “honest information sharing to promote participatory decision making, collaboration across all levels of the healthcare delivery system and a strengths-based approach to working with patients and families” [6, 47, 64]. In other words, family-centered care means valuing parents’ knowledge, incorporating their expertise into clinical care and supporting their role as a caregiver [66]. However, the implementation of this model has been reportedly unsuccessful in terms of quality and family-centeredness of care as parents face barriers to full participation in the care [6]. In 2002, a study interviewed 30 families who cared for children with chronic conditions [57]. Parents regularly mentioned the concept of “working the system” or “navigating the system” and expressed frustration working with health, social and school services [5, 6, 33, 57]. Initially, this is due to “not knowing what to ask”, but, with experience parents became better at articulating their needs [57]. However, due to a lack of family-centered principles of care in the system, parents had to develop different skills such as advocacy, negotiation, lobbying, management and searching [57]. Parents also spent a significant amount of time searching for complete and correct information, people, resources or services which they immensely needed [45, 57].

2.2.5 Importance of Continuity of Care

Continuity of care is important since CLHC often rely on multiple independent speciality pediatricians to treat each symptom. It has been shown that continuity of care can improve CLHC's quality of life and can be related to satisfaction of caregivers with the medical system [14, 15, 48]. Continuity is described as having three main dimensions: relational continuity, informational continuity and management continuity. Relational continuity refers to ongoing relationship between patient and consistent care providers. Informational continuity is defined as the use of prior information to inform current care decisions for the individual. Management continuity refers to timely, coordinated, and consistent services that complement the care within a shared care plan [35, 48, 58]. Miller et al. and Leary et al. point out that communication is an important aspect of continuity and can be integral to relationship building and a positive experience [44, 48]. Furthermore, multiple conditions need to be considered when deciding on treatment plans for CLHC (*i.e.*, holistic care or comprehensive care) and this relies heavily on communication between care providers. However, gaps in informational and management continuity [48, 72], along with the complexity of care coordination and challenges with communication and collaboration between stakeholders poses barriers to holistic care [10, 30, 33].

2.2.6 Communication Challenges and Barriers to Continuity of Care

Challenges with communication can arise at different points in the health care system. Community practitioners and stakeholders may not have access to complete patient information [5, 30, 38]. This often can result in inconsistencies and errors in the information and produce voluminous records [30]. Challenges with information sharing can include a lack of a common platform, difficulty accessing the care plan, accountability for information and so on [55]. Therefore, families of CLHC prefer to see the same care providers as this may ensure continuity of care and better information sharing, however, fragmentation of care is still very common and families need to repeat their story to each provider [18, 33, 48, 54]. Moreover, in the current system, parents are seen as the main source of information and need to transmit information among stakeholders and assume responsibility for care co-

ordination [38, 41, 45, 48].

Developmental transition points may also cause breaks in continuity of care because care services may need be organized differently depending on the age of the child. At these transitions points (*e.g.*, school or adult care) extensive coordination and communication needs to happen. These transitions could mean that they are no longer eligible for supportive services and even with extensive planning, the results are often a break in the delivery of care [18, 30, 48].

Hospital-to-home transitions are often challenging for caregivers as they need reliable communication with care providers. Families often need to accurately identify and manage symptoms such as secretions and seizures at home [50, 57]. A feeding regiment is also essential to follow at home. Medication may be hard to obtain and challenges could include difficulties with insurance, inability to obtain specific types of medication, or dosage and storage confusions [44, 50]. Follow-up appointments are often necessary and usually need to be coordinated by the caregiver [30]. Medical supplies and equipment and home nursing may need to be obtained or arranged for at-home care [44, 50].

2.2.7 Information Needs of Parents

Ranade-Kharkar et al. studied the information needs of care coordinators and families to support care coordination of CYSHCN and reported on 6 information goal type: situation understanding, care networking, planning, tracking/monitoring, navigating the health care system, and learning [56]. The author points that current health information technology solutions cannot provide the support needed to meet these complex information needs [56]. For parents, the first item relates to “understanding of assessments and goals of clinicians throughout the care process”, the second item refers to “keeping a record of contact information of the care network and understanding their roles”, the third item refers to “planning episodes of care such as complex surgeries”, the fourth item refers to “tracking symptoms, diet and response to medications”, the fifth item refers to “supporting care processes for their child and obtaining resources”, and the last item refers learning about the correlations between medications, symptoms, treatments, alternative medications etc [56].

2.2.8 Takeaways

These parents often feel trauma, fatigue, frustration, anger, distress, depression and inability to continue to provide care [18]. Parents are often distressed from the uncertainty of their child's future and health status, the traumatic experiences of interactions with the health care system, and the responsibilities of care coordination [18, 27, 33]. The takeaways from this section are that the challenges of care for CLHC are multifaceted and intertwined, with communication challenges amplifying them. Although there are numerous studies exploring these care challenges for CLHC caregivers, limited research has been done to understand the challenges of a parent "care coordinator" in the space of information management. In this space, Berry et al. studied parents of children with tracheotomy¹ and notes the considerable work that is required to assimilate, share and communicate this information to overcome the communication challenges [8]. An identifiable gap within this literature is that it is unclear what task-specific challenges exist for parents of CLHC when undertaking the huge role of information managers. Furthermore, it is unclear which of these challenges parents would like to be assisted with through digitalization.

2.3 Caregiver Strategies

Previous research has aimed to understand strategies of parent caregivers in terms of care coordination responsibilities and information management. Golden and Nageswaran found that parents immensely prefer more information sharing and quality communication with care providers[33].

Parents often keep updated lists and home records which track their child's care to be shared with physicians and providers quickly [8, 33]. For example, parents of children with tracheotomy created notebooks with section dividers for each health domain while others may generate or keep computer based documents [8]. Many parents also extract information from paper records and keep a care plan summary which contains allergies, medication and home nursing orders [8]. Other activities related to care coordination include compiling records generated by stakeholders, identifying and summarizing key points, tracking appointments/tests/consultation-

¹A breathing tube placed in the trachea

s/referrals, maintaining awareness of updates and new events, and maintaining a list of hospitals and locations [38]. Sezgin et al. surveyed 85 parents and found that 69% used a dedicated notebook or paper to take notes for tracking symptoms and health events and 31% used a digital tool such as a health app or note-taking app [62]. 76% of parents believed mobile phone and apps are ideal tools for tracking symptoms and events at home. Following appointments was the highest ranked tracking activity followed by setting reminders and tracking symptoms [62].

Research has shown that care providers and parents often rely on e-mail, phone or mail to cross institutional boundaries; but these are time-consuming and laborious methods of communication [38]. Other problems with these methods of communication can include limits for group conversations, asynchronous communication, slow transfer of information which can affect care decisions, and documents that are not searchable [38].

Care providers and parents also create and rely on documents such as the care plan and the care map². The care plan is a medical document that serves as a summary of health care needs of CLHC [1]. This document helps with care transition, provision and coordination [3]. The health care team usually leads the creation of the care plan with some collaboration with the family. Depending on the degree of the collaboration, these care plans may become centered on the needs of health care providers; families may feel “negative” towards this document as it only describes the medical problems [3]. Care maps are documents that are created by the family which provide a snapshot, focus on the family experience and family life, and demonstrate the connections between stakeholders [2]. These documents have been viewed as complementary by care providers and caregivers where the care map can provide an introduction to the care plan [3]. Care providers have reported that their understanding of the family from the care map can impact the way they provided care [3]. In addition, care providers have noted that the care map shows the family care priorities which in return enhanced their compassion, and helped to tailor the care to the family’s capacity [2].

Just as for their challenges, there has been limited research to understand parent caregivers’ strategies with regards to information management. For example, what

²Appendix Section A.2 and Section A.1 provide examples for a care map and a care plan template

type of documents do parents create? and when do they feel the necessity to share them? What do they do (or prefer to do) with a specific type of information? Can aspects of the parent-created information such as the care map and the care plan, be used in a digital tool? These strategies are important to understand for the development of task-oriented prototypes which can be designed based on current caregivers' workflows and what is familiar to them.

2.4 Solutions and Existing Tools

Although the research is limited, but it has been suspected that accessible, continuous, comprehensive, coordinated, compassionate, and family-centered care for CLHC can greatly reduce the health care cost and improve outcomes [10, 46]. Furthermore, expanding the use of technology to create centralized, internet-based health records containing shared documents within a system that tracks access to the information has been proposed by care providers and parents [8].

Parents and care providers described the qualities of an ideal record as one that is the “ultimate source of truth” and is also viewable, editable, and accessible by all providers in different settings [8]. However, maintaining paper copies is important for families who may not have electronic access [55].

2.4.1 Electronic Health Records

Electronic health records have been widely used; however, the existing tools lack standardization, may not be helpful for care coordination and may lack information that is important for collaboration (*e.g.*, referrals, consultation reports, care team information) [38, 51, 68]. Additionally, Horsky et al. found that activities related to care coordination such as document abstraction, aggregation and interpretation were not well supported in current EHRs [38]. Horsky et al. proposes a care coordination model with possible integration with current EHRs and notes that a web-based tool should support the following tasks: “increased situation awareness by allowing plan, visit and event tracking, allowing medication and problem list updates via secure email and embedded links, provide a two-way patient-facing portal for care instructions and requests and integrating updated information such as medication changes with the primary EHR after a reconciliation and confirma-

tion process” [38].

2.4.2 Existing Tools

Using user-centered design, Kurahashi et al. developed a web-based clinical collaboration system, Loop, to facilitate collaboration between care providers. The system was tested by patients with chronic diseases, caregivers and care providers. Loop’s core functions are composing, posting and reading messages and these features received positive feedback from the users [42].

Voice-assistive (VA) technologies have been proposed as a solution and studies have tried to understand the caregivers’ perspectives and tested the feasibility of VAs for note-taking [61–63, 67].

Slagle et al. created a child-centered medication management system with a scheduling feature, text-message alerts, reminder system, and medication administration tracker which received positive feedback from the caregivers [65].

Cheng et al. used human-centered design methods to create and test a mobile app for enteral tube care (G-tube). The participants identified important app requirements such as a homepage, a child’s profile, viewing and managing other users, a nutrition plan, displaying care routines, reminders, tracking inventory and health data, caregiver communication and troubleshooting. This app received positive feedback and some of the benefits mentioned by the caregivers included: flexibility to manage time, providing confidence and peace of mind, simplifying life and reducing error, supporting the child as a person and not a diagnosis. Areas of improvement included tracking and viewing longitudinal health data, organizing and editing notes, personalizing information in the child profile and highlighting resources [20].

Telemedicine video visits with real-time interaction with care providers integrated into the EHR proved to be useful in terms of safety in post-hospitalization follow-up [59]. Telemedicine has also been useful for care coordination, scheduling joint speciality visits, and reducing potential infectious exposure during the Covid-19 pandemic [43].

Ming et al. evaluated the feasibility of mobile complex care plans (MCCPs) for CLHC and studied their impact on parent experience and care coordination.

The MCCPs were developed by the nurses and reviewed by physicians. The MCCPs were paperless, integrated into the EHR and allowed bidirectional information transfer. The updates to the MCCPs were transferred to the parents via the EHR’s patient portal. Parents in this study experienced better communication and understanding from care providers. They also reported reduced stress [49].

2.4.3 Existing Design Guidelines and Feature Preferences

Sezgin et al. provides a parent-ranked list of features for an ideal health app with tracking appointments and medications as two of the highest ranked and voice interactive engagement as the lowest ranked. We used this list and other works [4, 28, 29, 42, 60, 65, 70] to prepare a list of potential caregiver-preferred features which we used to collect more data and describe in Chapter 4.

Other research has also provided guidelines or user requirements for medical digital tools. For example Chute et al. presents a set of 14 common user requirements from reviewing co-design projects and contrasts them with previous works. Some of these include, “sharing the patient experiences and outcomes to improve care”, “joint visualizations of clinical and personal data to help me and others see patterns and trends over time”. Other researchers have also found tracking and insights to be valuable for patients with complex needs [12]. Chute and French argue that an individual’s health goes beyond what an electronic health record system holds and needs to include personal, social needs and lived experiences. The author proposes that to remove the burden of “health story” telling for the patients, the patients should be the main point of integration, where they can share their information across care providers and stakeholders.

Furthermore, Desai et al. has laid a groundwork for the user-centered design of cloud-based longitudinal care plans by interviewing parents of CLHC and care providers to understand their design preferences and content priorities (Figure 2.1) [28, 70]. Some of the high-level design guidelines from these works include having redundancies in the system, centralized, accessible where and when they need it, consistent, balance between security and access, and collaborative. Some of the lower-level user requirements include table layout with search/sort/filter, familiar yet customizable layout and control over permission settings [28, 29] (Table 2.1).

We rely on these content priorities from Figure 2.1 and design guidelines from Table 2.1 in later chapters for building the prototype and developing our design principles.

Table 2.1: Combined design guidelines and requirements from caregivers and providers. Reprinted from Desai et al. [28, 29]

#	Design Guideline and Requirements from Caregivers and Providers
1	Familiar yet customizable layout
2	Problem-based content organization
3	Redundancies built into the platform
4	Table layout with search, sort, and filter functionality
5	Balance of structured versus unstructured data fields
6	Clear and family-centered terminology
7	Accessible where/when they need it
8	Find information quickly within the care plan
9	User-centered
10	Collaborative (Team leader, contributors, HIT system, messaging system)
11	Balance between access versus security
12	Control over permission settings

2.4.4 Takeaways

In summary, there are currently existing research-based and commercial tools which support different challenges with caregiving and care coordination duties for CLHC or other populations. However, limited research has been done to understand what design principles these technologies (or future ones) could use to increase their utility for caregivers. Also, no research has been done that implements these design guidelines into a caregiver-centered and working product.

<p>Profile header</p> <ul style="list-style-type: none"> • Name • Photo at baseline • Date of birth • Age • Sex • Hospital MRN • Code status • Allergies • Current weight • Language preference • Insurance provider <p>Emergency care plan</p> <ul style="list-style-type: none"> • Resuscitation/Stabilization • Airway • Breathing • Circulation • Other • My baseline^a • Baseline vitals • Baseline exam • Baseline symptoms • Tips for successful interactions with me^a <p>Active Issues List</p> <ul style="list-style-type: none"> • Active issue • Relevant subspecialties • Status <p>Active Issues Page</p> <ul style="list-style-type: none"> • Sick plan • Baseline management plan • Medical history^a • Medications^a • Care team^a • Appointments^a • Action items^a • Equipment^a • Memos <p>Medical history</p> <ul style="list-style-type: none"> • Date of event • Event • Clinical note • Linked active issues^b 	<p>Medication list</p> <ul style="list-style-type: none"> • Specialty • Medication name • Concentration • Directions • Prescriber • Notes • Linked active issues^b <p>Care team</p> <ul style="list-style-type: none"> • Specialty • Name • Role • Location • Phone • Linked active issues^b <p>Appointments/Referrals</p> <ul style="list-style-type: none"> • Specialty • Provider • Clinic/location • Last seen • Next scheduled • Notes • Linked active issues^b <p>Care goals/Questions</p> <ul style="list-style-type: none"> • Top health concerns • Care goals • Questions for the team • Linked active issues^b <p>Action items</p> <ul style="list-style-type: none"> • Date posted • Specialty • Action item description • Assigned to • Due by • Status • Notes • Linked active issues^b <p>Developmental/Community Services</p> <ul style="list-style-type: none"> • Therapy plan/goals • School services • Community resources 	<p>Diet and nutrition</p> <ul style="list-style-type: none"> • Route • Diet/Formula • Formula recipe • Formula rate • Notes • Linked active issues^b <p>Medical equipment</p> <ul style="list-style-type: none"> • Specialty • Equipment name • Vendor/company • Ordered by • Ordered on • Notes • Linked active issues^b <p>About me</p> <ul style="list-style-type: none"> • Home life • Other things to know about me • Tips for successful interactions with me • My baseline • Baseline vitals • Baseline exam • Baseline symptoms <p>Daily schedule</p> <ul style="list-style-type: none"> • Time • Task <p>Family notes</p> <ul style="list-style-type: none"> • Memos • Uploaded documents
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Figure 2.1: Combined care provider and caregiver content priorities for longitudinal care plans. Reprinted from Desai et al. [29].

Chapter 3

Data Collection Methods

In this work, we utilized an iterative design process with multiple user studies. This chapter will provide an overview of our recruitment process and data collection methods for each of the three user studies (Requirement Elicitation Interviews, Low-Fidelity and Med-Fidelity Design Feedback Interviews).

To recruit participants, we consulted the same broad pool of caregivers of CLHC for all three user studies. This pool is singularly difficult to access due to their own life complexity. Rather than making three separate participation calls, we maintained ongoing recruitment for the duration of the research and involved as many participants as possible during each phase's timeframe. Throughout, we used the same recruitment practices, detailed in Section 3.1.

3.1 Ongoing Participant Recruitment Process

This population (*i.e.*, caregivers, guardians or parents of CLHC whose child is currently living) was chosen due to their child's complex health needs which is much higher than other children who require pediatric health care. Other children and their families may be less exposed to the fragmentation of the health care system and the associated challenges with communication and data access/management. These parents caregivers have first-hand experience and thus the best insights into the information management and care coordination process and have devised strategies to handle these responsibilities on a daily basis.

These parents are already burdened with care and have very busy lives. In an effort to minimize intrusion and because of the typical difficulty of recruiting members of this population, we utilized opportunity sampling. We recruited participants through social media platforms, such as a Facebook group that is specific to parents of CLHC. We also recruited through a local children’s hospice e-mail list. We consulted the same pool of caregivers for all of the user studies and had ongoing recruitment. Participants received \$15 compensation for every hour of participation in the interviews. Group A parent participants were enrolled in Requirement Elicitation interviews, Group B participants were enrolled in Low-Fidelity Design feedback interviews and Group C participants were enrolled in Med-Fidelity Design feedback interviews (Figure 1.2). Two participants from Group A were motivated to also participate in Low-Fidelity Design feedback interviews.

3.2 Explore: Demographics, Feature Preferences, Characteristics, User Scenarios

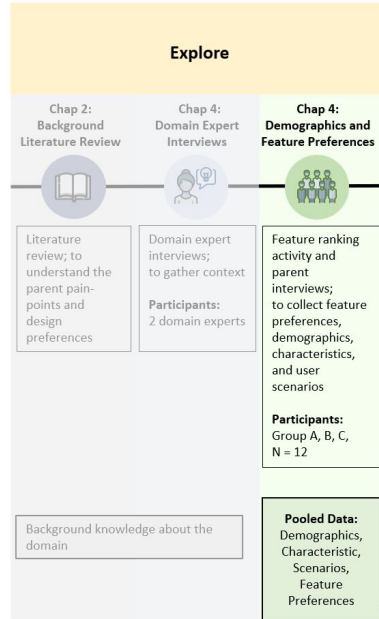


Figure 3.1: Demographics and Feature Preferences showing the pooled data from Groups A, B and C.

Figure 3.1 provides an overview of our data collection process. We collected and pooled data on participant demographics, feature preferences, characteristics, and user described scenarios which is presented in **Chapter 4**. The feature preferences data was collected at the end of interviews from all three study stages, (*i.e.*, from Groups A, B and C), during the feature ranking activity.

The feature ranking activity required the participants to rank a list of features based on its importance on a scale of 0 to 4 where 0 is “not important” and 4 is “very important” (Figure 4.1). We also presented the participants with an “Irrelevant bin” option for categorizing the features that were not relevant to their situation. We encouraged the participants to share a real life scenario where that feature would be useful or important which are summarized in Table 4.4. The participant characteristics were also pooled for all groups and are presented in Table 4.2.

3.3 Conceptualize: Requirement Elicitation Interviews and Low-Fidelity Design Feedback

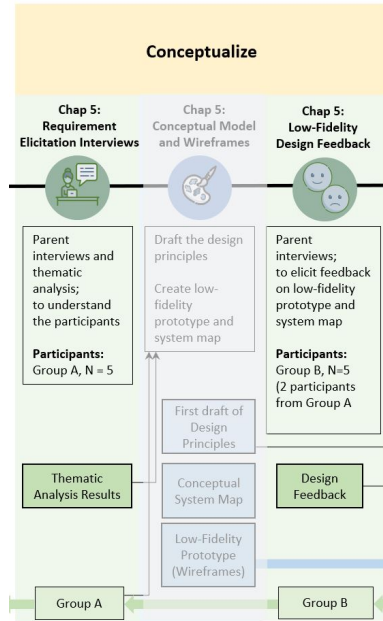


Figure 3.2: Requirement Elicitation Interviews with Group A and Low-Fidelity Design Feedback with Group B participants.

This section will describe the protocol for Requirement Elicitation Interviews and the Low-Fidelity Design Feedback (Figure 3.2).

3.3.1 Requirement Elicitation Interviews

In the Conceptualize phase (**Chapter 5**), the goal of our first user study with parent caregivers, described in **Section 5.1**, was to understand parent challenges and strategies.

To gain a better understanding of the parent caregivers, we conducted a user study with 5 participants (Group A). All the interview sessions were conducted remotely on Zoom. Each session was planned for 1 hour and the interviews were recorded and then transcribed manually. The interview questions were devised to be open-ended and the interviewer asked additional follow-up questions if participants appeared to put emphasis on certain subjects. The participants were asked about their challenges, workflows and strategies for organizing medical information. The interview questions included topics such as information management challenges and care coordination strategies (*e.g.*, medication information, appointments, medical equipment, feeding times etc). Additionally, they were also asked about tracking symptoms, language barriers, updating information, and searching for information. At the end of each interview, the participants completed the feature ranking activity.

The questions for the Requirement Elicitation Interviews are supplied in Section B.3.

3.3.2 Low-Fidelity Design Feedback

The goal of the subsequent user study in the Conceptualize phase (**Section 5.4**), was to get high-level feedback from the caregivers.

To elicit feedback on our prototypes, we interviewed five parents from Group B for feedback on the low-fidelity prototype. We followed the same protocol as Section 3.3.1. Two participants from group A were motivated to participate again in this phase. Cognitive walkthroughs were performed within the research team to ensure the stability and clarity of the prototypes before the interviews.

A technique that was used previously by Desai et al. was to get the participants

to sketch a design of the user interface. We avoided using these types of techniques due to the complex nature of the task and time limitations for the interviews.

Interview Sequence

At the beginning of each interview session, participants were asked similar but more close-ended questions about their challenges and strategies. Then they were presented with the conceptual system map (Figure 5.3). For Group B, more time was spent exploring the system map and they were asked whether anything should be added. Then, the participants were shown various sections of the wireframes which we felt would be more important to the participants based on what was discussed during the interview. All participants were encouraged to “think aloud” while looking at the prototypes.

At the end of each interview, we also asked the participants to complete the feature ranking activity.

The interview questions for the Low-Fidelity Design Feedback are supplied in Section B.4.

3.4 Refine: Med-Fidelity Design Feedback

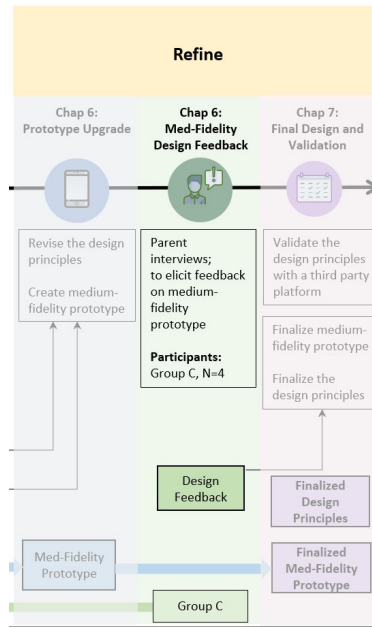


Figure 3.3: Med-Fidelity Design Feedback with Group C participants.

The goal of the next user study in the Refine phase, described in **Chapter 6**, was to get the caregivers’ feedback on our medium-fidelity prototype design (Figure 3.3).

To elicit feedback on our med-Fidelity design, we interviewed four parents from group C. We followed the same data collection protocol as Section 3.3.1 and the same interview sequence as Low-Fidelity Design feedback. For Group C, the system map was only shown as an overview of the prototype. Also, the participants walked through an implemented feature (*e.g.*, adding a symptom) with the interviewer, and they were asked to provide their thoughts on the utility of the feature, menu options, buttons, colors, navigation and whether the feature made sense.

Similar to Groups A and B, at the end of each interview, the participants also completed the feature ranking activity.

The interview questions for Med-Fidelity Design Feedback are supplied in Section B.5.

Chapter 4

Understanding Caregivers and Utilizing Domain Experts

In Section 4.1, we will discuss the input from two domain experts and engagement with TrustSphere which helped to frame and contextualize the problem. Then we will describe the pooled participant demographics and characteristics data. In the interviews conducted at each of our three user studies, we asked participants to rank the importance of features that might be included in an information management tool intended to support them. We describe the results of this cross-phase data in Section 4.3 and provide the parent described scenarios in Section 4.3.3.

4.1 Expert Input

During the Explore phase, we conducted two expert interviews (1 hour each) to understand the problem space with electronic health records, health information management and parent challenges.

4.1.1 Health Informatics Expert

The first interview was with a senior researcher with expertise in informatics who leads the digital health stream in a provincial pediatric research institute¹. The aim of this interview was to understand the current landscape of Electronic Health

¹Dr. Elodie Portales-Casmar

Records (EHRs). The main takeaways from this interview were:

1. Currently, most of the clinical data is on paper and Cerner² is usually used for registration and scheduling; only some clinics may use Cerner to store other data.
2. CST³ will not include all health authorities in BC, for example, Fraser Health is not included.
3. The care network and electronic medical records is very complex and may be in many different formats (PDFs, papers, charts etc.) and use different storage systems (Microsoft Access databases⁴ or RedCap⁵).
4. The transition to a centralized database, which started in fall 2021, will be slow due to limited resources.
5. The transition may not include historical records; it will include records from the system roll-out date.

4.1.2 Clinical Pediatrician Expert

The second interview was with a clinical pediatrician and clinical professor who leads a community-based hospice facility that cares for and supports CLHC and their families⁶. The aim of this interview was to use the pediatrician's expertise from real life situations and understand how the hospice facility functions in terms of management of health records and communication. We also wanted to get feedback on the map in Figure 1.1 and discuss ways of engaging and recruiting participants. The main takeaways from this interview were:

1. There are huge communication gaps in the network and there can be completely isolated "islands" of stakeholders in the community.

²A cloud-based Electronic Health Records platform built by Cerner Corporation

³The Clinical Systems Transformation project which aims to establish integrated plans of care and common electronic health records. The transformation will be accomplished by replacing existing systems with CST Cerner

⁴A database management system from Microsoft

⁵A web application for building and managing online surveys

⁶Dr. Hal Siden

2. Too much data gets sent to clinicians and they are simply limited by time to read it.
3. A big challenge is to take design principles and guidelines and make them into something that can work.
4. Another challenge is getting each person in the network only the information they need and in the way they need to see it.
5. Many digital health tools and apps are made but they do not have uptake.
6. Paper is actually sometimes more functional than EHR.

The clinician also echoed challenges that parents face for example:

1. Parents just want to be parents and they don't want to be managers.
2. Parents want to know who is in charge within the complex care network.
3. Access to personal health records is impossible for parents but highly needed.

Lastly, they discussed successful strategies that works within their respite facility such as:

1. Tight team of people and staff who work very closely.
2. Continuous and 24/7 communication with the family.
3. Complete access to health records.

This expert also identified channels of recruitment and highly encouraged our team to engage and talk with parent caregivers before designing any solutions.

4.1.3 TrustSphere Engagement

We had ongoing engagement with TrustSphere in the form of resource sharing. TrustSphere is a digital technology research cluster in the process of building a layer on top of CST as an experimental interface for diabetic patients through user-centered design methods. This engagement became important as we realized that developing a working patient-facing interface which contains health records is

complicated due to the multifaceted challenges with patient confidentiality, privacy and data security. These challenges are sometimes unanswered, and often require a legal framework with limited solutions or guidelines available. Therefore, we decided to sidestep the concerns with confidentiality in our design process. We also realized the potential for initiating change in the health care system starting with a well designed prototype or Minimum Viable Product (MVP).

4.1.4 Co-supervisor Domain Expert

The co-supervisor domain expert was involved in all phases of the study and has expertise as a clinical Occupational Therapist in the Neonatal Intensive Care Unit and is an investigator at the local children's hospital⁷. They provided ongoing guidance for this study based on their extensive experience working with different pediatric populations and their families. This input and feedback was very valuable in understanding the participant caregivers, designing the prototype and devising the design principles.

4.1.5 Takeaways

Overall, the interviews and expert input helped to find participant recruitment avenues, ground the problem and realize the complexity of the current challenges. They also pushed our design approach towards a more forward looking and futuristic solution where we made assumptions about future developments towards the centralized data infrastructures.

4.2 Participant Demographics and Characteristics

In this section, we will present the data on our parent participants demographics and characteristics as collected through all three user studies and described in Chapter 5 and Chapter 6.

⁷Dr. Liisa Holsti

4.2.1 Demographics

Table 4.1 summarizes participant demographics from each participant group (A, B, C) and all of them combined.

We highlight several key observations. All participants identified themselves as mothers of CLHC (question 4). An overlap between Group A and Group B is that they share two participants; one of these participants had moved their child to a group home and their primary language was not English. In Group C, one participant had a foster parent for their child. Although these children did not reside with the parents, both of the parents were in constant communication with their child's caregivers.

Based on the ratings, most participants relied on technology an average amount, and only one participant in Group A scored their reliance on technology as a 10 (question 6). Participants in all groups were relatively very comfortable with using digital technology and smart phones (question 8 and 9).

4.2.2 Characteristics

Answers to some of the interview questions are summarized in Table 4.2. Some characteristics of the parent participants, such as the types of technologies that they use, their concerns with regards to security of information and their methods of organizing information were collected. Some parents were not able to clearly explain their concerns with regards to security of medical information. Three participants were not very concerned with regards to security and confidentiality and wanted their information to be shared as easily as possible. One of these participants stated that "*We are a big open book*". One parent mentioned that they do not rely on any technologies for question 1. Two parents read what they included in a document called the "parent care plan" which they created and shared with stakeholders (question 4). Two parents also said that they have had no language barriers and people explained things very well (question 11).

We also asked some questions about how parents organize the child's medical information. The answers to these questions were very similar for each participant, therefore we did not include these in Table 4.2. In summary, the parents use a combination of physical tools such as binders, folders, summaries, notes, and digital

tools such as spreadsheets, and computer folders. One of the most commonly used tool was the calendar; in paper format and a digital format.

After some interviews, it became apparent that parents are creating and updating many of the documents mentioned in the interview (parent care plan, school communication book, About Me book, symptom logs etc). Parents may use different formats (paper or digital) without a consistent template and they may include customized information within them. The document names were also used interchangeably, for example, some parents referred to creating an “About Me” book, while others referred to an “interactions/communications dictionary”. We also quickly realized that “symptoms” is not the only category of items being tracked; parents were also tracking other variables such as nutrition, behavioral issues, injuries, amount of exercise etc. Additionally, some parents mentioned tracking these using the communication book for school.

Finally, it is important to note that the list of technologies utilized by parents and mentioned in this table (question 1) could be dependent on the geographical location of the family and the parent comfort level with using technology⁸.

⁸The geographical location can affect the technologies available to the parents depending on the local/provincial/regional health authority

Table 4.1: Participant demographics information. Group A were enrolled in Requirement Elicitation interviews, Group B provided feedback for Low-Fidelity Prototype and Group C for Med-Fidelity prototype. Two participants from Group A are also counted in Group B, but only counted once for All Groups.

#	Demographics questions:	Group A N = 5			Group B N = 5			Group C N = 4			All Groups N = 12		
		Mean	SD	N	Mean	SD	N	Mean	SD	N	Mean	SD	N
1	Average age (years)	42.6	4.6	5	42.6	6.3	5	43.5	13.5	4	42.4	8.3	12
2	Average age of the child with medical complexity (years)	12	3.9	5	11	5.4	5	8.8	7.4	4	10.1	5.5	12
3	Do you currently manage the child's data?												
	- Yes			4			4			3			10
	- No			1			1			1			2
4	What is your relationship with the child?												
	- Mother			5			5			4			12
	- Father			0			0			0			0
5	Is English your family's primary language?												
	- Yes			4			4			4			11
	- No			1			1			0			1
6	To what extent do you rely on digital technology to organize your child's health information on a scale of 0-10?	6.4	2.9	5	5	1.3	5	5.3	3.7	4	5.5	2.7	5
7	Would you rely more on technology if the tools were better?												
	- Yes			5			5			4			12
	- No			0			0			0			0
8	How comfortable are you with using digital technology on a scale of 0-10?	9.0	1.4	5	8.9	1.8	5	9.5	1.0	4	9.0	1.4	5
9	How comfortable are you with using smart phones on a scale of 0-10?	9.8	0.4	5	9.7	0.9	5	9.5	1.0	4	9.6	0.8	5
10	How skilled are you with organizing information electronically on a scale of 0-10?	6.6	3.9	5	7.0	3.9	5	8.5	1.0	4	7.8	2.6	5
11	How important is it for your family to have security of medical information on a scale of 0-10?	7.6	2.5	5	6.7	3.1	5	7.8	2.6	4	7.4	2.6	5
12	How important is it for your family to share medical information on a scale of 0-10?	9.2	1.1	5	10	0.9	5	9.8	0.5	4	9.6	0.8	5

Table 4.2: Summary of participant characteristics. Responses to open-ended questions are pooled together for all participant groups (A-C). N indicates the number of participants who provided an answer.

#	Interview Question	Combined Answers (N = 12):	N
1	What are the technologies that you rely on?	Email to get files sent or make appointments, calendar app, notes app, My e-Health, Zoom for some appointments, phone, text messages, spreadsheets, Google Docs, Pain app, Microsoft Word, PowerPoint, digital archives system for tests and X-rays, hospital records system, My Chart, email for doctor notes or reports, My Booklet BC, digital nursing charts, nursing orders, graphs, scanner, phone calendar	12
2	What are your concerns with regards to security of medical information?	Ensuring everything is correct and no misplaced information, have password protection, privacy and access, phishing or scam, privacy leaks, want to give access permission, information getting into the wrong hands, confidentiality, No concerns we want to share our information	12
3	Does it make sense for all your child's information to be accessed digitally?	Would love it to be digital, should have happened years ago, I prefer if everything is digital and nothing in the mail or somewhere that I can forget, it would save time and money for a lot of people, it would be the easiest way, it is realistic and needed	12
4	What do you include in the parent care plan?	Dates of hospital admissions, diagnosis, when things happened, when medications started, current medication and doses, mobility, equipment list, how to interact with the child, expectations for support workers, how to use equipment and troubleshoot, seizure protocol, care team names, major surgeries, a general overview, contact information, family contacts, how to administer medications, feeding plan, water intake, signs of distress (protocol, triggers, prevention), daily living (drooling, dressing, toileting), play/leisure activities, sleep, favorite activities, positioning and movement (transfers, sitting, crawling, standing, walking, mobility), communication	2
5	What is most challenging about dealing with large volume of health records?	Organizing, keeping reminders, signing things, filling-out papers, a lot of re-referring, a lot of emailing, a lot of keeping up to date, not having access, remembering where everything is, different logins, requesting funding, putting information together from different sources, knowing what is outdated, finding things, some doctors use digital communication and other doctors don't, number of people involved, explaining the information all the time	12
6	How do you access information in an emergency?	Email doctors or their office assistant, rely on the emergency staff to look at the child's records, I have most of it memorized, phone nurse clinician or complex needs social worker, they have all the records at children's hospital	5
7	What is in the child's communications book for school?	Food intake, input/output of water, how much movement they had and how they were moved during the day, fatigue, behavior, whether medication has been given, what happened at school, digestive issues, daily schedule and medication schedule, what educational material they worked on, seizure protocol, injuries	6
8	What is in the child's interactions/ communications dictionary/ About Me book?	How they eat and walk, language and what a sign means, how to read their body language, likes/dislikes, favorite color, short biography, what it looks like when they are feeling a certain way, child's interests, pictures, what does a look mean, what does crying/scratching mean, postures, gestures, expressions, communication devices, sounds, communication toys	6
9	How do you track symptoms?	In the communications book, calendar or phone, paper, use an app called Symple, graph ins/outs, seizure tracker, keep a log before specialist appointments, nurses track them, just watch them, symptom tracker	9
10	What symptoms do you track?	Pain, menstruation, diet, mood, medication side effects, abdominal pain, back pain, bladder pain, bladder spasm, chills, constipation, diarrhea, fever, gasping, headache, heartburn, irritable let pain, low appetite, muscle twitches, nausea, sleep, nutrition, seizures, bowel movements, urine output, oxygen saturation, temperature, respiratory rate, heart rate, blood pressure, headaches, visual disturbances, fatigue, fever, behavioral issues, how to resolve symptom	10
11	Have you ever had language barriers?	In the beginning, surgeons talk very fast and technical, you have to talk in "care providers' language", I have a pronunciation problem, medical jargon, some people explained everything	8
12	What are the most important attributes of an ideal tool or technology?	An online portal that can be accessed by multiple people, accessible on-the-go on my phone, no need to remember passwords, capture documents, take pictures, have a medical history that presents the full picture, ease of organization, search, have visualizations for ins/outs, have everything in one place, have a calendar, have a contacts list, a place to store therapy information, information for equipment delivery, access to consults and EHR, access to information about diagnosis and medical imaging, medical records should be automatically sent to parents, customizable	10

4.3 Feature Preferences and Ranking

At the end of every parent interview conducted throughout the research (Groups A, B and C), we asked the participants to complete the “feature ranking activity” where they ranked a list of preferred features based on their importance.

4.3.1 Procedure

We created an initial list of possible features based on previous research on the same (or similar) population and co-supervisor expert input [4, 28, 29, 42, 60, 62, 65, 70]. We placed this activity towards the end of the interviews so that parents would do this ranking having been primed to think about features by the preceding discussion. This activity was set up on a Miro board [52].

Figure 4.1 shows the setup for the feature ranking activity; the importance scale is 0-4 where 0 is “not important”, 2 is “somewhat important” and 4 is “very important”. The “Irrelevant bin” is for any features that the participants believed would not be relevant to their situation (grey box). Finally, we asked the participants to explain their ranking for each feature and/or to provide a scenario where that feature could be useful and add any additional missing features that is important for them Table 4.4.

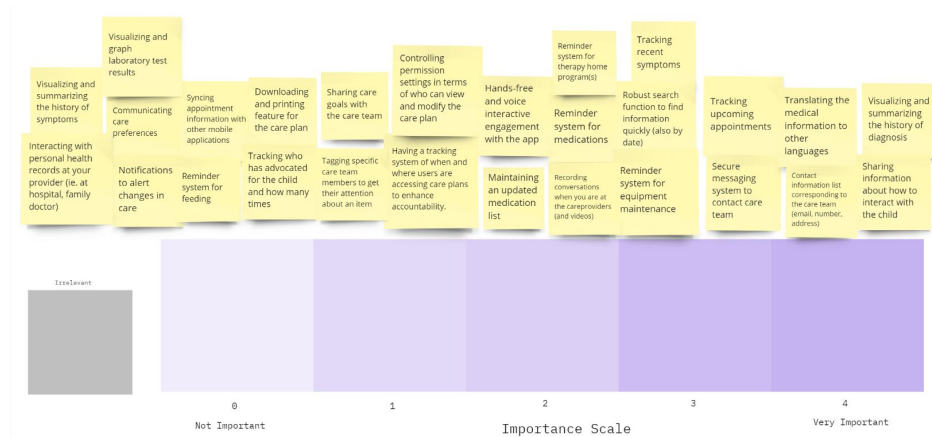


Figure 4.1: The set-up for feature ranking activity on the Miro board. The Irrelevant bin is represented as the grey box on the left.

4.3.2 Feature Ranking Activity Results

Figure 3.1 summarizes the results from the feature preferences ranking activity. In this case, we pooled the results as Group A, and All Groups: the first is what we had as we began our Conceptualize design phase (Chapter 5), and the latter was available as we finalized our Design Principles (Chapter 7). The table is sorted based on All Group rankings and contains all the items that were ranked. We have placed item number 27 as the last item because it was only ranked by the participant who did not speak English and was not ranked by other participants (*i.e.*, placed into “Irrelevant bin”).

Overall, many of the items on this list (19/27) had a mean of greater than or equal to 3.00 (pink rows in the table). At the beginning of the activity, some participants asked if it is possible to “*put everything in Very important bin*”, but later decided that some things could be ranked lower. Item rank 20 (Tracking who has advocated for the child and how many times) was added by the first participant.

The rankings between Group A and All Groups were fairly consistent with some minor differences. A notable difference is between the mean for item rank 6 (Sharing information about how to interact with the child) between Group A (4.00) and all groups (3.82).

Tracking

In terms of “Tracking” things, the most important features were tracking upcoming appointments (rank 2) and tracking recent symptoms (rank 7). There were mixed opinions for the feature to track who has advocated for the child; some parents found this very important, and others were unsure about the meaning or how it could be achieved.

Communication and Collaboration

In terms of communication and collaboration with the care team and stakeholders, “maintaining a contact information list which corresponds to care providers” (rank 1) is ranked as very important by all participants. Participants expressed that it is very difficult and time consuming to keep track of changes in care providers’ contact information. Participants also felt that it is important to be able to interact,

in real-time, with their health records at the care provider (rank 4). They mentioned that this will allow them to show important details, take notes and make changes. Some parents expressed excitement about a secure messaging system (rank 13) and the ability to tag specific care team members to get their attention about an item (rank 17). Recording conversations at care providers was important for some parents, however, others had mixed opinions (rank 25).

Visualizing

The features related to visualizing were all ranked relatively high (9, 10, 16). Parents also found the features related to setting reminders somewhat useful (rank 14, 18, 19). However, some participants expressed that some tasks became routine and they do not need reminders for these tasks (*e.g.*, reminder system for feeding - rank 22).

Others Features

Maintaining an updated medication list (rank 3) and a robust search function (rank 5) were highly ranked. The ability to share information about how to interact with the child was very important, especially for parents whose child is non-verbal (rank 6).

For older children, parents mentioned creating the “About Me” book to share with the school and their care team as a way of introducing their child. One parent of a younger child was unsure if this would be useful, but felt that it could be needed later.

Downloading and printing feature was important to some parents who wanted flexibility in the data format and felt that care providers are more likely to respond to paper documents (rank 12). One parent stated that “*care practitioners may not like to see me on the phone*”.

Some parents expressed excitement about the ability to sync appointment information with other mobile applications as they were annoyed with having to use multiple applications (rank 15). A few parents were uncertain about the meaning of “Notifications to alert changes in care” (rank 23). The feature for voice interaction with the app was ranked the lowest (rank 26). Translating medical information to

other languages was only ranked as “Very important” by the parent whose primary language was not English. However, the parents who did not rank this item emphasized that this feature could be very important to non-English speakers and travelers (rank 27).

Additional Features Added by Participants

At the end of the activity, participants were asked to add additional missing features to the activity board. However, these features do not have a ranking because not all the participants had the opportunity to rank them.

One participant added multiple items: nursing charts (frequency of breathing, heart rate, seizures), inventory for supplies (checklist, contact information, frequency of ordering, automatic ordering, date of next order), list of medications indicating what is covered under insurance, collaborative goals with school, viewing and making nursing orders, viewing prescriptions.

Another parent noted to add a section for school which includes the Individual Education Plan (IEP) and allows the therapists to link together and collaborate. One parent also wanted to record videos at their care provider in addition to recording conversations.

One participant wanted to include a list of medical equipment which contains serial number, time of receiving, who to call when it malfunctions, cleaning supplies. Another participant added “applications for grants that are linked to charities” (including doctors, or care provider communications).

Table 4.3: Feature preferences based on the caregiver-ranked importance of the feature on a scale of 0-4 where 0 is “Not important”, and 4 is “Very important”. Items that appear with lower than 12 participants were not ranked by all participants because the item was not relevant to their situation and they placed the item in the “Irrelevant bin”. The table is sorted based on All Group Mean column. Pink indicates the features with more than and equal to mean 3.00. Purple indicates the features that were highly ranked in Group A. Green indicates the features that were highly ranked in Group A and we prioritized for adding to the prototype.

Rank	Task/Feature	Group A Total N = 5			All Groups Total N = 12		
		Mean	SD	N	Mean	SD	N
1	Maintaining a contact information corresponding to care providers (e-mails, numbers, address)	4.00	0.00	5	4.00	0.00	12
2	Tracking upcoming appointments	3.80	0.45	5	3.92	0.29	12
3	Maintaining an updated medication list	3.80	0.45	5	3.92	0.29	12
4	Interacting with personal health records at your provider (ie. at hospital, family doctor)	4.00	0.00	4	3.91	0.30	11
5	Robust search function to find information quickly	3.80	0.45	5	3.83	0.39	12
6	Sharing information about how to interact with the child	4.00	0.00	5	3.82	0.40	11
7	Tracking recent symptoms	3.40	0.55	5	3.75	0.45	12
8	Controlling permission settings in terms of who can view and modify the care plan	4.00	0.00	5	3.75	0.45	12
9	Visualizing and summarizing the history of symptoms	3.40	0.55	5	3.58	0.51	12
10	Visualizing and summarizing the history of diagnosis	3.20	0.84	5	3.50	0.67	12
11	Outlining care goals to promote shared decision making	3.20	0.84	5	3.42	0.67	12
12	Downloading and printing feature for the care plan	3.20	1.10	5	3.42	0.79	12
13	Secure messaging system to contact care team members	3.80	0.45	5	3.42	0.90	12
14	Reminder system for medications	3.40	0.55	5	3.42	0.67	12
15	Syncing appointment information with other mobile applications (eg. personal calendar)	3.60	0.55	5	3.33	0.78	12
16	Visualizing and graphing laboratory test results	3.20	0.45	5	3.25	0.75	12
17	Tagging specific team members to get their attention about an item	3.20	0.84	5	3.25	0.97	12
18	Reminder system for therapy home program(s)	3.00	0.71	5	3.25	0.97	12
19	Reminder system for equipment maintenance	3.00	1.00	5	3.18	0.75	11
20	Tracking who has advocated for the child and how many times (e-mailing charities or government grants)	2.80	1.30	5	2.90	1.20	10
21	Saring care preferences with the care team	2.40	0.55	5	2.83	0.72	12
22	Reminder system for feeding	2.75	1.26	4	2.78	1.39	9
23	Notifications to alert changes in care	2.60	1.67	5	2.75	1.48	12
24	Tracking when and where users are accessing the care plan	2.20	1.10	5	2.75	0.97	12
25	Recording conversations at care provider	2.80	1.30	5	2.75	1.14	12
26	Hands-free and voice interactive engagement with the app	2.20	1.30	5	1.45	1.21	11
27	Translating the medical information to other languages	4.00	-	1	4.00	-	1

4.3.3 Features and Scenario Examples

Throughout the interviews, parents were sometimes asked to provide a reason for their feature ranking. We created Table 4.4 to provide context for when a feature could be useful based on the parent described scenarios. Parents did not provide scenarios for all the features, so we have only included the ones with scenarios and significance to our design steps.

4.3.4 Takeaways

The characteristics information and the feature ranking data were very rich, and narrowing down the most important things for parents proved to be challenging. For example, the stories provided in the context of tracking symptoms, visualizing and summarizing them, the current method of tracking these variables (on paper or spreadsheets) as well as their high rank, seemed to suggest a digital solution which can accommodate these tasks could be very useful. Another highly ranked feature was “Sharing information about how to interact with the child” in Group A, which corresponded to “About Me” books and “Communication Dictionaries”, which parents created to share with others.

Table 4.4: Scenarios described by parents about each feature to provide context for how it could be useful in real life.

Task/Feature	Parent Described Scenarios
Tracking recent symptoms	“I was able to correlate [mood] to the medicine [they] were taking and then we took [my child] off this because it’s creating all these side effects so when we took [my child] off the meds, then we did see an improvement... and that’s mainly what I’m tracking, the correlations.”
Tracking who has advocated for the child and how many times	“It is important to be able to keep track of how many times the doctors or social worker have asked for a certain thing that the government will be providing”
	“This is important, and should be somewhere that multiple people can view it. For example, be able to view when charities approve the application, or if therapist or doctor needs to send in a letter ...”
Interacting with personal health records at your care provider (e.g., at hospital, family doctor)	“I usually need to go to the beginning of time and start talking forever. But since they had all the information, we were pointing, what’s happening right now and how it related to the prior hospital stay. It was easier to communicate with the health care providers.”
Visualizing and summarizing the history of symptoms	”Our [child] has really low platelets and some of it is medicine induced... and there’s a medication for reflux that causes low platelets as a side effect but we never realized this until he was off the medication .. and now we put them back on and we noticed the same symptoms of low platelets. So then we compared the time that [child] was on it and when [child] was not... that’s what’s great about it. Also, it can be helpful for getting a special medical equipment“
	“When you talk to doctors, they don’t want to see stacks of paper ... they want to see trends and a correlation... this way they can make a quicker diagnosis. So that’s why I made PowerPoint presentations, which are very similar to a medical education presentation in rounds. I showed them the graphs and pie charts and the trends and I was able to communicate with the doctors. Um, but if you just show data on a symptom tracking app, it’s not going to do anything. you have to actually translate that into some sort of graphing... ”
Visualizing and summarizing the history of diagnosis	“Be able to see the progression of diagnosis on medical images”
Visualizing and graphing laboratory test results	“For example, my [child] gets iron infusions through IV. So we have to do a blood test a day before iron infusions and a blood test a month after...So, if I am able to see that the laboratory tests says iron has gone up or not, then I can decide if I need to make the iron infusion appointment”
Robust search function to find information quickly	“Just search a word – so I could search blood work and see every lab or I could search a social worker, a keyword or a date and see every aspect... I prefer the way Google is, you can make it as broad or as detailed as you need to be”
Sharing information about how to interact with the child	“My child is nonverbal but she communicates with gestures, signs and NOVA Chat so it would be really helpful to share this information”
Downloading and printing feature for the care plan	“It’s good to have the main information that you can change digitally, and then be able to print it for people to read if they don’t want to be looking on a screen”
	“It’s good to be able to give to paramedics, because people always want the paper copy.”
Notifications to alert changes in care	“My child was taken to a hospital because of a reaction to a seizure medication, and when we were admitted to a different hospital the medication was still on their list, and my child was given a dose of that medication that landed us in the hospital three weeks prior.”
Translating the medical information to other languages	“A lot of parents who speak multiple languages are almost dismissed because – you don’t understand English so you don’t count – So we have to find our inner voice, to be able to articulate and get our point across ... or a parent who is going through a crisis they need that language to give them the confidence to fight the daily battles”
	“Once when [my child] was very little and we were in Mexico, [my child] got sick and the doctor couldn’t understand...also it could be helpful for friends and family”

Chapter 5

Conceptual Modeling

This chapter's scope covers the Conceptualize design phase. Our objectives for these phases were to complete a scan of parent caregiver requirements (gleaned both from a range of domain experts and a sample of parent caregivers), then begin to capture these in the form of an emergent set of design principles targeted at this group, a conceptual model for an information management tool, and a low-fidelity (wireframe) prototype.

5.1 Requirements Elicitation Interviews

The goal of our first user study with parent caregivers was to understand parent challenges and strategies. For the data collection protocol, refer to Section 3.3. After the Requirement Elicitation Interviews, we analyzed the data using an affinity map and thematic analysis.

5.1.1 Affinity Mapping

Affinity mapping is a method used to quickly arrange qualitative data into categories, from which the researcher can generate other outputs such as the story of a user (*e.g.*, goals, pain-points) or constructed task examples that capture important use cases. We analyzed the data from our five Group A interviews using the affinity diagram approach inspired by Chapter 6 of *Contextual Design* by Holtzblatt and Beyer [36]. This step helps to familiarize the team with the data and quickly find

interesting categories.

The 3-person analysis team included 2 undergraduate volunteers and the author (who was also the interviewer).

We broke the interview data into segments of text contained in yellow sticky notes, then proceeded to aggregate the sticky notes into categories based on closely related context which got labeled using a blue sticky note (researcher Level 1, 83 categories). Then, moved to arrange them again and labeled them using pink sticky notes (Level 2, 27 categories). Lastly, we tried to group the pink notes and label them using green sticky notes (Level 3, 9 clusters).

We rearranged the Level 2 pink notes in two different ways, *Context* and by *Purpose*. Figure 5.1 shows the context-based arrangement of the completed affinity map with lower and higher level researcher categories in blue, pink, green notes respectively.

Context-based Arrangement: In the first method, we tried to arrange Level 2 categories based on context. This resulted in 9 clusters (green sticky notes), included below for completeness. We felt that this arrangement was too great an abstraction and left out the delicate details in the data.

Context-based clusters:

1. Organizing data is hard
2. Customizable schedule with reminders is helpful
3. An interactive digital solution is helpful
4. Wearing multiple hats in addition to being a parent is hard
5. Care providers and stakeholders can not share information and data
6. It is hard to obtain information
7. Child's data needs to be shared with ability to control access
8. Communicating my expectations of care is important
9. Medical data and terminology is hard to understand.



Figure 5.1: The set-up for the affinity map on Miro board (Method 1 - Context-based arrangement).

Purpose-based Arrangement: In the second method we tried to categorize the Level 2 categories around Level 3 clusters for strategies, challenges and “what is helpful”. The data from this categorization is presented in Table 5.1. In this table, we have only included some of the more prominent and notable categories (Level 2 - Pink) for each cluster in the table.

Although these categories are written in the first-person point of view, they are not direct quotes from the participants, but an accumulation of pieces of qualitative data put into categories that shape a user story (*i.e.*, an informal general explanation of the user’s pain points and tasks).

Although we used the affinity mapping method, we did not find this actionable because it proved to be difficult to directly map the challenges and strategies without the greater context. The strategies also seemed very broad and missing details. However, we are reporting this analysis as it built our confidence for the next step and familiarized the research team with the data.

5.1.2 Applied Thematic Analysis and Results

We analyzed our data using applied thematic analysis (inductive), which is used to analyze qualitative data and drive themes with methodological rigor. We used the method described by Guest et al. [34] and by Braun and Clarke [13]. The themes we obtained from this analysis are closely related to the affinity map in Table 5.1

Table 5.1: Challenges, strategies and preferences derived from purpose-based affinity mapping (Section 5.1.1).

Cluster	Categories
Challenges	Organizing, tracking, and keeping digital/physical copies of my child’s data is time-consuming, I am always worried about losing paper documents and errors
	I have challenges with accessing and using digital data in different platforms (<i>e.g.</i> , passwords)
	Understanding medical terminology and interpreting medical results is hard, I wish it was translated to normal English
	Balancing care coordination, caregiving and parenting is hard, I want to spend quality time with my child
	Managing family finances is challenging and I need to spend a lot of time to manage these documents
	Obtaining information/resources is hard and I need to rely on other people or the care team to find information (<i>e.g.</i> , word of mouth)
	Searching for information is time consuming, I don’t know where and what I could access
Strategies	I need to repeat my story many times and it is overwhelming and my voice is not heard by care providers
	I use a calendar to keep track of medication, symptoms, appointments
	I use digital and non-digital reminders (<i>e.g.</i> , alarms, paper schedule)
	I keep digital copies of documents
	I organize my child’s information in binders and use small folder for most important documents
	I often rely on my mind
	I don’t need reminders for routine and daily tasks (<i>e.g.</i> , feeding)
Preferences	I actively ask for resources to obtain them
	I use papers and hard copies for proof and communication with care providers
	My child should not be treated differently and should be seen as a human
	My child needs “holistic care” because everything about their care is linked (<i>e.g.</i> , medical equipment is needed to take a medication)
	I want resources and information in one place and centralized
	I want to control who has access to the data because confidentiality is important
	I want real-time documents that can be searched and edited on-the-go

but are more concrete, detailed and overarching as we used a qualitative software to assist with the analysis (NVivo Pro 12 [53]).

We broke down our qualitative dataset (interview transcripts) into smaller pieces and assigned a code to each piece of text. We defined a meaning for each code (*i.e.*, when to use or how to use) to keep the usage of the code consistent which generated a codebook. Using the software also allowed us to collect more quantitative data (*e.g.*, number of occurrences for each code). The coding and the codebook were created by the two undergraduate volunteers who had not studied this

topic beforehand; they coded each interview separately and then checked for convergence of the codes during one-on-one meetings. The codes and the codebook were revised again during team sessions which included the undergraduate volunteers and the author. As we grouped the codes into categories, overarching themes emerged.

The overarching themes were divided into two domains of caregivers' challenges (6 themes - accessing health information, finding resources, repeating the health story, navigating the health care system, managing finances, information management and its sub-categories) and strategies (6 themes - communicating, searching, remembering, sharing information, learning, information management and its sub-categories). The challenges were mapped to their corresponding strategies and the drawbacks (or advantages) to applying those strategies.

A summary of the outcome of this analysis can be found in Table 5.2. The strategies have been slightly reworded in table Table 5.2 to fit the context of the challenge. Please note that the challenge for "Information management" is an overarching theme composed of multiple categories indicated in Figure 5.2; these categories appear in the strategies column in Table 5.2. For example, "Organizing and maintaining information to share with stakeholders" from Challenge 3 in Table 5.2 is the "organizing" strategy utilized by caregivers under information management strategies theme.

Theme 1: Accessing Health Information

One of the challenges for caregivers is accessing health information and medical records (*e.g.*, reports, doctor notes, care plans, communications between doctors). Caregivers mentioned having to access records through multiple different places and in different formats (digital or physical). The strategies that caregivers use to overcome this requires communication with care providers through e-mail or phone calls or asking their pediatrician to access their records. The drawbacks to this strategy are that it is time consuming and error prone as there can be multiple versions of the child's records.

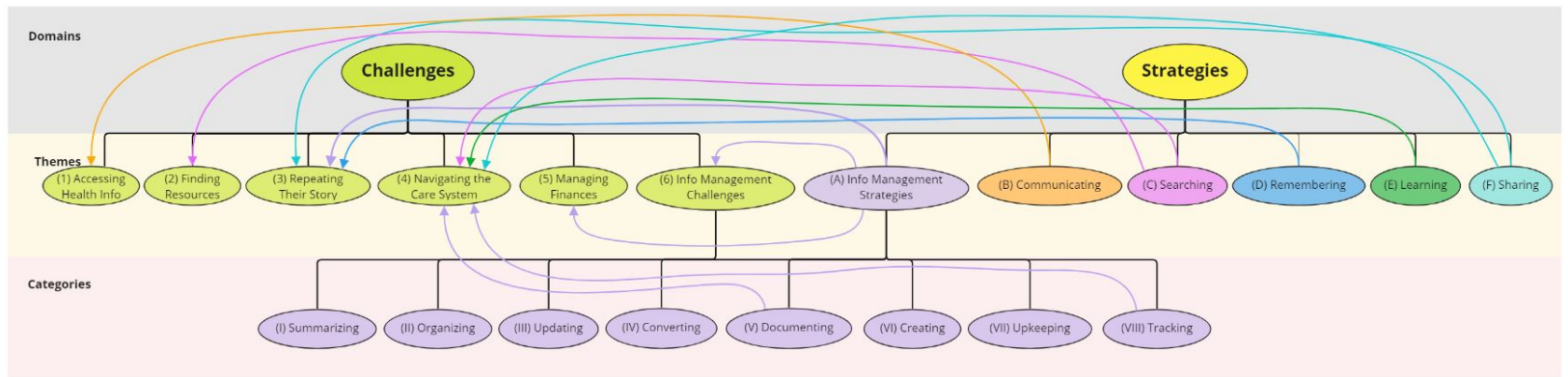


Figure 5.2: Strategies and challenges driven from the thematic analysis and mapped to each other; colors correspond to Table 5.2

Table 5.2: Caregiver challenges and strategies, N=5 (Group A). In the strategy evaluation column (+) is used to indicate advantages and (-) is used to indicate drawbacks of using the strategy. Colors, letters and roman numerals correspond to the Figure 5.2

mapping.

Challenge themes	Example of the challenge	Number of Occurrences	Caregiver strategies	Strategy evaluation (+/-)
(1) Accessing health information (e.g., care plan, medical records) is complicated	<p>“It’s all in different places, and they all have different ways of access to some of the things that you just don’t access on a regular basis because either you forget, or you forget your password.”</p> <hr/> <p>“If I need to make changes to it [care plan], I have to e-mail back and forth. But it’s not fully integrated and if I see practitioners outside of that hospital, it’s not linked. So I’m keeping separate records from healthcare practitioners.”</p>	4 interviews 8 occurrences	(B) Communicating with care providers to access health records and information	- Time consuming - Error prone
(2) Finding resources and information requires active search and prior knowledge	<p>“Care providers do not give a hand to guide you. You don’t know what you can qualify for to even ask for it, so there isn’t an example or a list that’s a clear option of what is available.”</p> <hr/> <p>“I feel like everything is kind of detached, there’s no one spot... maybe you want to be able to have connections with other families in the same area, maybe you want to see where is a wheelchair-accessible beach or trail, maybe you want to know about a new medication.”</p>	4 interviews 11 occurrences	(C) Searching for resources through online tools and word-of-mouth	- Time consuming - Might not be able to find the resource
(3) Repeating their story, becoming the central information holder and transmitting information between numerous stakeholders due to disjointed health records	<p>“You’re having to be the one answering all the questions... we’ve been in the trauma room and doctors are asking me what should be done.”</p> <hr/> <p>“There were situations where a treatment started that can be detrimental for something else... and I need to be in the picture to say there are other things going on.”</p>	4 interviews 21 occurrences	(A) ALL Information Management Strategies (F) Sharing data with stakeholders (D) Remembering information	- Stressful and traumatic - Time consuming - Only the caregiver has all the information and feels responsible to ensure holistic care - Error prone

Challenge themes	Example of the challenge	Number of Occurrences	Caregiver strategies	Strategy evaluation (+/-)
(4) Navigating the health care system and communicating with stakeholders (e.g., care providers and government) depends on the experience of the caregiver and their knowledge of medical terms	<p>“I’m not a medical assistant so I don’t understand the language and a lot of the abbreviations.”</p> <hr/> <p>“I would say that I am able to understand medical jargon now, er ..more easily and that was a learning curve... trying to figure out how and what to include and what it all meant.”</p> <hr/> <p>“it was a lot of work and very time consuming if you don’t speak a certain way to doctors or write emails to get a grant. I learned how to write these emails and what to say...but I know you’ll get a roadblock if you don’t say it a certain way.”</p> <hr/> <p>“This is 15 years in the making - this didn’t happen overnight. There was a quiet yes-yes-yes person. Whatever the doctor said, I didn’t challenge it.”</p>	5 interviews 38 occurrences	<p>(F) Sharing information in a specific way that stakeholders can recognize and respond</p> <p>(E) Learning about the health care system</p> <p>(C) Searching for information</p> <p>(A.V) Documenting health events</p> <p>(A.VIII) Tracking health data (e.g., symptoms)</p>	<ul style="list-style-type: none"> - Stressful to communicate with numerous care providers - Time consuming - Depends on the experience and language expertise of the caregiver
(5) Managing finances requires communicating with numerous stakeholders (e.g., government, charities, insurances)	<p>“I do all the ordering. And when the invoice comes, my husband does all the paperwork for insurance. Because that’s a part-time job.”</p> <hr/> <p>“I apply to different organizations for funding. Some things don’t get covered through regular plans and they don’t happen all at once, but it can take months from start to finish.”</p>	3 interviews 9 occurrences	(A) ALL Information Management Strategies applied to financial information	<ul style="list-style-type: none"> - Time consuming - Stressful + Flexible format depending on the situation and stakeholder
(6) Information Management: Managing masses of information is laborious and time consuming but necessary	<p>“There is a lot of error when it is not digital, because when I get the mail, and there’s an error, I have to call or email to get that corrected whereas if it’s online I could edit it.”</p> <hr/> <p>“I want quality time with the person I’m caring for, I don’t want to keep track of papers and files. . .”</p>	5 interviews 44 occurrences	(A) ALL Information Management Strategies	<ul style="list-style-type: none"> - Stressful to maintain and organize critical information - Time consuming - Error prone + Flexible format

Theme 2: Finding Resources

Caregivers can have difficulties with finding resources and information. Resources and information can include a new medication, a wheelchair-accessible trail (for recreational activities), a community, or funding sources. Caregivers mentioned that there is no centralized place to find resources. Currently, the main strategy is to rely on word-of-mouth, information from the care team and researching. This is time consuming and some things might be difficult to find if they do not know what to search for.

Theme 3: Repeating their Story

Decentralized, difficult to access health records and unfamiliar care providers results in the caregivers becoming the most reliable source of information. The caregivers have to repeat their story many times. For example, their child's story may consist of things that happened during the last hospital visit, or how a specific care procedure should be done or what diagnosis they have. The caregivers' strategy to share the most accurate information is through organizing, updating, maintaining, tracking and sharing documents. They must also manage different formats of documents (physical and digital) and sometimes both. Converting documents helps to prevent losing information and is sometimes easier to share. Being the main source of information causes immense stress for parents and they report that they have to be in the picture to ensure collaborative care. They also report feeling responsible to remember important information and worry about losing critical documents.

Theme 4: Navigating the Health Care System

The challenges with navigating the health care system and communicating with numerous stakeholders are multi-faceted and could arise in different contexts for caregivers. This may arise from the inexperience of the caregiver, their difficulty with medical jargon or their primary language. Caregivers with older children mentioned the amount of time that was required to learn how to communicate with stakeholders and learn how to navigate the system. For example, they come to know what documents or pieces of information about their child that should be shared with each stakeholders (*e.g.*, nurse, school, government, care providers etc.)

in a way that they can respond to it. Other strategies include learning about the system, and searching for information. A unique strategy was documenting and tracking data (symptoms or other variables) to present to the stakeholders. These strategies are stressful, time consuming and greatly rely on the experience of the caregiver.

Theme 5: Managing Finances

Managing finances was not frequently mentioned, however, it was emphasized by some caregivers who reported that they spend a significant amount of time keeping track of all the finances, applying for insurance, government funding or charities.

Theme 6: Information Management Challenges

The biggest theme which encompasses many categories (Figure 5.2) was related to challenges with maintaining, organizing, creating, filling-in masses of documents and records in various formats. Most of these “challenges” are also considered a “strategy” that helps parents with the current system, however, we decided to add them under the challenges domain because parents do not want to spend time doing these tasks; they just want to spend quality time with their child. Parents utilized laborious strategies in this space, for example converting documents between physical and digital formats, creating unique ways of categorizing information, summarizing documents, keeping documents up-to-date, tracking documents. A positive outcome of maintaining documents in multiple formats is that some parents believed “a paper can go a long way” and some care providers prefer paper formats.

Other Challenges and Strategies

Other challenges were mentioned less frequently and are not included in Table 5.2. These consisted of ordering supplies, tracking tasks (*e.g.*, who has done what during the day), tracking changes in appointments, tracking medications, balancing caregiving and work (or parenting), and tracking changes in the care team. Similarly, some of strategies that were mentioned included setting reminders, using calendars, and taking photos or videos.

Theme 7: Humanizing and Personalizing

Another theme emerged which could not be cleanly categorized into a task-based challenge, but was mentioned by caregivers in the context of “information shared with stakeholders” (although this theme can also be considered a challenge, we have not included it in Table 5.2). This theme relates to humanizing and personalizing the child and family. Currently, parents create an “About me” book (in paper format) for their child which they share with school or care providers (mentioned by 4 out of 5 participants). This book is a way to introduce their child, provide information about how to interact with them, what are their likes/dislikes, what they are like outside of the hospital, who is in their family, and their communication abilities. Additionally, they may share their care preferences, care goals, nutrition plans, supplies list, daily schedules, and summary care plans. Caregivers may also track symptoms, collect visit summaries, behavioral cues and other care events to share with other stakeholders. In the context of humanizing and personalizing the child, one parent said:

“I think everyone should have an [About me book], so your child doesn’t become a subject or an object... the primary goal is to tell someone who doesn’t know anything about your child, their cues. What does this look mean? My child is nonverbal so I took multiple different pictures for different scenarios. Scratching can mean multiple things to my child. It’s not always -I’m bored or I’m tired... that’s maybe the [child’s] way of soothing [themselves]. We updated that booklet every year, starting in grade four or five and circulated it among [child’s] aides at the school. It’s not something that I would give to a healthcare provider that see’s [child] for five minutes. But wouldn’t it be wonderful if that whole thing comes up on the screen of the healthcare provider right before they see the patient. So they kind of get to know a little character ... a person. We would save so much time!”

The same parent continued: *“This way you personalize the child. The child is actual human, the child has a family, and a story that goes with each picture ... like a photo book. And you pass it to every caregiver. My child is not a number, my child matters, And these are [child’s] likes and dislikes. One example is my [child] can’t see so putting [child] in front of a TV to stimulate [child] is never going to work. So [child] needs to work one on one with an iPad, hand over hand activities.*

So that is outlined in the Communication book. So it explains... These are things [child] can and [child] cannot do. And focuses more on the positive, not [child's] deficit... Not a happy book but a realistic book ... care should be the same across the board...The fact that healthcare providers and therapists are putting this little population in a different category is just hard to swallow.”

Another parent said: *“The about me and home life stuff is super important for people to understand where [child's] at and what [child's] general day to day surroundings are.”*

5.2 First Look At The Design Principles

By combining what we learnt from the literature review, thematic analysis, affinity map and feature rankings from Group A (Section 4.3), we drafted a first iteration on a set of design principles (DPs) which aim to minimize the challenges for parent strategies. We iteratively refined these principles as we progressed through the subsequent design phases, and will present a stabilized version in Chapter 7.

The insights organized among many of our themes (identified in Table 5.3) clearly indicate that in order to ensure easy access and avoid fragmentation, *data, documents and information should be centralized, sharable, searchable, real-time, accurate, secure and interactive*. It is important to note that this over-arching objective cannot be addressed at the level of the user-facing interfacing until they have been accommodated by the underlying data structure of the digital health information management system.

Then, using the strategy evaluation column in Table 5.2, we concluded that current caregiver strategies result in caregiver burden and are accompanied by significant downsides. Plus, caregivers are already burdened by many other challenges. Therefore, an information management system aiming to improve their situation should reduce caregiver burden by saving time, reducing stress, reducing errors caused by using numerous modes and formats of communication, eliminating the need to remember information, and eliminating communication challenges between and with stakeholders.

The design principles should be devised by directly targeting each of the caregiver challenges which are causing the immense caregiver burden and driving the

caregivers to use these burdensome strategies in the first place. The DPs should also consider the feasibility of addressing the challenges using technology.

In the following, we describe the design principles we derived with respect to apply to a user-facing care coordination and data management system.

5.2.1 Grounding the Design Principles

DP1-Provide a Holistic View

Definition: The interface should aim to include everything about the care for the patient, because all care aspects are linked (holistic care). This principle was devised from the third challenge where fragmentation of data leads to parents repeating their story and feeling that they must be in the picture to ensure that care providers have a holistic view of their child. Furthermore, parents need to manage and keep all the information about their child in a way that can be presented to other stakeholders (challenge 4 and 6).

Provenance: Challenge 3, 4 and 6

Design Implication: This is an overarching principles and shows up in many places in the design. For example, the system conceptual map is very interconnected and aims to include as much information as possible about the child. The child's profile and the Medical Timeline are also specific examples of providing a holistic view.

Short Notation: [DP1-Holistic]

DP2-Personalize and Humanize

Definition: The interface should humanize and personalize the patient and the family.

Provenance: This principle is directly in response to the gap in the care system to humanize and personalize the child and the family (derived from the thematic analysis). Another supporting data is the high ranking for the feature to "Share information about how to interact with the child" (rank 6). Other research [28] found having an "About Me" section which includes likes/dislikes, siblings, pets, and tips for successful interaction with the child is important. Vo et al. has also

reported that personalization is a weakness in current mHealth apps [69].

Design Implication: We added a “Home Life book” and an “Interactions book” for child’s profile.

Short Notation: [DP2-Personalize]

DP3-Facilitate Communication and Collaboration

Definition: The interface should facilitate communication and collaboration with care providers.

Provenance: This links to the challenges with communication which has been discussed in other research and reflected in our data in challenge 1, 3, 4 (accessing information, repeating their story, and navigating the system) and also reflected in the laborious strategies for sharing information. Furthermore, highly ranked features such as maintaining a contact information list (rank 1), interacting with personal health records (rank 4), messaging system (rank 13) provide additional supporting data. This has also been mentioned by Desai et al. and referenced in Table 2.1 [28].

Design Implication: We created a Care Team section which contains features such as a messaging system, contact information list and Q&A board.

Short Notation: [DP3-Collaborate]

DP4-Avoid Jargon

Definition: The interface should limit medical jargon and use positive language (*i.e.*, not child’s deficits).

Provenance: This directly relates to challenge 4 (navigating the health care system) as participants mentioned not understanding the medical jargon in the beginning and the examples given in Table 4.2 about language barriers. It also relates to humanizing the child by using positive language. Desai et al. also mentions using “family-centered terminology”[28].

Design Implication: We avoided using language that could have negative connotations, be care-provider centered or be considered as medical jargon.

Short Notation: [DP4-Jargon]

DP5-Capture History and Provide Insight

Definition: The interface should maintain an accurate and historical record of events and provide accessibility and insight into the data through caregiver-centered visualizations.

Provenance: This is added to address challenges with accessing information, navigating the care system (*e.g.*, having to track different variables and collect insights to share with care providers), repeating their story, maintaining and organizing documents and sharing them. Also, highly ranked features related to visualizing health records (rank 9, 10, 16) and tracking recent symptoms (rank 7).

Design Implication: We have added a “Medical Timeline” which provides historical records of events and insights into symptoms, care provider visits, lab results or other factors. The Calendar can also be used to track historical appointments/referrals. Furthermore, the Child’s Profile such as the Home Life book (later changed to Life Journal) can provide a place to record events.

Short Notation: [DP5-Historical]

DP6-Share and Access Confidentially

Definition: The interface should balance confidentiality, accessibility and sharability.

Provenance: Added to address challenge 1 (access to health information) and the high importance for sharing medical information for the families as in Table 4.2. A related principle from Desai et al. notes the importance of balancing security and ease of access [28].

Design Implication: We identified but explicitly set this item out of our scope at this stage, for reasons noted in Section 5.2.2.

Short Notation: [DP6-Confidential]

DP7-Integrate Information

Definition: The interface should integrate data pieces and enable data linkage.

Provenance: We realized that there our design will have many zones to provide a holistic view without a way to link them. However, parents mentioned creating “summary care plans” to send to different stakeholders which is a way of sum-

Table 5.3: Mapping of the caregiver challenges, the DPs and the data structure implications summarized from Section 5.2

#	Challenge theme	Related Design Principle	Data Structure Implication
1	Accessing health information	DP3, DP5, DP6	Centralized, Sharable, Secure
2	Finding resources and information	Out of scope	Centralized, Searchable
3	Repeating their story and transmitting information between stakeholders	DP1, DP3, DP5, DP7	Sharable, Real-time, Interactive, Centralized
4	Navigating the health care system and communicating with stakeholders	DP1, DP3, DP4, DP5, DP7	Real-time, Interactive, Sharable
5	Managing finances	Out of scope	No implications
6	Information management challenges	DP1, DP5, DP7	Accurate, Secure, Searchable
7	Humanizing and personalizing	DP2, DP4	No implications

marizing and condensing data. This also relates to the challenge with maintaining, organizing, and creating documents which is laborious and time consuming.

Design Implication: This is an overarching principle and appears in different locations, but one of the main implications was creating a feature to generate custom “Reports” (later changed to Summaries) which enables linking data pieces.

Short Notation: [DP7-Integrate]

5.2.2 Completeness of the Design Principles

We have attempted to address the multifaceted challenges for caregivers through these DPs. However, these DPs do not address the challenges with managing finances, because although this can be related to information management due to the number of stakeholders and documents required, we felt that the scope is too large for the purposes of a digital solution aimed at helping with care coordination and information management.

Also, in terms of finding resources, parents mentioned that there is no central place to find resources and information. This challenge could translate to a design principle such as “the interface should include information and resources”, however, we thought that this is not feasible in an interface due to the scope of resources that parents may want to search for. Additionally, we are not fully aware of all the things that parents may want to search for.

Lastly, we felt that DP6-Confidential is also outside the scope of this project due to the difficulty with designing an interface around this principle and the nuances surrounding confidentiality.

Table 5.3 provides a summary for the mapping of each DP to the caregiver challenge.

5.3 First Look At The System Conceptual Model

After the Requirement Elicitation Interviews, we began the process of conceptualizing and creating the “information management” system. Using the content priorities for caregivers from Desai et al. [29] (Figure 2.1), the feature preferences, the thematic analysis and the design principles, we created a conceptual system map which included the high level system structure as well as the linkage between the content. In Figure 5.3, the dashboard node and the connecting nodes are shown.

One of the first branches that we added to this system map was the Calendar. The concept and utility of a Calendar appeared repeatedly in the interview data as a tool that the parents are very familiar with and relied on; furthermore, a great deal of caregivers’ tasks are temporally based, such as scheduling, tracking and searching or reviewing history. Therefore, it made obvious sense to create this system with a calendar to keep track of time, hold appointments, reminders and tasks.

Immediately after the Calendar, the Medical Records (later called Medical Timeline) node was created because accessing these records are one of the biggest pain points for parents. Within Medical Records, we wanted to provide a way to visualize various information since visualizations were ranked relatively highly in Table 4.3. The next item that was immediately obvious was a way to communicate with the care team; therefore the Care Team node was created. Within the Care Team node we wanted to have a contact list and messaging system as these were feasible features from Figure 3.1. Parents had mentioned challenges with advocacy, writing grants, therefore we created a branch to include these items. Items and content that were mentioned in Desai et al. [29] and Figure 2.1 which were more related to the child rather than the parent/caregiver activities were grouped under Jane’s profile.

Another design consideration which is visible in Figure 5.3 was the addition of “Bookmarks” to every node that connected to child nodes. The Bookmark feature would allow bookmarking pieces of content and data within each page and generating a custom summary from the bookmarks in the “Reports” node. This feature is specifically created to address [DP7-Integrate] and increase sharability of information as caregivers expressed the need to share custom information summaries with different stakeholders. Similar to the bookmarks, a Search feature within every page would allow for rapid search for information in the parent node and all its connected branches.

At this stage, one of our challenges was categorizing the content into primary and secondary nodes since there were multiple options and our user study did not reveal any clear direction about participants’ preferences for the content organization. For example, the Care Plans node could have been a branch of the node for Jane’s profile. The organization of other branches, for example, within Jane’s profile, were based on what would be most intuitive, simple, and allow rapid access to a piece of information without clicking through a lot of menus or pages. We generally aimed to create the linkages between the nodes to optimize the overall layout.

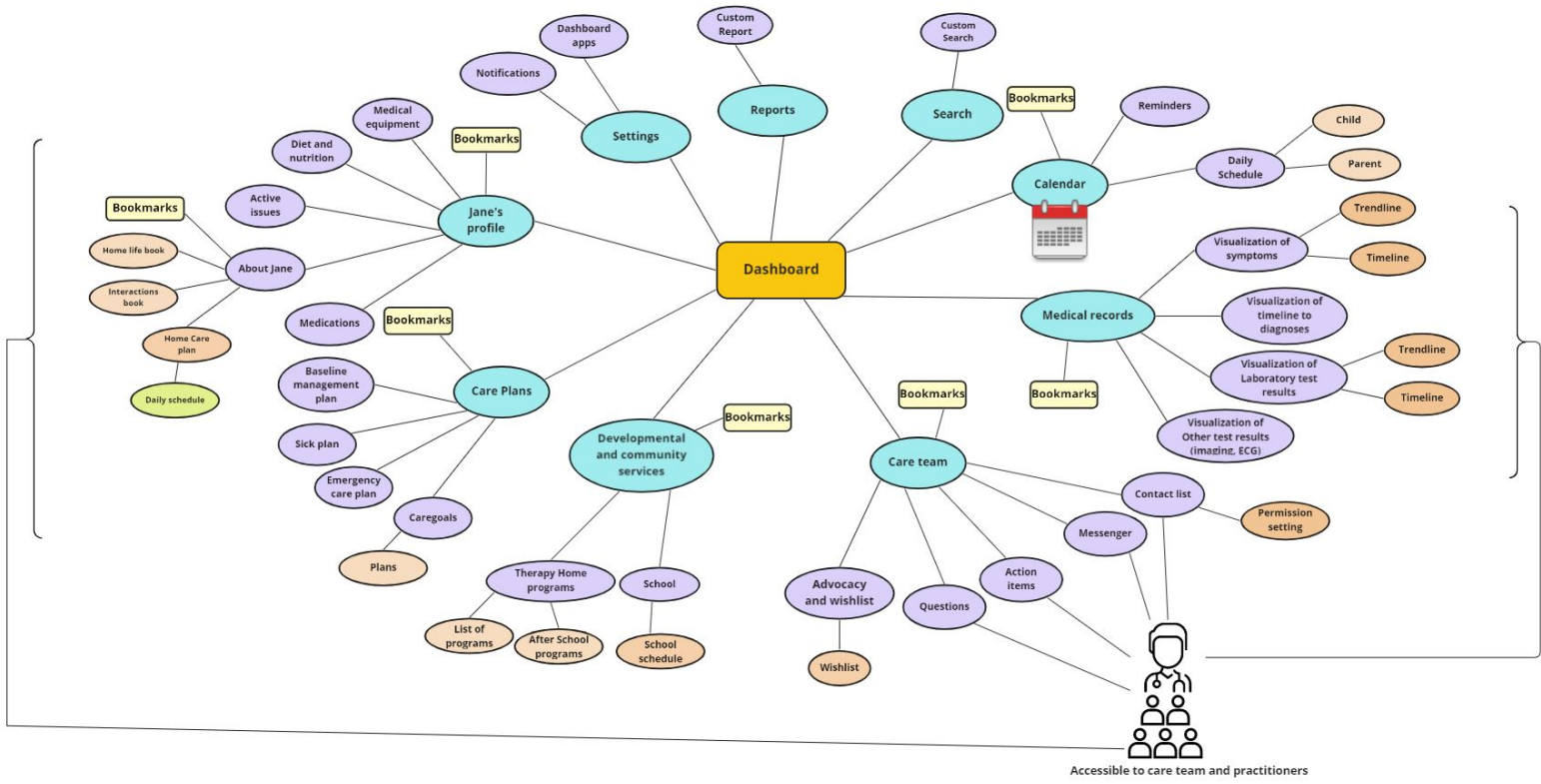


Figure 5.3: The first iteration of the conceptual system map.

5.4 Low-fidelity Prototype: Wireframes for Initial User Reactions

Based on the conceptual system map, we began the process of wireframing and creating low-fidelity prototypes.

5.4.1 Prototyping Platform and Process

Initially, the wireframes started as simple sketches. However, it soon became challenging to keep track of all pages that corresponded to the system map and their content. Therefore, we moved the prototype development to Figma, which is a collaborative interface design tool [32]. Figma allows for rapid development of user interface designs and has a toolbox to add a host of interactivity such as clickable buttons, page scroll and so on. Therefore, Figma allowed us to build more sophisticated and clickable wireframes which made the complex navigation and organization of the panels easier. We did not build many different versions for each page because our efforts were focused on building as many pages as possible. However, we experimented with icons, texts, labels, colors and general layout of items on each page. These design decisions were made in a group of 3 researchers (2 undergraduate volunteers and the author) and sometimes with the consultation of co-supervisors.

5.4.2 Design Overviews of Key Sections

Figure 5.4 shows three sample panels from the wireframe stage of the Dashboard, the Medical Timeline (labeled as Medical Records on the dashboard) and the Home Life Book which is within “Jane’s profile” on the dashboard. More wireframe panels can be found in Section D.1.

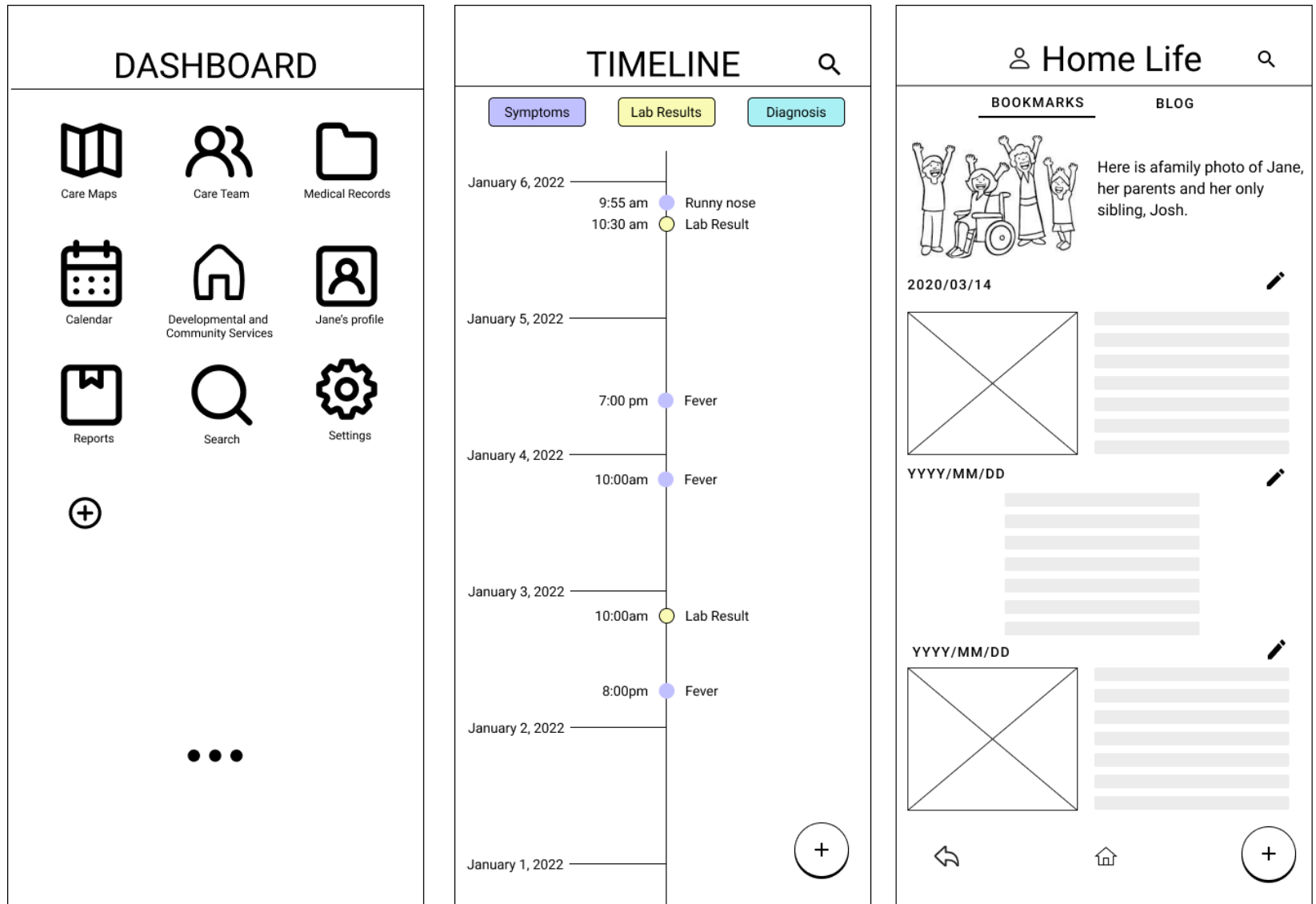


Figure 5.4: Three sample panels showing the Dashboard, the Home Life Book and the Medical Timeline during the wireframing process (Low-Fidelity design).

Interactive and On-The-Go

Our draft design guidelines (Section 5.2) specify that data, documents and health information should provide real-time, on-the-go and interactive access to their child's data. Therefore, we prioritized that the interface should be smartphone-compatible; meaning, at this design stage, that it should fit in a smartphone-sized screen and follow the norms and language of familiar mobile phone applications. A desktop interface would create road blocks to easy access as caregivers could only access their information using a computer. An even better design should enable both the desktop and smartphone responsiveness to provide maximum accessibility.

Dashboard

We also realized that some parents may want to see different contents on their dashboard and/or pages depending on their needs (*e.g.*, Jane's Profile appearing on the dashboard). Therefore, an immediate resulting feature would be a dashboard design which allows addition of shortcuts to any desirable page. For example, parents may want to see Care plans under Jane's profile or Medication list under the main dashboard. This also enables building user-generated redundancy which is a guideline mentioned by Desai et al.. Another guideline that is mentioned by Desai et al. is "simple and familiar" layout, therefore we modeled the dashboard after other homepage designs on many smartphones [29]. We used a white background for all the pages because we realized that these pages can get very complex and will require use of different colors to make items stand out to the user.

Medical Timeline

To design the "Medical Timeline" which is linked to DP5-Historical, we wanted to include visual features that parents care about. For example, information regarding each of the child's diagnosis (diagnostic history), lab reports and tests, history of symptoms. As this page was meant to represent historical events, it was an intuitive decision to have an interactive but simple timeline graphic that allows scrolling through the dates.

Care Team

The “Care Team” page contains features to contact the care team members, ask questions, assign action items and generate an “Advocacy Wishlist”. The advocacy wishlist was added to address the parents’ concern regarding tracking communications and items that are funded through government grants or charities. Although we did not create any wireframes for the the “Settings” page, we planned that this page should enable setting view/edit permissions and managing notifications.

Child’s Profile

“Child’s Profile” assimilates all the information about the child, for example, list of medical equipment, diet and nutrition, the “Home Life Book”, the “Interactions Book” and other pages. The “Home Life Book” was designed to address the parents concern with humanizing and personalizing their child outside of the hospital (DP2), therefore, we designed this page with a blog format. Similarly, the “Interactions Book” was designed to enable a way of documenting how to interact with the child and the child’s behavioral cues.

Care Plans

The “Care Plans” page provides the ability to manage different care protocols, such as the “Baseline management plan” or “Sick Plan”. The ”Calendar” page is meant to contain appointments, daily schedule and tasks.

5.4.3 Analyzing the User Reactions

To analyze the user feedback, we (undergraduate volunteers and author) used a pragmatic analysis method. We transcribed the interviews and collected all the feedback for each panel. Then we decided on the “sentiment” that was expressed in each passage (*e.g.*, negative, positive, neutral). We also took notes on all the suggested changes and evaluated their feasibility.

The general sentiment about the **system map** in Figure 5.3 was positive and that “it is organized well”. Also, all parents expressed positive sentiments about having pages for “Reports” (which allows generating custom summaries through bookmarks), “Search” and “Calendar”. Two parents mentioned the importance of

having a tutorial on how to use these features. All parents understood the concept of the “bookmarks” and “Reports” when the explanation was provided by the interviewer. Additionally, two parents recognized that they already have much of this information in paper format and expressed the need to be able to upload these documents. One parent mentioned that the school section could be more complex as there can be physiotherapists in school which may send their own types of report.

Regarding the **Medical Records** page, four parents expressed a neutral sentiment and others were positive about the visual aspect. Two parents mentioned that more options for sharing should be added with an emphasis for sharing symptoms (*e.g.*, e-mail). Additionally, two parents emphasized the importance of having a medication tracker (when medications started and stopped). Caregivers also wanted to see how symptoms were resolved, and have the ability to add “Amount (*e.g.*, small/medium/large or a scale)” and “Duration” for symptoms. Additionally, the ability to see a trend (or bar graph) for these variables versus time was well liked by three participants. One parent mentioned that the graphs should look like nursing charts because “doctors understand that information to make quicker diagnoses”. One parent commented that the bar graphs should also show different components of the lab results (*e.g.*, Vitamin C, Iron). One parent mentioned several important points; for example, having the ability to create user categories for variable tracking on the timeline, representing the symptoms as a duration line (rather than a point) to see “overlaps”, and filtering based on specific symptoms or medications. Other suggestions included seeing new referrals to a doctor and ER reports on the timeline. Lastly, they also mentioned that “behavior” could also be added as a category on the timeline.

Two parents did not like the word “diagnosis” as a category of items on the Medical Timeline because as one parent explained: “sometimes the word diagnosis is a little difficult, a lot of kids live without a diagnosis. And just because you see that clinic doesn’t mean you actually have a diagnosis of it. Like my [child] only has very few actual diagnosis and a lot of kids do not even have that diagnosis. So even though “flu” might make sense and even though the doctor would call it something, I have no idea what that means. I don’t know if there’s another word for “diagnosis” ... a lot of diagnosis are not as simple as the flu”.

For the **Care Team** page, two of the participants wanted to see the contact

information categorised/sorted based on specialty and also have the ability to add their own categories (*e.g.*, school staff). Additionally, one parent wanted an indication of how the care team members are linked (*e.g.*, show linkage between the booking clerk or nurse clinician at the pediatrician office). The ability to search the contact list and color code it was also mentioned by one participant. On the Q&A Board, one parent wanted to see customizable categories for the posted questions as well as a feature to create private questions. Also the ability to attach pictures to the questions was pointed out.

The same parent who suggested to add “Advocacy and Wishlist” into Figure 3.1 found the **Advocacy and Wishlist** page helpful and mentioned that it would be useful to keep notes about the follow-up communication and the status of items. The parent mentioned that this page needs to be more comprehensive and move outside of the “Care Team” and include the supplies and equipment which are funded through charities, grants or government.

All parents liked seeing a color coded **Calendar** and were excited for more organization if the calendar is synced with other apps. They thought it would be helpful to have the ability to add multiple calendars and view them all together or separately using a filter option and in different colors (*e.g.*, school calendar, medications calendar, appointments calendar etc.). One caregiver suggested the ability to print or e-mail the calendar to a grandparent or someone else. Lastly, they pointed out that it would be useful to have reminders and holidays added to the Calendar.

Within the **Child’s profile**, in the **Interactions Book**, one parent noted that some behaviors may not be categorised as “expressions” (or the child may not have facial muscle control) but could be called “body language”. They also expressed the need to have custom user categories for organizing interactions (*e.g.*, sounds, language, toys and items, icons from communication devices). Additionally, they mentioned that videos/photos will be important to upload here. Parents also mentioned that some behaviors can be indicative of symptoms which could be tracked and integrated on the Medical timeline. In the **Home Life Book**, parents mentioned that there are some school activities that could be added to this page, and that not all activities are “at home”. In the same manner, they also wanted to track and record the activities or “home-work” which the child engages in towards completing

their care goals. One parent mentioned that they use the information on the child's Facebook to track activities towards caregoals.

For the **Care Plans** page, one parent mentioned that it is important to be able to edit the headers and labels to create a custom care plans (*e.g.*, seizure care plan).

5.4.4 Design Implications

We reconsidered the labels for some of the pages based on the user feedback. For example the "Home Life Book" was changed to "Life Journal" because we wanted to include all life events (*e.g.*, school events). Additionally, we changed "Reports" to "Summaries" as reports seemed to be ambiguous to some parents.

We also moved the Advocacy and wishlist page outside of Care team and attempted to make it more comprehensive. Further improvements were made to the Medical Timeline to show overlap of events and trends over time. Additional categories of items under the Home Life book and Interactions book were also added.

As we moved to medium-fidelity prototype we heard that parents would like to have custom categories or pages for information organization. Therefore, we added a feature which allows the user to add a custom category using the "Add group" button in the top menu on many pages.

Related to the same feedback, we also added a new design principle **DP8-Customize and Allow Flexibility** [DP8-Customize]. The interface should be highly customizable and flexible to meet the needs of different families. This principle didn't manifest directly from the challenges in thematic analysis, but as we interviewed more caregivers we realized that a degree of customizability (typically suggested in the form of information color-coding) is needed to match their needs for tagging pieces of information. A degree of "flexibility" in terms of organizing the data structure within the user interface (for example, adding new shortcuts to the dashboard, or adding new customized data categories) is also a highly desirable feature.

Chapter 6

Prototype Blueprint

After the conceptualization stage, we began the process of creating a blueprint in the form of a medium fidelity prototype. Our goal was to bring the DPs into life, refine them and create a prototype that serves as an example of following the DPs. Therefore, we started with improving the low-fidelity prototype by incorporating the user feedback and moving to a medium-fidelity prototype. We then obtained user feedback from Group C on our medium-fidelity prototype and finalized it. This chapter will contain some of the finalized version of the prototype and discuss the most notable features.

6.1 Medium-fidelity Prototype: Blueprint for a Deployment Version

After confirming that our low-fidelity prototype was generally capturing our user's needs we began creating more sophisticated task-centered prototypes (medium-fidelity) using Figma [32]. The goal of this proptotype was to provide a blueprint for a deployment ready version of the app and collect feedback on specific features. This step also allowed us to transform the feature preferences from Figure 3.1 and Table 4.4 to create some features that parents need and/or wish to do on a regular basis. We also wanted to informally evaluate the prototypes with real users and elicit lower-level feedback to determine whether our design is understandable and usable. Due to time limitations, we only collected this type of feedback on a

selected subset of pages (Child's Profile and Medical Timeline).

Note: The prototype panels presented as figures are the finalized prototype and not intermediate steps.

6.2 The Child's Profile

We focused our design efforts on the Child's Profile (Figures 6.3, 6.1 and 6.2) as it was one of the more complex sections of the app which contained multiple sub-branches and included important features for the parents. The Child's Profile contains various pages such as the Life Journal, Interactions book, Medications, Care goals, Diet and Nutrition, and so on. As we were interested to understand how parents would like to represent their child in a digital health tool and wished to collect more feedback on these pages, we focused on refining the design for the Life Journal and Interactions book and added feature examples.

We also incorporated the "Advocacy and Wishlist" page from the low-fidelity prototype into Equipment and Supplies. This seemed to be the most straightforward solution to integrate information for funding and charities with medical equipment and supplies (Figure 6.2).

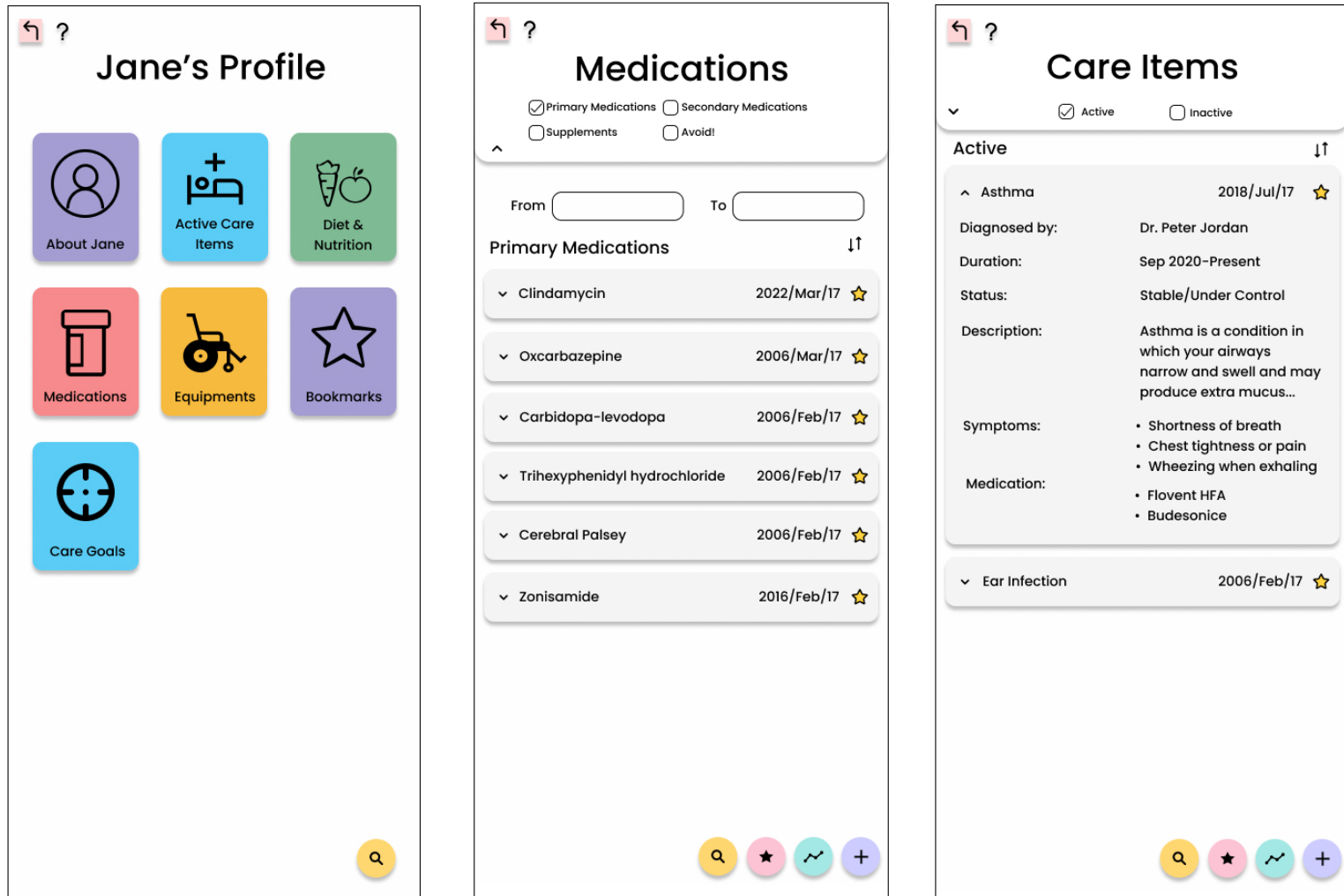


Figure 6.1: Three panels showing the finalized Child's Profile Dashboard, the Medications list and the Care Items.

Equipment & Supplies

Equipment Supplies Therapies

- Pending Wheelchair
December 15, 2021 Sandy sent another request
Funding Source: At Home Program
Sandy White
- Wished Music Therapy
December 20, 2021 Drafted application with Bob
Funding Source: Canuck Place
Bob Winters
- Recurring Syringes
December 20, 2021 Received order of syringes
Funding Source: BC Government
Sandy White John Smith
- Complete Funding
December 19, 2021 Received grant
Funding Source: At Home Program

Diet & Nutrition

Primary Nutritions Secondary Nutritions Avoid!

Primary Nutritions

- Whole Grains
Amount: 200 grams
Frequency in a Day: Every 8 Hours
Notes: Jane likes to eat plain brown rice.
- G-Tube Formula 1
- G-Tube Formula 2
- Avocados
- Nut Butters
- Olive Oil
- Dark Leafy Greens

Care Goals

Primary Goals Secondary Goals Extra

Primary Goals

- Practice using communication device at school
Supervisor: Josh Sanders (teacher)
Start day: January 15, 2022
Associated diagnoses:
Notes: Recently got a communication toy, so Jane needs to practice using it to communicate
- Using sign language

Figure 6.2: Three panels showing the finalized Equipment & Supplies, Care Goals and Diet & Nutrition.

6.2.1 About Jane

The feature examples here aimed to present the dashboard for Child's Profile, the Life Journal and the Interactions book to the parents. Additionally, we wanted to understand the general sentiment (*i.e.*, like or dislike) for these pages and whether the navigation and menu system is clear.

Based on DP2-Personalize, we believed the feature to add a new life event such as "Language Practice" into the Life Journal would be important to parents because it applies to personalizing and humanizing their child and family by presenting their life outside of the health care system. It can also be important in terms of documenting any activities towards specific care goals (Figure 6.6). The prototype implements this feature by "Adding a new post to the Life Journal".

Another feature example is about parents expressing the importance of sharing how their child interacts with others. For example, this feature adds "clenching fists" as a new post to the Interactions book (Figure 6.5).

6.2.2 User Feedback

The user feedback for the Life Journal and the Interactions book was limited, however these pages were liked by the parents. Also, the participants were able to successfully complete the tasks on each page. Two parents mentioned the addition of "Community life" and "Recreation" as other possible categories of activities on the Life Journal.

6.2.3 Other Pages within Child's Profile

Other pages within the Child's Profile include the child's Daily Schedule (which links to the calendar), Equipment & Supplies, Diet & Nutrition, Care Items, Care Goals, Medications, and the list of Caregoals depicted in Figure 6.2 and Figure 6.1. These pages are important as they provide a holistic view about Jane and many aspects of her care. In designing these pages, we followed the design principles to integrate data, provide customizability and flexibility. We also followed the principle from Desai et al. and kept a consistent and familiar layout for these pages [29].

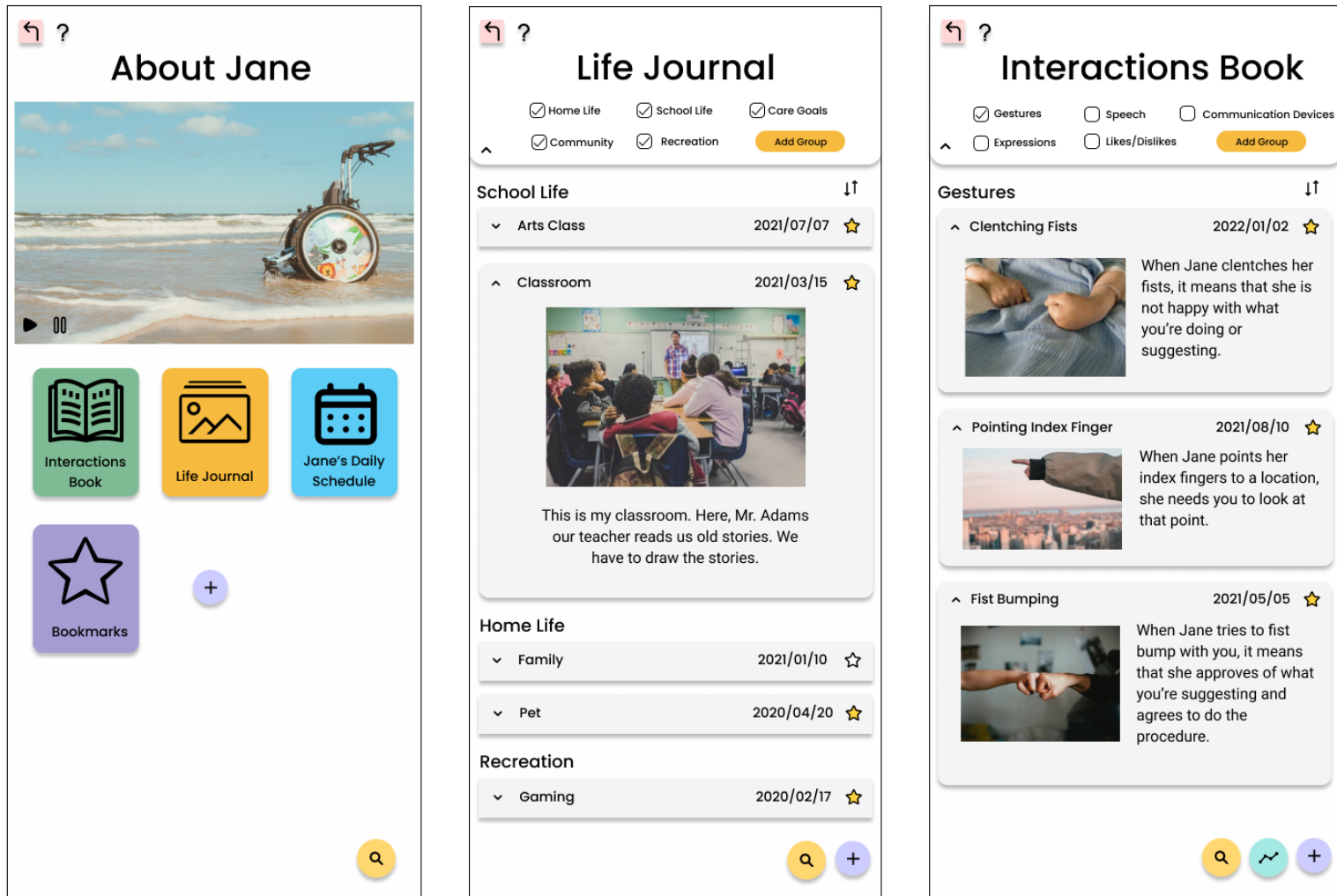


Figure 6.3: Three panels showing the finalized About Jane dashboard, the Life Journal and the Interactions book.

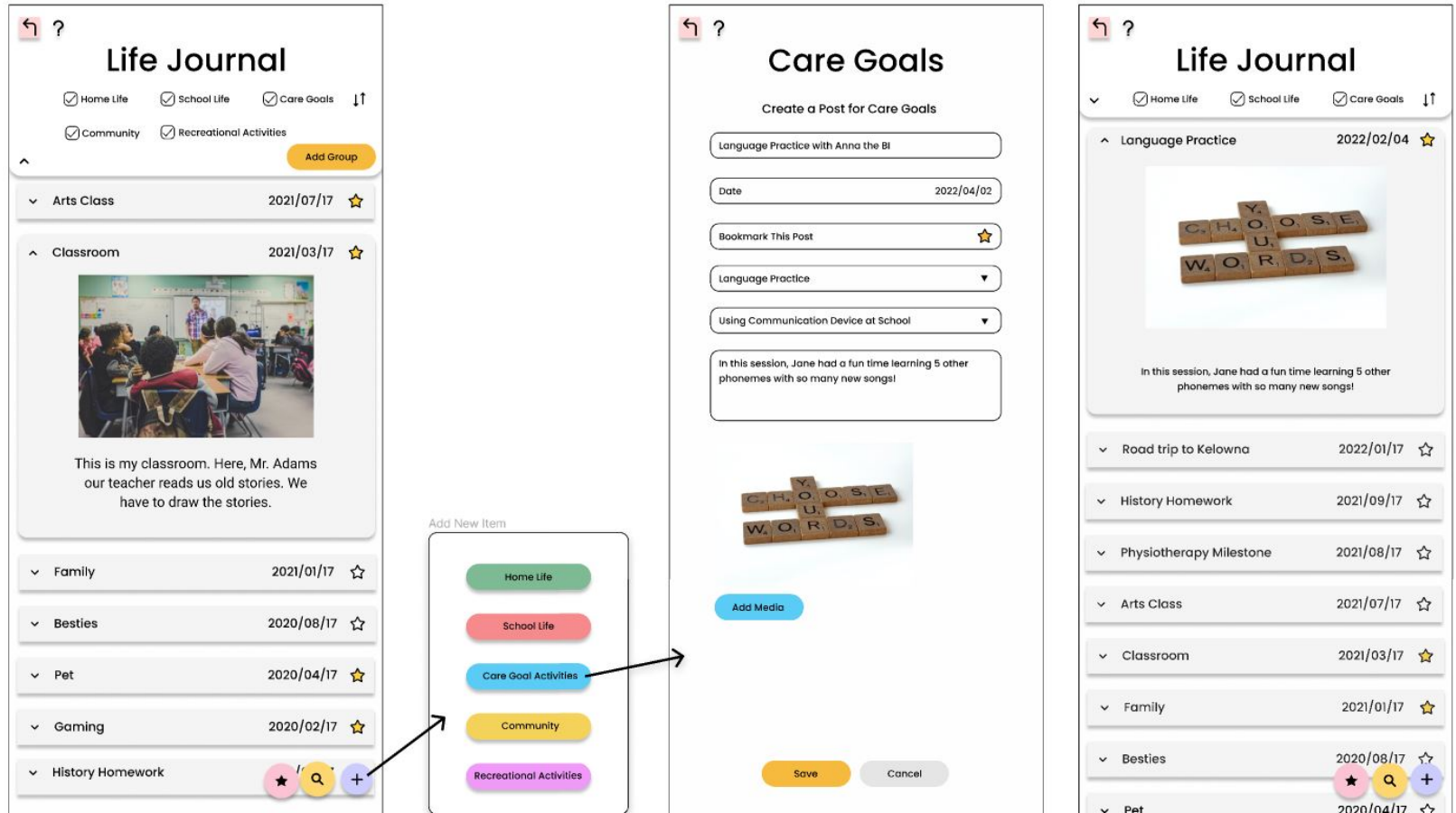


Figure 6.4: Adding a new life event, Language Practice, to the Life Journal. Arrows indicate the connection and navigation between pages within the feature.

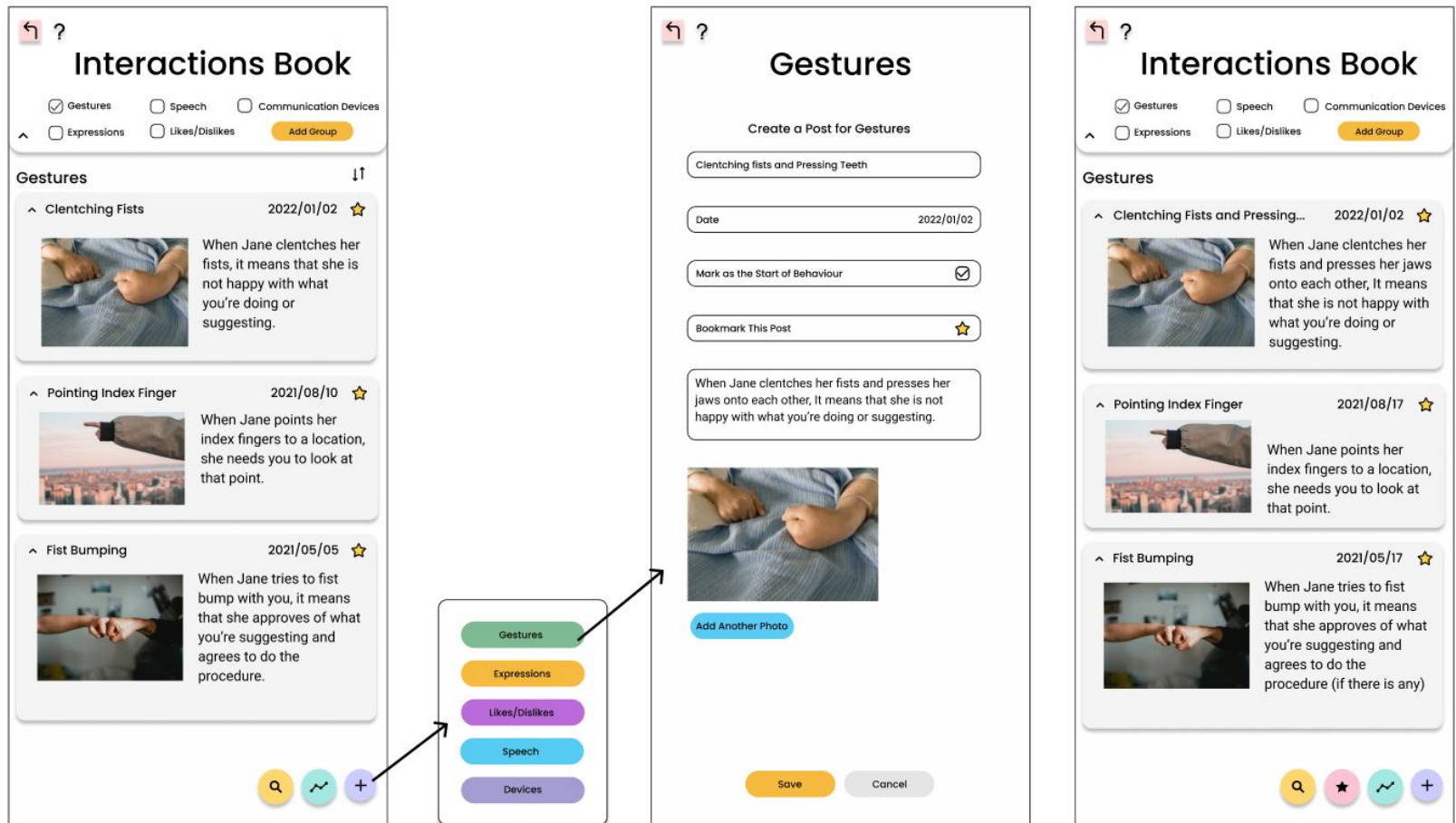


Figure 6.5: Adding a new interaction, Clenching Fists, to the Interactions Book. Arrows indicate connection and navigation between pages within the feature.

6.2.4 Features

An important feature on the About Jane “dashboard” is the ability to upload an introductory video about Jane. Another feature that is visible on this dashboard is the “Add button” (circular purple button) which enables the user to add any other page shortcuts to the dashboard. The Life Journal and the Interactions book have pre-made categories for documenting the child’s life events and interaction methods and also the ability to add new categories using the “Add Group” button. This design is consistent with all other pages to allow the addition of user created data categories. These data categories can be filtered using the check boxes on the top menu.

Another visible feature is the “Search button” (circular yellow button) which enables searching for information using text or dates. Each “item card” or “info card” within these pages can be added to the bookmarks using the yellow star icon on the top right corner of the card. This enables the users to integrate any data pieces from within the system and generate custom summaries through the Reports page or the Bookmark pages. Lastly, an additional important feature that was discussed within the research team was to enable the user to link and view the behavioral cues, medications, care items as part of the Medical Timeline. This feature (circular green button on the bottom right corner) will allow parents to directly navigate to the Medical Timeline from the Child’s Profile and visualize these items.

6.3 The Medical Timeline

The Medical Timeline is a significant section of the prototype and relies on our initial plan to have a futuristic approach with this project. This page allows access to historical medical events (*e.g.*, lab reports, hospital visits, symptoms etc). We considered various similar designs for this page, however parents had previously emphasized being able to see “overlaps” for events, hence the design which enabled this ability was prioritized.

There are many feature examples that we could have chosen for this page, however tracking recent symptoms was highly ranked in Table 4.3. Therefore, some important feature examples for this page were: adding a new symptom category,

tracking a symptom and graphing it.

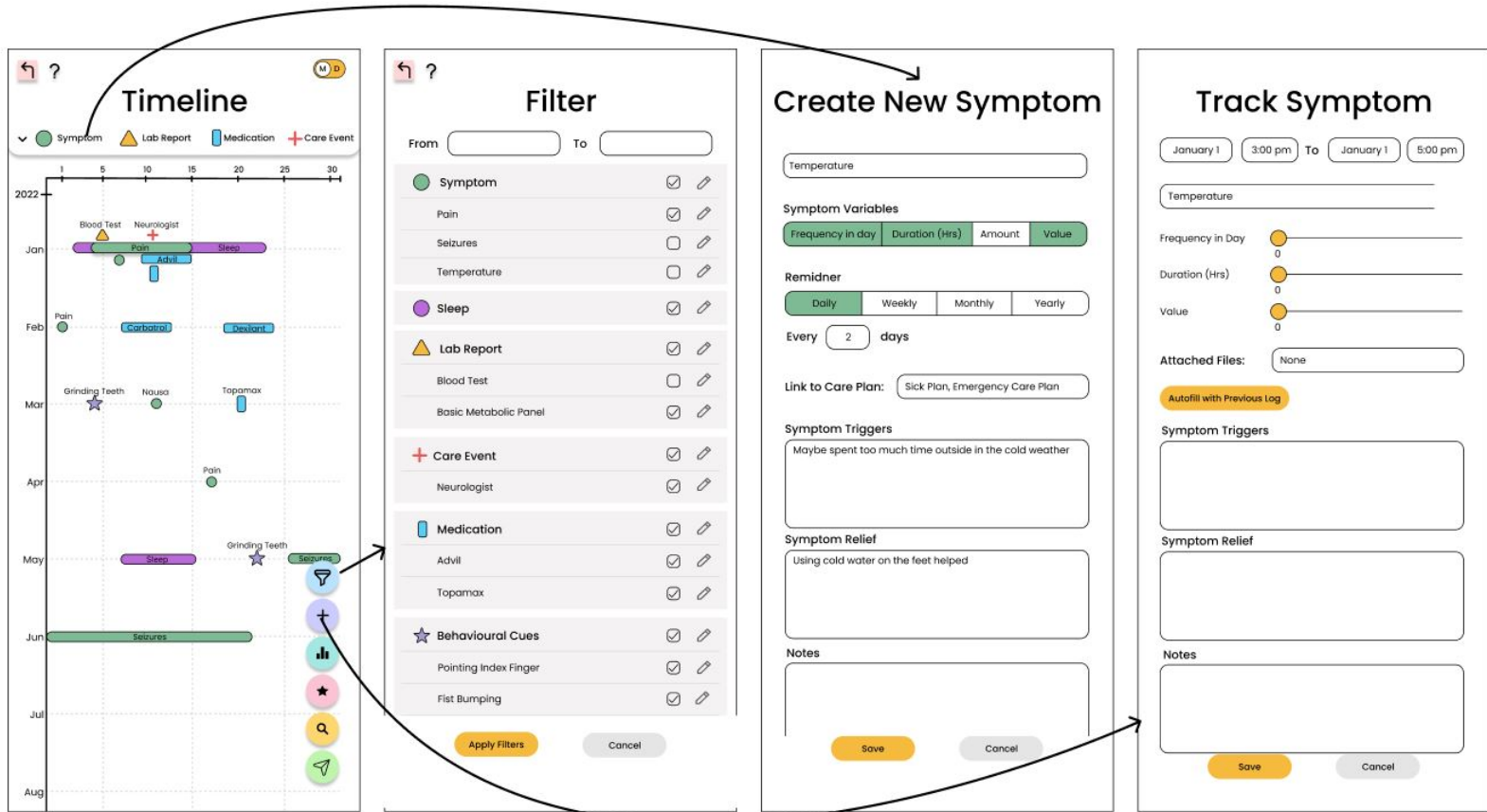


Figure 6.6: Adding a new symptom, track a symptom and filter item categories on the Medical Timeline. Arrows indicate connection between pages within the feature. Arrows indicate the connection and navigation between pages.

6.3.1 User Feedback

The “Zoom In/Out” interaction which we designed as a way to toggle between Monthly and Daily timelines was not intuitive for parents. Parents commented that they prefer to click somewhere or see clear buttons to toggle between the two timelines. Figure 6.7 shows the Monthly and Daily timelines with the toggle feature added to the top right corner.

The Share button also did not appear to be intuitive and one parent noted that the “airplane icon” could work better. On the Graph Preview page, one parent tried to rearrange the symptom graphs and pointed out that being able to re-align the graphs could be a useful feature.

Additionally, parents wanted the ability to attach media files (*e.g.*, videos, photos) and to create a reminder when tracking or creating a symptom. Also, integrating or linking a symptom with the corresponding Care Plan (*e.g.*, link the Seizures symptom to the Seizure Care Plan) was pointed out by one parent. One participant noted that an extra input field could be added for “symptom aggravation or triggers” when tracking a symptom and that the user should be notified to create a Care Plan if the symptom appears regularly.

6.3.2 Features

The researcher-made item categories on the Medical Timeline (Figure 6.7) included Symptoms, Lab Reports, Medications, and Care Event (Care Event was previously called Diagnosis or Active Issues, but this was changed to “Care Events” due to the negative connotation associated with “Issues”). Each of these items can have subcategories, for example, Symptoms can have a subcategory for seizure, temperature and so on. Another notable feature on the Medical Timeline includes the ability to toggle between monthly or daily views. The filter on the Medical Timeline is more sophisticated than other pages due to the numerous item categories which may crowd the timeline if they are all visible. The user can begin the process of creating a new symptom category by choosing certain variables for each symptom (Frequency in day, Duration/Amount, Value) and inputting a time to be reminded for tracking the next entry. Additionally, the user can create a graph of the chosen variables for any of the items that were tracked. These graphs can help

to determine relationships, find overlaps, and provide insight into how each variable changes through time (for example, view the effect of frequency of seizures and duration of sleep or find whether a medication is causing a harmful symptom/behavior).

One challenge with the symptom tracking and creating a comprehensive visualization is that parents would like to track many different things (Table 4.2, question 10) and this should be taken into account for future iterations.

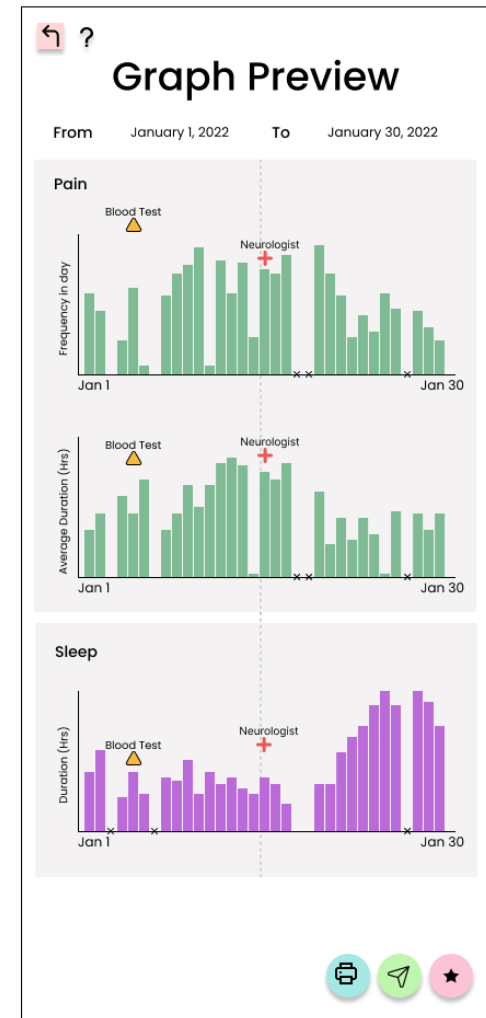
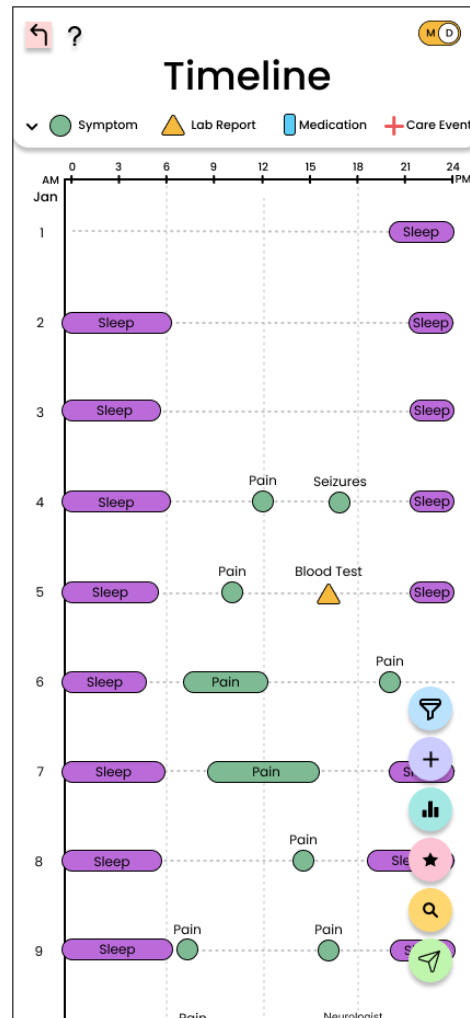
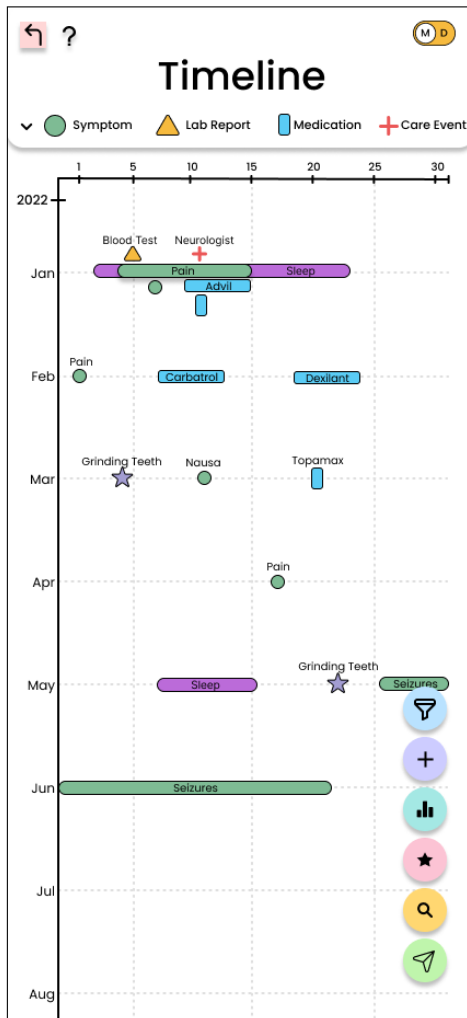


Figure 6.7: Three panels showing the finalized Medical Timeline (monthly and daily) views and the graph preview feature.

6.4 Other Pages

We also designed other pages that we believed could be important to parents and sought to collect some limited feedback during the interviews. These pages are the Calendar, child's Daily Schedule (which is accessed through Jane's Profile and the Calendar), and the Dashboard (Figure 6.8). Due to time limitation, any other pages that we designed (or improved) did not receive direct feedback. These pages are the Care team (and all its sub-branches), Reports, Supplies and Equipment, Diet and Nutrition, Care Items, Medications, Caregoals, and Care Plans (Section C.1).

For the design of these pages, we used previous research and feedback as a guide. We aimed for a familiar design as Desai et al. found this to be important [29]. For example, for the Calendar, we used features such as the ability to toggle visibility for different calendar instances (similar to Google Calendar). We also kept the design consistent with other pages; for example, we used the same menu buttons for adding custom categories of care provider contacts in the Care Team (Figure 6.8, Figure 6.9).

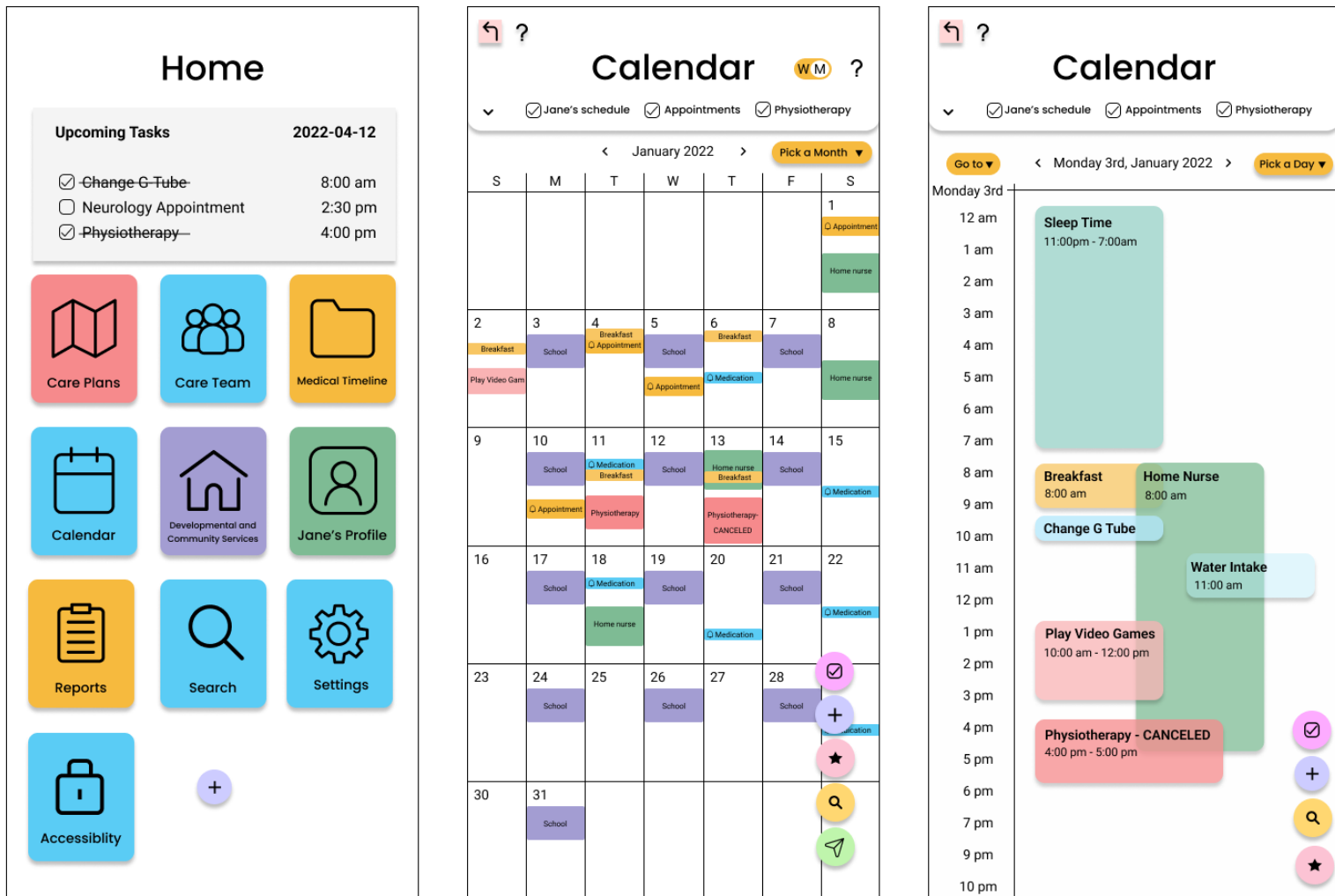


Figure 6.8: Three panels showing the finalized Dashboard, monthly Calendar and the Daily Schedule.

Care Team

▼ Pediatrics School Physiotherapy ↑↓

- Sandy White**
Vancouver General Hospital
Primary Pediatrician
604-310-1010
- Bob Winters**
Sunny Hill
Physiotherapist
604-310-1010
- John Smith**
School
Teacher
604-310-1010

+ ★ 🔍 📍 🧑

Messages (1)

Action Items (1)

Questions (2)

Action Items

▼ Pending Complete Unknown ↑↓

- Pending** Check problem with the wheelchair
Deadline: January 5, 12:00pm
Bob Winters
- Complete** Send Jane's school documents to Sandy
Completed on: January 3, 5:00pm
Sandy White John Smith

+ ★ 🔍 📍

Q&A

▼ Equipment Medication Care goals ↑↓

- What is this button on the wheelchair?**
Waiting for John to respond
Equipment
- Are we eligible for respite services?**
Waiting for Bob to respond
- How often should my child be taking the medication?**
Sarah's answer: Once a week at the same time
Medication
- Does this piece of equipment need to be replaced?**
John's answer: Based on the photo, it should still be fine for now
Equipment

+ ★ 🔍 📍

Figure 6.9: Three panels showing the Care team, Equipment and Funding and the Q/A board.

6.4.1 User Feedback

As mentioned previously, the interviews did not explore these pages in detail and the feedback is limited. Parents generally liked the design and colors in the dashboard, but mentioned that it would be ideal to see a customizable list of “Upcoming tasks” that links to the calendar. The upcoming tasks should include both the child’s tasks and the caregiver activities. In addition, one parent noted that “Medical Records” is not a good term to refer to the page which contains the timeline of events, therefore this name was changed to “Medical Timeline” in the final prototype. Another similar feedback was that the term “Reports” does not fully explain the purpose of the Summaries page and two parents assumed that this is referring to medical reports, therefore this page name was changed to “Summaries” (Section C.2).

Parents also mentioned that the calendar should help with keeping a record of canceled appointments. Additionally, on the calendar, there should be an option to mark an activity as “one-off” or “repeated”. One parent mentioned that “Care plans” should be called “Care protocols”. Two parents mentioned that there should be a tutorial or Help button on each of the pages.

6.4.2 Features

The Care Team includes pages such as Action Items which allow users to tag members of the care team with an action and track the status of the item. Similarly, the collaborative Q&A board is used for asking questions and tagging members of the Care Team to get their attention about an item.

A feature idea that we discussed in the research team was to visualize the organization of the care network in the Care Team page (blue button in the middle section). This would be similar to the care maps that parents create and would show how the care network is connected and organized.

Another feature idea was to allow certain sections of the prototype to be turned on/off for the user in the Settings page. Other types of utilities in Settings can be changing the language, fonts, or colors. In the Accessibility page, the users can change view/edit permissions for the members of the care team (Section C.3).

6.5 Iteration on the Prototype

Figure 6.10 provides a summary of the final stage of the **prototype** and how much each page has changed based on the over all user feedback received in all stages of the design and user interviews (including Table 4.3).

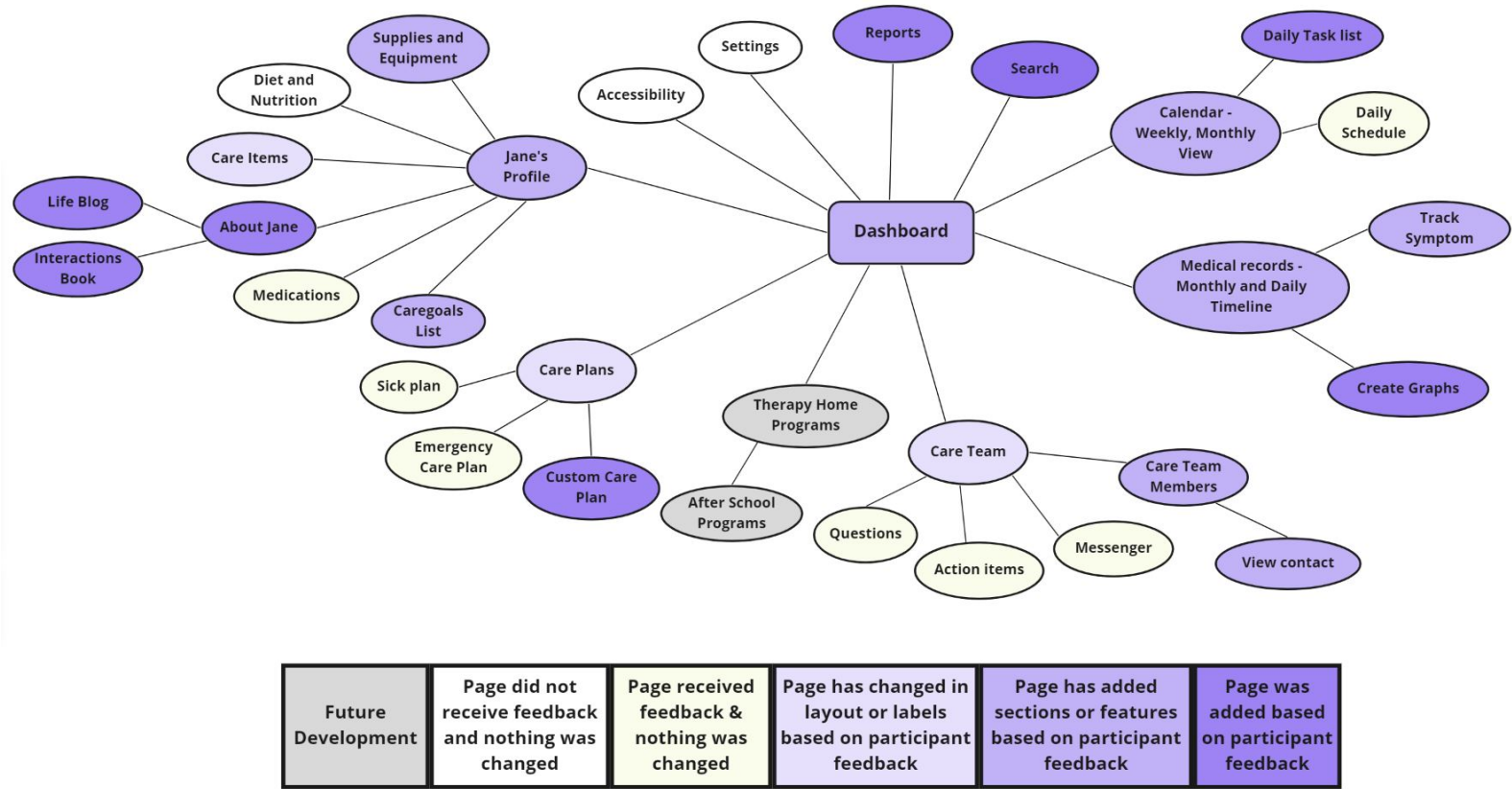


Figure 6.10: The finalized conceptual system map showing the degree of change for each page based on the user feedback.

Chapter 7

Design Principles

In this chapter we will provide the finalized description of our caregiver-centered design principles, assess our prototype based on these principles, and provide details on how to apply them to other digital health platforms to understand how they can match the needs of caregivers of CLHC within such a platforms.

7.1 Finalizing the Design Principles

At a high level, analysis of our participants' feedback allowed us to finalize the DPs which emerged in Section 5.2.

Since our participants did not include many non-English speakers, only one of them raised issues regarding difficulty with English medical terms and communication with care providers. However, when other participants were asked about this, they mentioned that it is not relevant to their family but would be very important to other people and could be helpful while traveling. This is not being included in the design principles because we do not have enough data from non-English speakers, but we would like to mention that such a principle could be added with more data.

7.1.1 Describing the Design Principles

In this section, we will provide detailed description of the emergent DPs and their implications for design.

DP1-Provide a Holistic View

The interface should aim to include everything about the care for the patient, because all care aspects are linked (holistic care). This principle relates to the well-documented gap in the literature and in our data that the current care system and decision making fails to view the child's complex diagnosis as a whole. Caregiver-centered digital health technologies could fill this gap by assimilating and integrating all the information about the patient to make it easier for parents to share and for stakeholders to access this information.

DP2-Personalize and Humanize

The interface should humanize and personalize the patient and the family. We believe this is one the most important principles and it is rarely talked about in the context of digital health tools. In fact, our data shows that caregivers care deeply about this in the context of sharing how their child communicates, what their family looks like, what their life is outside of the hospital, what are their care preferences and what are their child's likes/dislikes etc. Previous research shows that the increased use of technology and the automatization and fragmentation of care, has lead to dehumanization and depersonlization of patients [17]. Patients have reported that they have been viewed as a "group of symptoms" rather than a human which negatively affects their relationship with care providers. There is no clear definition for "humanization of care", however key elements include respect for patient's uniqueness, individuality and humanity [17]. We believe this is even more prominent for caregivers of CLHC because they are exposed to the health care system for a long period of time and very frequently. Also, as seen in the content priorities research by Desai et al., these ideas can be transferred to digital health tools by providing a section to include personal information about the child, their home life and family [29]. In addition, extensive information can be included about how to interact with the child and what their body language means which is very useful for non-verbal children.

DP3-Facilitate Communication and Collaboration

The interface should facilitate communication and collaboration with care providers. This design guideline is very general because communication and collaboration can be achieved through different methods in a cloud-based technology. Sharability of health data and the ability to interact in real-time with the data while at the care provider are important aspects of this principle. Another aspect of this principle is that an interface aiming to create a collaborative space needs to consider both the caregivers and care providers usability.

DP4-Avoid Jargon

The interface should limit medical jargon. This principle ties into other DPs such as DP3, because it aims to make the interface and data usable for the caregivers. Once the caregivers feel confident with the medical terminology, the communication with care providers can improve. Desai et al. use of family-centered language has been emphasized [28]. Furthermore, similar to the concept of humanizing the patient, vocabulary that may have negative connotation should be avoided and “the focus should be on what the child can do, the positives, and not the negatives” as one parent participant suggested. Our own data from parents also show that medical jargon poses barriers to communication with care providers (especially for new parents). This can be very important for non-English speaking families and travelers.

DP5-Capture History and Provide Insight

The interface should maintain an accurate and historical record of events and provide accessibility and insight into the data through caregiver-centered visualizations. This principle was devised to address the big issue with accessibility to health data and the complexity of providing this data to the caregivers. It is also meant to encompass and address the challenges with “tracking” information and events by keeping historical records. For example, some parents have mentioned that their child’s complex symptom patterns often makes it difficult to discern between the symptoms of new acute problems or the symptoms of the complex disease progression [44]. This complexity makes it difficult for care providers to know when

escalation of medical care is necessary. Therefore, our data and previous research shows parents rely on symptom tracking to generate records which facilitates communication with care providers. It is not only data accessibility and sharability that is important, but presenting the data in an *accessible* and *comprehensible* way which can be understood and used by caregivers (and care providers) is also critical. Parents do not want to see a complicated graph with lab results, but a simple way to view and track the most important health concerns (associated doctor's notes and lab results) and share their own insights with care providers. This principle is also very important for empowering caregivers and integrating the data from at-home events with medical health records.

DP6-Share and Access Confidentially

The interface should balance sharability, accessibility and confidentiality. This design principle was also mentioned by Desai et al. as “Balance between access versus security” [28]. However, we have added *confidentiality* and *sharability* because parents mentioned that it is a huge task to provide consent to different organizations for using and accessing their data (*e.g.*, filling-in forms and signing things). They have also mentioned that there are security barriers to accessing some information either for themselves or for stakeholders. Therefore, the interface for a digital technology, should prioritize accessibility and sharability while giving users the authority to provide consent and user-access. Specific features should be designed to make this process painless and easy.

DP7-Integrate Information

The interface should integrate data pieces and enable data linkage. This principle is devised to address the issue with handling and sharing fragmented data in different formats and with different providers. This principle also aligns with Chute and French who propose that the patient should be the main point of information integration [21]. Furthermore, data integration is key because busy caregivers should only have to create or update a data piece one time rather than having to do this more than once and in different sections of the interface. They should also be able to retrieve pieces of data from different sections and link them together to share

with stakeholders as they need (parents do this laborious task manually when creating care plan summaries). Without this principle, it would be difficult to share fragmented data with stakeholders who have very different needs (*e.g.*, school, at-home nurses, care team members).

DP8-Customize and Allow Flexibility

The interface should be highly customizable and flexible to meet the needs of different families. This principle was derived mainly from the user feedback on the prototypes which indicated that parents may have different needs in terms of using color to tag pieces of information. For example, parents need customizability to change the colors for symptom categories on the Medical Timeline or they may want to change the colors of calendar events or the items on the main dashboard (*i.e.*, tag information using colors). Additionally, they may want the flexibility to add their own custom made data categories or pages (*e.g.*, custom care plans) that matches their own mental model for data organization.

7.1.2 Assessing the Prototype with the Design Principles

DP1-Holistic: Our prototype satisfies DP1-Holistic through attempting to include many dimensions of holistic care. For example, the child's Profile and the Medical Timeline assimilate information to present a holistic view of the child.

DP2-Personalize: We dedicated a section of the prototype to humanize and personalize the child through the Interactions Book and Life Blog. These blogs offer a place to include photos and videos and document the child's activities.

DP3-Collaborate: The Care Team page contains a collaborative Q/A board, a messaging system, a list of contact information etc. which aimed to create a collaborative space. We also designed menu features that allow sharing, printing or emailing information to help with communication.

DP4-Jargon: We avoided using terms that may be confusing or ambiguous to parents to address DP4-Jargon.

DP5-Historical: We created a visual representation of showing historical and current health information on the Medical Timeline.

DP6-Confidential: A design principle that we could improve on is DP6-Confidential. This design principle is difficult to address and explore through prototyping and user-testing because it is multi-layered and would require a fully functioning prototype to test. We also assumed that this aspect is resolved (through our engagement with TrustSphere). Although a limited solution, one idea is to add a parent-controlled feature in Settings which enables giving edit/view access to other users using their email address (Section C.3).

DP7-Integrate: To address DP6-Integrate, we created the Summaries page which works by bookmarking information throughout the app and integrating these bookmarks into custom user-created summaries. Another example of integration is that documented behaviors in the Interactions book can be viewed on the Medical Timeline. The Supplies and Equipment list is also integrated with information about the funding source (charity, government etc).

DP8-Customize: To address DP8-Customize, the user interface is highly flexible through the addition of custom user-created pages and categories. Furthermore, our ideas for enabling customizability included adding optional shortcuts to the dashboard, and changing colors of the data categories.

7.2 Validating the Design Principles in a Separate Context

As a validation step to assess the practicality of the design principles, we applied our design principles to a third party digital health platform. We wanted to understand whether this platform can be used by caregivers of CLHC and patients with complex chronic conditions. To gain an understanding of this platform, we talked with their product experts and used their tutorial videos. Then, we performed a gap analysis¹ to identify the workflows within the third party platform's and map their features with each of our DPs.

To illustrate how this worked and what kind of feedback it was able to provide, we briefly summarize the results of this analysis.

This platform appeared to excel in some aspects of our emergent DPs. For ex-

¹A gap analysis compares the current state with an ideal state to highlight opportunities of improvement. It allows organizations to determine how to achieve their business goals.

ample, in terms of DP3-Collaborate, they provided numerous “social media type” features. Some of these features included messaging system, Q/A board, notifications etc. They also had some aspects of DP2-Personalize in this platform by allowing the user to create a user profile and adding information about their family.

Other DPs could be improved to align better with the needs of care coordination and information management for CLHC caregivers. For example, this platform could improve on DP8-Customize by allowing custom and user-created data categories which would allow the user to create their own data management system. Additionally, DP7-Integrate could be improved by allowing integration between all the various data pieces about the patient. This platform had the ability to upload documents, however, it was not possible to link the data within these documents or retrieve specific data from them. We felt that DP2-Personalize was limited and could include details about the user’s “life outside of the hospital” or their methods of interaction. DP5-Historical could also be improved in terms of “accessibility” because this platform did not provide an easy, visual or intuitive way for the caregivers to explore and understand their medical data.

Lastly, we also compared our list of preferred features with the third party platform’s features (Figure 3.1) which allowed for discovery of more detailed gaps.

This method of gap analysis, which combines the design principles and the list of preferred features, can provide insights for other digital health platforms and allow opportunities for implementation or improvement of specific features. Overall, this type of comparison is straightforward and efficient. It has validated the utility of our DPs and can produce actionable feedback for other platforms if they want to move towards interfaces for caregivers of CLHC.

Chapter 8

Discussion

This project is about utilizing user-centered design to provide a vision for the future and address the current challenges with communication in the health care system for CLHC. We have identified a ranked list of important features for a technology-based solution which parents of CLHC highly prefer. Additionally, we have devised a list of design principles that could provide guidance for future digital health solutions for this population. Also, We have presented a solution in the form of a prototype which implements these design principles. This is the first time such an extensive prototype has been tested with users through multiple design iterations. Our results from the feature rankings and thematic analysis are matched closely with previous research and reflect the findings about caregiver challenges, strategies and their design preferences. In this chapter, we will further discuss the impact of the DPs and their group-specificity, and acknowledge the limitations of our work.

8.1 Revisiting the Research Questions

In this section we will revisit our research question and discuss how we have addressed them.

8.1.1 RQ1: What do Caregivers Need?

Our first research question was “*What do caregivers need (e.g., features, interactivity, content) in a digital tool solution? and, What are the design principles for creating this digital solution?*”

These questions can be answered through combining the data from the caregiver-ranked list of features and the results of the thematic analysis, and our DPs. We found that tracking appointments and symptoms (and other variables), maintaining a contact information list, controlling permission settings, visualizing and summarizing the history of symptoms, maintaining an updated medication list, robust search function, sharing information about how to interact with the child were some of the most preferred features. Furthermore, the parents were enthusiastic to see these features implemented as a prototype. Our design principles were devised to reflect these requirements and align very closely with the family-centered care model, which focuses on integrating the expertise and preferences of parents into the care system.

In Figure 8.1 we have created a map of the system and how this system can interact with different stakeholders and caregivers. Information continuity is ensured through the centralized database which allows the stakeholders to store their data in a centralized location. Since communication is a big component of information continuity, this communication pathway is also ensured through the Care Team space, Summaries and Medical timeline. The caregiver uses their expertise to add information into the information management system, which gets added into the centralized database and can be retrieved by stakeholders (and vice-versa). The caregiver is also the key point of integration. Collaboration on various aspects of care can also happen on the same platform through granting view/edit permissions to the stakeholders.

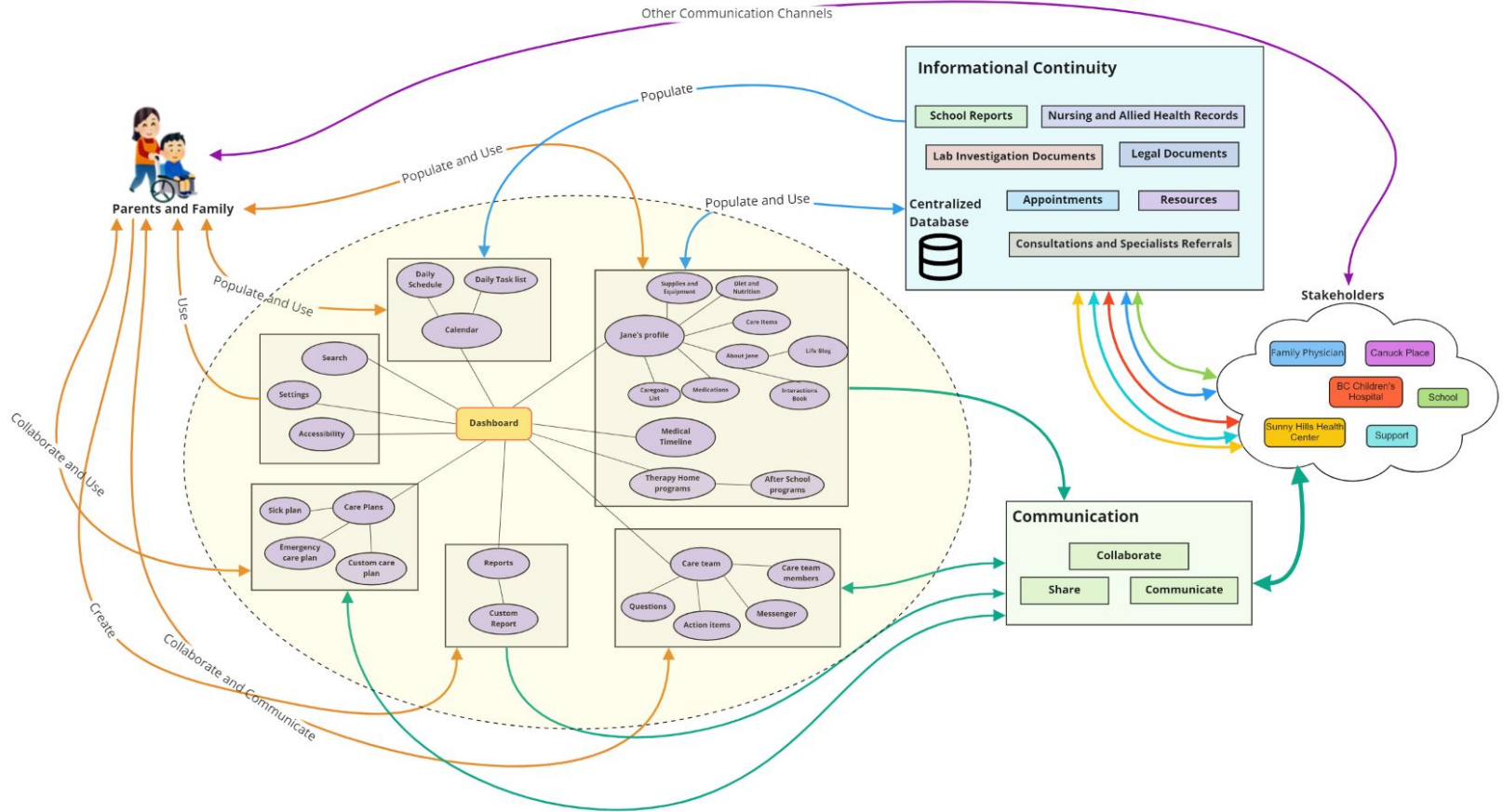


Figure 8.1: Map of how the interface can fit into the bigger context of informational continuity and communication between stakeholders and caregivers. The items included in the centralized database, and the stakeholders cloud are not an exhaustive list. Other items such as resources, parent created documents, and parent collected data for home-events could be included in the database.

8.1.2 RQ2: Group-Specificity of the Design Principles

Our second research question was *“To what extent are this group’s health-coordination needs divergent from others? Where they are, can we identify principles to assist with designing tailored solutions?”*

Because the CLHC population is one of the most medically complex, some of our findings in this work can be extended to other populations of caregivers with patients who are not as medically complex. However, the unique traits that caregivers of children with medical complexity possess are their multiple roles of a parent/caregiver/care coordinators, the lifetime duration and complexity of the illness, the large impact of care fragmentation on the family, the number of stakeholders involved, the amount of information, the high degree of family resource use and their dependency on the caregiver. Hence, some of our principles can be group-specific and targeted towards these caregivers.

DP1-Provide a Holistic View is technically important for any patient with at least moderately complicated or interlocking care issues, since all of the patient information should be available when making care decisions. Therefore, on its own, this principle is generic and could be extended to other populations. Where this principle becomes more unique is when it is coupled with **[DP7-Integrate]**. The amount of data and the degree of data integration required to link the various aspects of the patient data is much more extensive for CLHC compared to other groups. The caregiver overhead involved in maintaining such a system might not merit the benefit if needs are not sufficiently demanding.

DP2-Personalize and Humanize is generic in a sense that interfaces should personalize and humanize all patients. However, where this DP might translate to a profile picture, patient name, and family information for other patients, it translates to much more personal information for CLHC. The type and degree of “humanization and personalization” is different because caregivers already try to and need to share personal information about their child by creating the “About Me” books and “Communication Dictionaries”.

DP3-Facilitate Communication and Collaboration is a relatively broad principle which can be beneficial to many patients in terms of design features (*e.g.*, messaging system, contact information list). However, the extent of collaboration re-

quired between caregivers and stakeholders for care of CLHC is clearly much more intertwined. For example, the need to interact with personal health records or editing and sharing information in real-time and on-the-go can be unique to this population.

DP4-Avoid Jargon is a generic principle and many patients would likely benefit from this.

Similar to DP3, **DP5-Capture History and Provide Insight** is one of the more unique principles because of the caregiver's need to provide at-home care, symptom management, all the while being advocates for their children. Through providing caregivers with an accurate and historical record of events in a way that is understandable and provides insight, they can be empowered to be advocates in the care decisions for their child. Additionally, this principle can help care providers collect data and insights when the child is not at the hospital.

DP6-Share and Access Confidentially can be unique in some ways and generic in others. For example, confidentiality and security of health data is important to many patients. However, what can be unique about the network of stakeholders and caregivers is their immense need to also share and access data. Therefore, some caregivers may prioritize sharability and accessibility of information over security and confidentiality.

[DP7-Integrate Information] is a fairly unique principle because other populations likely do not need a high degree of data integration. When coupled with **DP1-Provide a Holistic View**, this DP becomes very important to prevent fragmentation in the information management system.

The uniqueness of **DP8-Customize and Allow Flexibility** is the flexibility aspect required in interface to incorporate all the data pieces for CLHC. However, the customizability aspect which can apply to tagging information using colors may be more generic.

Urgency of the DPs

Based on our broad knowledge about this field, we evaluate the principles based on their urgency (*i.e.*, what happens if each one is missing?). We believe the most urgent DPs are DP1-Holistic and DP7-Integrate which are overarching and directly

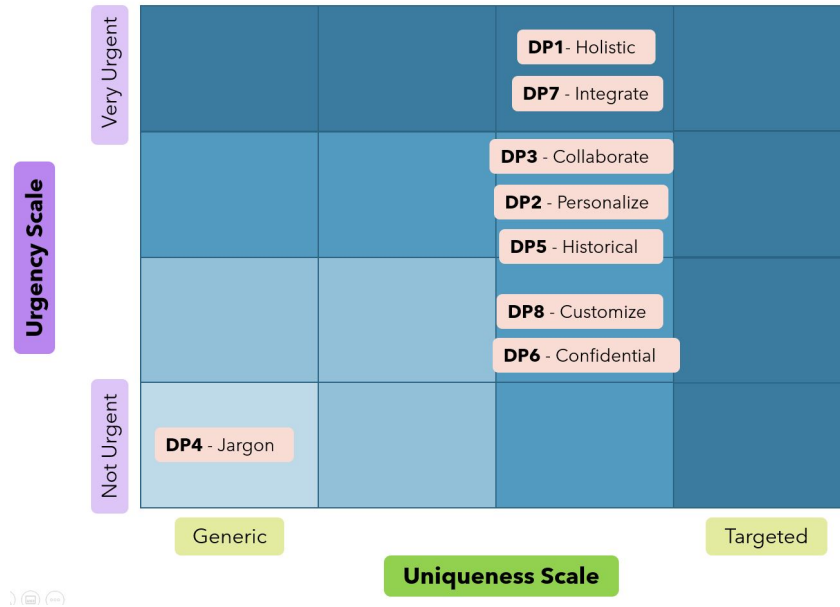


Figure 8.2: Urgency and Uniqueness on a scale of 0-4

address the challenge with large volume of health records. Without these principles, fragmentation of health records would be reflected in the digital solution; the solution would also be fragmented due to the amount of information. Then the combination of DP2-Personalize, DP3-Facilitate, and DP5-Historical are important to provide a method for sharing the health records and addressing the challenges with communication and collaboration with care providers. Without these principles, the digital solution would only become a reflection of current EHR systems which do not support collaboration, and personalization or provide insights.

Takeaways

Figure 8.2 provides a summary of the urgency and uniqueness analysis on a 2D plot. In terms of uniqueness, every DP appears to have both generic and unique aspects (*i.e.*, depends mainly on the *extent* of uniqueness). In terms of urgency when implementing these DPs, some DPs can be more urgent than others.

8.2 Reflecting on the Impact of our Design Principles

Family-centered consultation helped to generate hidden principles. Organizing and articulating parents' input into design principles, then adhering to this in our process changed the design direction of the prototype in concrete and significant ways.

8.2.1 Family-Centered Consultation Generated Hidden Principles

Through consultation with families, we generated principles that we would not have considered when we started this project.

Families wanted their children to be viewed as a whole rather than a set of symptoms, and this led to the creation of **DP1-Holistic**. The understanding that caregivers wish to share family stories, what their child did outside of hospital, how to communicate and interact with them, and their desire for more humanization of their family, lead us to create **DP2-Personalize**. **DP3-Collaborate** was created to address the challenges with communication and ensure families can communicate and collaborate with care providers. **DP4-Jargon** was created as parents told us about their difficulties with understanding medical terminology and navigating the health care system. The realization that caregivers want to view historical health events in a way that provides them with understanding and insight into the data lead to creation of **DP5-Historical**. **DP6- Confidential** was created to address the challenges with security and accessibility to health data where parents expressed their own difficulties and other service providers with accessing their health records. **DP7-Integrate** was created to address the challenges with fragmentation of health data and ensure integration between all the data pieces. Parents also wanted to have custom and user-created data categories in the interface, which lead to the creation of **DP8-Customize**.

8.2.2 Adherence to Principles Led to Targeted Design Innovations

Adherence to the DPs led us to targeted design innovations within the prototype.

For example, **DP1-Holistic** indicates that the interface should include everything about the child because everything is linked. Due to the complexity of care for CLHC and the various information pieces that are required to provide this care (e.g., information about feeding equipment and daily schedule, allergies, are all

required just for taking medication) we were motivated to build the prototype in a way that can include (at the minimum) the most important information required for caring for CLHC. However, without **DP7-Integrate** and the realization that parents regularly need to link and integrate information to create custom information packages (*e.g.*, "parent care plans") we would not have added the Summaries page.

The degree of flexibility enables users to categorize information in the prototype through custom user-created data categories or user-created pages (like the Care Plans), would not have happened without **DP8-Customize**.

To address **DP2-Personalize** we included pages for the Interactions Book and Life Blog. To address **DP6-Historical**, we created visualizations for the the Medical Timeline.

8.3 Limitations of Process and Threats to Validity

Member check-ins as well as addition of multiple sources of data could be added to improve the trustworthiness and validity of the user studies. Revisiting the same participants in future interviews and making sure the prototype designs and the DPs resonate with their needs is of highest priority to improve our confidence.

Other improvements could include using different sources of data. Although, the data from the interviews and feature preferences could be considered as different sources (qualitative and quantitative), other sources of data such as observations of users, obtaining copies of caregiver-created documents and in-person interviews could have been added to improve the validity of the process.

Although we used multiple coders for the thematic analysis of Requirements Elicitation Interviews, other coders may be able to identify additional themes that were missed or code the interview transcripts completely differently than our group. Furthermore, in Low-Fidelity and Med-Fidelity prototype feedback, a more rigorous thematic analysis could have been utilized to identify specific themes related to usability problems, such as navigation, meaning of icons, layout etc.

In terms of the user studies that were aimed to obtain feedback from parents, it would have been better to create multiple different designs for each section of the prototype and ask participants for their opinion. Objective measurements, such as time to complete a task or number of errors could be added during usability tests to

provide better evaluation. Additional user studies with focus groups, and continuous engagement with the same set of participants could provide more insights into the types of documents that caregivers share.

Previous research indicates that caregivers prefer to be in control of the information flow [48]. For example, a parent may not want to share some reports from the hospital with the school. With the increase of electronic health records and integration between stakeholders, it is important to understand how parents like to regulate the follow of information through a digital solution such as the one proposed in this work. Therefore, more questions should have been asked about information sharing to understand the parents' preferences.

Limitations of this research are that all of our parent participants were mothers in similar age range who were mostly very comfortable with using technology which could have introduced bias in our data and impacted the design decisions. Additionally, only one participant was a non-English speaker which could have affected our analysis in terms of the importance of the feature for translating to other languages. Interviewing more diverse participants could help with improving generalization and reducing bias. Another technique that may provide better insights for feature preferences could utilize surveying a larger number of parent caregivers.

Chapter 9

Conclusion and Future Work

Through engagement with the parent caregivers and experts, our realization has been that a comprehensive solution to the complex communication challenges and care fragmentation will not only require a digital transformation, but also depend on changes in the health care system that *will* involve many entities and faces a lack of inertia. In addition to system transformations, there are technical barriers such as the development of the centralized health records database which would allow universal access to the patient's personal health records.

In this project, we are only trying to address a small part of the problem in the hopes to inspire movement towards a futuristic possibility. As a starting point, we have offered a step towards digitalization of voluminous health records, by showing *how* such a solution should or could work from the family's perspective. To this end, we have derived a set of caregiver-centered design principles for further development of digital information management and care coordination tools. Some of these principles are general and could benefit a number of other patient populations, while others, such as humanization, insights into health data, and integration of information can be population specific. With further research, these design principles also have the potential to be extended to other chronic conditions. In addition, we have created a prototype that serves as a real example of how these design principles could be implemented.

For this prototype to fully meet the claim of an implementable blueprint, it will require additional user studies to collect feedback on all parts of the prototype.

Future user studies and user testing should include exploration of data flow and integration in more detail. Furthermore, objective measurements and A/B testing could be done on various parts of the prototype to improve the design.

It is also critical that future research aims to understand how to accommodate other users (nurses, school staff, care providers, family members, etc), how these users could collaborate and communicate in practice, and which design guidelines could be devised for them.

A final evaluation in the form of a longitudinal study that develops, implements and evaluates some sections of the prototype in the form of a Minimum Viable Product could be performed. If participants are not available for longitudinal studies, other users with similar characteristics and experiences could be recruited. The most important aim of this type of study is to understand whether this information management system can realistically be used by parents and caregivers in real life and to assess its actual value to them.

A foreseeable challenge with this implementation is that many sections of this prototype rely on integration of information with other sections. Another challenge is that the database system which contains the personal health records is not easily accessible and many of the records could take multiple years to be transferred to this database. However, these challenges could be resolved by using mock patient data and a divide-and-conquer approach. In such an approach, the prototype can be broken up and implementation efforts can target the more urgent features.

The accessibility and comprehensibility of medical records as well as the management of numerous binders that hold these records are the biggest pain-points for parents. Therefore, an impactful and easily achievable piecewise implementation can be the Medical Timeline which allows access and insights into health information and has the potential to be a standalone application. A secondary target which might not need to rely on the centralized database infrastructure and could solely be populated with the parent data is the Child's Profile. Implementing and evaluating these pieces would be a bigger step towards digitalization and could provide valuable insights into how caregivers can utilize such a technology.

Partnerships with other research groups who have experience with implementation of digital health tools, such as TrustSphere, or other ongoing projects such as SloCan [7] can help to speed up future studies.

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Appendix A

Care Map and Care Plan

A.1 Sample Care Plan

A.2 Sample Care Map

Figure A.1: Sample care plan. Reprinted from Adams et al.

Date of last revision:
Author of last revision:

Comprehensive Care Plan

(Insert institution name here)

PATIENT NAME
DOB: (patient's date of birth)
MR #:
Primary Insurance:
Secondary Insurance:

Parent/Guardian Name(s)
Street Address
City, Province/State
Home telephone number(s)
Mobile telephone number(s)
Work telephone number(s)



Primary Diagnosis: (List primary diagnosis)
Secondary Diagnoses: (List secondary diagnoses)
1.
2.
3.

Alerts: CPR STATUS and allergies

Description of child (2-3 lines): Developmental milestones, communication, likes/dislikes

Important Family Information (2-3 lines): Relevant information about family constellation, child custody etc.

Most Involved Health Care Providers/Emergency and Medical Contacts:

List up to a maximum of 3 (all other care providers are listed at end of care plan)

Name	Role	Contact Information
	e.g. pediatrician/trained health care provider who best knows this patient and their contact information should be listed here.	Address: Telephone: Fax: E-mail:

Current Daily Medication Scheduled/PRN/Complementary or Alternative Medications

Weight (Date recorded):

Medication	Dose	Route	Schedule	Specific information
				Include preparation/reconstitution instructions

EMERGENCY MANAGEMENT GUIDELINES: (This section includes information related to presentation and treatment when the child presents to the ED)

Common Presentation	Approach to Work-up	Approach to Treatment
A succinct list of presenting signs can include presenting diagnoses, physical examination relevant for the patient	An approach for work-up should be presented here especially if not common practice	An approach to treatment should then be outlined especially if not common practice

Detailed Information about Patient's Medical History (review of systems)

BODY SYSTEM	Diagnoses	Presentations, Relevant Tests, and Common Treatments
NEUROLOGY	List Relevant Diagnoses • •	List common presentations, relevant tests e.g. MRI, and common treatments
HEENT	List Relevant Diagnoses • •	List common presentations, relevant tests e.g. MRI, and common treatments

DIET/NUTRITION

Type (oral, enteral, parenteral):

Description:

TECHNOLOGY

Type	Details
Respiratory	oxygen (how it is administered and settings); tracheostomy (kind, size, notes); ventilation (invasive vs non-invasive, settings); suction (catheter size, kind of suctioning required); nebulizer (treatments needed)
IV Access	PORT (insertion date, issues); PICC (insertion date, issues); CVL (insertion date, issues)
Nutrition	enteral feed tube (kind, route, size)
Mobility equipment	wheelchair; walker; stander; AFO's
Other	

Hospitalizations:

Date of admission	Date of discharge	Main Issues
DD/MM/YYYY	DD/MM/YYYY	Main issues during hospitalization

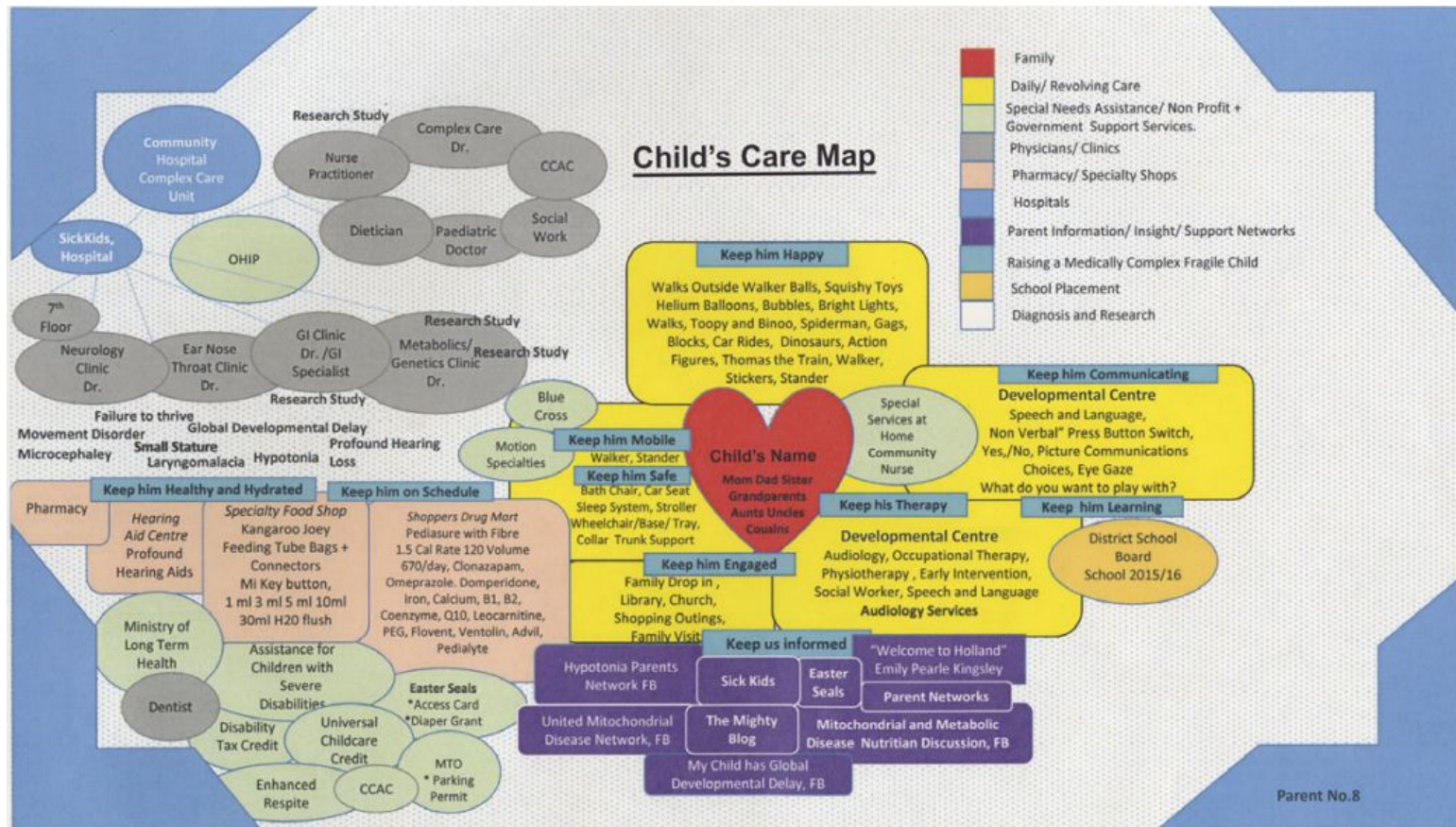
Glossary of Medical Terms:

Term	Definition

List of health care providers & Locations of Care:

Name	Role	Contact Information
	e.g. Physician/Sub-Specialty; Nurse Practitioner/Sub-Specialty; Home Care Nurse; Clinic Nurse/Sub-Specialty; School Nurse; Dietician/Social Worker; Physiotherapist; Occupational Therapist; Speech/Language Pathologist; Pharmacist; Durable medical equipment suppliers; School; Daycare	Address: Telephone: Fax: E-mail:

Figure A.2: A sample care map. Reprinted from Adams et al.



Appendix B

Study Documents

B.1 Study Recruitment Poster



THE UNIVERSITY
OF BRITISH COLUMBIA

Accessibility to Personal Health Records for Caregivers of Children Living with Health Complexities (CLHC)

The challenges with communication between those who care for CLHC is well documented and reported by both parents and medical professionals. This leads to a burden on families who need to repeat their story many times, have limited access to their child's data, and need to manage a high volume of historical health records.

In this study we hope to understand how caregivers manage their child's health records as well as identify their needs for a digital solution. The study will take approximately 1 hour and involve interacting with and testing some website (or mobile app) prototypes **remotely**. Then participants will answer some questions regarding their experience with the prototypes.

Participants will receive \$15 compensation per hour of study in the form of an Amazon, Indigo or Starbucks gift certificate.

Location: Remote (a secure Zoom link will be provided)

Eligibility: Parents or caregivers of children living with health complexities

To sign up for this study, please email Kattie. If you have any questions, please contact any member of the study team:

Kattie Sepehri, Graduate Student -- Dept of Computer Science, UBC -- ksepehri@cs.ubc.ca

Dr. Liisa Holsti, **Co-investigator** -- Dept of Occupational Science and Occupational Therapy, UBC liisa.holsti@ubc.ca

Dr. Karon MacLean, **Principal Investigator** -- Dept of Computer Science, UBC, maclean@cs.ubc.ca



B.2 Study Consent Form



THE UNIVERSITY OF BRITISH COLUMBIA

Department of Computer Science
2366 Main Mall
Vancouver, B.C., V6T 1Z4

Study Consent Form

Principal Investigators: Karon MacLean, Department of Computer Science, UBC, 604-822-8169, maclean@cs.ubc.ca and Liisa Holsti, Department of Occupational Science and Occupational Therapy, UBC, 604-875-2000 ext:5200, liisa.holsti@ubc.ca

Graduate Student Investigator: Kattie Sepehri | ksepehri@cs.ubc.ca

Research Assistants: Sara Niasati and Vita Chan

Introduction: This work is affiliated with the UBC department of Computer science. The title of this study is User Centered Design Principles: Accessibility to personal health records for caregivers of Children Living with Health Complexities - **Substudy 2**. Please note that we are seeking parents or caregivers of Children Living with Health Complexities.

Funding source: This research is funded by the NSERC CREATE grant. This research is a part of a graduate degree and will contribute to a graduate thesis (public document).

Purpose: The overall purpose of this research is to understand the caregiver's needs with accessing and managing their child's personal health records. The purpose of this substudy is to evaluate the efficacy of proof-of-concept prototypes of a related web (or smartphone) application. If you agree to participate, you will interact with some digital prototypes and be asked some questions regarding your experience while using the prototypes..

What you will be asked to do: After you have read this document, we will respond to any questions or concerns that you may have. Once you have signed this consent form, you will be asked to:

- use video screen share
- turn on camera
- answer interview questions

This should take about **60 minutes** or less and be completed in one session. The sessions will also be video and/or audio recorded. Please let us know if you are uncomfortable with the recording. Also to protect your identity, please use a nickname when you join the Zoom session.

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Risks & benefits: This experiment contains no more risk than everyday computer use. There are no direct benefits to participants beyond compensation. Some participants may find that dedicating time to the study or talking about their experience with their child evokes discomfort. If this is the case, you can request to terminate the interview and withdraw your participation from the study at any time.

How the data collected will be used: Data collected (including any audio/video recordings) will be used for analysis and may also be used for research presentations and by the student investigator to form the basis of their thesis research and/or be submitted as a research publication. Video or audio excerpts will be edited to remove identifying information (including but not limited to obscuring face and/or voice) and will not be used in publication unless permission is given below. Please note that once the data is made publicly available, you will not be able to withdraw this data.

Compensation: \$15 per hour paid in the form of an Amazon, Indigo or Starbucks gift certificate

Confidentiality: The results of your participation will be reported without any reference to you specifically. All information that you provide will be stored in Canada. It will be treated confidentially and your identity will not be revealed in reporting the study results. Any presentation venue, such as a scholarly conference, will require that participants be non-identifiable in the video/images.

Data Retention: Identifiable data and video/audio recordings will be stored securely in a locked metal cabinet or in a password-protected and encrypted computer account. Only the principal investigators and the graduate student will have access to this data. All data from individual participants will be de-identified so that their anonymity will be protected in any reports, research papers, thesis documents, and presentations that result from this work.

Who can you contact if you have complaints or concerns about the study? If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Indicate your agreement to **one** of the following options by providing your **initials** :

I agree to have **audio** recorded: Yes No

I agree to have **video** recorded: Yes No

I agree to have **anonymized video or audio excerpts** presented with the findings:

Yes No

I, _____, have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I hereby consent to take part in this study. However, **I realize that my participation is voluntary and I am free to withdraw at any time.**

Participant's Signature

Date

Ethics ID number: H21-02184

B.3 Requirement Elicitation Interviews

INTERVIEW SCRIPT

1. BEGINNING / INTRO

Topic of interview, Context, Ethics/Ethical sensitivity, Informed consent.

- *Thank you for coming, please make yourself comfortable. I am Kattie, a graduate student at the faculty of computer science at UBC.*
- *The aim of this interview is to find out more about how you access and manage your child's personal health records.*
- *The reason I'm speaking with you is because I'd like to find out more about your personal experience as a caregiver for a child living with health complexities. The aim of this interview is to find out more about how you access and manage your child's personal health records.*
- *The interview itself should last around 1 hour or less.*
- *I know you've already signed a consent form but I just want to check that you're still comfortable with doing this interview and consent to moving forward.*
- *Wonderful, please let me know if you need to take a break or stop at any time.*
- *Also, please don't feel obligated to answer all questions; if there is a question you are not comfortable answering just let me know and we'll move on. As mentioned in the consent form, if you feel uncomfortable with this study, you can withdraw at any time.*
- *I just want to double-check that you are comfortable with the level of confidentiality we are applying to this interview. Any information collected will be securely stored in Canada and your identity will not be revealed in the reporting study results nor in any excerpts that may be shared in a class project presentation. You may also avoid using the names of children or organizations that you are part of.*
- *If there are any technical difficulties and the Zoom session closes, please wait around 5 minutes and join back the same session.*
- *Lastly, are you comfortable with the audio and video being recorded for this session? The reason for recording is so that we can go over recordings later to ensure we are addressing all of the key points in our work. You are welcome to keep your camera off if that makes you more comfortable.*

2. MIDDLE / MAIN BODY

This interview is a semi-structured interview and the interviewer may choose to use any of the following topics within the 1-hour limit. Topics and follow-ups will depend on the direction of the interview.

Possible topics may include:

- *Brief information about the child and the medical complexity*
- *Data management strategies*
- *How they interact and use the data on a day-to-day basis*
- *Most significant data needs*
- *Scenarios where they have used a type of data*
- *Card ranking and categorizing activity*
- *Their struggles and challenges (eg. scenarios) with managing their child's data*
- *Interactions with care providers where data access could cause challenges*
- *Where and in what way they want to see a certain data*
- *Their use and thoughts about technology (ie. smartphone or computer)*
- *Types of medical records that they have to handle*

2.1 Family Profiling (carry out the same block for all participants)

Examples of Introductory questions (~5 minutes)

- What are your preferred pronouns? Does your child have any preferred pronouns?
- Could you tell me a bit about yourself, your family, and your child?
 - What condition or diagnosis does your child have?
 - What equipment do they use?
- To what extent do you currently rely on digital technology to organize your child's health information - on a scale of 1-10, where 1= not at all, 10= fully
 - (b) Would this rating go up (would you rely more) if the tools were better? (yes/no)
 - What are the digital technologies that you rely on?
- How comfortable are you with using digital technology [insert what was mentioned above] on a scale of 0 to 10? 10 being very comfortable.
- How comfortable are you with using smart phones on a scale of 0 to 10? 10 being very comfortable.
- How skilled do you think you are with organizing information electronically on a scale of 0 to 10? 10 being very good.
- How important is it for your family to have security of your medical information on a scale of 0 to 10? 10 being you would like your data to be very secure.
 - What are your concerns with regards to security of medical information?
- How important is it for your family to have the ability to share medical information on a scale of 0 to 10? 10 being very important.

Examples of demographic questions (~5 minutes)

- How old is your child with a complex diagnosis?
 - *If they are uncomfortable with this, they can use age bins: 0-5, 6-10, 11-15 (pattern)*
 - *If they mention that their child is deceased, ask how long ago it was.*
- *Are you the primary caregiver of the child with medical complexity?*
- *Is English your family's primary language or prefer not to say?*
- *Do you consider your relationship to the child as the mother, the father or other or prefer not to say?*
- *I'm going to ask you your age using categories. Can you put yourself into one of the following age bins: Less than 35, between 36 and 45, and more than 45, or prefer not to say.*

Examples of questions about data management strategies and challenges (~20 minutes)

- I'm now going to ask specifically about you and the ways in which you interact with your child's health information **currently**.
- Can you think and imagine positively about a world where all your child's information is accessible digitally vs do you think that it would be impossible or not desirable?
 - Does it make sense in the future for all the child's information to be accessed digitally or is this not realistic, why is it not, and why are you uncomfortable with it?
- How do you organize your child's medical records?
 - *If they mention a binder, ask what the binder looks like and what sections it has.*
- How do you manage information about medications for your child?
 - Do you use any medication management or reminder apps?
- How do you manage feeding times and reminders for your child?
- How do you manage information about medical equipment (ie. feeding tube) for your child?
 - Where do you find information about the medical equipment?
 - Where do you find information about grants to obtain this equipment?
- What are some of the most challenging aspects of dealing with a large volume of health data (ie. having a binder) on a regular basis?
 - How often do you find yourself searching for information? What kind of information?
 - What type of information do you have the most difficulty finding? Why?
 - What do you do if you need to access some information very quickly or in an emergency?
- Do you have a communications book for your child?
 - How do you use this?
 - What information does it have?
- How did your information management strategies change based on the age of the child?
- How did your information management challenges change based on the age of the child?

Examples of questions about interactions with care providers

- How often do you need to update the information and records for your child (care plan or care map)? What sort of information could be missing?
 - What do you do when there is missing information?
- How do you track recent symptoms?
 - How far back do you need to track symptoms?
 - In what way would you use this information?
- How do you track appointments?
 - How frequent and in what way do you want to be notified about appointments?
- Have you ever had any language barriers, for example not understanding the medical terms etc. When do they usually encounter these the most?

Example of questions about technology use

- What do you think are the most important attributes of an ideal tool or technology to use for managing your child's health records?
- What technologies do you have access to? For example, laptop, smartphone etc.

2.2 Design activities (First 5 participants)

Using sticky notes (each row will be 1 sticky note), ask them to rank and order the tasks below in terms of their importance

- Can you provide an example of a scenario for each task?

#	Task
1	Tracking recent symptoms
2	Tracking upcoming appointments
3	Maintaining an updated medication list
4	Communicating care preferences
5	Outlining care goals to promote shared decision making
6	Syncing appointment information with other mobile applications (eg, personal calendar)
7	Downloading and printing feature for the care plan
8	Notifications to alert changes in care
9	Secure messaging system to enable care team members to ask questions, clarify the rationale behind decisions, or resolve conflicting information within the care plan.
10	Having a tracking system of when and where users are accessing care plans to enhance accountability.
11	Controlling permission settings in terms of who can view and modify the care plan

12	Hands-free and voice interactive engagement with the app
13	Visualizing and summarizing the history of symptoms
14	Visualizing and summarizing the history of diagnosis
15	Interacting with personal health records at your provider (ie. at hospital, family doctor)
16	Visualize and graph laboratory test results
17	Tagging specific team members to get their attention about an item
18	Reminder system for medications
19	Reminder system for feeding
20	Reminder system for therapy home program (s)
21	Reminder system for equipment maintenance
22	Robust search function to find information quickly
23	Translating the medical information to other languages
24	Tracking who has advocated for the child and how many times

3. END

Thanks, additional points, queries, ethics.

- do you have any questions to ask or anything you would like to mention about what we discussed today?
- Do you feel comfortable to be contacted for the next phase of the study again?
- I am also wondering about your interest in a continued involvement with this research, as there is a chance that we would need to have a co-design participant in the process?
- What is your preferred gift card between Amazon, Starbucks and Indigo?
- Thank you so much for talking with me and sharing your experience. Please let other parents or caregivers know about this study and I would like to encourage you to participate in the next phase of the study. In the next phase, we will need participants to test our prototypes, like a website or an app.

B.4 Low-Fidelity Design Feedback

INTERVIEW SCRIPT

1. BEGINNING / INTRO

Topic of interview, Context, Ethics/Ethical sensitivity, Informed consent.

- *Thank you for coming, please make yourself comfortable. I am Kattie, a graduate student at the faculty of computer science at UBC.*
- *The reason I'm speaking with you is because I'd like to find out more about your personal experience as a caregiver for a child living with health complexities. The aim of this interview is to find out more about how you access and manage your child's personal health records. We will also test some of our preliminary prototypes and ask you to provide feedback about them.*
- *The interview itself should last around 1 hour or less.*
- *I know you've already signed a consent form but I just want to check that you're still comfortable with doing this interview and consent to moving forward.*
- *Wonderful, please let me know if you need to take a break or stop at any time.*
- *Also, please don't feel obligated to answer all questions; if there is a question you are not comfortable answering just let me know and we'll move on. As mentioned in the consent form, if you feel uncomfortable with this study, you can withdraw at any time.*
- *I also want to double-check that you are comfortable with the level of confidentiality we are applying to this interview. So that is any information collected will be securely stored in Canada and your identity will not be revealed in the reporting study results nor in any excerpts that may be shared in a class project presentation. You may also avoid using the names of children or organizations that you are part of.*
- *If there are any technical difficulties and the Zoom session closes, please wait around 5 minutes and join back the same session.*
- *Lastly, are you comfortable with the audio and video being recorded for this session? The reason for recording is so that we can go over recordings later to ensure we are addressing all of the key points in our work. You are welcome to keep your camera off if that makes you more comfortable.*

2. MIDDLE / MAIN BODY

This interview is a semi-structured interview and the interviewer may choose to use any of the following topics within the 1-hour limit. Topics and follow-ups will depend on the direction of the interview.

Possible topics may include:

- *Brief information about the child and the medical complexity*
- *Data management strategies*
- *How they interact and use the data on a day-to-day basis*
- *Most significant data needs*
- *Scenarios where they have used a type of data*
- *Card ranking and categorizing activity*
- *Their struggles and challenges (eg. scenarios) with managing their child's data*
- *Interactions with care providers where data access could cause challenges*
- *Where and in what way they want to see a certain data*
- *Their use and thoughts about technology (ie. smartphone or computer)*
- *Types of medical records that they have to handle*

2.1 Family Profiling (carry out the same block for all participants)

Examples of introductory questions (~5 minutes)

I am now going to ask you some questions that should take around 5 minutes to answer in total.

- *Could you tell me a bit about yourself, your family, and your child?*
 - *What condition or diagnosis does your child have?*
 - *What equipment do they use?*
- *To what extent do you currently rely on digital technology to organize your child's health information - on a scale of 1-10, where 1= not at all, 10= fully*
 - *(b) Would this rating go up (would you rely more) if the tools were better? (yes/no)*
 - *What are the digital technologies that you rely on?*
- *How comfortable are you with using digital technology [insert what was mentioned above] on a scale of 0 to 10? 10 being very comfortable.*
- *How comfortable are you with using smart phones on a scale of 0 to 10? 10 being very comfortable.*
- *How skilled do you think you are with organizing information electronically on a scale of 0 to 10? 10 being very good.*
- *How important is it for your family to have security of your medical information on a scale of 0 to 10? 10 being you would like your data to be very secure.*
 - *What are your concerns with regards to security of medical information?*
- *How important is it for your family to have the ability to share medical information on a scale of 0 to 10? 10 being very important.*

Examples of demographic questions (~5 minutes)

- How old is your child with a complex diagnosis?
 - *If they are uncomfortable with this, they can use age bins: 0-5, 6-10, 11-15 (pattern)*
 - *If they mention that their child is deceased, ask how long ago it was.*
- *Are you the primary caregiver of the child with medical complexity?*
- *Is English your family's primary language or prefer not to say?*
- *Do you consider your relationship to the child as the mother, the father or other or prefer not to say?*
- *I'm going to ask you your age using categories. Can you put yourself into one of the following age bins: Less than 35, between 36 and 45, and more than 45, or prefer not to say.*

Examples of questions about data management strategies and challenges (~15 minutes)

- I'm now going to ask specifically about you and the ways in which you interact with your child's health information **currently. These questions should take around 15 minutes in total, we are looking for brief responses.**
- Does it make sense in the future for all the child's information to be accessed digitally or is this not realistic, why is it not, and why are you uncomfortable with it?
- How do you organize your child's medical records?
 - *If they mention a binder, ask what the binder looks like and what sections it has.*
- Do you use any medication management or reminder apps?
- How do you manage feeding times and reminders for your child?
- How do you manage information about medical equipment (ie. feeding tube) for your child?
- What are some of the most challenging aspects of dealing with a large volume of health data (ie. having a binder) on a regular basis?
- What do you do if you need to access some information very quickly or in an emergency?
- Do you have a communications book for your child? How do you use this? What information does it have?
- Do you have a parent care plan for your child?

Examples of questions about interactions with care providers

- How do you track recent symptoms?
 - How far back do you need to track symptoms?
 - In what way would you use this information?
- How do you track appointments?
- Have you ever had any language barriers, for example not understanding the medical terms etc. When do they usually encounter these the most?

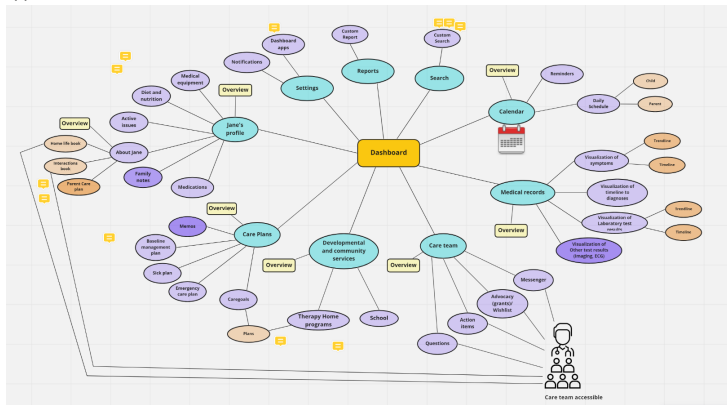
Example of questions about technology use

- What do you think are the most important attributes of an ideal tool or technology to use for managing your child's health records?

2.2 Design activities

Examples of design activities (20-30 minutes)

- I'm now going to ask you about our prototypes and would like to **get your feedback on our designs of this digital system**.
- I will be sharing my screen to show you an overview of our prototype designs. In this app, the child's name is Jane.



- This board shows the overview map of a system where your child's personal health records would appear digitally (for example in an app). Each of these items (blue) link to the main dashboard (orange). The purple objects are sub-pages and so on. The lines represent main interactions that would be available at each page.
- Do you have any feedback on the arrangement, organization and linkage of the items that we have on here.
 - *If they want to change any of the items around, ask for a scenario or reason why they would like to make this change*
- **Now I would like to get your feedback on the prototype zones.**

Other possible questions to ask:

- If you could change something about this prototype, what would it be and why?
- Can you provide an example of a real scenario where you would use one of these pages?
- What do you expect to see in this product in the future?
- What features do you find most valuable?
- Which aspects of this app do you find most useful?
- On the [template] pages, which of this information pieces are useful and which are not?

3. END

Thanks, additional points, queries, ethics.

- Do you have any questions to ask or anything you would like to mention about what we discussed today?
- Do you feel comfortable to be contacted for the next phase of the study again?
- I am also wondering about your interest in a continued involvement with this research, as there is a chance that we would need to have a co-design participant in the process?
- What is your preferred gift card between Amazon, Starbucks and Indigo?
- Thank you so much for talking with me and sharing your experience. Please let other parents or caregivers know about this study and I would like to encourage you to participate in the next phase of the study. In the next phase, we will need participants to test our prototypes, like a website or an app.

B.5 Med-Fidelity Design Feedback

INTERVIEW SCRIPT

1. BEGINNING / INTRO

Topic of interview, Context, Ethics/Ethical sensitivity, Informed consent.

- *Thank you for coming, please make yourself comfortable. I am Kattie, a graduate student at the faculty of computer science at UBC.*
- *The reason I'm speaking with you is because I'd like to find out more about your personal experience as a caregiver for a child living with health complexities. The aim of this interview is to find out more about how you access and manage your child's personal health records. We will also test some of our preliminary prototypes and ask you to provide feedback about them.*
- *The interview itself should last around 1 hour or less.*
- *I know you've already signed a consent form but I just want to check that you're still comfortable with doing this interview and consent to moving forward.*
- *Wonderful, please let me know if you need to take a break or stop at any time.*
- *Also, please don't feel obligated to answer all questions; if there is a question you are not comfortable answering just let me know and we'll move on. As mentioned in the consent form, if you feel uncomfortable with this study, you can withdraw at any time.*
- *I also want to double-check that you are comfortable with the level of confidentiality we are applying to this interview. So that is any information collected will be securely stored in Canada and your identity will not be revealed in the reporting study results nor in any excerpts that may be shared in a class project presentation. You may also avoid using the names of children or organizations that you are part of.*
- *If there are any technical difficulties and the Zoom session closes, please wait around 5 minutes and join back the same session.*
- *Lastly, are you comfortable with the audio and video being recorded for this session? The reason for recording is so that we can go over recordings later to ensure we are addressing all of the key points in our work. You are welcome to keep your camera off if that makes you more comfortable.*

2. MIDDLE / MAIN BODY

This interview is a semi-structured interview and the interviewer may choose to use any of the following topics within the 1-hour limit. Topics and follow-ups will depend on the direction of the interview.

Possible topics may include:

- *Brief information about the child and the medical complexity*
- *Data management strategies*
- *How they interact and use the data on a day-to-day basis*
- *Most significant data needs*
- *Scenarios where they have used a type of data*
- *Card ranking and categorizing activity*
- *Their struggles and challenges (eg. scenarios) with managing their child's data*
- *Interactions with care providers where data access could cause challenges*
- *Where and in what way they want to see a certain data*
- *Their use and thoughts about technology (ie. smartphone or computer)*
- *Types of medical records that they have to handle*

2.1 Family Profiling (carry out the same block for all participants)

Examples of introductory questions (~5 minutes)

I am now going to ask you some questions that should take around 5 minutes to answer in total.

- *What are your preferred pronouns? Does your child have any preferred pronouns?*
- *Could you tell me a bit about yourself, your family, and your child?*
 - *What condition or diagnosis does your child have?*
 - *What equipment do they use?*
- *To what extent do you currently rely on digital technology to organize your child's health information - on a scale of 0-10, where 0= not at all, 10= fully*
 - *(b) Would this rating go up (would you rely more) if the tools were better? (yes/no)*
 - *What are the digital technologies that you rely on?*
- *How comfortable are you with using digital technology [insert what was mentioned above] on a scale of 0 to 10? 10 being very comfortable.*
- *How comfortable are you with using smart phones on a scale of 0 to 10? 10 being very comfortable.*
- *How skilled do you think you are with organizing information electronically on a scale of 0 to 10? 10 being very good.*
- *How important is it for your family to have security of your medical information on a scale of 0 to 10? 10 being you would like your data to be very secure.*
 - *What are your concerns with regards to security of medical information?*
- *How important is it for your family to have the ability to share medical information on a scale of 0 to 10? 10 being very important.*

Examples of demographic questions (~5 minutes)

- How old is your child with a complex diagnosis?
 - *If they are uncomfortable with this, they can use age bins: 0-5, 6-10, 11-15 (pattern)*
 - *If they mention that their child is deceased, ask how long ago it was.*
- *Are you the primary caregiver of the child with medical complexity?*
- *Is English your family's primary language or prefer not to say?*
- *Do you consider your relationship to the child as the mother, the father or other or prefer not to say?*
- *I'm going to ask you your age using categories. Can you put yourself into one of the following age bins: Less than 35, between 36 and 45, and more than 45, or prefer not to say.*

Examples of questions about data management strategies and challenges (~20 minutes)

- I'm now going to ask specifically about you and the ways in which you interact with your child's health information **currently. These questions should take around 20 minutes in total.**
- Does it make sense in the future for all the child's information to be accessed digitally or is this not realistic, why is it not, and why are you uncomfortable with it?
- How do you organize your child's medical records?
 - *If they mention a binder, ask what the binder looks like and what sections it has.*
- How do you manage information about medications for your child?
 - Do you use any medication management or reminder apps?
- How do you manage feeding times and reminders for your child?
- How do you manage information about medical equipment (ie. feeding tube) for your child?
 - Where do you find information about the medical equipment?
 - Where do you find information about grants to obtain this equipment?
- What are some of the most challenging aspects of dealing with a large volume of health data (ie. having a binder) on a regular basis?
- Do you have a communications book for your child?
 - How do you use this?
 - What information does it have?

Examples of questions about interactions with care providers

- How often do you need to update the information and records for your child (care plan or care map)? What sort of information could be missing?
 - What do you do when there is missing information?
- How do you track recent symptoms?
 - How far back do you need to track symptoms?
 - In what way would you use this information?
- How do you track appointments?

- How frequent and in what way do you want to be notified about appointments?
- Have you ever had any language barriers, for example not understanding the medical terms etc. When do they usually encounter these the most?

Example of questions about technology use

- What do you think are the most important attributes of an ideal tool or technology to use for managing your child's health records?

2.2 Design activities

Examples of design activities (20-30 minutes)

- Now I am going to share a map of the prototype to show you the areas that the app will have.
- I'm now going to ask you about our prototypes and would like to **get your feedback on our designs of the child's profile. I will also ask you to complete some tasks.**
- I will be sharing my screen to show you examples of our prototypes.

SPECIFIC QUESTIONS

- **Child profile:**
- How should the timeline look like ? Should it only have one behavior or multiple behaviors? Where should it be?
- Should there be a delete button? How should it be accessed? Should there be an edit button on each post or on post preview only?
- How do you want to share this page with other stakeholders ?
- Do you prefer this compared to your current method?

Example of tasks for the participant to complete

Dashboard questions:

- What do you think about the dashboard?
- What do you think about the task list?
- What do you think about a limited choice for colors of the pages?

Possible questions to ask:

- If you could change something about this prototype, what would it be and why?
- Can you provide an example of a real scenario where you would use one of these pages? (maybe)
- What do you expect to see in this product in the future? (maybe)
- What features do you find most valuable?
- Which aspects of this app do you find most useful?
- Which of the information pieces are useful and which are not?

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1. **(Visualize and interact with records at care providers)** The first task is to imagine that your child is discharged from the hospital, and the child continues to have symptoms through the following week. You take your child back to the hospital and want to show them the hospital records and at-home care events from last week
 - How will you share the health records information, starting from the dashboard? Which page would you navigate to?
 - Using the bookmark feature, what information would you want to tag to share with the care provider?
 - What do you think about the filter feature.
 - Now Zoom into the graph and look at the daily view. (Discern two points in the graph (Pain Jan 4th to 15th))
 - **Task** You want to add a new type of symptom, for example Headaches to the timeline, what would you click on? Walk through this task and explain how you think about the prototype.

Health records questions:

- What should be bookmarkable on these pages?
 - How do you like the menu at the top and does it make sense to you?
 - How do you like the look of this filter and does it make sense to you?
 - Should there be a home page for health records before this page?
 - How do you want to share this page with the care provider (print, email or show on the phone)
 - What do you think about the colors and symptoms?
 - How much information do you imagine you will be looking at? Do you think this timeline would be too crowded?
 - Do you prefer this compared to your current method?
 - How would you add a new item, such as a new Lab Report to this chart?
 - Should the generated graphs that are not so important be savable (rather than bookmarked)
 - Discerning two points on the medical records chart between monthly view and daily view
2. **(Tracking symptoms)** Imagine you have noticed a new symptom and wish to track this and the procedure you used (eg. seizure) to alleviate the symptom. Create a new symptom and add notes and date. (start from the dashboard)
 - Now create a graph of the symptom to show how it has changed historically.
 3. **(Sharing information about how to interact with the child)** The next task is to create a sharable communication dictionary for Jane. This booklet will contain

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information about who Jane is, home life, hobbies, how your child communicates etc.

- **Task** You want to see the Jane's daily schedule which shows what a day is like for Jane. Then you want to add a new event to the calendar that is called "Language practice".
- Now you are at the Language practice session with Jane, and you want to document what is happening. Where would you add this?
- **Task** You want to add a new gesture called "Clenching fists" as a gesture to the child's interaction book. Bookmark this gesture, so that you can see it for future reference in "bookmarks"
- **Task** You notice that Jane has been Clenching her fists as a sign of unhappiness and you want to document this. Where would you add this?
- **Task** You want to graph all the behavioral cues on the medical records timeline to see how things have changed. What would you click on?

Child profile questions:

- Should there be a delete button? How should it be accessed? Should there be an edit button on each post or on post preview only?
- How do you want to share this page with other stakeholders ?
- Do you prefer this compared to your current method?

3. END

Thanks, additional points, queries, ethics.

- do you have any questions to ask or anything you would like to mention about what we discussed today?
- Do you feel comfortable to be contacted for the next phase of the study again?
- I am also wondering about your interest in a continued involvement with this research, as there is a chance that we would need to have a co-design participant in the process?
- What is your preferred gift card between Amazon, Starbucks and Indigo?
- Thank you so much for talking with me and sharing your experience. Please let other parents or caregivers know about this study and I would like to encourage you to participate in the next phase of the study. In the next phase, we will need participants to test our prototypes, like a website or an app.

Appendix C

Prototype Miscellaneous Pages

C.1 Care Plans

Home icon, Care Plans, ?

- Emergency Plan (Red icon)
- Sick Plan (Green icon)
- Baseline Plan (Blue icon)
- Sick Plan 2 (Green icon)
- Seizure Plan (Green icon)
- Baseline Plan (Traveling) (Blue icon)
- Bookmarks (Purple star icon)
- + (Add button)

Emergency Plan, ?

Resuscitation and Stabilization 2021/05/17 ★

- ▼ Airway
- ▼ Breathing
- ▼ Circulation
- ▼ Other
- + (Add button)

Baseline 2021/05/17 ★

- ▼ Baseline Vitals
- ▼ Baseline Exam
- + (Add button)

Tips for Successful Interaction 2021/05/17 ★

- ▼ Likes/Dislikes
- ▼ Communication Tools
- + (Add button)

Search icon, + (Add button)

Sick Plan, ?

Resuscitation and Stabilization 2021/05/17 ★

- ▼ Medication
- ▼ Feeding
- ▼ Therapies
- ▼ Other
- + (Add button)

Baseline 2021/05/17 ★

- ▼ Baseline Vitals
- ▼ Baseline Exam
- + (Add button)

Search icon, + (Add button)

C.2 Summaries


🏠 ↶ Summaries ?

- CALENDAR REPORT Create report
- JANE'S PROFILE Create report
- MEDICAL RECORDS Create report
- CARE TEAM Create report
- D&C SERVICES Create report
- CARE PLANS Create report
- CUSOM REPORT Create report


🏠 ↶ Jane's Profile Summary ?

About Jane

Life Blog

- My family is big! 2021/08/17 🗑️
 Here is my family. I live with my mom, my grandma and my 3 siblings!

Interactions

- Pointing Index Finger 2021/08/17 🗑️
 When Jane points her index fingers to a location, she needs you to look at that point.
- Fist Bumping 2021/05/17 🗑️

Medical Equipment

- Wheelchair 2021/05/17 🗑️
- Shower chair 2021/05/17 🗑️

🔍 🖨️ 📍 +

🏠 ↶ Custom Summary ?

CHOOSE THE PAGES THAT YOU WOULD LIKE TO GENERATE THE REPORT FROM

- CALENDAR
- JANE'S PROFILE
- MEDICAL RECORDS
- CARE TEAM
- D&C SERVICES
- CARE PLANS


Generate report

C.3 Others


Figure C.1: Accessibility page and the symptom pain log (accessed through the Medical Timeline)

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
🏠 ↶ **Accessibility** ?




Jane (CHILD)
604-310-1010
email@email.com




Susan
Mother (Primary Caregiver)
604-310-1010
email@email.com




Michael
Father (Primary Caregiver)
604-310-1010
email@email.com



Sandy White
Vancouver General Hospital
Primary Pediatrician
604-310-1010
sandy.white@email.com




Bob Winters
Sunny Hill
Physiotherapist
604-310-1010
bob.winters@email.com



John Smith
School
Teacher
604-310-1010
john.smith@email.com

+

🏠 ↶ **Jane** ?



Date of Birth 2013/01/01
Age 9
Sex Female
Weight 67 lbs

Contact information:

Phone number: 604-310-1010
Email: email@email.com

Medical Information

Primary Hospital: Vancouver General Hospital
Family Doctor: Sandy White
Primary Insurance: Sun Life

App Access:

- Care Maps
- Care Team
- Medical Timeline
- Calendar
- Developmental and Community Services
- Jane's Profile
- Reports
- Search
- Settings and Accessibility
- Grants and Supplies

Edit

Delete

🏠 ↶ **Pain Log** ⬆

^ January 14, 10:00am ★

Value: 2 out of 10

Symptom Trigger(s):
Most likely due to lack of quality sleep.

Symptom Relief:
Temporary relief from Advil.

Notes:
If Advil stops helping with symptom relief, contact doctor again.

∨ January 13, 12:00pm ★

∨ January 12, 1:00pm ★

∨ January 11, 7:00pm ★

∨ January 11, 11:00am ★

∨ January 10, 7:00am ★

∨ January 9, 2:00pm ★

∨ January 9, 7:00am ★

∨ January 8, 2:00pm +

∨ January 7, 9:00am - 3:00pm ★

∨ January 6, 7:00am - 12:00pm 🔍

Appendix D

Prototype Wireframes

D.1 Low-Fidelity Prototype Wireframes

CARE TEAM

1

Advocacy Wishlist

Action Items

Questions

Messages

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Sandy White
Vancouver General Hospital
Primary Pediatrician
604-310-1010

Bob Winters
Sunny Hill
Physiotherapist
604-310-1010

John Smith
Vancouver General Hospital
Occupation Therapist
604-310-1010

+

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Symptom Tracker

January 1, 2022

5:00 PM

Symptom

Variables Frequency in day Duration Amount

Frequency in day
1

Duration
1 min

Symptom Relief: ADD REMINDER

Notes:

SAVE
CANCEL

TRENDLINE

Symptoms
Lab Results

Symptoms

Cofactors

Dates

Frequency **Duration**

Frequency

January 1 Feb 1

Duration

January 1 Feb 1

Sleep

January 1 Feb 1

Create Symptom

January 1, 2021

5:00 PM

Symptom

Variables Frequency in day Duration

Amount +

ADD REMINDER

SAVE
CANCEL