

Master Thesis

Living in Data, Together

Connecting people with chronic illness and their companions in dyadic relationship through health data sharing.

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“

It's a world that flows in
one direction:
data comes from us,
but it rarely returns to us
...
So how can we turn data
around?

– Jer Thorp,
Living in Data (2021)

Prefece

My design career began in Thailand with data visualization and storytelling on social issues. Over time, my focus shifted from big datasets to everyday data, what it means to people and how it can be used.

Growing up in a Thai family, **health has always been a family matter in our culture**. It was normal for grandparents to live with us until their last days. Now, while my parents remain independent, I notice my mom tracking her blood pressure for upcoming check-ups and my dad mentioning doctor visits more often.

As chronic illness rises and more care happens at home, health data collected from our bodies and daily lives through digital technologies becomes abundant. Yet how families share and make sense of these data together remains largely unexplored, as most tracking tools focus on the individual, while these health data could also become relational material and an opportunity to stay connected, as explored in this thesis.

Inspired by **Jer Thorp’s Living in Data** (2021) and its call to bring data back to the people, I explored how health data can become material for sharing and care rather than just numbers, through the lens of **data humanism** (Lupi and Posavec, 2016) and what I define as **data intimacy**, the closeness that develops when people share personal data with trust and intention so that loved ones can understand and care for each other.



Acknowledgement

This project wouldn't exist without Jacky and Marieke, my dearest supervisors who were kind, understanding, open-minded, and super patient with my messy thinking and ongoing anxiety. Your feedback consistently revealed insights I'd missed, helping me reflect and grow. I'm deeply grateful to you both. :-)

Jacky,

I am so happy to have found someone who shares my values around the humanistic and intimate sides of data. Thank you for guiding me to new perspectives on data I didn't even know existed, helping me find the right terminology, sharing invaluable resources, and asking critical questions that pushed me to think deeper. You have been incredibly inspiring!

Marieke,

Thank you for sharing your personal experiences and for being so grounded and pragmatic, always asking me to reflect on what I really want while reminding me to 'relax' when I need it most. I'm constantly inspired by your calm and caring energy. I eventually watched *How To Make Millions Before Grandma Dies* and did cry a lot.

My dearest participants,

Thank you for generously sharing your time and stories about how you navigate health situations together through those long sessions. Despite the challenges of remote sessions across different time zones, our hours together offered surprising insights and wonderful personal experiences that I still think about today, all shared with open hearts and kindness.

To my own family and dear friends everywhere in this world,

Thank you for your support in every form imaginable, for listening to my struggles, brainstorming solutions when I was stuck. You offered help before I even knew I needed it. And thank you for all the memes that made me chuckle through the anxious moments.

Thank you for all your support and care !

Best,
Sai / Pitshaya

Note on Use of AI

As part of this research, I used ChatGPT (OpenAI) and Claude.ai as a supportive tool for writing, reflection, and visual communication. It helped with rephrasing ideas, grammar and language refinement, informal translation of Thai participant quotes, articulating insights, and drafting initial illustration.

All AI-generated outputs were reviewed, edited, or reworked by me to ensure they aligned with the research context, ethics, and participant voices. *AI was not used to analyze data or generate findings.*

Abstract

Context & Challenge

Most chronic care happens at home within families, yet digital health technologies remain individually focused despite research showing family involvement could significantly improve outcomes. In Thai culture, intergenerational caregiving is deeply embedded in family practices, creating a gap between collective care values and individual-centered health tools.

Research Aim

This research aimed to understand how health data sharing can support meaningful connections between **Thai adult children and their parents** managing chronic conditions, developing design framework that address the question "How might we design for relational use in health data?"

Approach

Grounded in **data humanism** philosophy that values human stories and lived experiences behind numbers, the study explored **data intimacy** as the closeness that develops when people intentionally share personal data with trust. Using **participatory design and contextmapping methods**, it engaged four Thai parent-child pairs (n=8)—*parents aged 60+ with metabolic conditions and their adult children*—**across two research cycle**s. Families tracked personal health data, participated in paired co-creation sessions, and designed adaptive sharing approaches for different health situations for their own future. The framework was validated with international design students (n=5) from diverse cultural backgrounds.

Key Findings & Research Contributions

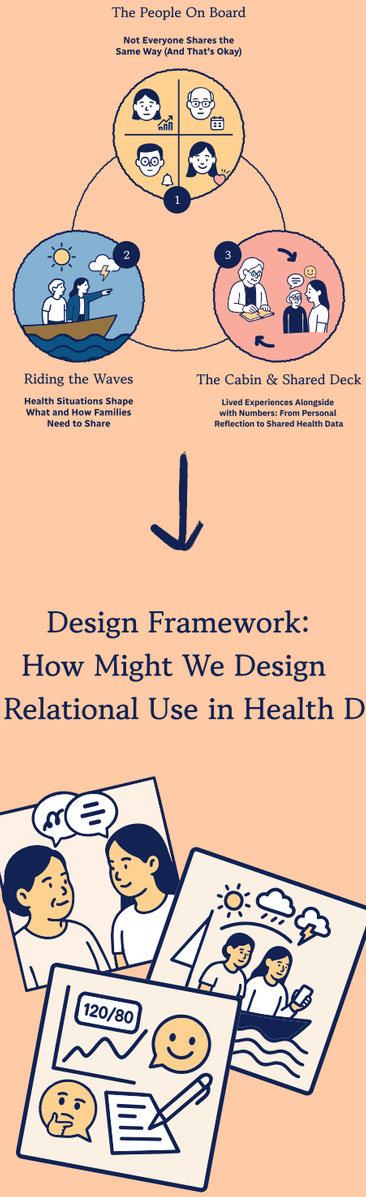
Analysis of family co-creation activities revealed three interconnected perspectives: Thai families demonstrate **four distinct sharing patterns** that adapt over time rather than fixed settings; their expressed needs suggest data sharing requirements shift across four non-linear phases from stable periods to health crises, and reflection; and their preferences indicate potential for using data as collaborative and long-term shared data tools, combining medical numbers with personal context. These insights challenge individual-focused health informatics by revealing how families could practice collaborative sensemaking around health data. Addressing the question **"How might we design for relational use in health data,"** the research develops eleven design principles organized around three pillars—designing with relationships, adapting to changing health situations, and honoring lived experiences behind data—with potential for translation into practical tools for digital health technology design and family conversation facilitation across cultural contexts.

Recommendations

While grounded in Thai parent-child dynamics, validation with international design students (n=5) suggests these insights could extend to other close relationships managing health prevention or chronic illness across cultural contexts. Future applications may include family conversation facilitation tools, emotionally safer health data sharing approaches, and prevention-focused design that supports gradual health communication and connection before crisis happens.

Key Insights:
Health as a Shared Journey:
How Families Navigate
Health Data Together

Three Perspectives That Shape
Health Data Sharing



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Design Framework:
How Might We Design
For Relational Use in Health Data

Figure 1: Three perspectives on family health data sharing translated into eleven design principles.

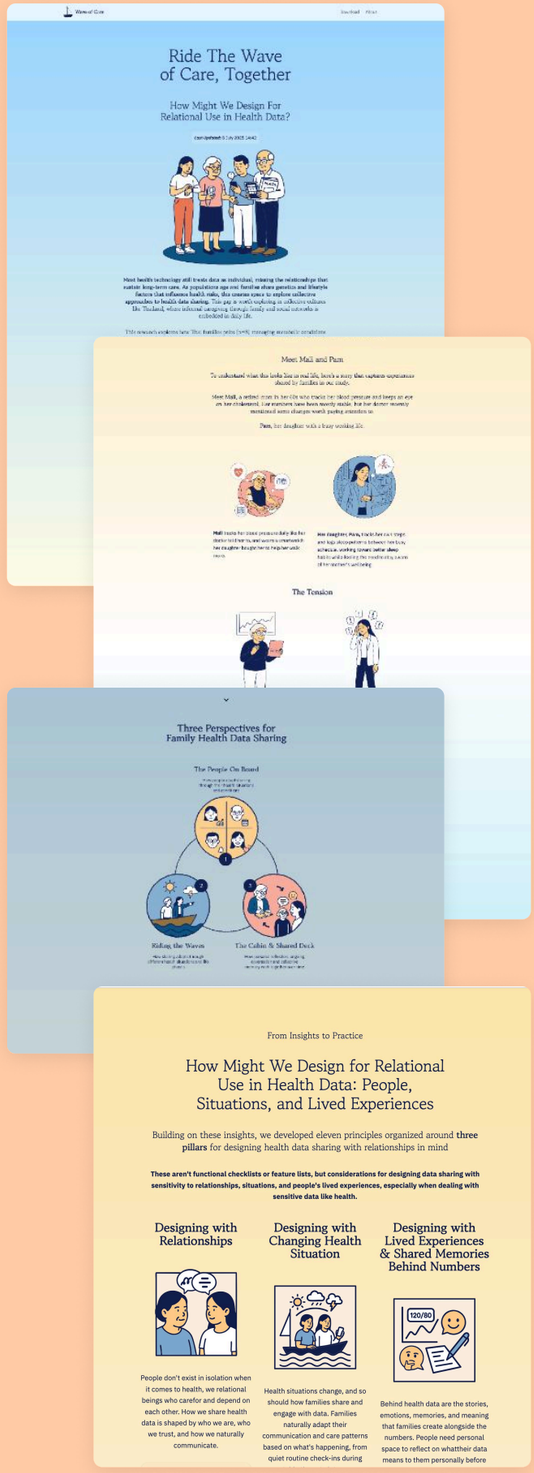

Figure 2: The Wave of Care storytelling website, which communicates research findings and design principles to design practitioners (https://wave-of-care.webflow.io/)

Reading Guide: Navigating the Wave of Care

A journey through understanding how families share health data to connect and care for each other



Chapter 1

Introduction

What's the goal? Why this research matters and what we're trying to understand.

Meet the main question: "How might we design for relational use in health data?" and discover why Thai parent-child pairs managing metabolic conditions became the starting point.

→ Go to page 15

Chapter 2

Background

What we already know about digital health data and family involvement in metabolic care

It covers literature on metabolic syndrome, digital health and personal informatics, and family roles in Thai caregiving. These foundations set the stage for perspectives like data humanism and data intimacy to offer more relational and contextual ways of thinking about health data.

→ Go to page 23

Chapter 3

Approach & Methodology

How we actually did this research

Why participatory design with adult-child pairs? The methodological choices, ethical considerations, and how working with 4 Thai parent-child pairs across two cycles let families become co-creators of knowledge.

→ Go to page 35

Chapter 4

Cycle I – Initial Findings & Framework

Initial insights from families' current practices and wishes

Four key findings emerge: generational differences in health data approaches, behavioral archetypes within families, the "wave" metaphor for health journeys, and what data actually matters to families. The foundation for deeper exploration.

→ Go to page 61

Chapter 5

Cycle II – Key Findings

How families design adaptive sharing across health situations

When families move from talking about sharing to actually designing it, three perspectives emerge: People on Board (relationship dynamics), Riding the Waves (situational adaptation), and Cabin & Shared Deck (personal & shared spaces).

→ Go to page 75

Chapter 6

Final Outcome: Design Framework

How Might We Design for Relational Use in Health Data?

Fifteen insights become eleven design principles organized around three pillars. The **Wave of Care** website—translating research into a tool for designers to design with relationships in mind.

→ Go to page 91

Chapter 7

Validation

Could these insights & framework work beyond Thai families?

Validation with design students with diverse cultural backgrounds reveals the framework's broader potential, emotional safety needs, and opportunities for prevention-focused design with further development and adaptation.

→ Go to page 109

Chapter 8

Discussion

What we learned and how it fits with existing knowledge.

What we learned and how it connects to existing research. Situating findings within personal informatics literature, reflecting on the methodological approach of working with parent-child pairs, and examining the shift from individual to relational approaches in health technology design.

→ Go to page 121

Chapter 9

Personal Reflection & Future Vision

Personal reflections on what this research means for me and what I learned as a person.

The researcher's journey from data design to participatory design with data, and imagining myself in a world where health technology works with relationships.

→ Go to page 143

Table of Content

Preface 4
Acknowledgement 6
Abstract 7
Reading Guide 9
Table of Content 11

Chapter 1: Introduction 15

1.1 Research Problem & Opportunity 16
1.2 Project Context & Scope 16
1.3 Project Goals & Research Questions 18
1.4 Research Approach 19
1.5 Research Overview & Cycles 20
1.6 Conclusion 22

Chapter 2: Background 23

2.1 Chronic Illness and Metabolic Syndrome: Lifestyle Challenge 25
2.2 Digital Health Data & Personal Informatics: Supporting Everyday Health Management 25
2.3 Family Involvement & Thai Caregiving Culture: Seeing Health as a Family Matter 26
2.4 From Individual to Shared: Health Tracking in Social and Family Contexts 28
2.5 Philosophical Foundations: Data Humanism & Data Intimacy 25
2.6 Conclusion: Design Opportunity 33

Chapter 3: Approach & Methodology 35

3.1 Introduction 36
3.2 Participatory Design Approach with Pairs of Family Members 36
3.3 Personal Positionality: How I relate to this research 38
3.5 Participants 40
3.6 Ethical Consideration & Sensitivity 42
3.7 Data Collection Methods 43
3.8 Cycle I: Research Activities & Development 43
3.9 Cycle II: Research Activities & Development 45
3.10 Data Analysis Methods 47
3.11 Conclusion 60

Chapter 4: Cycle I – Initial Findings & Framework 61

4.1 Introduction 62
4.2 Generational Perspectives: Understanding the Parent-Child Context 63
4.3 Behavioral Archetypes: Common Sharing Patterns Across Families 65
4.4 Health Data Sharing Journey: Adapting Sharing to Different Health Situations 68
4.5 Data Sharing Insights: What Data Matters and How They Could Work 71
4.6 Conclusion 43

Chapter 5: Cycle II – Key Findings 75

5.1 Introduction: From Vision to Design Decisions 76
5.2 Three Perspectives That Emerged from Thai Family Design Decisions 76
5.3 Toward Design Principles 84
5.4 Conclusion 90

Chapter 6: Final Outcome: Design Framework 91

6.1 Introduction 92
6.2 Design Framework with Three Pillars 92
6.3 Design Artifact: Ratioanale and Development 103
6.4 Conclusion 108

Chapter 7: Validation 109

7.1 Introduction 110
7.2 Validation Goals & Approach 110
7.3 Participants & Session Activities 111
7.4 Data Collection, Data Processing & Analysis 115
7.5 Validation Results 117
7.6 Key Design Opportunities 122
7.7 Website & Framework Feedback 125
7.8 Conclusion 126

Chapter 8: Discussion 127

8.1 Research Recap and Validation Outcomes 128
8.2 8.2 Expanding from Individual to Collaborative Health Data Approaches 129
8.3 Health Data Sharing in Adaptive Situations 131
8.4 Shared Lived Experience & Memory Behind Numbers 132
8.5 Data Humanism and Data Intimacy: Philosophical Foundations 133
8.6 Initial Validation: From Thai Families to Multicultural Perspectives 134
8.7 Methodological Reflections 136
8.8 Limitations 138
8.9 Future Research Directions 139

Chapter 9: Reflection & Future Vision 143

9.1 Personal Reflection 144
9.2 Living in Data, Together: Envisioning What It Could Feel Like 147

References 149

Appendices 153

Appendices

A1. Original Design Brief
A2. Ethics & Consent Documents
A3. Recruitment Materials
B1. Sensitizing Toolkit
B2. Digital Session Boards (Cycle I & II)
B3. Co-Design Tools (Cycle II)
C1. Validation Materials
D1. Sample: Translated Quotes Table
D2. Cycle I Analysis
D3. Cycle II Analysis
E1. Design Principles
E2. Website Storytelling Structure



Introduction

What's the goal? Why this research matters and what we're trying to understand.

This chapter lays the foundation for exploring health data as relational material within Thai family care contexts. It defines the scope of the project and introduces the main research question: How might we design for relational use in health data? The research explores this question through the specific context of Thai parent-child pairs managing metabolic conditions, examining how health data sharing might strengthen care relationships within this cultural and health context.

It also outlines **the participatory design approac**h that positions families as co-creators, and provides an overview of **the two-cycle research structure** that moves from understanding current health data sharing practices to co-designing adaptive ways of sharing.

1.1 Research Problem and Opportunity
1.2 Project Context & Scope
1.3 Project Goals & Research Questions
1.4 Research Approach
1.5 Research Overview & Cycles
1.6 Conclusion

1

1.1 Research Problem & Opportunity

The Problem & Gap

Most **digital health** technologies are designed for individuals, creating a significant gap in supporting **family involvement—**despite research showing that tracking is often social and collaborative rather than personal (Rooksby et al., 2014) and that family participation significantly improves chronic care outcomes (Deek et al., 2016; Rosland et al., 2012).

Most chronic care happens at home, where digital tools like smartwatches, blood pressure monitors, and health apps help track symptoms and guide daily decisions, yet these tools ignore how health actually unfolds as shared family experiences. This mismatch is particularly pronounced in cultures like Thailand, where intergenerational caregiving is deeply embedded in family practices.

The Opportunity

Chronic illness is rising globally, often manifesting as shared family experiences. Metabolic conditions, precursors to heart disease, stroke, and diabetes, carry higher risks within families due to both genetic factors and shared lifestyles (Han & Lean, 2014; Woods et al., 2022).

This research explores how health data sharing could be designed to support family involvement in managing metabolic conditions, treating data as relational material that families can share, discuss, and use to strengthen ongoing care relationships rather than isolated individual metrics.

1.2 Project Context & Scope

Context of study

This research focuses on **Thai parents and their adult children** living with metabolic conditions such as high blood pressure, high cholesterol, and high blood sugar. These conditions are common in Thai families and are mostly managed at home rather than in hospitals. Day-to-day care often involves informal conversations and small supportive actions that happen naturally in the family setting.

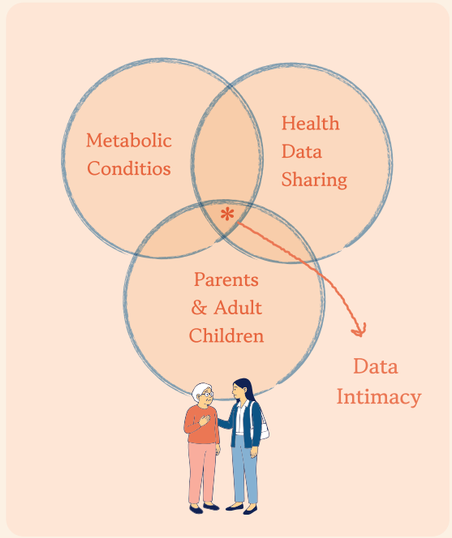

Figure 3: he intersection of health data sharing, family relationships, and metabolic care creates the research context for exploring data intimacy.

Scope of exploration

The study works with **parent–child pairs** (four pairs, n = 8) to explore how health data might support these everyday relationships. It begins with simple lifestyle data such as steps, sleep, and food—because these are easy to collect and talk about—and then expands through co-creation sessions to imagine how families might share. The focus is on the **pair relationship**, looking at how data can flow in **two directions: not one person tracking and the other monitoring**, but both sharing, exchanging, and interpreting health data together.

Why this context matters

Metabolic conditions are relevant for this research because they often run in families due to genetics and shared lifestyles, creating health concerns that span across generations (Han & Lean, 2014; Woods et al., 2022). As entry points to more serious chronic diseases like heart attack and stroke, they require **long-term lifestyle managemen**t where **family involvement** can significantly improve outcomes (Deek et al., 2016; Rosland et al., 2011).

Unlike acute conditions that demand immediate medical intervention, metabolic conditions are managed through **ongoing everyday practices** such as diet and exercise, alongside **regular health checks**. This creates natural opportunities for **family involvement,** aligning with Thai family culture where children often begin caring for parents even before practical support is needed (Wongsawang et al., 2013).

These conditions also connect directly to **everyday lifestyle tracking** such as steps, sleep, and diet. This makes them more approachable for family discussions than critical or emotionally sensitive illnesses, while also providing accessible participants for the research. Within this context, the research explores **data intimacy**—how people can feel closeness through sharing personal health data with trust and intention, allowing family members to understand and care for each other (see Chapter 3 for detailed methodology).

1.3 Project Goals & Research Questions

Project Goal

This research aimed to understand how we might design for relational use in health data sharing between Thai parents and adult children managing metabolic conditions. The study explored how families currently track health data, how they envision sharing it within their relationships, and what design considerations could support meaningful connections.

through health data. The research questions guiding this design project are:

Main Research Question:

How might we design for **relational use** in **health data sharing** between **Thai parents and adult children** managing **metabolic conditions**?

The main research question is addressed through two sub-questions explored in iterative cycles, with Cycle II building on Cycle I findings.

Sub-questions:

Cycle I: Understanding Context & Developing Initial Frameworks

RQ1: How and why do Thai parent-child pairs managing metabolic conditions track and share health data? What do they need and wish?

Cycle I: Building & Refining on Initial Findings towards Final Frameworks

RQ2: How might health data sharing adapt over the family journey of long-term care between Thai parents and adult children managing metabolic conditions?

1.4 Research Approach

To explore how health data might support care within adult–child pairs, this study used **participatory design** and c**ontext mapping** methods with *four Thai adult–child pairs (n = 8).* These approaches were chosen because they create space to learn directly from families' own practices and values, rather than imposing predefined models of data sharing.

Grounded in the philosophies of **data humanism** and **data intimacy** (detailed in Chapter 2), the approach treated health data as personal and situated rather than objective truth (Lupi, 2017). Using contextmapping methods, families were engaged as experts of their own experiences to explore how health data could be interpreted and exchanged in ways that reflect their relationships.

As shown in Figure 4, the research unfolded through a series of pair activities, including **individual sensitizing exercises, family conversations, co-creation sessions, and reflection on emerging ideas**. Using their own health data as starting points, family members discussed current sharing experiences and co-designed future approaches that fit their family dynamics. Drawing on norms of reciprocity in Thai caregiving (Thaweesit, 2021), these sessions were structured as two-way exchanges, where both members contributed and interpreted data together rather than one acting as **"tracker"** and the other as **"tracked."** This approach allowed us to study how health data can become relational material within ongoing family relationships (see Chapter 3 for the full methodological rationale).



Individual health data sensitizing activities

Parent-child pair data sharing conversations

Collaborative co-creation sessions on health data sharing futures

Initial framework feedback & co-reflection

Figure 4: Two-cycle participatory design approach with Thai parent-child pairs: from individual health data tracking through co-creation to framework validation

1.5 Research Overview & Cycles

This research unfolds as an exploration of how health data can become more than numbers—potential material for care and connection within families. The study was designed as an iterative journey, where initial discoveries shaped deeper investigations, allowing families' own experiences to guide the research direction. As shown in Figure 4, the study progresses through **two iterative cycles with** Thai families.

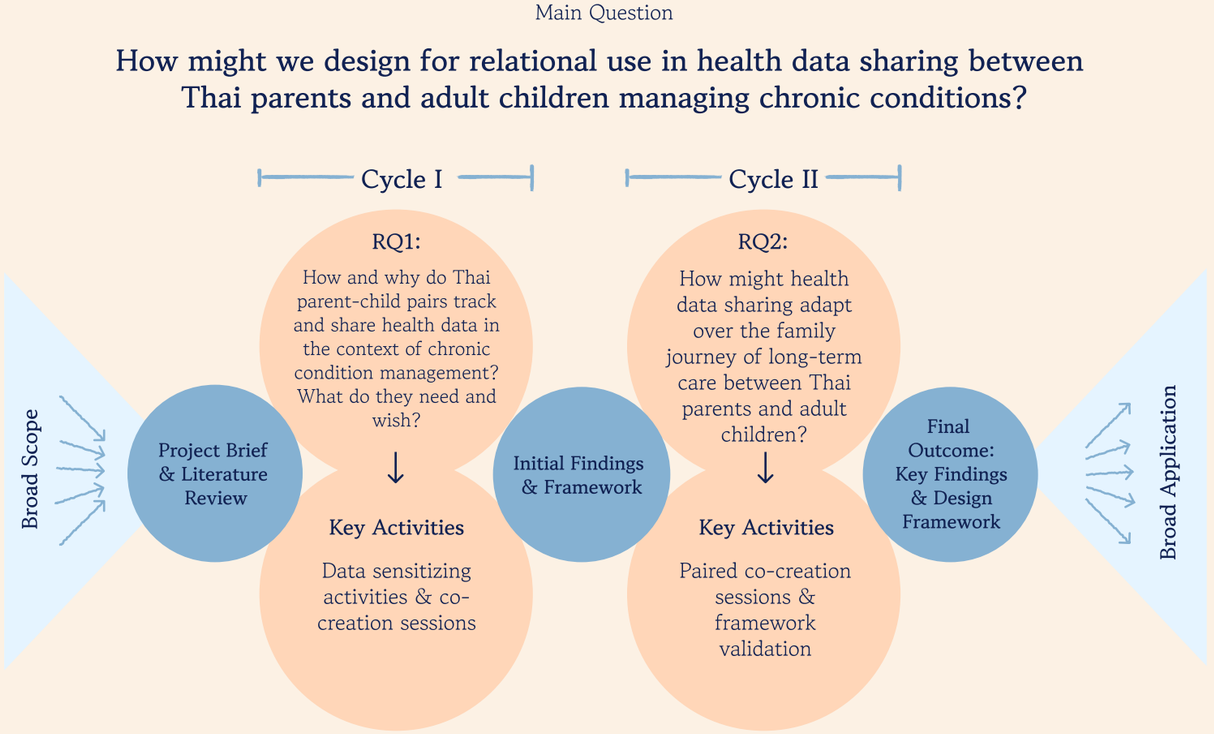

Figure 5: Research design with two cycles: Cycle I explores current Thai parent-child health data sharing practices (RQ1), and Cycle II explores adaptive sharing across health journey phases (RQ2), with initial findings informing framework development and broader validation.

The Iterative Structure

The research evolved organically through two interconnected cycles. Rather than following a predetermined path, each cycle built upon insights from the previous phase, with families' voices and needs shaping what came next. This iterative approach proved essential because families consistently revealed complexities that couldn't be captured in a single research phase.

From Broad Exploration to Specific Co-Design

Cycle I: Understanding Current Practices (Chapter 4)

***RQ1**: How and why do Thai parent-child pairs managing metabolic conditions track and share health data? What do they need and wish?*

Parent-child pairs explored their health data practices through sensitizing activities and co-creation sessions, establishing initial insights about sharing patterns and family needs.

Cycle II: Co-designing Adaptive Approaches (Chapter 5)

***RQ2:** How might health data sharing adapt over the family journey of long-term care between Thai parents and adult children managing metabolic conditions?*

The same pairs became co-designers, negotiating how sharing could adapt across different health phases—from stable periods to health crises—translating insights into actionable frameworks.

Collaborative Knowledge Building

Throughout both cycles, families served as co-creators whose insights shaped the research direction itself, ensuring that emerging frameworks remained grounded in lived experience rather than theoretical assumptions.

The two cycles collectively informed integrated design insights that move beyond the original Thai context toward broader principles for family-centered health technology design, as detailed in the following chapters.

Framework Development towards Broader Application

The insights from these two cycles were synthesized into eleven design principles organized around three pillars **(Chapter 6)**, communicated through the Wave of Care website for design practitioners. Validation with international design students from diverse cultural backgrounds **(Chapter 7)** revealed possibility for broader applicability and additional design opportunities around emotional safety and prevention-focused approaches.

1.6 Conclusion

Now we've learned about the motivations and questions that set up this project — a curiosity about the everyday roles health data might play in people's lives, especially within the context of chronic care. This chapter outlined the research background, goals, and participatory approach, offering a foundation for exploring how people make sense of health information in their own ways.

This project began by by listening — to the realities and context of family life, to shifting needs, and to the possibilities that emerge when we design with others. Through **participatory design** and **context mapping methods**, the study invites families to reflect on and share their own data, & experiences and imagine futures together.

The next chapter provides the background that shaped this inquiry, focusing on metabolic care, digital health data, personal informatics, and the role of family in chronic illness.



Background

What we already know about family health and data sharing

As **chronic conditions** like metabolic syndrome become more common (Saklayen, 2018), healthcare is increasingly shifting toward everyday, family-centered care alongside clinical treatment. This chapter lays the foundation for understanding how health data fits within this broader landscape — drawing together literature on metabolic syndrome, digital health and personal informatics, and the role of family caregiving in Thai culture.

It also introduces the philosophical foundations of **data humanism** and **data intimacy**: seeing data as situated in people's lived experiences and exploring how sharing personal data can create closeness and understanding within relationships. Together, these perspectives help frame the relational context in which health data could be experienced — setting the stage for the participatory methods explored in the next chapter.

2.1 Chronic Illness and Metabolic Syndrome: Lifestyle Challenge
2.2 Digital Health Data & Personal Informatics: Supporting Everyday Health Management
2.3 Family Involvement & Thai Caregiving Culture: Seeing Health as a Family Matter
2.4 From Individual to Shared: Health Tracking in Social and Family Contexts
2.5 Philosophical Foundations: Data Humanism & Data Intimacy
2.6 Conclusion: Design Opportunity

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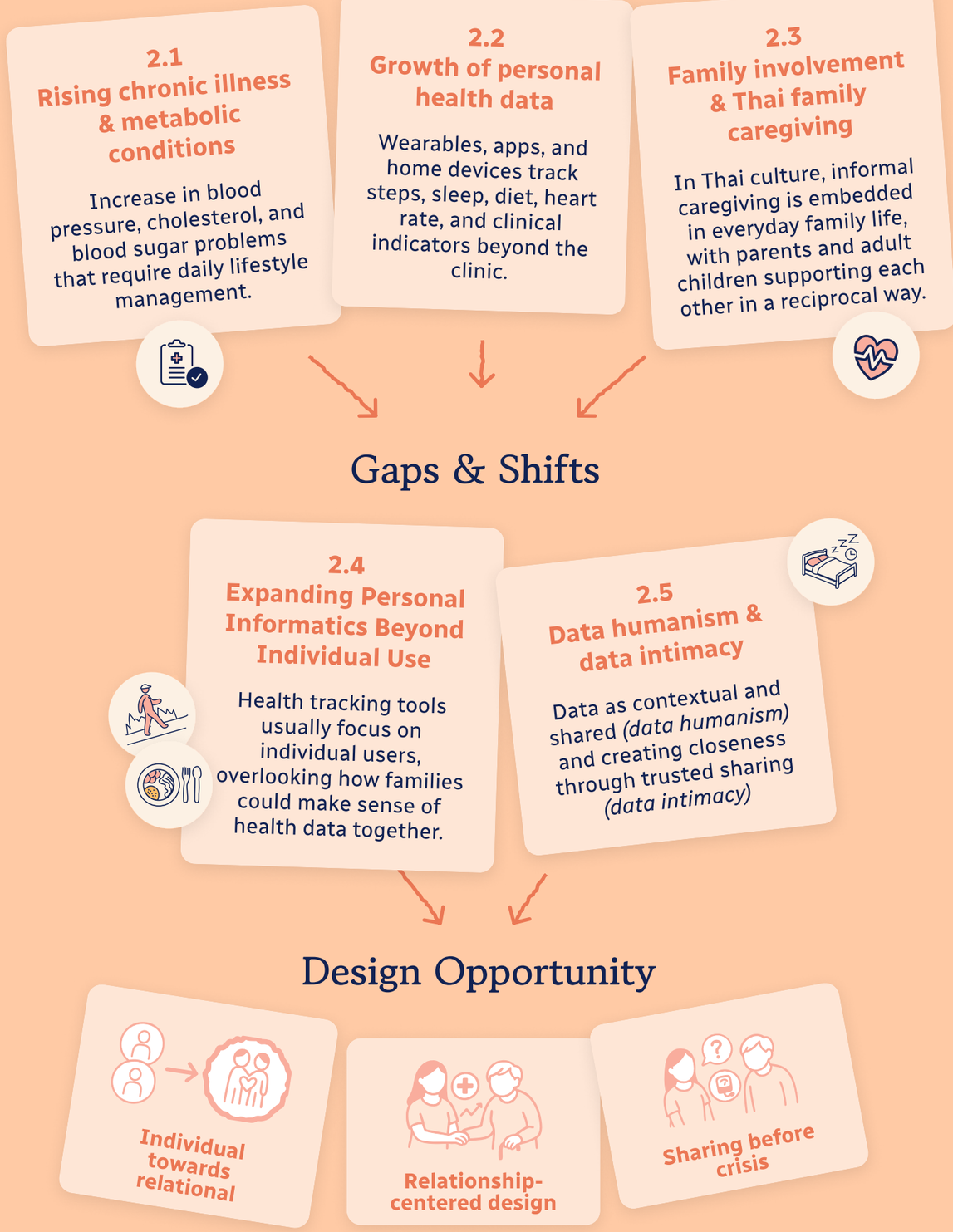


Figure 5: Chapter 2 logic: from individual metabolic care and personal health data to design opportunities for family health data sharing

2.1 Metabolic Syndrome: A Behavioral & Lifestyle Challenge

The global rise of **non-communicable diseases (NCDs)** is straining healthcare systems worldwide, pushing a shift toward person-centered care that extends beyond clinical encounters to include people's daily lives and social contexts. This shift emphasizes prevention, behavior change, and long-term management to improve population health and well-being (Thomas, 2023).

Metabolic syndrome (MetS) is a combination of cardiometabolic risk factors including high blood pressure, elevated blood sugar, unhealthy cholesterol levels, and abdominal obesity. Together these factors increase the risk of developing cardiovascular disease and type 2 diabetes (Han et al., 2015; Pan et al., 2008). In Thailand, **MetS** affects a significant portion of the population, with prevalence ranging from 11.7% to 25.8% in men and 8.2% to 26.3% in women (Sakboonyarat, 2022).

Because MetS develops **gradually through lifestyle and daily habits**, interventions require a focus on long-term behavioral change (Dobrowolski et al., 2024). However, most personal informatics tools remain individual-focused, overlooking **the social and relational aspects of health** (Vizer et al., 2019; Rooksby et al., 2014).

2.2 Digital Health Data & Personal Informatics: Supporting Everyday Health Management

Digital health technologies do more than provide tools; they continuously collect and produce streams of clinical and behavioral data that make care more adaptive and responsive.(Marsch, 2021; Ashrafzadeh & Hamdy, 2019). Through features such as food logging, physical activity tracking, medication reminders, and remote monitoring, these technologies transform everyday actions into data that guide personal insights and long-term treatment decisions. They support behavior change by tracking essential health factors—such as physical activity, nutrition, smoking cessation, alcohol consumption, stress management, and medication compliance (Szerencsés et al., 2024)—and enable patients and their families to take a more active role in managing conditions like diabetes and metabolic syndrome (Ashrafzadeh, 2019). Wearables, mobile applications, and home monitoring devices now collect both clinical measurements (e.g., blood pressure, glucose levels, heart rate) and behavioral patterns (e.g., activity, sleep, diet), producing detailed data that inform personalized chronic condition management. Such data capture "the richness and granularity of individuals' behavior, the confluence of factors that impact behavior in the moment, and the within-individual evolution of behavior over time" (Marsch, 2021).

Personal Informatics (PI), as described by Li et al. (2010), refers to systems that help individuals collect and reflect on personal data to support behavior change and self-understanding. These systems include tools for tracking steps, sleep, diet, and more. They help people overcome the limits of memory and attention, making it easier to notice patterns, stay accountable, and make informed decisions. While PI systems have their roots in the **Quantified Self** movement, which emphasizes self-knowledge through numbers, later studies have shown that tracking practices can be shaped by social context as much as by individual goals.

However, many personal informatics tools still focus on individual users, overlooking the social and relational nature of health (Vizer et al., 2019; Rooksby et al., 2014). While these digital approaches improve self-management, they also highlight the limits of focusing solely on individuals. For conditions like metabolic syndrome—where genetics, daily routines, and long-term care are deeply shared—**family involvement** can strongly influence lifestyle changes, adherence, and long-term outcomes (Deek et al., 2016; Rosland et al., 2011).

2.3 Family Involvement & Thai Caregiving Culture: Seeing Health as a Family Matter

The Role of Family in Patient-Centered Care

In person-centered care, patients are viewed not only as individuals but also as members of families, communities, and broader social contexts. Most health behavior theories recognize the importance of social support, and family members often serve as a key source of that support (Miller et al., 2013). While they may not be medically trained, family members play vital roles in managing appointments, supporting medication routines, encouraging healthy behaviors, and offering emotional care.

Family Involvement in Metabolic Health Management

Research shows that involving family members in care leads to better outcomes. In metabolic conditions such as hypertension and diabetes, shared responsibilities often help patients sustain long-term behavior change. For example, Maslakpak et al. (2018) found that family involvement in hypertension care improves adherence to medication, dietary changes, and regular check-ups. Similarly, Woods et al. (2022) observed that families often pass down knowledge of health risks across generations, treating conditions like high blood pressure as shared concerns rather than individual problems.

This family-centered perspective is especially relevant for metabolic syndrome, where both genetics and shared lifestyles contribute to health risks. Studies show that people with a family history of diabetes or cardiovascular disease are more likely to develop metabolic conditions themselves (Chiu, 2020). This highlights the importance of approaching prevention and management through a family lens, not just as personal responsibility.

Thai Cultural Context of Family Caregiving

In Thai culture, families have long held a central role in caring for elderly and dependent members. Wongsawang et al. (2013) describes this as natural caregiving, a deeply rooted practice where care is offered not only based on need, but also as a way of showing respect and affection. This caregiving often begins before older adults require practical assistance, emerging as part of everyday life rather than a formal obligation.

This natural caregiving extends beyond physical tasks to include emotional presence, coordinating care routines, monitoring well-being, and offering encouragement. These practices are shaped by strong cultural values that emphasize interdependence and collective responsibility. Many Thai individuals feel guided by a sense of duty to their parents, and may prioritize family needs over personal goals.

This cultural approach to family care becomes particularly relevant as Thailand's population ages and chronic conditions such as hypertension, diabetes, and high cholesterol become more common. While many older adults can manage these conditions independently, family involvement often enhances long-term care outcomes. Research shows that family-centered care interventions in chronic illness contexts lead to improved self-management, reduced hospital visits, and stronger emotional well-being, reinforcing the value of relational approaches in chronic care (Deek et al., 2016; Cené et al., 2015; Rosland et al., 2011).

These findings show that family involvement is not only about providing practical help but also about sharing information and staying connected, which raises new questions about how health data, originally collected for individuals, can become part of collective care.

Long-term Reciprocity of Intergeneration Care

Beyond duty and affection, reciprocity serves as a fundamental organizing principle in intergenerational care relationships. Gouldner's (1960) conceptualization of reciprocity as a universal moral norm—where benefits received create inherent obligations to return equivalent value—has been applied by Klaus (2009) as a theoretical foundation for understanding why adult children provide care for their parents.

However, intergenerational care operates through what Wentowski (1981) identifies as **long-term reciprocity**, where "without expectation of exact repayment [...] relationships will balance themselves over the very long term". Research on intergenerational relationships in Asian contexts demonstrates this principle, with support frequently framed as "giving back" through accumulated cycles of exchange rather than immediate transactions (Mehta & Leng, 2002; Antonucci & Jackson, 1990).

Research on Thai dementia care reveals that carers perceived reciprocation through the lens of connectedness with care recipients, interpreting exchanges through intimate and cultural knowledge (Netiparatanakul, 2020). These patterns demonstrate that caregiving operates as accumulated reciprocal exchange strengthening intergenerational ties across decades rather than through immediate returns.

2.4 From Individual to Shared: Health Tracking in Social and Family Contexts

From Individual to Social Tracking

While digital health tools and personal informatics systems are often designed for individual use, tracking data rarely stays private. Especially in long-term care and chronic illness, these data quickly become part of daily conversations, shared concerns, and decisions made together.

Researchers have shown that personal tracking often shifts from an individual to a social practice. Rooksby et al. (2014) introduced the concept of Lived Informatics, highlighting how tracking is shaped by context and is often social rather than purely personal. Their study found

that people commonly monitor walking, exercise, food intake, weight, and sleep across multiple tools, adapting them to situations. Importantly, behavior change emerged not from a single tool but from engagement across these technologies within social contexts. This insight reframes tracking as a social activity, emphasizing co-present tracking, relationships, and collaboration rather than just individual self-monitoring.

Building on this, Elsden et al. (2017) proposed Documentary Informatics to describe how personal data can function as a record of life events, something to revisit and reflect upon like a diary or photo album. Rapp et al. (2016) further observed that while interest in self-tracking often fades over time, it can be sustained within small, trusted groups. Sharing data in these groups offers new perspectives because other people's data can act as prompts for memory, self-reflection, and conversation (Yan et al., 2024). Together, these studies show that tracking is not only a matter of data capture or behavior change but also a way of weaving data into social relationships and narratives.

Health Tracking in Family Context

In chronic illness contexts, most current health informatics tools still focus on individuals, overlooking the collaborative nature of care. Vizer (2019) calls for models that treat tracking as a shared practice, including family members and informal caregivers within a wider care network. In family settings, health data can become a bridge for staying connected across generations. Li et al. (2020) describe how older adults and their adult children used shared self-tracking data such as step counts or sleep patterns to strengthen communication. These small glimpses of each other's routines prompted casual check-ins and supportive messages, turning data into moments of relational care.

Health communication also changes over time. Sandbulte et al. (2019) found that willingness to share health information within families depends on relationship quality, sense of care, and life events such as illness or surgery that act as turning points for more open communication. This raises an important question: can we design tools that encourage open health conversations before crises occur? Such tools could help families reflect on health in everyday life and create new opportunities for care instead of waiting for emergencies to drive these discussions.

More recent critiques highlight that self-tracking is never neutral but shaped by the social and cultural contexts in which it is produced and interpreted, with meaning emerging through interaction rather than numbers alone (Lupton, 2017). This perspective is often described as a shift from a quantified self, which treats numbers as objective measures, toward a **qualified self,** where data is understood in context and shaped by interpretation and social interaction (Ruckenstein & Schüll, 2017; Lupton, 2017). These critiques open up approaches that consider the lived experiences and relationships around data, which forms the basis for the next section.

2.5 Philosophical Foundations: Data Humanism & Data Intimacy

Building on the view of data as relational and contextua, this research drew on two concepts to frame its perspective: data humanism, which focuses on the context and lived experience behind numbers, and data intimacy, which explores how sharing personal data can support closeness and understanding within families.

Data Humanism: From Objective Metrics to Relational Material

The idea of data humanism is a philosophy that resists the speed and objectivity of traditional data systems and instead values slowness, subjectivity, and emotional resonance (Lupi & Posavec, 2016; Kim et al., 2019). While originally emerging in data visualization, this philosophy provided a grounding for rethinking personal health data, especially when shared among family members in this research.

According to Lupi (2017), the core principles include:

Embrace Complexity – Tell rich, layered stories through data that reflect the fullness of lived experience

Move Beyond Standards – Allow data to take on personal and culturally grounded forms rather than forcing it into rigid formats

Sneak Context In (Always) – Actively embed personal context and meaning into data through reflection and interpretation, rather than expecting apps to define who we are

Remember That Data is Flawed (As We Are) – Acknowledge data's imperfection to open space for nuance, care, and more human-centered ways of knowing

Although data humanism principles are gaining recognition, few HCI studies have applied them in practice. Recent work has begun exploring how collaborative approaches can make personal data more relational.

PAIRcolator (Yan et al., 2025) demonstrated how synchronous collaboration and tangible data representations could make personal data feel relational through guided prompts and live tactile comparison. Reciportrait (Yan et al., 2025) reimagined personal data sensemaking through immediate, turn-taking collaboration, supporting mutual reflection through shared sketching sessions with a focus on imperfection and conversation rather than efficiency.

These studies represent **momentary reciprocit**y—collaborative practices that function within bounded sessions but can strengthen enduring relationships. While intergenerational reciprocity operates across decades, this momentary form emerges through immediate turn-taking during data exploration.

This research builds on these momentary collaborative practices, but applies them within long-term family relationships. While data exploration sessions are time-bounded, they occur between family members whose reciprocal relationship spans years. The immediate collaborative sensemaking becomes embedded within extended cycles of intergenerational support

Data Intimacy: Being close from disclosing personal data to each other

While data humanism provides philosophical grounding, this research also explores data intimacy, a concept recently defined in HCI literature but offers crucial insights for family health data sharing.

Drawing from psychology and communication studies, intimacy typically refers to *emotional closeness, trust, mutual disclosure, and responsiveness*. According to Reis and Shaver (1988), intimacy develops when one person shares something personal and the other responds with understanding, validation, and care. Current HCI research frames data intimacy through several definitions:

Data intimacy as relational, affective, and vulnerable encounters with data practices that emphasize care, trust, and contextual meaning (Gómez Ortega et al., 2024).

Data intimacy as quiet, ambient interactions where digital tools adapt to users' routines and reflect personal rhythms of life (Wundsam et al., 2024).

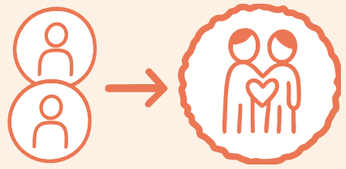
Data intimacy as platform-mediated sharing of imperfect health data as affective practices to express emotional experiences and build connection (Rentschler & Nothwehr, 2024).

In this project, **data intimacy** is defined as a relational practice of getting to know each other through personal disclosure. It is not focusing on monitoring or control, but about sharing data in ways that support mutual understanding and care, within context of families managing chronic health conditions. These philosophical foundations guided the choice of participatory methods to capture what emerges when families actually track, choose to share, and discuss health data within their existing relationships.

2.6 Conclusion: Design Opportunity

Looking at the current literature, threel opportunities emerge that became the starting points for this research:

From Individual-Centered to Relationship-Centered Design



Research shows that personal tracking practices are shaped by context, often involving others (Rooksby et al., 2014) and that families can benefit from shared health data (Li et al., 2020). Yet most commercial health tools remain focused on the individual. The gap is not in knowing that tracking can be social, but in translating these insights into designs that support relationships and family dynamics.

Learning from Everyday Family Care



Existing caregiving practices, such as Thai natural caregiving built around mutual care responsibilities, highlight how health management already happens in relational ways. These practices remain underexplored as inspiration for designing data tools that strengthen these relationships instead of imposing individual-centric models.

Supporting Early Sharing Before Crisis



Studies of family communication (Sandbulte et al., 2019) show that health discussions often become more open only after major events such as a diagnosis, hospitalisation, or crisis. This suggests a design opportunity for tools that encourage earlier, everyday sharing of health information, so that conversations and care do not depend solely on crises to occur. This is especially relevant for this study, which focuses on metabolic conditions that are non-critical and develop gradually over time, making early, low-pressure sharing a natural part of prevention and ongoing care.

These gaps point to the need for participatory research that works directly with families, because only by engaging with their everyday realities can we understand how health data sharing tools might support care relationships as they evolve with changing health situations and family dynamics, particularly in specific cultural contexts.

The next chapter outlines how this research approached these questions through participatory design, positioning Thai families as co-creators in exploring what health data sharing within families could look like.

Approach & Methodology

How we actually did this research

This chapter explains how this study addressed the research questions introduced in Chapter 1 by working directly with Thai parent–adult child pairs to explore their current health data tracking and sharing practices and to co-design futures they wish and need.

3.1 Introduction
3.2 Participatory Design Approach with Pairs of Family Members
3.3 Personal Positionality: How I relate to this research
3.5 Participants
3.6 Ethical Consideration & Sensitivity
3.7 Data Collection Methods
3.8 Cycle I: Research Activities & Development
3.9 Cycle II: Research Activities & Development
3.10 Data Analysis Methods
3.11 Conclusion

3

3.1 Introduction

Research Questions

First, we need to come back to the main focus of this study:
How might we design for relational use in health data sharing between Thai parents and adult children managing chronic conditions?
To address this, the research was carried out in two iterative cycles.

- **Cycle I explored**: How and why do Thai parent–child pairs track and share health data in the context of chronic condition management? What do they need and wish for?
- **Cycle II built on initial findings to explore:** How might health data sharing adapt over the family journey of long-term care between Thai parents and adult children?

These cycles were conducted using participatory design and context mapping methods, which are described in the following sections of this chapter.

3.2 Participatory Design Approach with Pairs of Family Members

Why participatory design with context mapping methods

Much existing digital health research has been designed around disease-specific models and tends to assume that patients and clinicians will find value in generating and sharing health data (Marsch, 2021). To complement these approaches, this study explored how families find value in health data beyond the clinical setting—looking at how personal data, which captures everyday experiences outside the clinic, can become meaningful in the context of close family relationships.

Participatory design provided the foundation by positioning participants as partners in the research process, with expertise in their own experiences (Sanders & Stappers, 2012). This approach aligns with **data humanism** (Lupi, 2017), which treats data as personal and situated rather than objective truth, valuing the complexity and context of people's lived experiences with their health data.

Contextmapping methods fit this philosophy through generative techniques that uncover tacit knowledge (knowledge people can act upon but cannot readily express in words) and latent needs (needs people are not yet aware of) (Sleeswijk Visser et al., 2005). This approach reveals

what people know, feel and dream" (Sanders, 2001) through **sensitizing, group sessions, analysis, and communication** (Sleeswijk Visser et al., 2005).

Together, these methods enabled understanding how families navigate health data sharing within their existing relationships—using an iterative, co-design approach that could both uncover current practices and support families in imagining new ways of sharing data together, ultimately exploring **data intimacy** through their own lived experiences.

Reciprocal approach and why parent-child pairs

In the health data context, rather than positioning one family member as the tracker and another as the tracked, this research used **paired sessions designed around reciprocity**, where both parties could share, compare, and interpret data together. This setup enabled co-creation sessions where family members discussed their experiences, asked questions about each other's preferences, and negotiated how sharing would work within their specific family dynamics.

This approach also grew out of my prior work with myocardial infarction patients, where participants naturally brought family members into individual interviews for mutual reflection on shared health experiences. Paired sessions offered several methodological advantages: participants felt more comfortable with familiar partners and could reveal insights about each other that might not emerge in individual or stranger-group settings (Sleeswijk Visser et al., 2005). Recent research confirms this approach—the PAIRcolator study demonstrated how working in pairs fosters reciprocal inquiry and interpretation of data experiences, promoting structured conversations where both participants actively generate and refine shared understandings (Yan et al., 2025).

For family health data sharing, this reciprocal approach allows existing relationship dynamics to surface, with family members drawing on intimate knowledge of each other's histories, routines, and concerns. This rich contextual sharing enabled authentic data practices to emerge while positioning the researcher as observer, listener and facilitator.



Figure 6: Illustration of parent-child reflecting on their personal health data together after pre-session sensitizing activities.

Roles of participants and researcher

Following participatory design principles, this study positioned **family participants as co-creators and stakeholders** rather than subjects. In line with the collaborative end of the participation spectrum described by Shirk et al. (2012), participants were engaged in a co-created research model where they actively contributed to shaping both the focus and process of the study.

Participants influenced the research agenda by identifying topics that mattered to them, selected their own focus for health data tracking, and contributed to the interpretation of insights.

My role as researcher shifted throughout the process: at times facilitating structured activities and preparing materials, and at other times stepping back into an active listening role, allowing families to adapt and lead discussions in ways that reflected their experiences and needs. Through analysis of these sessions, I developed initial frameworks that were then brought back to participants for feedback and refinement.

This iterative process—where I synthesized patterns from sessions, then returned to families for validation and co-creation—ensured that frameworks evolved through genuine collaboration. This co-created, participatory model aimed to ensure that the knowledge generated was grounded in the lived experiences and priorities of the families (Spinuzzi, 2005; Shirk et al., 2012).

3.3 Personal Positionality: How I relate to this research

Why: In participatory research, researchers are not neutral observers—I interpret and co-create meaning through my own lens. This section offers context on how my lived experiences shape my engagement with family health data sharing.

My positionality: I grew up in a Thai family surrounded by intergenerational care. My grandma lived with us through multiple chronic conditions until her last day, shaping how I see health as a shared family experience rather than individual tracking.

My background sits at the intersection of Southeast Asian collective society and industrial design education. I approach this work reflecting on

how personal health data, often framed individualistically, might instead support relational care within families.

My design practice has evolved from expert-driven approaches to participatory methods focused on listening and being responsive to participant input. Witnessing **my own family's health involvement** pushed me to question how health tools might work differently for future families navigating intergenerational care.

3.4 Study Design Overview

This research employed a two-cycle structure that evolved organically as families shaped the inquiry through their lived experiences with health data sharing. The design was intentionally flexible, allowing the methodology to adapt based on participant needs and emerging directions rather than following rigid predetermined frameworks.

Structural Approach

Cycle I : Understanding Context & Developing Initial Frameworks

RQ1: How and why do Thai parent-child pairs track and share health data in the context of chronic condition management? What do they need and wish?

Focus: Exploring current family health data practices and future wishes

Methods: Data sensitizing workbooks, family conversations, co-creation sessions

Approach: Both participants tracked health data and reflected on current and desired sharing practices.

Cycle II: Building & Refining on Initial Findings towards Design Framework

RQ2: How might health data sharing adapt over the family journey of long-term care between Thai parents and adult children?

Focus: Co-designing adaptive sharing systems across health journey phases

Methods: Card sorting activities with health journey canvases, paired co-creation

Approach: Participants chose, negotiated, and designed sharing scenarios while reflecting on values and concerns for long-term care

Evolution and Connection Between Two Cycles

Rather than isolated phases with different familis, the research design allowed for methodological evolution based on what families revealed. The shift from Cycle I to Cycle II represented a progression from broad exploration to specific co-creation, moving from understanding what and why families share data to exploring when, how and under what conditions sharing occurs.

- **Participant Continuity:** The same four Thai parent-child pairs (n=8) participated across both cycles, enabling deeper relationship building and more nuanced exploration of family dynamics over time. This continuity captured how families' perspectives evolved through sustained engagement with health data sharing concepts.
- **Flexibility and Adaptation:** Throughout both cycles, families could modify research materials, choose their own tracking focus, and adapt activities to fit their specific relationships and health situations.

3.5 Participants

Recruitment Process & Strategy

The study began with a recruitment survey designed to find families who were already engaging with health tracking in some form and were willing to take part as parent–adult child pairs. The survey, shared via social media, flyers, and community groups, asked about chronic health conditions, family roles, current tracking habits, openness to discussing health within the family, and availability *see Appendix A3 for complete recruitment survey and poster)*

A total of 27 people responded. From these responses, four pairs were selected. The selection focused on families managing **non-critical, metabolic-related conditions** *(e.g., high blood pressure, high cholesterol, high blood sugar)* that involve informal home care and lifestyle adjustments. Respondents who reported serious conditions such as cancer, did not have a parent–child pair available with metabolic conditions, did not track health data, or indicated that participation would feel too sensitive or uncomfortable were not included to ensure emotional safety in discussions and health data sharing.

Participant Profiles

Four parent–adult child pairs (n = 8) took part in the study across two cycles. All participants were Thai, which provided a shared cultural and linguistic background for discussing health and family dynamics.

- **Adult children**: Aged 25–40
- **Parents:** Aged 60–75
- **Health conditions:** Each pair was managing one or more metabolic-related conditions such as hypertension, high cholesterol, or high blood sugar, which require ongoing lifestyle adjustments and home care.
- **Health tracking experience:** In each pair, at least one family member had some experience with tracking everyday health data (e.g., steps, sleep, diet) using tools like smartwatches or apps.
- **Living situations:** Two pairs lived together in Thailand, while the other two pairs lived apart, with one member abroad.

Participation was voluntary, with no financial incentives, and all participants provided informed consent.

Pair Code	Pseudonyms	Family Role	Age	Health Concerns	Tracked Data	Living Situations / Location
P1-P	Mindful	Dad	60–75	High Cholesterol	Steps	Remote (UK / Thailand)
P1-C	J.	Daughter	25-40	None	Steps	
P2-P	PJ	Mom	60–75	High Blood Pressure, High Sugar Level, Weight	Steps, Sleep, Food	Live Together / Thailand
P2-C	Joe	Son	25-40	High Blood Pressure, Weight	Steps, Sleep, Food	
P3-P	Dolly	Mom	60–75	Weight, Stress	Food	Live Together / Thailand
P3-C	Myra	Daughter	25-40	High Cholesterol	Food, Sleep	
P4-P	Chuenchom	Mom	60–75	High Blood Pressure, Weight, Osteoartritis	Steps, Sleep, Food	Remote (UK / Thailand)
P4-P	Kim	Mom	25-40	Stress	Steps, Food	

Table 1: Overview of participants (n=8), showing their family roles, ages, health conditions, chosen tracking data, and living situations. All pseudonyms were self-selected by participants to maintain privacy while avoiding impersonal coding systems. The first row color serves as each participant's unique color code, consistent with their pairing throughout the research cycle for analysis consistency.

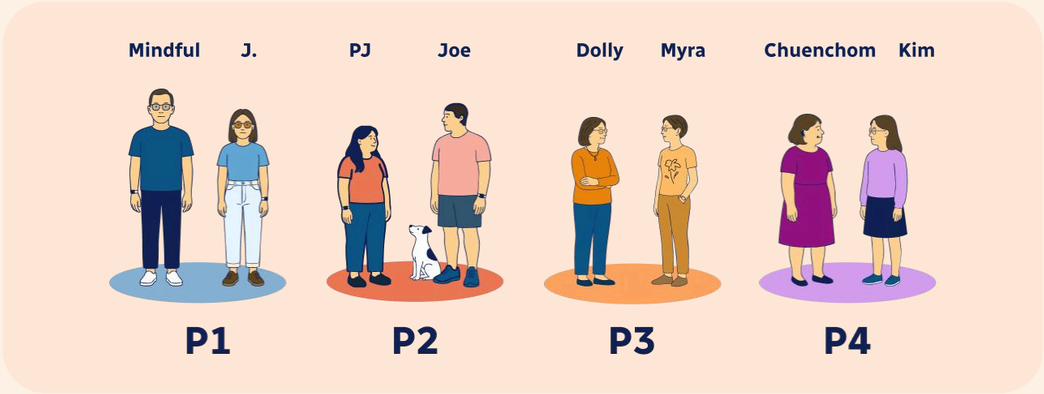


Figure 7: Illustrated representation of the four Thai parent-child pairs with their own chosen fictional names, designed to protect participant privacy while maintaining the human connection to this research.

3.6 Ethical Consideration & Sensitivity

Handling of Sensitive Personal Health Data Only participants who chose to continue beyond the initial survey provided personally identifiable data. Data was pseudonymized with participant-chosen pseudonyms, ages collected in ranges, and tracking choices made without restrictions. This was communicated through consent forms, sensitizing materials, and verbally reinforced in sessions. **Participants could leave anything blank or skip uncomfortable topics.**

Informed Consent All participants received detailed information about research purpose, methods, activities, and rights before providing written consent. They were reminded they could withdraw at any time without consequence.

Emotional Sensitivity and Care Practices Recognizing the emotional weight of discussing personal health and family relationships, participants could **express comfort levels, skip questions, or adjust their involvement**. Sessions were conducted in participants' preferred language (English or Thai), with materials designed to be supportive and non-intrusive.

See Appendix A2 for complete HREC application documents, Appendix A3 for consent form templates, and Appendix B for ethics reminders used in sessions and sensitizing materials design.

3.7 Data Collection Methods

Background Information: Personal and demographic information was collected through Microsoft Forms surveys distributed before participation, gathering details about health conditions, tracking experience, family dynamics, age range and country of resident.

Session Materials & Artifacts: Online conversations were supported by visual prompts including metaphor cards and health data type cards, which served as starting points for discussion. The completed cards, arranged layouts, and collaborative annotations from these activities became part of the data collection, capturing how families conceptualized and negotiated their health data sharing preferences.

Sensitizing Materials & Personal Data: Before each session, families received a data sensitizing toolkit *(PDF for printing or online Figjam board)* and completed tracking activities on paper, sharing photos via email. All materials were pseudonymized and compiled for analysis. Families adapted these materials—*choosing which health data to track, modifying templates, or adding personal notes*—and these adaptations themselves became valuable data, revealing individual preferences and comfort levels. Participants could leave sections blank or filter content before sharing, and these choices also informed the analysis.

3.8 Cycle I: Initial Exploration

Set-up

Key Research Question: How and why do Thai parent-child pairs track and share health data in the context of chronic condition management? What do they need and wish?

Focus: Understanding current family health data practices and future aspirations

To explore these questions, Cycle I combined individual sensitizing activities with collaborative family sessions. This approach allowed participants to first reflect personally on their health data experiences before engaging in family discussions and co-creation, ensuring conversations were grounded in current experiences while opening space for envisioning future possibilities.

Cycle I Activities Overview

This cycle began with a **Preparation Phase** where I held introductory meetings with parent-child pairs to explain research goals and activities, walk through sensitizing materials, and build trust while establishing participants' role in shaping the project. This led to Phase

Key Activity 1:
Individual Sensitizing
(10-15 mins for 5-7 days)



Participants individually completed personal health data tracking and reflection activities to prepare for family discussions.

Key Activity 2:
Parent-child Data Sharing
& Co-creation Sessions
(60-90 minutes)



Three-part sessions where families shared their tracked data, discussed current practices, then co-designed future health data sharing systems through metaphor exploration and scenario building.

The following **Figure 8** shows how these activities were implemented in practice, showing actual participant materials and session formats.

Cycle 1 : Research activities

1

Pre-session Data Sensitizing Activities

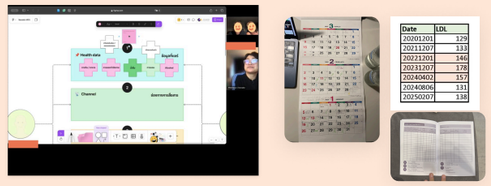
Each participant tracked their own health data and completed a sensitizing booklet for one week.



2

Parent-child Data Sharing & Co-creation Sessions (online)

Parent-child pairs shared and reflected on their tracked data together, then co-designed a family sharing system and chose a metaphor that represented their approach. (



Participants dragged health data cards they wished to share onto their own online canvas.

They shared and reflected on their data using various personal materials *(e. g.spreadsheets, booklets, calendars)*

Figure 8: Cycle I Research Activities Overview

Key Activity 1: Sensitizing Activities with Health Data

Within contextmapping methods, sensitizing activities served as a preparatory phase where participants documented and reflected on their own health data experiences and sharing practices before group sessions (Sleeswijk Visser et al., 2005). These activities transformed participants from passive subjects into active co-researchers, creating rich material for subsequent collaborative discussions. The goal wasn't to evaluate health behavior with their data, but to generate material that would support deeper family conversations and collaborative sense-making about health through their personal data experiences.

Toolkit Development Process

Initial Draft: Gathered participant feedback on content and format during introduction sessions.
Template Refinement: Participant feedback shaped design decisions, including expanding food logging beyond meals and clarifying prompts. Supervisor feedback led to adding visual elements like emojis to balance the text-heavy design.
Privacy Features: Added clear instructions for participants to filter, edit, or delete data before sharing, ensuring disclosure control without obligation.

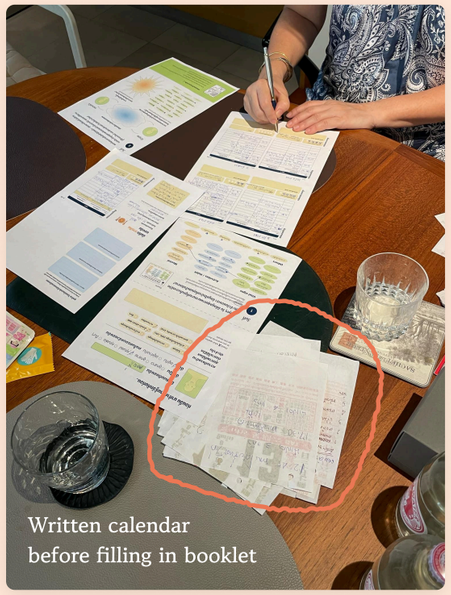


Figure 9: Participant adapted by writing down personal notes on their paper calendar first before completing the booklet, creating their own way for controlling and filtering what would be shared in sessions.

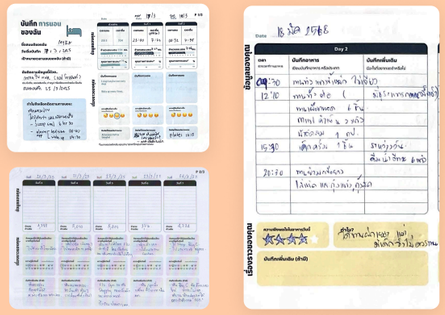
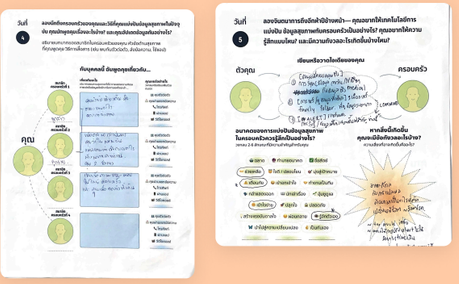
Data Sensitizing Toolkit

The sensitizing toolkit was shared 1-2 weeks before sessions and comprised two parts: personal data tracking with contextual reflection and exploration of family health sharing practices. As shown in **Figure 9,** participants filled in the toolkit as preparation for sessions.

Toolkit Structure:

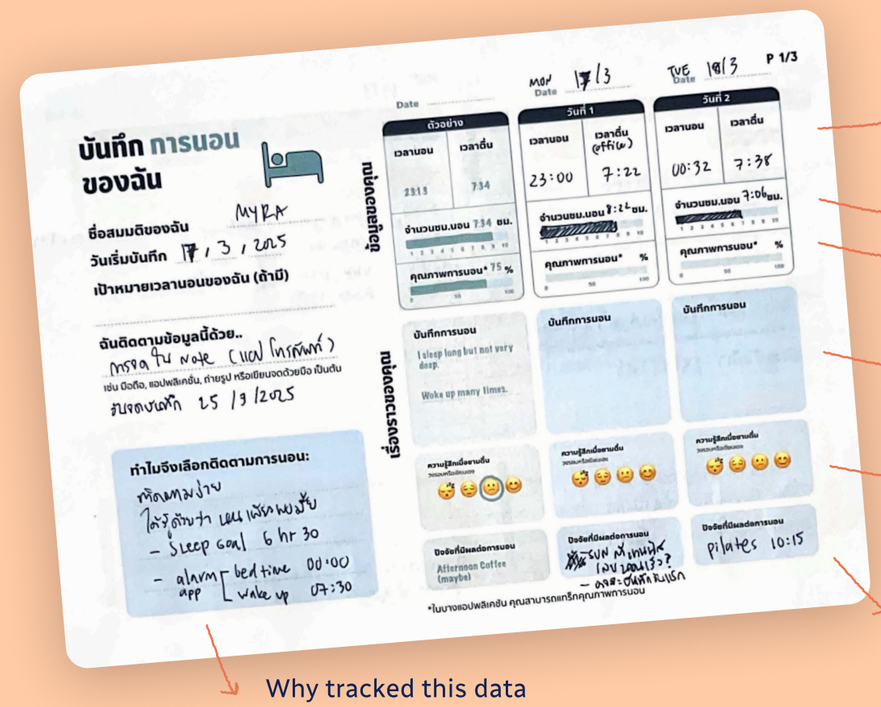
- **Part 1: My Data Reflection Sheet** Focused personal data tracking and daily reflection over 5-7 days
- **Part 2: My Data Tracking & Family Sharing Workbook** Existing family health data sharing experiences and wishes

See following sections for details of both parts (complete English toolkit pages available in Appendix B.1 - Sensitizing Toolkit)

Toolkit Structure	Part 1: My Data Reflection Sheet	Part 2: My Data Tracking & Family Sharing Workbook
Sample pages		
	Figure 10: Sample completed data tracking sheets with participant entries for steps, sleep, and food tracking data.	Figure 11: Sample filled-in family sharing workbook
What's inside?	**This part focuses on individual reflection on personal data tracking.** Each participant selected a focus area—steps, sleep, or eating—and tracked it for 5-7 days, using the template flexibly and skipping sections as needed. Alongside their data logging, participants could record mood, add contextual notes, or capture key moments. Blank spaces were also provided for unprompted personal reflections.	This booklet guided each participant through 5-day daily reflections exploring how health data plays a role in their family lives and how they wish to share it in the future. The daily prompts moved participants from identifying personally meaningful health data to envisioning future family sharing approaches, covering topics like current family health communication patterns, sharing preferences, and concerns about data privacy.
Participant Control & Data Filtering	To ensure participants maintained control over their data narrative, upon completing the tracking period, they were encouraged to review, edit, filter, or delete any content before sharing in pair sessions. Guided reflection questions helped them consider patterns and sharing preferences: • **"Did you notice any factors that influenced your habits this week?"** • **"What would you want to share with your family, and why?"** This process allowed participants to determine what felt meaningful or worth sharing, ensuring authentic disclosure rather than obligated transparency.	
Why	This part invited participants **to spend time and reflect with their actual tracking data and numbers,** adding personal notes and context through a handwritten, slower process. Following **data humanism** principles, it helped participants think about what their data meant to them personally and what might be meaningful to share with family, valuing the lived experiences behind the numbers.	Building on their tracking experience, this part used contextmapping methods to help participants **expand beyond current numbers** to think about health information that mattered in their family relationships. It guided them to revisit past sharing experiences, reflect on present practices, and envision future possibilities - moving from what they tracked individually to what felt meaningful to share together. This allowed parent-child pairs to ask each other questions about their different perspectives and explore what kind of sharing might work for their relationship.

Part 1: My Data Reflection Sheet

Participants chose to track one type of behavioral data—sleep, steps, or eating—based on their personal interests, with family members not required to track the same data type. The sample below shows a participant's sleep tracking.



Bed Time & Wake Up Time

Sleep duration

Sleep quality (%)

Additional Note

Feeling when wake up

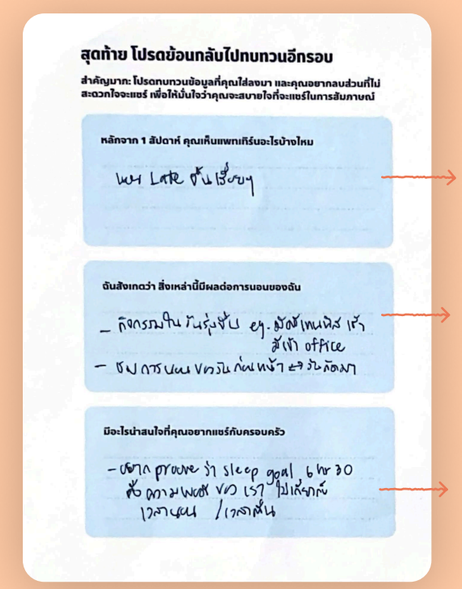
Sleeping Factors

Why tracked this data



Post-Tracking Reflection

After a week of tracking, participants take time to look back at their data and see what patterns emerged. They reflect on what influenced their habits and decide what feels nice or meaningful to share with their family member. This gives them control to filter or edit anything before the family session, ensuring they only share what feels comfortable and worthwhile.



What pattern do you see?

What factor might affect my sleep?

Anything interesting to share?

Figure 12: My Data Reflection Sheet Components including filled in sleep tracking sheets, and reflection questions.

Part 2: My Data Tracking & Family Sharing Workbook

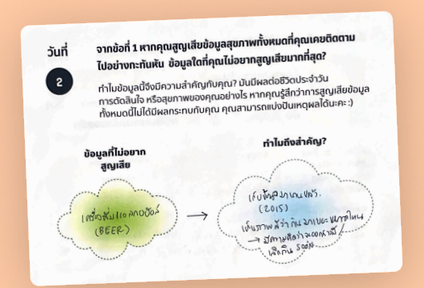
This workbook guided participants through daily reflections that progressed from personal health data awareness to envisioning future family sharing approaches. Each day built toward preparing participants for family co-creation sessions.

Personal → **Family** → **Future**

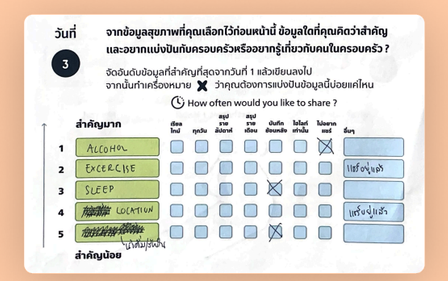
Day 1: Personal health data reflection and connection between different data



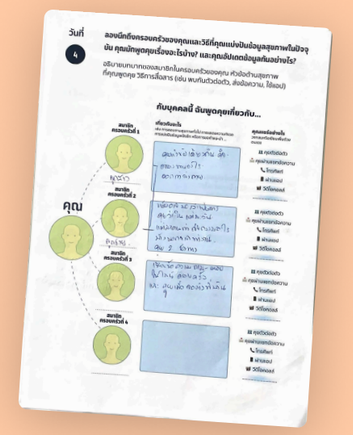
Day 2: Most meaningful personal health data selection



Day 3: Current family health communication and sharing patterns *(what data and with whom)*



Day 4: Sharing preferences and comfort levels *(who and how often)*



Day 5: Future visions and concerns about family health data sharing



Figure 13: Complete 5-day workbook sequence demonstrating the progression from individual health data reflection to family sharing preferences and concerns.

After completing both booklets individually, participants brought their input to **the Parent-child Data Sharing & Co-creation Sessions** in following section

Accessibility Considerations

Since participants were based in both Thailand and the UK, and came from different generations with varying tech comfort, the toolkit was offered in both digital and printable formats. Feedback gathered during these intro meetings helped refine the materials for clarity and usability. This early involvement not only improved the toolkit but also gave participants a sense of ownership and comfort before starting the activities.

Key Activity 2: Parent-child Data Sharing & Co-creation Sessions

Session Set up

All sessions were held online, as participants were based in different countries (Thailand and the UK). Participants were asked to submit their completed sensitizing toolkits 1--2 days in advance, allowing me to review their materials and loosely structure the conversation around the data they chose to share. Sessions followed three parts: personal data tracking, current family sharing, and co-designing future scenarios.

Session Dynamics and Roles

The researcher acted as an **active listener** while participants were encouraged to share, discuss and ask each other questions. This approach allowed participants to control the timing and flow of conversations. The researcher would occasionally ask "why" questions or request clarification to surface underlying assumptions and make implicit knowledge explicit for the research. My goal was to encourage mutual decision-making and surface shared expectations, preferences, and concerns while keeping sessions conversational and relaxing.

Session Outline

After participants completed their booklets, they joined co-creation sessions that followed a structured format balancing open conversation with focused exploration. These 60-90 minute sessions moved from individual reflection to collaborative future envisioning, creating space for both personal insights and family negotiation through three main activities:

Introduction (5-10 minutes)
Established participant rights, consent for recording, and session goals. Emphasized participants control over sharing and the collaborative nature of the research. Researcher and participants introduced themselves again to make session feel comfortable for open and casual conversation.

Part 1: Sharing Tracked Health Data (15-20 minutes)
Parent-child pairs reflected on their personal tracking data from the toolkit, discussing patterns, insights, and experiences with data collection. They shared what health data they currently tracked and what felt important to them

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Part 3: Future Family Health Data Sharing Workshop (15-20 minutes)
Using individual input from the provided booklet, pairs reviewed each other's future health sharing visions and negotiated their future system together. They determined what health data to share, selected mediums, and imagined their system through metaphors such as *"time capsule," "family garden,"* or *"mirror"* to make abstract data sharing concepts more tangible and relatable. These metaphors helped families express their values, while they also addressed potential risks and concerns about their envisioned sharing system.

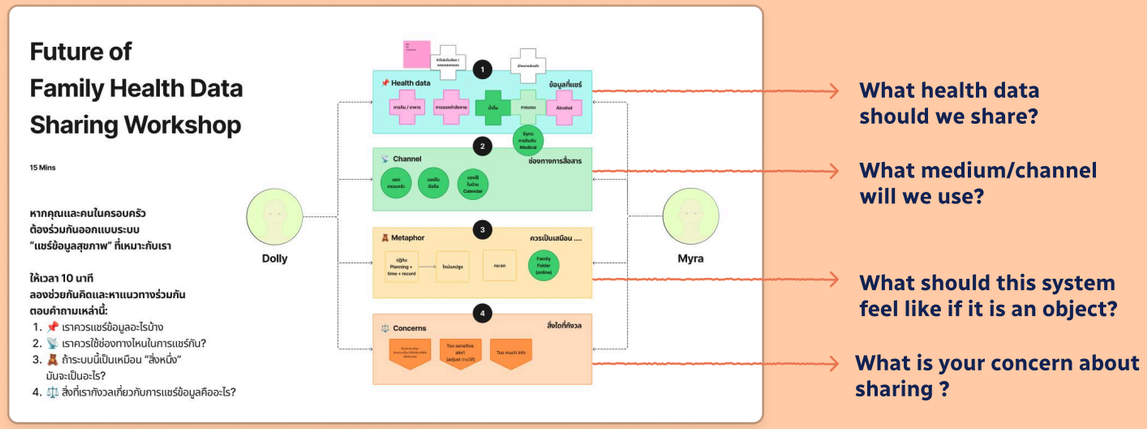


Figure 14: Family health data sharing design canvas addressing four key questions: what health data to share, what communication channels to use, what the system should feel like, and what concerns exist about sharing

Closing (5-10 minutes) Session wrap-up and invitation to continue participation in the next research cycle.

These sessions allowed families to move from sharing personal tracking experiences to collaboratively designing health data sharing approaches that fit their specific relationship dynamics.

Session Materials

Sessions were held remotely via Microsoft Teams in Thai language. To support online discussion and co-creation, all session materials were prepared in shared FigJam boards for remote participants, including:

- Participants' toolkit reflections to guide discussion
- Future sharing workshop canvas with cards for designing personalized sharing systems (as described earlier) *(see Appendix B2)*

However, most participants preferred using their printed materials during sessions, which supported more natural conversations while maintaining researcher coordination.

3.9 Cycle II: Framework Refinement & Co-Design

Set-up

Key Research Question: How might health data sharing adapt over the family journey of long-term care between Thai parents and adult children?

Focus: Co-designing adaptive sharing systems across health journey phases

Built on insights from Cycle I key findings and initial framework, this cycle shifted from exploring broad future health data sharing system to co-designing specific sharing approaches with families across different health situations. The focus moved from understanding what and why families share data to exploring when and under what conditions sharing occurs, positioning participants as co-designers validating and refining initial frameworks through their lived experiences.

Key Activities Overview

Framework Validation & Co-Creation Sessions (90-120 minutes) Two-part collaborative workshops where families first provided feedback on initial insights from Cycle I, then used card-sorting activities and health journey mapping to co-design their ideal adaptive sharing approaches across different health phases.

Session Structure

The following illustrates how these collaborative workshops unfolded through two sub-activities:

Part 1: Insights & Interaction Samples
(20-30 minutes)



Sessions began by sharing key learnings from Cycle I and presenting possible interaction formats based on participants' previous experiences. Participants provided feedback on initial insights while exploring sample interaction scenarios, discussing which combinations of interactions they could envision using in different situations.

Part 2: Co-Creation Through Health Journey
(45-60 minutes)



Families used design decision cards and health journey canvases to select, negotiate, and configure their preferred sharing approaches across four health phases (normal, small changes, critical events, recovery) in Health Data Journey Canvas **(see Figure 19)** . This collaborative decision-making enabled families to design systems that adapted to their changing health situations which revealed underlying values.

Session Materials

Cycle II sessions used carefully designed materials to support both validation and co-creation activities**. Part 1 materials** included translated insights from Cycle I and interaction examples developed from participant experiences, while **Part 2** featured a collaborative design toolkit with the **"Wave**" health journey canvas and comprehensive card sets covering family archetypes, health phases, data types, communication styles, and underlying values and concerns.

All materials were designed in both Thai and English with visual icons to facilitate discussion, allowing families to select, combine, or modify elements as they designed their personalized health data sharing approaches.

Part 1: Insights & Interaction Samples

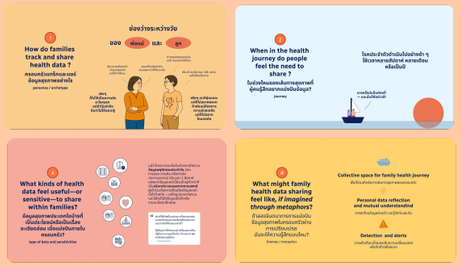


Figure 15: Presenting Cycle I key insights to participants for validation and feedback

Summary of Insights

Summary of Key Insights developed from participants' own Cycle I experiences and translated into Thai, allowing families to see how their input had shaped initial frameworks and serving as a foundation for them to give feedback and validate or expand upon these collaborative findings.

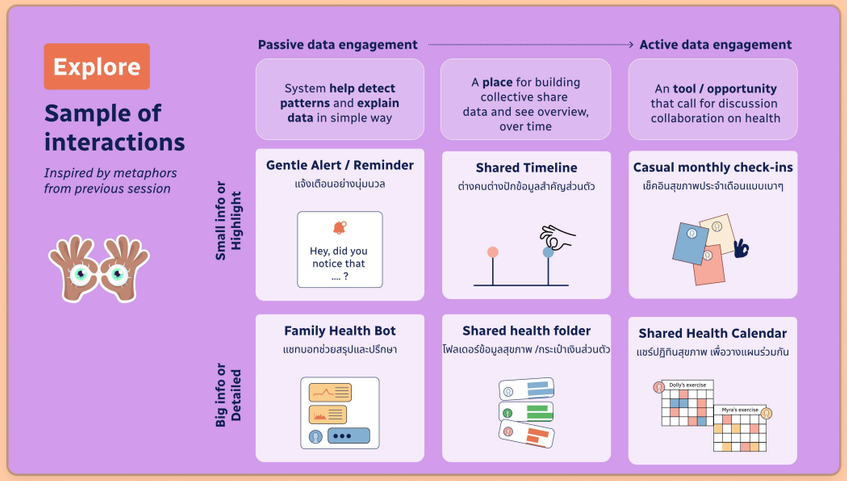


Figure 16: Interaction samples illustrating different ways of interacting for active and passive data engagement. Participants used these as an initial prompt to talk about their preferences and as a starting point for the co-design workshop.

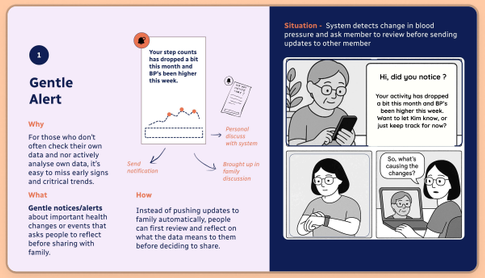


Figure 17: Sample scenario (Gentle Alerts) showing how gentle alerts ask mom to notice changes first before sending updates to her daughter, then they could discuss in person later.

Interaction Samples

Interaction Samples synthesized from participant experiences in Cycle I, providing both generations with concrete starting points for discussion rather than beginning from a blank slate. These samples included various communication styles and data presentation formats with scenarios drawn from families' own experiences, giving participants familiar examples such as *"shared timelines," "gentle alerts," "shared calendars," and "check-in bots"* they could discuss, pick from, adjust, and combine to build their personalized sharing systems.

Part 2: Co-Creation Through Health Journey

The Wave: Health Data Journey Canvas

Health Data Journey Canvas featuring 4 health phases *(normal, attention, co-ordination, reflection) with distinct colors* to place data cards representing different types of health information and sharing preferences that participants could arrange, modify, or expand together.

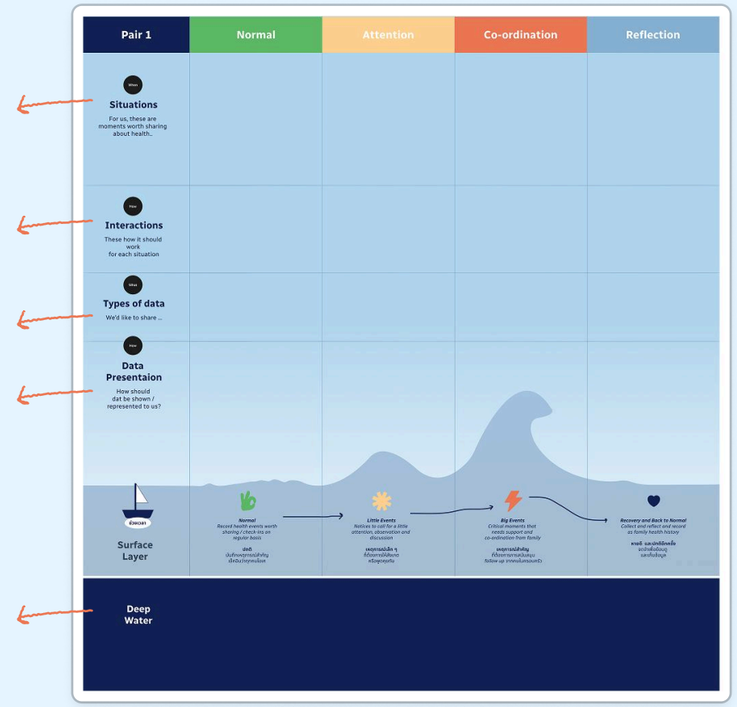
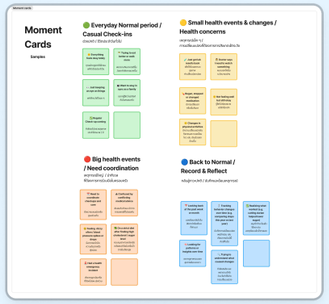


Figure 18: The Wave: Health Data Journey Canvas with 4 health stages for arranging data design cards (see Appendix B2.2 for complete FigJam board)

Health Data Cards Samplea



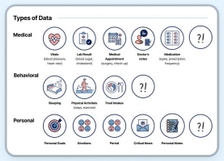


Figure 19: Health Data Cards Samples (Moments Cards & Types of Data) which participant collaboratively placed in each health stage.

Comprehensive card sets were developed across five dimensions *(Who, When, What & Where, How, Why & Why Not)* to support this adaptive approach. Cards included family archetypes, health journey moments, data types, interaction styles, and underlying values and concerns which participant would arrange in canvas, to help them discuss how each stages should work and how they could share.

Developments & Iterations

The Cycle II session format evolved through several key methodological insights. **Early design iterations revealed that families don't make sharing decisions through simple voting or single "best" solutions**, but rather through adaptive combinations that change with circumstances. This led to a flexible card-based approach that allowed families to configure multiple elements rather than choose fixed options.

The session structure emerged from recognizing families as stakeholders in framework development - rather than just testing predetermined concepts, sessions were designed to first validate Cycle I findings, then build upon that validation through collaborative design. Interaction examples were developed directly from Cycle I insights (e.g., "Gentle alerts," "Shared timelines"), providing concrete starting points while encouraging families to adapt these concepts to their specific relationships and needs.

Digital tools and canvas layouts were continuously refined after each session to ensure accessibility across participants' varying technological comfort levels while preserving the collaborative decision-making focus and activity structure *(development iterations shown in Appendix B3).*

3.10 Data Analysis Methods

Following contextmapping methods (Sanders & Stappers, 2012), the analytical process combined transcripts, sensitizing materials, and co-creation artifacts through "analysis on the wall"—a light analysis approach that arranges data visually to interpret how participants made meaning through stories, decisions, and interactions, surfacing deeper values, latent needs, and concerns.

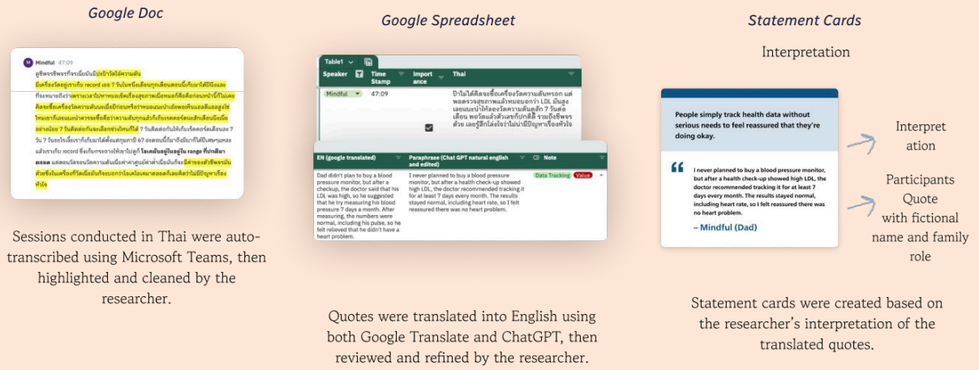
Data Collected

- Video recordings of co-creation sessions
- Completed sensitizing toolkits from all participants
- Session transcripts in Thai with English translations
- Digital artifacts created during sessions (FigJam boards)
- Researcher field notes and observations

All sessions were conducted in **Thai** to ensure natural expression, with materials provided in participants' preferred language. Main data collection occurred through parent-child sessions, recorded via Microsoft Teams with automatic transcripts and timestamps.

Data Processing

I manually adjusted transcripts where participants shared physical space to properly identify speakers. Translation and cultural interpretation were handled carefully to preserve meaning and context—relevant quotes were highlighted and moved into a spreadsheet, then translated to English using Google Translate combined with ChatGPT for more natural language. Each quote was tagged with themes like data tracking, family sharing, concerns, and values, creating **statement cards** for analysis. See **Figure 21** for an example statement card



Sessions conducted in Thai were auto-transcribed using Microsoft Teams, then highlighted and cleaned by the researcher.

Quotes were translated into English using both Google Translate and ChatGPT, then reviewed and refined by the researcher.

Statement cards were created based on the researcher's interpretation of the translated quotes.

Figure 20: Data processing workflow showing progression from original quotes through translation to statement cards for clustering and analysis (see Appendix D1 for sample translated quotes table)

Making of Statement Cards

Based on contextmapping methods framework, I adopted their statement card format for this research. Each statement card contains three key elements: the original participant quote in small font, my analytical interpretation as a paraphrase in large text, and a color band identifying the specific participant. Maintaining original quotes preserved authentic voices and allowed others to reinterpret the data independently. This visual format created moveable units that I could arrange digitally to identify patterns during clustering analysis.

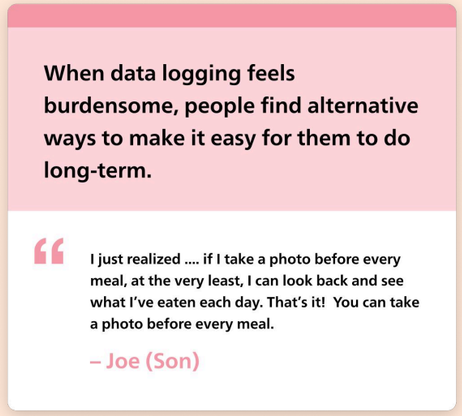


Figure 21: Sample statement card format with researcher's interpretation (top) and original participant quote (below)

Themetic Clustering

In contextmapping, this process is called **"analysis on the wall"**—*a form of thematic clustering* that involves visually arranging materials like statement cards, sticky notes, and other data on physical walls through collaborative sessions to identify patterns and build insights. This "light analysis" approach works best with small sample sizes and allows for analyzing the "messy" data collected in generative design research, providing both information and inspiration simultaneously.

In this study, I adapted this approach digitally, arranging statement cards on digital boards to identify patterns and translate lived experience into actionable design insights (Sanders & Stappers, 2012; see Appendix D2 for clustering maps and Figure 22 for digital clustering process).

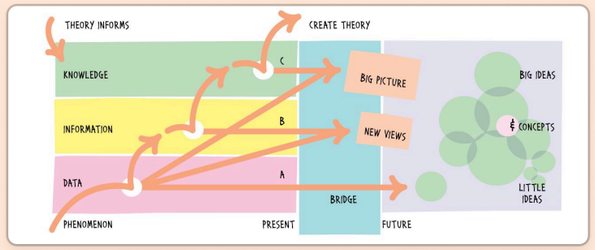


Figure 22: Bridging from research to design involves a shift from understanding the present situation to constructing possible futures. (Sanders & Stappers, 2012).

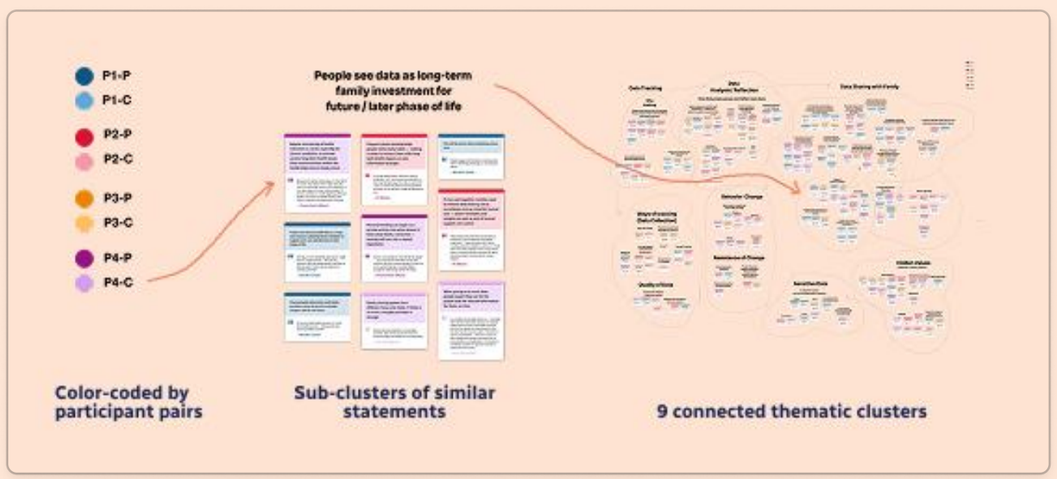


Figure 22. Statement cards color-coded by participants and organized into thematic clusters

1. **Statement cards** are color-coded by participant pairs to maintain connection between family members while differentiating individual perspectives.
2. **Within each key theme,** similar statements are grouped together into sub-clusters, such as *"people see health data as long-term family investment for future, later phase of life."*
3. **Nine key thematic** clusters emerge from the analysis, visually connected on the board to show relationships—for example, data tracking leads to data reflection, which leads to data sharing.

Different Clustering Approaches for Each Cycle

Cycle I clustering identified nine key themes around health data practices within families:

1. **Data Tracking -** motivations and approaches to health monitoring
2. **Ways of Tracking -** methods and tools used for health data collection
3. **Quality of Data -** perceptions of health data accuracy and reliability
4. **Behavioral Change -** how health data influences health behaviors
5. **Resistance to Change -** barriers to adopting new health practices
6. **Data Analysis/Reflection -** making sense of collected health information
7. **Data Sharing With Family -** why and how they share and wish to share
8. **Sensitive Data -** concerns around private health information
9. **Hidden Values -** underlying beliefs extending beyond family health dynamics

These clusters revealed both values and concerns, current sharing practices and future wishes around health data within families, uncovering deeper insights that influenced health data practices **(see detailed results in Chapter 4).**

Cycle II required multiple re-clustering to capture the complexity of design decision-making of families also it needs to go beyond the immediate wants and needs to see underlying values of why people chose to do so with data for certain situatations. Analysis focused on why families made design certain choices during co-creation. *(see Appendix D3 for journey-based and insights clustering maps).*

- **Session-based clustering (thematic similarities)** - grouped insights by shared themes, such as "Findings Feedback, Tone of Voice of The System"
- **Insights clustering (actionable design implications)** - synthesized findings to connect user values with specific design opportunities, for example "Data sharing adapts to care journey stages"
- **Journey-based clustering (reorganized along health phases)** - reorganized themes according to health journey stages, for example "Small health events: People want to pay attention to symptoms that could lead to serious health events"
- **Values-based clustering (underlying values)** - analyzed clusters to identify core values driving choices, for example "Ease & Comfort: People want sharing and tracking to feel natural, familiar and emotionally light, not overwhelming or performative"

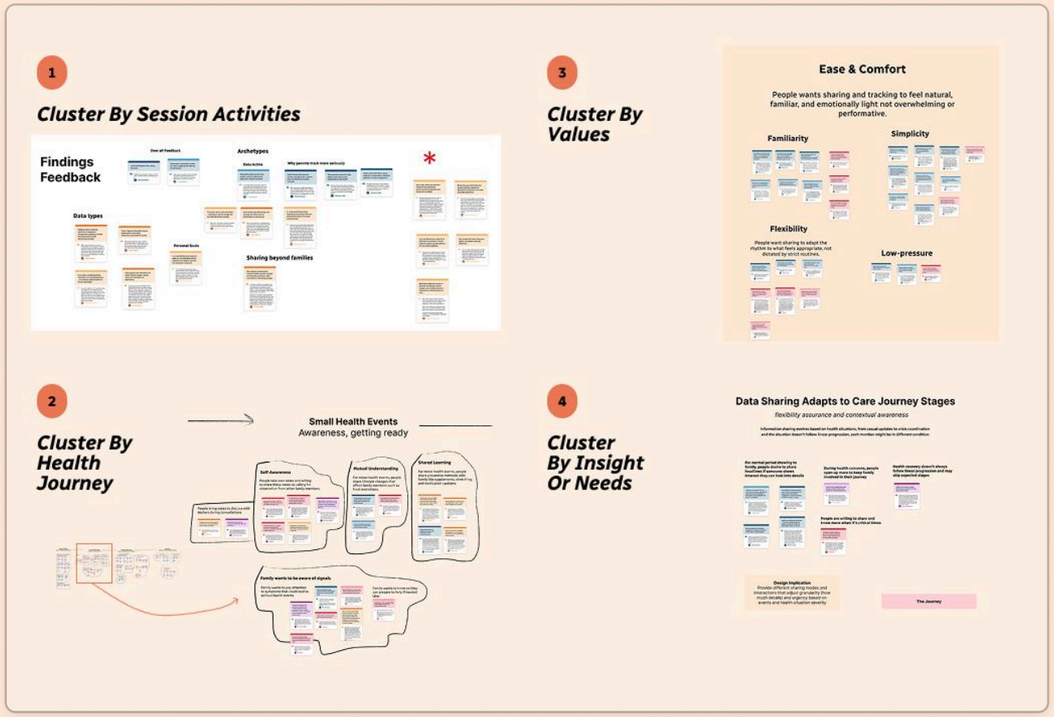


Figure 23: Multiple clustering rounds demonstrating how themes were progressively refined and reorganized through iterative analysis

Synthesis: Key Findings and Framework Development

The clustering and synthesis process was essential in bridging raw participant input with the direction of this project. By grouping responses not just by theme but by underlying values, situational shifts, and relationship dynamics, this process uncovered the emotional and interpersonal layers often hidden behind tracking behaviors.

These patterns formed the early groundwork in Cycle I, structured into thematic groupings detailed in Chapter 4 (Initial Findings). In Cycle II, those insights were expanded and validated, resulting in three refined frameworks that explain how families navigate data engagement, care rhythms, and shared meaning-making, presented in Chapter 5 (Key Findings). Finally, these frameworks laid the foundation for Chapter 6 (Final Outcome), where findings were translated into design framework for health data sharing that respond to the realities of family life with chronic care.

3.11 Conclusion

This chapter detailed a participatory grounded in data humanism and data intimacy to explore intimate contexts like family health data sharing by working with parent-childs across two research cycles.

Approach & Methods

Used participatory design and contextmapping grounded in data humanism philosophy to center Thai parent-child pairs (n=8) as experts of their own experiences. This reciprocal approach allowed existing relationship dynamics to surface, with family members drawing on intimate knowledge of each other's histories, routines, and concerns, essential for exploring the data intimacy and relational dimensions of adult-child health data sharing.

Two-Cycle Evolution

Cycle I explored current family health data practices and future wishes through data sensitizing workbooks and family conversations. **Cycle II** built on these findings through card sorting activities with health journey canvases, where the same 4 Thai parent-child pairs co-designed adaptive sharing scenarios while reflecting on values and concerns for long-term care.

Analysis Process

Transformed participant quotes into **statement cards**, then clustered into key themes with sub-clustering using *"analysis on the wall"* technique—this approach bridges lived experiences with **key insights & frameworks** presented in the following chapters.

The next chapters build on this foundation: Chapter 4 presents initial key findings and frameworks, followed by Chapter 5, which introduces refined frameworks that inform the final design outcomes in Chapter 6.

Cycle I – Initial Findings & Frameworks

How and why do Thai parent-child pairs track and share health data in the context of chronic condition management? What do they need and wish?

In this first cycle we explore current practices, needs, and wishes, and begin shaping early ideas for how sharing could work. What emerges reveals family health data sharing can be relational, generational, and situational while surfacing the critical question of when families choose to share across changing health circumstances.

4.1 Introduction
4.2 Generational Perspectives: Understanding the Parent-Child Context
4.3 Behavioral Archetypes: Common Sharing Patterns Across Families
4.4 Health Data Sharing Journey: Adapting Sharing to Different Health Situations
4.5 Data Sharing Insights: What Data Matters and How They Could Work
4.6 Conclusion

4

4.1 Introduction

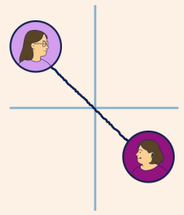
Cycle I explored: How and why do Thai parent-child pairs managing metabolic conditions track and share health data? What do they need and wish?

In this first cycle we explore current practices, needs, and wishes, and begin shaping early ideas for how sharing could work. Starting from observing pairs share their tracked data, generational differences emerged—parents approaching health data with medical purpose while adult children tracked more casually. Analysis revealed behavioral patterns along data engagement and sharing axes. In co-design activities, families consistently described their health through the lens of time, viewing sharing needs as situational rather than static. Participants revealed that medical data held primary meaning while behavioral tracking served as background context, expressing desires for something long-term yet low-pressure. While families could articulate what **they wished** to share and why, a critical question surfaced: **when?** *When do families choose to share more? When do they pull back? How do health situations shift family data sharing dynamics?*

From this cycle's context exploration Four themes emerged:



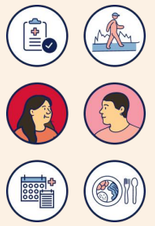
4.2 Generational Perspectives: How life stages shape health data attitudes and behaviors



4.3 Behavioral Archetypes: Revealing family engagement patterns (*Data Engagement Level X Sharing Openness)*



4.4 Family Health Journeys: Sharing needs shift through cycles of concern and calm along chronic conditions over long periods



4.5 Health Data Sharing Insights: Identifying what health data could become meaningful and why families could share

4.2 Generational Perspectives: Understanding the Parent-Child Context

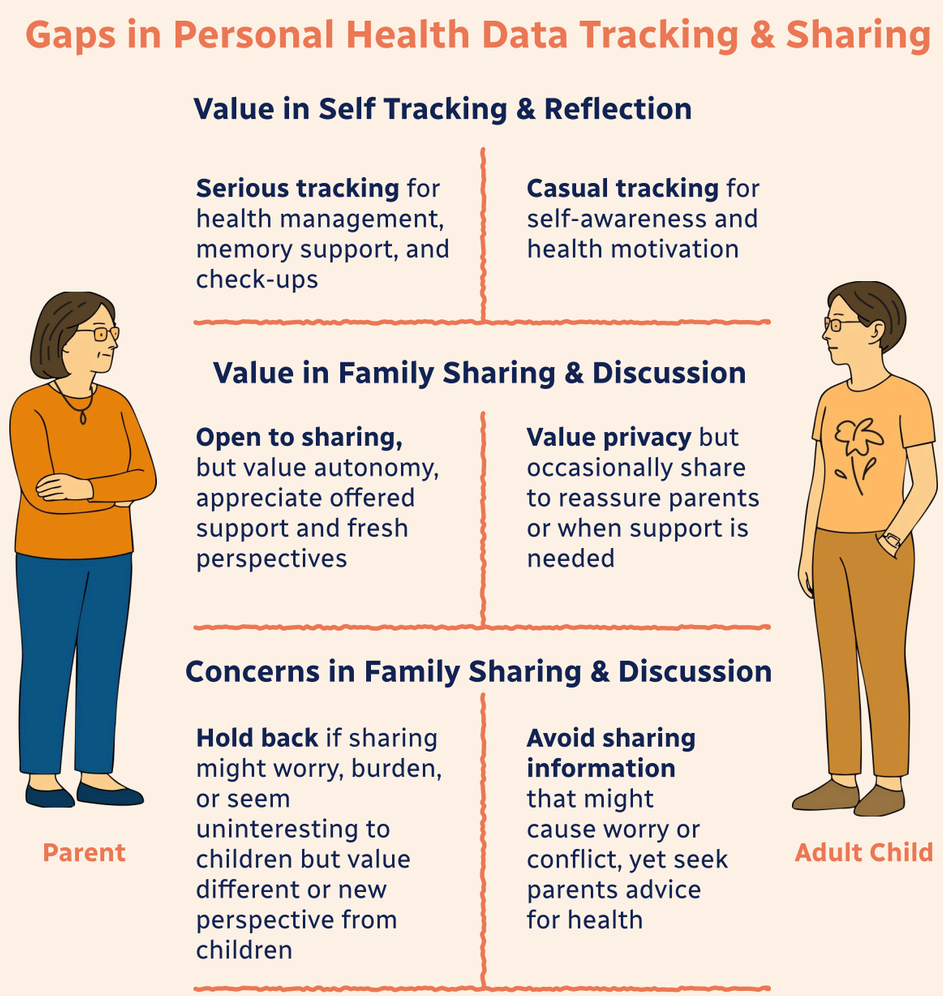


Figure 24: Generational differences in values, and concerns between parents and adult children

First of all, understanding generational differences is essential for designing family health data sharing, as age and life stage fundamentally shaped how families approached health data. Parents in their 60s-70s managing chronic conditions brought different perspectives than their adult children in their 20s-40s establishing wellness routines. **These generational perspectives revealed how and why families track and share differently**, with life contexts, health priorities, and relationship dynamics influencing both tracking behaviors and sharing comfort levels

In all pairs, parents expressed serious intention in their health data tracking, treating retirement as an opportunity for proactive care. During data tracking activities, they paid more attention to details by adding water intake to food tracking, writing foods in greater detail, and often using personal calendars before transferring information to research booklets. They mentioned upcoming health check-ups as important checkpoints, viewing their tracking as preparation to show progress or discuss concerns with doctors. As **PJ (Mom)** explained: "*I'm having issues with both blood pressure and diabetes. If we want to reduce the amount of medication, I need to adjust ourselves by increasing the number of steps I walk each day...*" **Mindful (Dad)** demonstrated this goal-oriented approach: *"On average, I walk more than 10,000 steps a day... Over the past 7 years, I've averaged around 12,000 to 16,000 steps per day." with a clear goal to avoid relying on medication when found out he had high cholesterol.*

Adult children approached tracking more casually, often for self-awareness or health motivation. As **J (Daughter)** noted: *"I feel like I want the data to look good... it feels satisfying. So I end up eating vegetables with every meal, at least when I cook for myself."* Yet some discovered unexpected value through reflection. **Joe (Son)** noted: *"At first, I thought just putting the data into my phone or writing it down wouldn't make much of a difference. But when I sit down to write it and review it, instead of just relying on memory, it's like analyzing the past... easier to see things clearly."*

When it came to sharing, parents expressed being more open though they valued autonomy. PJ (Mom) took notes on personal paper before transferring selected information to booklets, demonstrating thoughtful filtering. **Adult children valued privacy more**, as **Joe** explained: "Personal goals? I don't think others should know them. Otherwise, it might lead to nagging..."

These differences created tension. The same approach could feel empowering to parents while seeming intrusive to children. As PJ (mom) explained: *"I'm comfortable sharing... when I come back from a health check-up, I tell everyone. But if I assume they're not interested, so I don't say."*

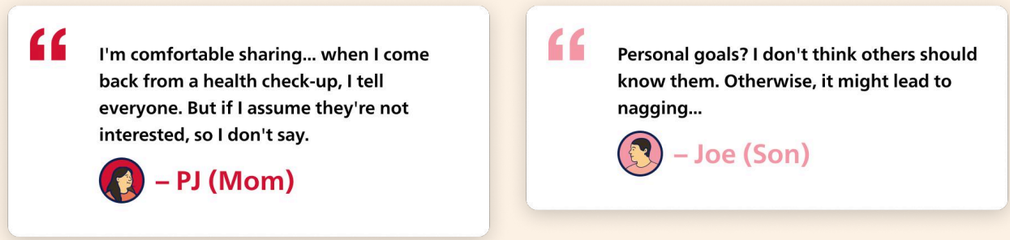


Figure 25: Contrasting quotes from one parent-child pair showing conflicting perspectives that result in health information withholding

4.3 Behavioral Archetypes: Common Sharing Patterns Across Families

The generational differences revealed in 4.2 led to a important discovery about **how and why families share differently**: within the same family, members often showed different behavioral patterns sharing. Rather than aligned family sharing, individual attitudes toward data engagement and family openness created distinct archetypes that could coexist within a parent-child.

Framework Development: Mapping behaviors across all sessions revealed two key dimensions that shaped how individuals approached health data sharing. I mapped participants into these dimensions based on their quotes and observed behaviors: **Data Engagement Level (Personal Axis) and Family Sharing Openness (Relational Axis).**

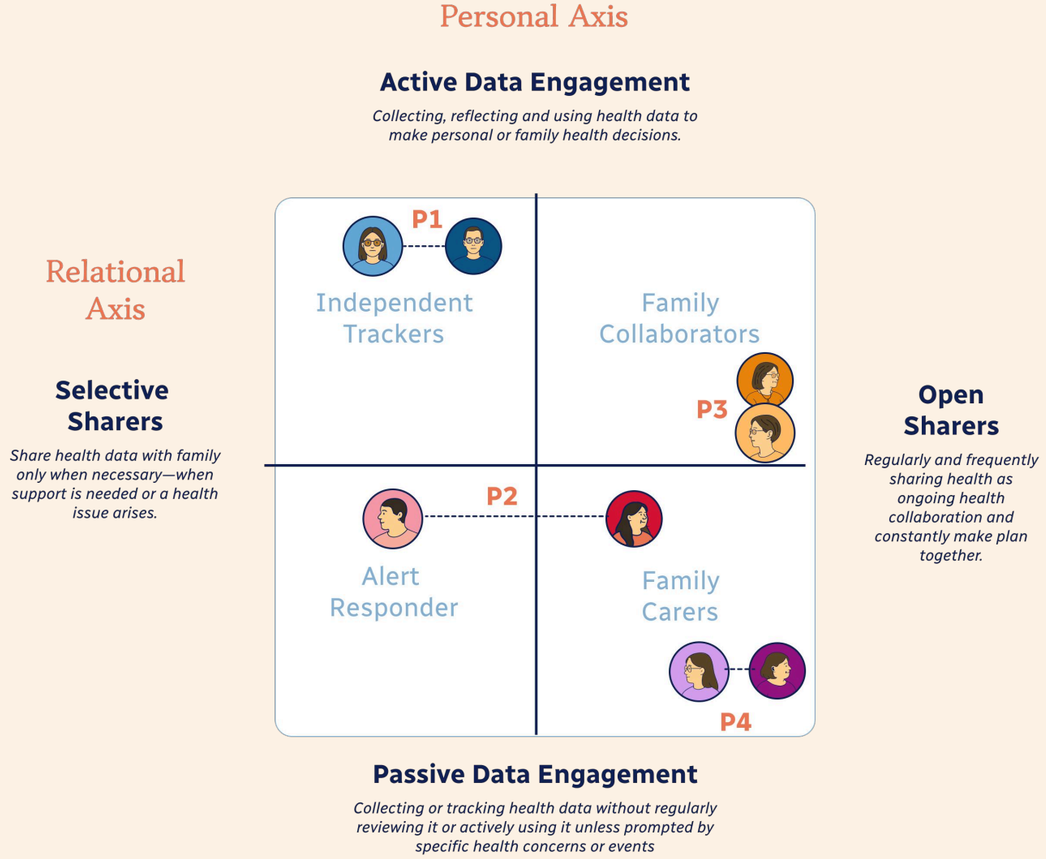


Figure 26: Initial framework using two-axis tensions to map behaviors and attitudes toward data tracking and family sharing, with assumptions later refined through Cycle II validation.

- **Data Engagement Level (Personal Axis): A**ctive engagers who collect, reflect and use health data for decisions versus passive engagers who track without regular review
- **Family Sharing Openness (Relational Axis):** Open sharers who regularly collaborate versus selective sharers who share only when necessary

Four Behavioral Archetypes Emerged:

Independent Trackers

Active data engagement, Selective sharing

Highly engage with personal health data but prefer occasional check-ins rather than constant sharing.

As **Mindful (Dad**) noted: *"On the days I track, most of the steps — around 30% to even 50-60% … come from that morning exercise."*

His daughter J takes a different but equally active tracking, focused on consistent healthy food rather than detailed numbers: *"I take photos and organize them into albums … like, what I've eaten."*

She explained sharing number could bring motivations to do better: "*Knowing someone else will see it, I feel more motivated to do better. Especially when it's Dad … he likes to brag about his step count. So on days when I haven't walked much I'll go out for a walk just to increase my steps."*

Family Collaborators

Active data engagement, Open sharing

Highly engage with personal health data but prefer occasional check-ins rather than constant sharing.

Dolly (Mom) described her approach: *"I share information with both my daughter and son … I mostly share by asking them about their schedules."* Her family used both Google and physical calendars in the kitchen to collaborate on health appointments and schedule exercises to sync with each other.

However, collaboration isn't always mutual. **Chuenchom (Mom)** expressed this challenge: *"Honestly, I wish Kim would track their sleep too … Kim doesn't sleep much. With such a heavy study load, it seems like she's not getting enough rest."*

Table 2: Active Data Engagement archetypes - Independent Trackers and Family Collaborators

Alert Responders	Family Carers
Passive data engagement, Selective sharing	*Passive data engagement, Open sharing*
Prefer minimal tracking with gentle nudges when needed.	Share naturally in conversations but lack systematic tracking.
Joe (Son)'s quote represented this approach seeing data logging as a burden: *"I like looking at the summaries, but I don't really enjoy logging the data myself."* He also noted the complexity of family dynamics in sharing: *"Family power dynamics are tricky.... we don't really know how much control or influence there is within each family. Even if someone gives consent to share their data, it might just be out of politeness or family pressure, not genuine willingness."* **Kim (Daughter) also showed concern about genuine consent:** *"When it comes to sharing health data, it really has to be based on mutual consent. Like, I'm comfortable sharing only this much ... and that should be enough. It has to come from a place of willingness. Because if there's no psychological safety, then it doesn't work."*	**PJ (Mom) demonstrated this:** *"I'm comfortable sharing ... like, when I come back from a health check-up, I tell everyone I met that day. But if I just assume they're not interested, so I don't say."* **Myra (Daughter) echoed this pattern:** *"We usually don't know the health details, like actual numbers from check-ups.* *Most of what gets shared is about schedules, which often ends up involving exercise plans."*

Table 3: Passive Data Engagement archetypes (Alert Responders and Family Carers)

These behavioral patterns often coexisted within families, requiring members to navigate and accommodate each other's varying approaches to health data sharing. Effective health sharing tools need to work with these differences rather than expecting everyone to share alike. While these patterns explained how families approached sharing differently, a critical **"when"** dimension emerged from their future visions: participants consistently described health sharing as something that would change over time, adapting to different health situations and family circumstances.

4.4 Health Data Sharing Journey: Adapting Sharing to Different Health Situations

While families engaged in casual, day-to-day health conversations, their deeper vision centered on health data sharing as a long-term family investment extending far beyond their current stable situations. Families consistently viewed their health through the lens of time—spanning months, years, and even decades—recognizing that chronic conditions unfold across extended periods requiring sustained attention and adaptive care approaches. Many parents carried experiences from caring for their own aging parents, shaping how they approached their own health management while hoping to prepare their children without creating immediate burden. This lens of time, seeing health as a continuous intergenerational journey rather than isolated incidents, influenced their forward-thinking approach to data sharing and family preparation.

Mindful (Dad) explained his proactiveness in monitoring due to his parent. "*My dad passed away from diabetes, so I have to stay aware and watch out in case it affects me too. But so far, there haven't been any issues .. my blood sugar levels are still normal."*

Chuenchom (Mom) captured this anticipatory perspective: *""If it's within normal range, it's fine. But if there's a serious change, like 'you're in the risk group' or 'you have stage 3 kidney disease,' it needs to be discussed about health in the future. In families dealing with chronic conditions, this close monitoring is essential."* This perspective of anticipating future needs emerged repeatedly, with **Mindful (Dad)** also reflecting: *"One day, if I can't update the app myself, I might want my family to know ... it's kind of like preparing for future."*

The wave metaphor emerged from families' visions of how health sharing should feel. Mindful (Dad) explained: "A ship isn't a bad metaphor, it's like, okay, as a family, we're all on this journey together. We need to take care of each other and make sure we all make it safely to the other side." His daughter J added: "It's that sense of being a team, like we're all crew members, each with a role in keeping the ship moving forward."

The ship and wave metaphor captured how families wanted sharing to adapt to changing health circumstances. Rather than static data tracking, they envisioned flexible sharing that could shift from routine check-ins to intensive support as needed.

Four distinct phases emerged, each with different sharing needs:

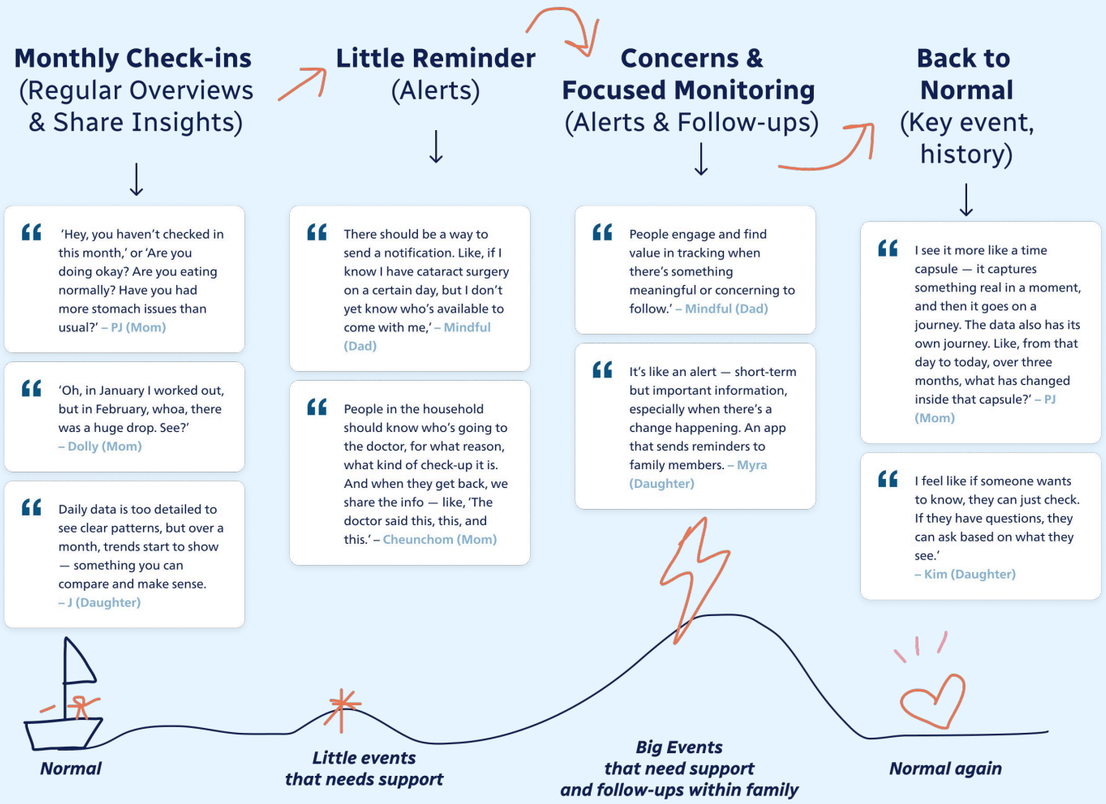


Figure 27: Initial health journey framework showing phase transitions over time - from normal routine through minor and major health events to a new normal with reflection (additional framework iterations in Appendix E1)

These situational insights emerged from co-creation activities where families envisioned future health data sharing systems. As illustrated in **Figure 27**, four distinct phases emerged, each requiring different sharing approaches. During normal periods, families desired light monthly check-ins without pressure. When little events arose, they wanted gentle alerts and focused coordination. Big events called for frequent monitoring and collaborative care planning. Finally, during recovery phases, families sought to archive experiences and build collective memory.
Crucially, these phases weren't sequential but adaptive—families could skip directly from stable to crisis or cycle back and forth. **Table 4** summarizes these shifting sharing needs across health situations. **This understanding revealed the critical "when" dimension that would shape Cycle II's exploration of adaptive sharing approaches.**

Stage	How they want to share	Evidence / Quote
1. Normal	**During stable periods, families desire light, casual connection**	**PJ (Mom)** described this gentle checking: "Hey, you haven't updated this month, or Are you doing okay? Are you eating normally? Have you had more stomach issues than usual?" Monthly check-ins and personal highlights support ongoing awareness without pressure.
2. Little Events	**When small changes arise, families want gentle coordination and alerts**	**Myra (Daughter) envisioned this as:** "It's like an alert... short-term but important information, especially when there's a change happening. An app that sends reminders to family members."
3. Big Events	**During health crises, families shift to focused monitoring with intensive support**	**As Mindful (Dad) noted:** "People engage and find value in tracking when there's something meaningful or concerning to follow."
4. Back to Normal	**After events pass, families want to archive experiences and build long-term collective memory.**	**PJ (Mom) captured this beautifully:** "I see it more like a time capsule. It captures something real in a moment, and then it goes on a journey. From that day to today, over three months, what has changed inside that capsule?"

Table 4: Two-axis framework for mapping data tracking behaviors and family sharing attitudes. Initial assumptions were refined through Cycle II validation.

4.5 Data Sharing Insights: What Data Matters and How They Could Work

Although participants began by tracking everyday **behavioral data (sleep, steps, diet) for one week**, co-creation sessions revealed this served primarily as background context for medical results rather than the focal point families wanted to share.

For people managing metabolic conditions, medical indicators took clear priority over lifestyle tracking, sometimes following doctor recommendations. **Mindful (Dad)** explained: *"I never planned to buy a blood pressure monitor, but after a health check-up showed high LDL, the doctor recommended tracking it for at least 7 days every month. The results stayed normal... so I felt reassured there was no heart problem."*

Participants wanted to share and connect through **medical overviews and significant health events, not detailed daily behavioral monitoring.**

What Families Actually Want to Share: Three Data Groups

During co-creation workshops, families grouped data types by their willingness to share, revealing three distinct categories. **Myra (Daughter)** captured families' vision for integrating these different data types: *"I'd like to have more integrated information — like syncing lifestyle data, such as eating and daily habits, with medical data. I just feel like there should be a way for our everyday life data and our medical records to come together."*

Data Group 1: **Health Indicators (Shared & Actionable)** Lab results, vitals, and medical appointments serve as family health inventory that can be archived and reviewed to track changes. Parents often know these numbers by heart and take pride in improvements, while children gain health knowledge through involvement in appointments. J (Daughter) emphasized their importance: "I feel like the annual health check-up report is the best, because it already gives an overview summary. Everything else is kind of a subset under that overall health result."

Data Group 2: **Lifestyle Context (Background & Supportive)**
Steps, food, and sleep could provide monthly overviews to look back and see patterns. Families prefer sharing overviews rather than exact numbers, especially for families that don't share often.

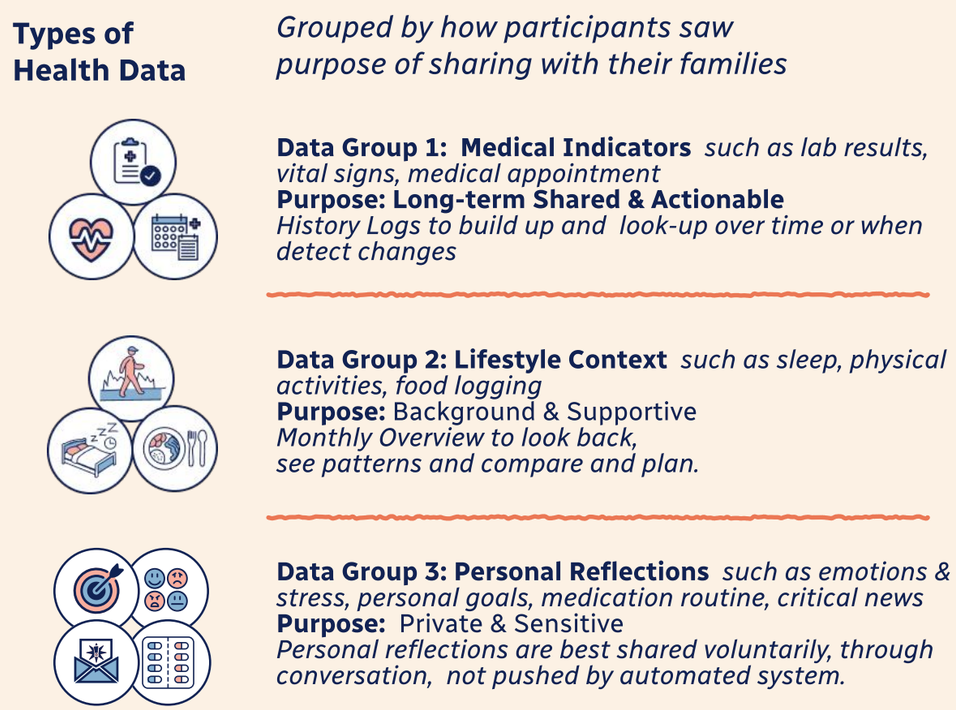


Figure 28: Three types of health data grouped by participants' perceived purpose for family sharing, showing varying levels of automation appropriateness.

Data Group 3: Personal Reflections (Private & Sensitive) Emotions, personal goals, medication routines, and stress are best shared voluntarily through conversation, not pushed by automated systems. **Kim (Daughter)** illustrated this preference: "*I am stressed, but I can manage it. I'm not just saying I'm not stressed. It's more about handling it myself. And* honestly, we talk every day anyway, so it's not like it needs to be said." These deeply personal matters require human connection rather than data interfaces.

Future Visions Through Metaphor

When envisioning ideal sharing systems, participants naturally reached for metaphors that humanized data and emphasized relational meaning. **PJ (Mom)** described data as "*a time capsule that captures something real in a moment, and then it goes on a journey*", emphasizing how health information evolves in significance over time. Others described data as a **"mirror"** for personal reflection or envisioned a **"cell"** of trusted members beyond family such as friends and extended family who could access information based on mutual care and readiness.

4.6 Conclusion

Cycle I revealed that family health data sharing is fundamentally relational, generational, and situational. Four key insights emerged:

How and why do Thai parent-child pairs managing metabolic conditions track and share health data?





Parents and children track differently because they are in different life stages

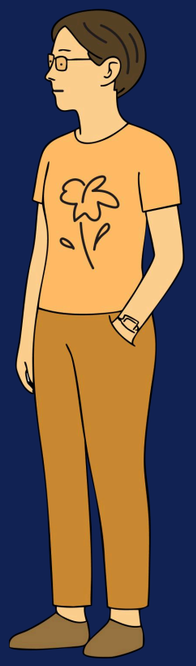
arents tracked health data seriously for medical management and memory support, while adult children tracked more casually for self-awareness and motivation, creating different sharing comfort levels and privacy concerns within families.

People in the same family might track and share differently

Four distinct archetypes emerged *(Independent Trackers, Family Collaborators, Alert Responders, Family Carers)* that could coexist within the same family, requiring systems that accommodate different engagement levels and sharing preferences rather than one way fits all

What do they need and wish?





People need health data sharing that adapts over time

Families envisioned health data sharing as a long-term investment that would shift through different phases—from routine normalcy to minor health events to major health events—requiring flexible sharing that could evolve from gentle check-ins to intensive support.

People need one place to collect different data for long-term

Families wanted to integrate different types of data—*medical, lifestyle, and personal*—depending on their situations and conditions, rather than focusing on single data types, as each family member might be in different life stages with different concerns. Some data could be shared as history logs for long-term tracking, some data worked better as summaries over details, and some data needed clear intention and required in-person conversation rather than automated notifications.

Setting the Stage for Cycle II

These initial findings established that families need adaptive systems, but the specific mechanisms of how and when sharing should occur remained unexplored. **Chapter** 5 builds on these findings toward design frameworks in Cycle II, where families co-designed their preferred sharing approaches across different health situations, revealing the deeper motivations behind their design decisions and leading to three refined frameworks that shaped family health data sharing practices.

Cycle II – Key Findings

How might health data sharing adapt over the family journey of long-term care between Thai parents and adult children?

Building on Cycle I findings, this phase shifted from exploring family preferences to co-designing actual sharing systems. The initial wave framework was brought back to families, who then co-designed health data sharing approaches across different health stages. When families made concrete design decisions, three distinct perspectives emerged: **People on Board** (relationship dynamics), **Riding the Waves** (situational adaptation), and **Cabin and Shared Deck** (lived experiences and collective space). These perspectives generated fifteen key insights revealing how families navigate health data sharing within their existing relationships and changing circumstance

5.1 Introduction: From Vision to Design Decisions
5.2 Three Perspectives That Emerged from Thai Family Design Decisions
5.3 Toward Design Principles
5.4 Conclusion

5

5.1 Introduction

Cycle II: Validating and Refining Initial Insights

In Cycle II sessions, participants resonated with the initial framework from Cycle I, recognizing themselves in the behavioral archetypes and health journey phases. However, when providing feedback, they helped identify gaps in my understanding from previous findings.

This cycle focused on the **when** and **how** of health data sharing: when families moved from imagining future sharing to actually designing concrete choices—placing cards on canvases, selecting interaction styles, and negotiating sharing across health phases—new insights emerged.

Research Question: How might health data sharing adapt over the family journey of long-term care between Thai parents and adult children?

This transition from abstract discussions to specific design decisions revealed underlying values that became explicit when families had to choose options for their actual relationship dynamics.

5.2 Three Perspectives That Emerged from Thai Family Design Decisions

"When Thai families moved from discussing health data sharing systems in broad terms from previous sessions to making concrete design decisions through the wave framework, three distinct perspectives emerged that shaped how they approached each choice. These perspectives validated and refined initial findings from Cycle I, revealing that behavioral archetypes and health journey phases were interconnected in more complex ways than originally theorized.

The "wave" metaphor became central finding because participants found it powerful for making sense of complex health situations.. During sessions, families brought past health experiences into discussions—sharing stories of previous injuries requiring family coordination, operations, and future health fears such as cancer. This metaphor made abstract health journeys tangible, allowing families to see themselves navigating changing waters together. These three perspectives show how relationship dynamics, situational adaptation, and personal context interconnected dimensions of family health data sharing.

Three Perspectives on the Wave Journey

People on Board represents the individual characteristics and behavioral patterns that each family member brings to health data sharing - their personal approach to tracking, their comfort with technology, and their sharing preferences.

Riding the Waves captures how families navigate through different health situations and phases of their chronic care journey - from calm periods of routine monitoring to turbulent times requiring intensive support and coordination.

Cabin and Shared Deck describes the relational dynamics and communication patterns within the family - the private spaces where individual reflection happens and the shared spaces where family members could come together to discuss, plan, and support each other's health decisions.

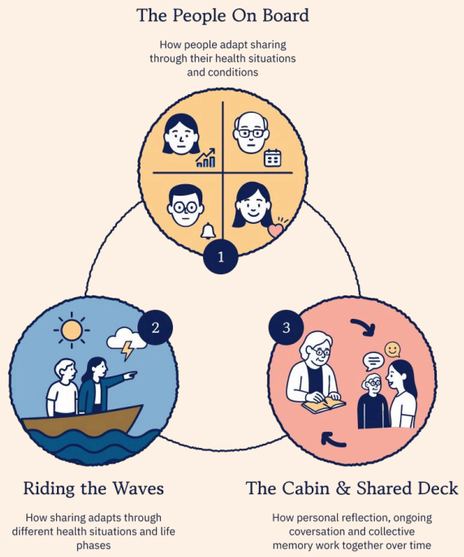


Figure 29: Three perspectives framework showing how relationship dynamics, situational adaptation, and lived experiences shape family health data sharing

Together, these three perspectives show how families work as a crew navigating their health journey, with each dimension influencing how they share health data and adapt their approach based on changing circumstances.

5.2.1 People On Board: How Family Relationships Could Shape Data Sharing Behaviors

Moving Beyond Surface Preferences to Underlying Values

Building on Cycle I findings, this revealed that sharing and data engagement are adaptive responses to changing needs rather than fixed personality traits. Families intensify tracking when they notice concerning symptoms or prepare for doctor visits, and increase sharing when seeking emotional support, practical help, or simply wanting someone to understand what they're experiencing during health challenges.

The archetype naming also evolved to be more precise: **Family Collaborator Becomes Data Collaborators** (focusing on data-specific collaboration) and **Family Carers Become Daily Carers** (focusing on everyday conversational sharing).

Two Key Dimensions That Shaped Sharing

Through the co-design sessions, it became clear what each behavioral pattern needed from health data sharing systems:

Data Intimacy
Relational Axis (X)

Selective Sharing ⟷ *Open Sharing*

How people approached sharing personal data within relationships, whether openly **sharing regularly** as part of daily connection, or **selectively sharin**g with clear boundaries only when it felt important or useful.

Data Engagement Style
Personal Axis (Y)

Active Tracking ⟷ *Passive tracking*

The approach people took when **engaging** with data, whether a*ctively tracking, reflecting and using for decision-making and action*, or **collecting data passively**, engaging only when specific health concerns or alerts arose.

Four Health Data Sharing Behavioral Patterns

Through the design sessions, it became clear what each behavioral pattern needed from health data sharing systems:

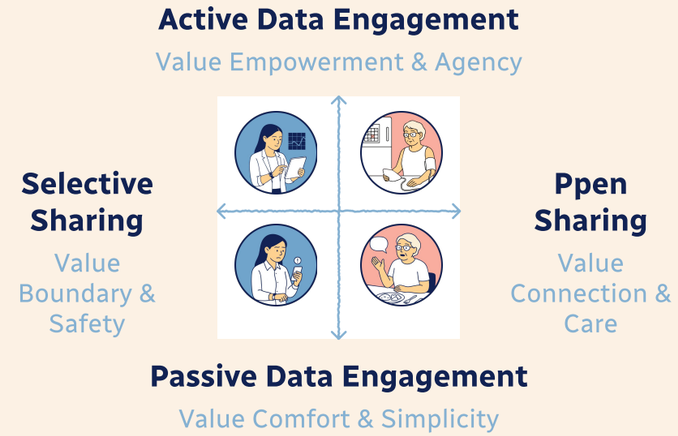


Figure 30: Four health data sharing behavioral patterns positioned along Data Intimacy (relational) and Data Engagement Style (personal) dimensions

Behavior Patterns	How they track & share	How they want
Independent Trackers *Active & Selective* 	Track their own data actively but share selectively, preferring occasional check-ins rather than constant updates	Safe spaces for self-reflection with full control over what and when to disclose.
Data Collaborators *Active & Open* 	Actively track and openly share data as basis for family planning and decision-making.	Tools that help sync information and plan effectively as a team. They see health information as a folder or drawer everyone can access.
Alert Responders *Passive & Selective* 	Avoid regular tracking effort, share only when necessary or prompted	Gentle nudges when attention is truly needed, minimal effort in data logging, data processing until it matters.
Daily Carers *Passive & Open* 	Share naturally in everyday conversations but struggle to capture the bigger picture	Structure and guides to organize what's most relevant from their daily caring interactions.

Table 5: Health data sharing behavioral patterns Independent Trackers, Data Collaborators, Alert Responders, and Daily Carers

Dynamic, Not Fixed: How Families Influenced Each Other

Building on Cycle I findings, this revealed the adaptive nature of sharing and data engagement behaviors. When families positioned themselves on the behavioral map, they found it difficult to pinpoint exact locations, instead using other archetypes as comparison points. These dimensions shift over time, and within one family, members don't follow the same patterns—some value frequent updates while others prefer sharing only when it's impactful. Within families, members adapted their approaches based on circumstances and each other's needs. Chuenchom, who identified as a **"Data Collaborator"** and valued sharing health updates to help manage family health appointments, could adjust her approach when her daughter valued privacy or was simply busy: "*It's fine if we don't do it... if we have time later, we can come back and check ourselves. But we'll keep recording continuously anyway. It shouldn't be too strict like 'hey, have you checked this yet?' It doesn't demand or ask because it depends on convenience.*"

Kim demonstrated this flexibility even more dramatically, positioning herself as an "**Alert Responder**" during normal periods but becoming willing to shift toward **"Data Collaborator"** during health challenges: *"A gentle alert works because I usually focus on my work. I don't pay much attention to health, not actively tracking much. If I do track, it's only things I really care about, like my menstrual cycle."* However, when imagining serious health situations, her approach changed: *"Check-ins are like telling others what happened. For example, if I have cancer, I need to talk and say, 'I went for tests and they found this thing. I'm not sure what stage it is because they need to keep doing more tests...' But at least we know...I feel like I'm not fighting this alone."*

For Kim, sharing behavioral data felt sufficient during stable periods, but when situations intensified, her focus shifted toward emotional support and companionship as collaboration became more important. These behavioral shifts—triggered by changing health situations and family dynamics—revealed that sharing patterns adapt to circumstances rather than reflecting fixed personality traits, leading to the second perspective: how families navigate health data sharing as situations evolve.

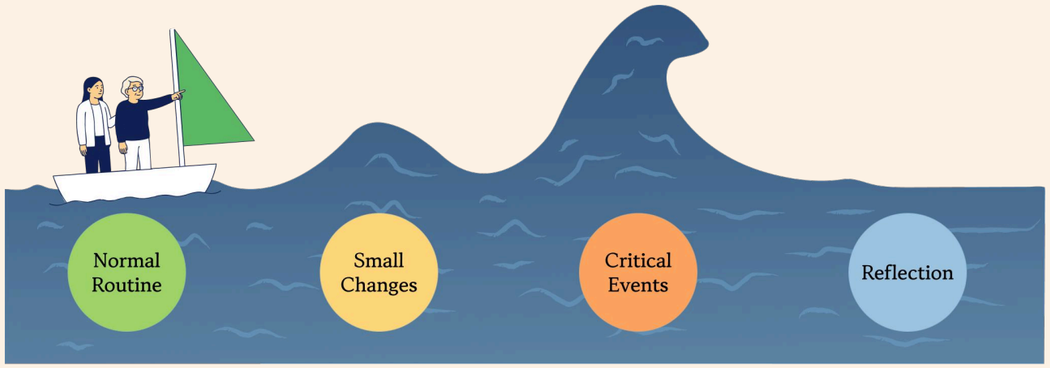
5.2.2 Riding the Waves: How Families Could Adapt Sharing Through Health Situations

Moving Beyond Fixed Sharing to Situational Adaptation

While Cycle I revealed that families had different sharing preferences, Cycle II's design activities showed **sharing is dynamic: families adapted their approaches based on changing health situations.** When co-designing own systems across different health phases, it became clear that their needs shifted dramatically depending on whether they were navigating **calm periods, emerging concerns, health crises, or recovery phases.** This perspective mapped how families viewed health through the lens of time, recognizing that sharing changed across situations rather than following fixed patterns.

Four Phases of Health Data Sharing

These shifting health situations created four distinct phases that families could move through, each requiring different approaches to health data sharing and family coordination. Since chronic care unfolds over months and years, families could naturally develop rhythms that avoided the stress and drain of constant intensive monitoring. Each phase brought its own sharing needs and family dynamics.



Health Phase	Sharing Approach	Interaction Preferences & Tool Examples
Phase 1: Normal Routine *Stable Sea* 	During stable periods, families shared health information lightly and spontaneously to maintain connection	When concerning changes emerged, families became more attentive to early signs and prepared for potential support needs
Phase 2: Small Changes *Windy Wave* 	When concerning changes emerged, families became more attentive to early signs and prepared for potential support needs	Observation tools and gentle alerts to help notice patterns and decide when attention is needed
Phase 3: Critical Events *Stormy Sea* 	For serious conditions, families wanted intensive coordination with frequent check-ins and detailed sharing	Progress updates, treatment plans, care guides, and emergency information sharing
Phase 4: Recovery & Reflection *Calm Water* 	After health events, families looked back to identify causes and compare before/after differences	Reflection tools and event logging to detect patterns and prevent future issues

Table 6: Four Phases of Health Data Sharing Journey

Low Pressure, Long-Term Investment:

Families valued sustainable sharing practices over perfect tracking, viewing health data as a long-term family investment that builds collective memory without creating daily pressure or monitoring stress.

Non-Linear and Adaptive Journey

Families demonstrated that health journeys were not linear progressions. They could skip from stable directly to crisis, stay in detection mode for years, or cycle back and forth based on new developments. This required sharing systems that could adapt flexibly rather than assuming predictable patterns.

"*Sometimes there are steps that skip stages in the process. When someone is sick, some people don't fully recover but may gradually get better. But it might not follow every step in order. It's like encountering obstacles, but in the end, we still have to take care of health for everyone.*"
— Chuenchom (Mom)

5.2.3 Private Cabins to Shared Decks: From Personal Reflection to Shared Health Data

From Personal Space to Shared Space

While Cycle I revealed that families wished to integrate different types of health data with varying levels of sensitivity, some data could be shared as neutral history logs, while other data needed personal processing and intentional conversation rather than automated sharing.

In Cycle II's co-design activities, when families discussed what types of data to share and how to present it, they demonstrated that personal processing and family sharing worked together lead to metaphor, **individual "cabins" for private reflection complemented "shared decks" for family connection.** This perspective showed how families balanced private data sensemakeing with shared knowledge building, with both aspects supporting their overall approach to health data.

Three Types of Health Data and Their Sharing Context

Through co-design activities, families revealed how they organized health data into three distinct categories, with participant quotes showing how each type could be shared and for what purpose.

Medical Related *Shared & Actionable*	**Lifestyle Context** *Background & Supportive*	**Personal Reflections** *Private & Sensitive*
“Blood pressure is really important for me because you need to have a record to send to the doctor. But you don't have to do it every day. You can keep it personal but sharing is okay too. You don't have to report it to others every day.” — **Chuenchom (Mom)** *“When I keep detailed notes, the doctor likes it because it helps them understand what's going on with me.”* — ***Dolly (Mom)***	*"If Joe has gout and needs to eat certain foods only, everyone at home has to help watch out—making sure he doesn't eat this or that. Another is based on the checkup results, which come with their own indicators."* **— PJ (Mom)** *"If it's about controlling the diet, it definitely needs to be shared because at home we eat together, we cook and eat together. So if there's anything to watch out for, I think it's necessary to let everyone know."* **— J (Daughter)**	*"If your mother suddenly tells you that she has stage 4 cancer, people need time to get over it. They might not be able to think about it at all."* **— Kim (Daughter)** *“For the reflection part, We can also added feelings, like emojis. It's about supporting each other, like 'feeling good today.' It's like sharing feelings and emotions for both the patient and the caregiver, more like encouraging each other."* **— Chuenchom (Mom)**

Table 7: Three Types of Health Data and Their Sharing Context

Some people see tracking as a burden, but they're willing to share if it helps their family over time. Sustainable sharing and ongoing conversation matter more than perfect tracking or precise numbers. It's the ongoing conversation, bringing personal insights to shared spaces where everyone can learn, that keeps the relationship alive.

Understanding this co-existing space between private and shared reveals that families don't need rigid boundaries—they need flexible spaces that allow personal processing to naturally flow into collective understanding. This points to opportunities for creating health data spaces that honor both individual boundaries and collective values.

5.3 Toward Design Framework

These fifteen insights emerged from families' design decisions across the three perspectives—**People on Board, Riding the Waves, and Cabin and Shared Deck**—showing how health data sharing was shaped by relationships, situations, and personal meaning-making. Each insight card shows how these findings were derived from participant quotes. Together, these insights revealed patterns that pointed toward **design principles** for supporting how families share health data to care for each other.

Key Insights from People on Board

KI1.1 Trust and Care Shape Data Sharing: What families shared reflected personal values and relational connection, with trust, closeness, and family roles determining data flow between members.	*"My son made a good point... each family has a different ability to share. In some families, people tend to nag or gossip to extended relatives, so that makes others less willing to share."* **— Mindful (Dad)**
KI1.2 Data Enables Understanding, Not Monitoring: Ongoing sharing built mutual understanding, opening doors to check-ins and deeper conversations about noticing, understanding, and supporting rather than surveillance	*"The part that I think if it's useful to share is that my parents will be relieved that I am doing exercises."* **— J (Daughter)**

KI1.3 Reciprocal and Uneven Sharing is Natural: People adapted throughout life situations, with shifting roles and engagement levels being normal family health dynamics rather than human flaws to fix.	*"It's important that people understand these reminders aren't about invading someone's freedom or privacy. It's more about how living together means using shared data in a way that benefits everyone. It's about seeing the value in sharing data for mutual support."* **— PJ (Mom)**
KI1.4 Different data engagement styles needed different presentations: Active data engagers wanted detailed patterns while passive engagers preferred simple summaries, requiring systems to accommodate both approaches within families.	*"When data's sent to me, it doesn't have to come every day. But when it does, I want it to be data that reflects daily-level insights in summary."* **— J (Daughter)** *"Keep it simple and easy to understand...no need for anything complicated."* **— PJ (Mom)** *"Yeah, like don't use jargon or technical terms. It should be straightforward."* **— Joe (Son)**
KI1.5 Data should support, not replace, ongoing conversation: Data served as materials for family conversations rather than replacement for human connection. Numbers became starting points for deeper discussions about health, routines, and care needs.	*"It's good because it's like something we already talk about in daily life, you know? Health matters that we already discuss. For retirees like us, if there's something that becomes a pattern for us, it helps us think, and we just follow the steps."* **— Chuenchom (Mom)**

Key Insights from Riding the Waves

KI2.1 Share Meaningful Moments, Not Micro-Details: People shared health highlights that invited genuine family curiosity and care, avoiding constant updates that created monitoring pressure	*"If I'm eating a lot of veggies lately, or sleeping well these days, I might share that."* **— J (Daughter)** *"Lately, I've been trying out some sports or activities I've never done before."* **— Mindful (Dad)**
KI2.2 Navigate Health Uncertainty Together: When concerns arose, families shifted from privacy to transparency, becoming willing to share more as a way to navigate uncertainty and provide meaningful support.	*"My son made a good point... each family has a different ability to share. In some families, people tend to nag or gossip to extended relatives, so that makes others less willing to share."* **— Mindful (Dad)**
KI2.3 Build Shared Family Knowledge for Future Storms: Sharing created repositories of family health knowledge for future reference, allowing families to compare situations and learn from past experiences	*"Most of the time, when you ask patients, they have to ask their kids or grandkids because sometimes they can't remember. But their kids or grandkids will know, because if it's a major surgery, family members will have to be involved...they'll go stay with them, take care of them. So you have to ask a family member."* **— Chuenchom (Mom)**
KI2.4 Routine Sharing Prepares for Crisis Response: Families with established sharing practices during stable periods could coordinate better during health crises than those who struggled to suddenly collaborate	*"It's not really about being sick. It's more about small events to maintain or prevent issues—keeping things within manageable limits."* **— Myra (Daughter)**
KI 2.5 Health Journeys Are Non-Linear and Families Perceive Events Differently: Health progress didn't always evolve in linear ways, and family members perceived the same events differently depending on their experiences and roles. Critical events could happen suddenly without gradual warning signs, requiring families to adapt their sharing approaches flexibly.	*"Sometimes there are steps that skip stages in the process... It's like encountering obstacles, but in the end, we still have to take care of health for everyone."* **— Chuenchom (Mom)**

Key Insights from Cabin & Shared Decks

KI3.1 Personal Context Enhances Clinical Understanding: People combined medical data with behavioral context to understand health holistically, seeing lived experiences as complementary to clinical metrics.	*"It's not about test results or diagnoses...that kind of information stays in the medical folder, where we keep doctor's info separate from our own notes."* **— Myra (Daughter)**
KI 3.2 Data as Memory Aid, Reflection and Planning Tool People used data as memory aids supporting personal planning, bringing self-learnings into conversations for connection or support calls	*"It's like, here's what my lifestyle was like before I got this condition. Then, after getting it, it changed to this."* **— J (Daughter)** *"Sharing and viewing data in one place — like a kind of family folder — would make sense, especially for the long term. It should all be stored in one place and kept over time, so we can look back and see the results."* **— Myra (Daughter)**
KI3.3 Numbers Can Lead to Conversations Personal data reflection can ealed patterns pointing to deeper emotional circumstances, surfacing feelings people chose to bring to family for support.	*"Check-ins are like telling others what happened... I went for tests and they found this thing. I'm not sure what stage it is because they need to keep doing more tests... But at least we know—I feel like I'm not fighting this alone.."* **— Kim (Daughter)** *"If we keep this data and make it viewable to family members, it becomes a way to share information with each other. Then maybe once a month, we can talk about it — like, should we improve something?"* **– PJ (Mom)**
KI 3.4 Personal Data Space Co-exists with Shared Data Space: People needed quiet reflection space and privacy control while contributing to the family's collective memory through casual data sharing. Families needed individual data spaces that allowed different sharing styles, with sharing frequency varying based on health focus, conditions, and situations.	*"Talking about medicine doesn't really have much effect because it's very personal. They just take the meds. But maybe it's good to let the family know that there are a lot of meds now, and why—just so they understand. In summary, it's ok to share."* **— Mindful (Dad)**
KI3.5 Build Collective Memory Without Pressure: Families valued health sharing as ongoing care building long-term collective memory, prioritizing sustainability over perfect tracking	*It's not about competition; we just want to know if something happens often enough, if it's okay or if it needs attention."* **— Myra (Daughter)** "If big event has already happened, we might only look back at it again if, say, after one or two years, symptoms came back." **— Kim (Daughter)**

These **fifteen insights** reveal how families actually practice care through data. They work together across **relationships, situations, and personal meanings** rather than existing as separate dimensions.

The People On Board insights showed that sharing behaviors are dynamic responses to family circumstances, not fixed personality traits. **Riding the Waves** insights revealed how families intuitively adapt their sharing based on changing health situations**. The Cabin and Shared Deck** insights uncovered how personal reflection co-exists with collective memory-building, where health numbers become conversation starters and family collective health history.

Together, these insights point toward **design opportunitie**s that work with relational dynamics—supporting how families naturally negotiate care, adapt to circumstances, and create meaning from shared health experiences. The next chapter translates these interconnected insights into design principles.

4.6 Conclusion

Cycle I revealed that family health data sharing is fundamentally relational, generational, and situational. Four key insights emerged:

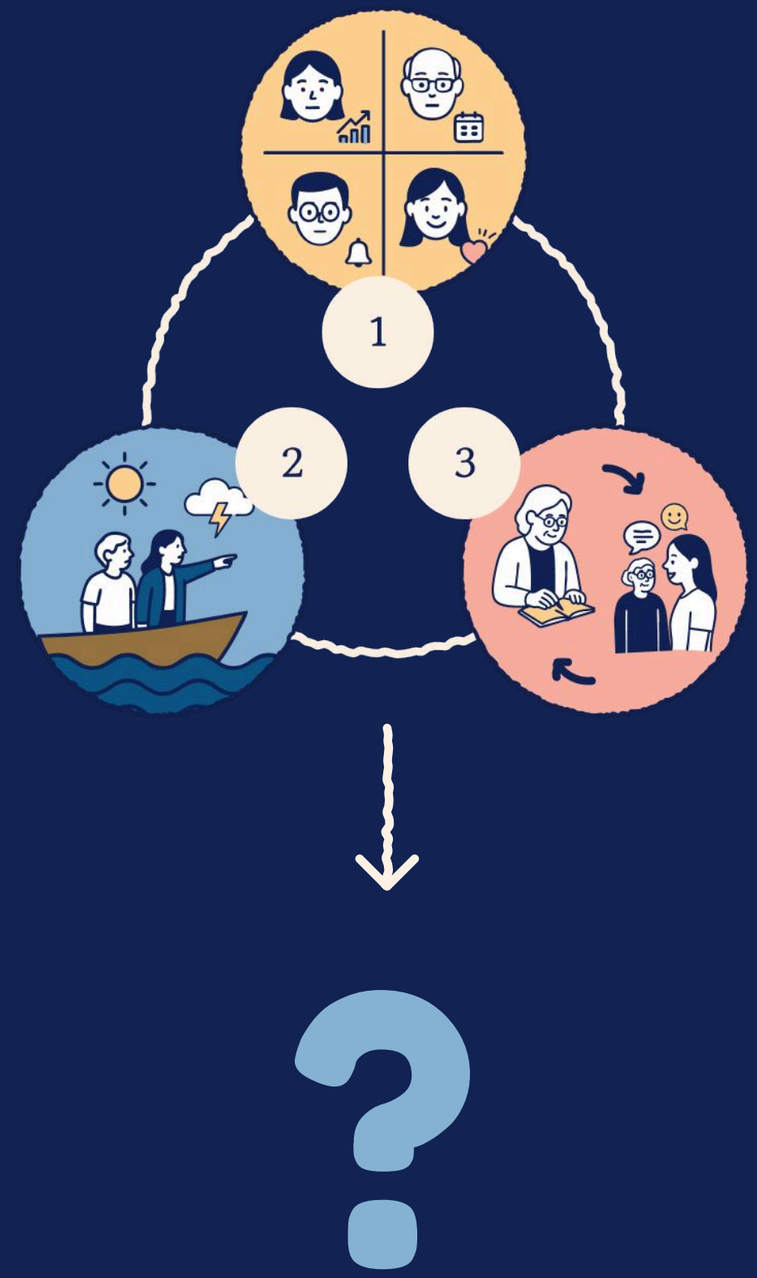
How might health data sharing adapt over the family journey of long-term care between Thai parents and adult children?

Cycle I to Cyle II: From Who & What to When & How

While Cycle I identified what families wanted from health data sharing—different behavioral archetypes, adaptive journey phases, and integrated data types—Cycle II revealed why and how these preferences worked in practice. The shift from speculation to concrete design choices uncovered the underlying values and relational dynamics that drove families' sharing decisions.

Three Perspectives Toward Design Principles

These fifteen insights emerged from families' design decisions across People on Board, Riding the Waves, and Cabin and Shared Deck, revealing patterns in how families approached relational health data sharing within their cultural context, showing that health data sharing involves relationships, timing, and lived experience towards shared memories. The insights pointed toward design principles for creating technology that could support how families share health data to care for each other. **Chapter 6** translates these insights into design framework for relational use in health data



Chapter 6 translates these insights into design principles for creating technology that could support how families could share health data to care for each other.

Final Outcome: Design Framework

How Might We Design for Relational Use in Health Data?

From both research cycles, this chapter brings insights together into actionable design guidance. Fifteen key insights from Thai families' experiences become eleven design principles organized around three pillars that address the central question: "How might we design for relational use in health data?" The Wave of Care website translates this research into a practical tool, enabling designers to design with relationships in mind.

6.1 Introduction
6.2 Design Framework with Three Pillars
6.3 Design Artifact: Ratioanale and Development
6.4 Conclusion

6

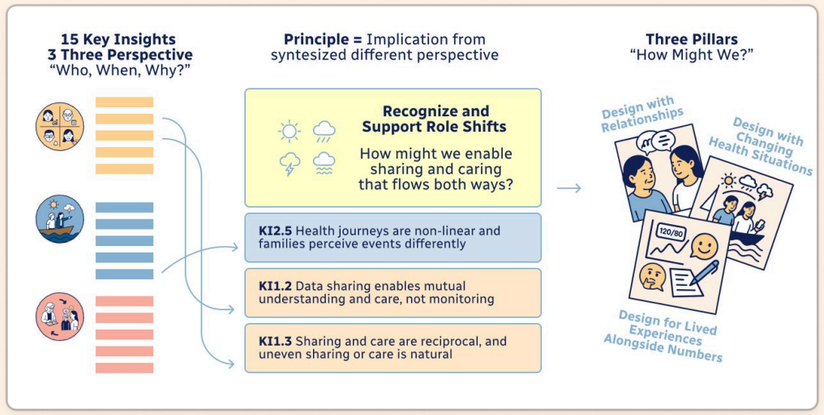
6.1 Introduction

While these insights emerged from Thai families, they point toward considerations that could be relevant for other contexts designing for relational use in health data. This chapter translates fifteen insights across three perspectives into actionable design considerations, representing the communication phase of contextmapping where research findings are transformed into guidance for designers (Sleeswijk Visser et al., 2005; Sleeswijk Visser, 2009). As Sleeswijk Visser (2009) emphasizes, *"Rich experience information cannot be communicated as a set of facts. Designers are active recipients of the information and by a process of understanding and sense making they are able to act upon this information in their design process."*

As a researcher who hope ton bring insights from lived experiences to designers for future health tools, I developed eleven design considerations organized around three pillars to foster empathy and provide inspiration. *These aren't checklists to follow, but lenses for reflection and imaginination*—ways to stay connected to the lived experiences of families navigating health together while imagining how technology might better support their existing care relationships.

6.2 Design Framework with Three Pillars

The fifteen insights from three perspectives, **People on Board (who)**, **Ride the Wave (when)**, and **Lived Experiences to Shared Memories (why)** were synthesized to create design principles that address implications from different perspectives (see Figure 31). This process moved from understanding current behaviors to identifying cross-perspective patterns to formulating "How Might We" design questions organized under three pillars.



Figue 31: Synthesis process from research insights (Who, When, Why?) to design principles and framework (How Might We?)

The eleven principles are organized under three pillars that represent different design approaches:

 Pillar 1: Designing with Relationships	 Pillar 2: Designing with Changing Health Situations	 Pillar 3: Designing with Lived Experiences & Shared Memories Behind Numbers
1.1 Design with Reciprocity in Mind **1.2 Support Different Ways People Care** **1.3 Respect Different Communication & Information Styles** **1.4 Build Trust Through Clear Signals and Boundaries**	**2.1 Adapt to Life's Changing Health Moments** **2.2 Recognize and Support Role Shifts** **2.3 Nurture Sustainable & Long Term Health Journeys**	**3.1 Foster Safe Spaces for Personal Reflection Before Sharing** **3.2 Add Life Context Alongside with Health Numbers** **3.3 Embrace Imperfect Tracking Methods** **3.4 Let Data Start Reflection and Conversation**

Table 8: Three-pillar framework organizing eleven design principles for health data sharing within relationships

How to use these principles:

These principles are not definitive guidelines but a starting point for human-centered design with relationships in mind. They are designed to evolve and improve as they are applied and expanded upon.

Use them as lenses for reflection—consider current experiences with relationships and existing health technology, then imagine how data sharing could work differently with these considerations in mind.

Each principle is made of four components:

Principle: The core design consideration captured in a clear, actionable statement	**Design Question:** A *"How might we..."* question to guide reflection and spark design ideation
Description: Context explaining the underlying behaviors and needs around health data tracking and sharing	**Supporting Quotes**: Participant voices that ground the principle in lived experiences

Figure 32: Four-component structure of design principles

Pillar 1: Designing with Relationships

While health can be a personal matter, many people find meaning in sharing their experiences and health data with those closest to them. How families navigate this sharing reflects their different communication patterns and boundaries

 **1.1 Design with Reciprocity in Mind**	**How might we enable sharing and caring that flows both ways?**
Challenge ***"one shares, one monitors"*** dynamics. People could share more when they witness mutual vulnerability and support even with different health data. Design for reciprocal sharing that could enable care from both sides rather than one-way surveillance.	*If we share information with each other, we get to know what issues people are dealing with, even if they're not officially 'sick.' I thought of something and shared it. Whether you do something with it or not is up to you.* **–Dolly, Mom**



1.2 Support All the Ways Families Care

How might we design health data sharing to support different way families care?

Beyond ***practical coordination***, sharing might enable emotional support, decision-making, and collective learning from health experiences. Families could share for understanding, coping, preparing, and just being present with each other.

"For example, if I have cancer, I need to talk and say, 'I went for tests and they found this thing. I'm not sure what stage it is because they need to keep doing more tests, blood work, and other things.' But at least we know...I feel like I'm not fighting this alone"
– Kim, Daughter



1.3 Respect Different Communication Styles

How might people prefer to receive health information?

Enable people to express and receive health concerns through comfortable channels, *conversation, notes, or quiet logs.*

Accommodate different preferences: from quiet detailed logging to simple summaries with emotional cues to active alerts with guidance how to take action.

We use a calendar, yeah. Because with a calendar, you can see how often something repeats in a month—it's clear with lines or colors (...) When the time comes, I just check the calendar and see only the exercise events. Then I immediately know where the repeats are. **– Myra, Daughter**

"Keep it simple and easy to understand, no need for anything complicated. Yeah, like don't use jargon or technical terms. It should be straightforward."
–PJ & Joe, Mom & Son



1.4 Build Trust Through Clear Signals and Boundaries

How might we balance openness with privacy?

Support people's emotional safety in with flexible sharing controls that respect their open and selective sharing in relational dynamics. Data sharing could be intentional rather than automatic, allowing people to customize what they share, how much detail, when, and with whom.

"In some families, people tend to nag or gossip to extended relatives, so that makes others less willing to share." **–Mindful, Dad**

"I see it as folders—personal or family. Everything gets recorded with family as default. If you want something personal, you set it as personal.
–Joe, Son

Pillar 2: Designing with Changing Health Situations

Health situations change, and so should how families share and engage with data. Families naturally adapt their communication and care patterns based on what's happening, from quiet routine check-ins during stable times to intense coordination during health crises. These three principles recognize that data system that adapts with life's changing health moments.



2.1 Adapt to Life's Changing Health Moments

How might people in relationships adapt from calm to concerned to crisis?

See health as event-based—one-time, ongoing, intense periods, temporary sharing—rather than "share once and for all." Support sharing patterns that match situation intensity and duration, including heightened attention during uncertainty.

"Emergency events, like dizziness or low blood pressure, are important and need attention. But if it's just a yellow-level warning, it means you should be cautious and take care of yourself, not necessarily an orange-level alert."
–Joe, Son.



2.2 Recognize and Support Role Shifts

How might peoples adapt from calm to concerned to crisis?

Over time, family members naturally change their involvement levels based on life circumstances, health situations, and relationship dynamics. Design systems that acknowledge and support these role transitions rather than locking people into fixed caregiving patterns

"During the orange phase (big events), I feel like we need to check-in because it's starting to look like a bigger issue. And if suddenly the doctor says 'okay, this is a big deal'.. suppose it's cancer....we need to check in to see what stage it is, how we need to do family support."
–Kim, Daughter



2.3 Nurture Sustainable Family Health Journeys

How might we design for the long term sharing, not just today?

Focus on gentle, long-term engagement rather than perfect tracking. Support families to build collective health knowledge over time, adapting through different health phases without pressure or burnout.

"Imagine if you had to be asked every day, 'How are you?'... you probably wouldn't want to answer all the time. Or if you had to check in frequently, you'd get tired of doing it so often. But if there's information just sitting there, and you can check it whenever it's convenient or necessary, that works better." – **J., Daughter**

Pillar 3: Designing with Lived Experiences & Shared Memories Behind Numbers

Behind health data could be the lived experiences and shared memories that families create alongside the numbers. People might need personal safe space to reflect on what their data means to them personally before deciding what to share, and tools could support people by acknowledging the human imperfection and context behind data collected from them.



3.1 Foster Safe Spaces for Personal Reflection Before Sharing

Where or how might people have safe space for private processing?

Let people privately explore and engage with their data without performance pressure, allowing them to make sense, add context and filter what they want to share, when, and how much detail to include with other people.

“I only write things down when there's a noticeable change, not routine stuff. I note weight changes on my phone along with special days like holidays. I don't do this daily, just when something's different. At first, I keep it private” **–Cheunchom, Mom**



3.2 Value Life Context Alongside Health Numbers

How might people make sense or notes from their health data?

Support multiple ways of knowing by combining medical data with lived experience stories. Allow families to add context to numbers and value different health perspectives, encouraging personal stories alongside clinical data.

"We will write it in everyday language, our own words. We don't write like doctors do, it's not formal. If you want the medical version, look at the official report. What we're doing is something else... It's about our perspective, not the doctor's." **– Myra, Daughter**

 **3.3 Embrace Imperfect Tracking Methods**	**How or when might people actually track in their real life?**
Recognize that focus and tracking naturally fluctuate based on life circumstances. Support inconsistent data engagement without guilt or pressure, as sporadic or short-term meaningful tracking could serve people better than failed attempts at perfect consistency.	*“It's like a calendar, but it doesn't have to be daily. Maybe not every day of the week.. like 3 or 5 days a week, whenever it's convenient.”* **– Cheunchom, Mom**
 **3.4 . Let Data Start Reflection and Conversation**	**How might data lead to reflection and spark conversation rather than replace it?**
Personal reflection and curiosity about one's data can open the door to conversations or care. Data should be companions to these conversations, not replace them.	*"One of the benefits of turning logging into a regular habit is that it challenges what we think we know about ourselves. When I looked at the actual records, it was clear: I don't really eat at regular times."***–Dolly, Mom** *"Mom's been way more serious about food lately. If something's too salty, she will tell us to cut back. We have these conversations regularly."* **– Mindful, Dad**

While grounded in Thai adult-child pairs managing metabolic conditions, these principles might extend to other contexts where people share sensitive or intimate data around care, whether between partners, friends, or communities. These represent work in progress: insights from one specific cultural and health context that require further validation and refinement through real design practice.

6.2 Design Artifact: Rationale and Deve6.lopment

Why This Artifact: From Research to Practice

To test and develop these ideas further, I designed and created a **storytelling website** (https://wave-of-care.webflow.io/) that translates research insights & framework into an accessible narrative experience for designers interested in the health data domain. The website aimed to use story with participant voices with the wave journey metaphor that emerged from sessions to guide designers through the three research perspectives as a cohesive story.

The **storytelling approach** aims to create holistic understanding by following families through different health situations, showing how data sharing naturally evolves and how design can support rather than complicate these human dynamics. This represents the communication phase of contextmapping, where research findings are transformed into accessible formats for design practitioners.

The wave metaphor serves as the website's foundation because participants identified these shifting health situations as the research's most surprising and relatable insight. This metaphor became powerful because it helped participants articulate experiences they'd never fully recognized, making it an intuitive framework for designers to understand. This format serves multiple purposes:

- **Accessible communication:** Packaging complex research findings into storytelling with metaphor for design practitioners to explore at their own pace
- **Practical toolkit:** Providing designers with starting considerations to navigate and envision how data sharing can support relationships and health in their work
- **Iterative & ongoing development:** Creating a "living document" that uses the website's dynamic nature for potential future updates through community input and version control, starting from this Thai context
- **Broader application:** Making relational dynamics around health data accessible beyond academia, as universal experiences people can recognize and apply in their own context

Target Audiences and Expected Value

Design Students & Design Practitioners Design students, UX/UI designers, service designers, and design researchers interested in or experienced with digital health design.

Expected Value

- Extend current health design practice by understanding how families could share and manage health together
- Opening new possibilities and give starting considerations for designing health tools that work with relationship.

Broader Applications

While designed for designers, these insights might also be valuable for HCI researchers exploring relational data approaches and healthcare professionals interested in family-centered care. This validation phase prioritizes the primary audience of design students and practitioners. Given the project's scope and timeframe, focusing on designers allows for meaningful insights into how relational health data concepts can be integrated into design practice.

Design Goal

Develop a **website artifact** that enables designers to understand relational dynamics in health data sharing and envision designing health tools that work with relationships.

The website serves as both a **validation tool** and **design artifact**, testing whether participants can understand and relate to the three design perspectives and health phases, connect the framework to their existing personal experiences, apply the framework to their own relationships and health data contexts, and envision future applications beyond the original Thai context.

Success Indicators

To evaluate the effectiveness of the Wave of Care website in achieving its design goals, I established four key success indicators that would demonstrate whether designers could meaningfully engage with and apply the framework framework:

- **Framework Comprehension:** Participants can understand the three design perspectives and health phases and relate to their own experience
- **Reflective Engagement:** Evidence of connecting framework to existing personal experiences
- **Adaptive Application:** Ability to apply framework for their personal relationship and health data and use the framework in ideation process
- **Future Vision:** They can envision future use of framework beyond original Thai Context

Website Development Prototye Tool

Built using **Webflow**, the prototype demonstrates all components can be communicated through story that people understand and could relate. Each section had participant voices and scenarios, allowing families to speak directly to audiences.

Website Development Timeline

Phase 1: Development (2-4 weeks)

- **Story & Structure Building:** Draft the continuous family narrative, mapping the three-perspective flow (people → waves → cabin/deck → principles)
- **Visual Design:** Create metaphor illustrations and diagrams for key insights, adapting existing research visuals for web presentation
- **Development:** Build single landing page narrative flow in Webflow add participant quotes.
- **Refinement:** Test communication with peers *(sequence, visuals,* writing) and final refinement to prepare for validation with target users

Phase 2: Validation (1 week)

- **Validation with Design Students & Practitioners:** Gather feedback on , and potential application of the design framework

Phase 3: Final Adjustment (1 week)

- **Implementation of feedback:** Refine content, navigation, and interactions based on validation insights. Fix typos.

6.3 Design Artifact: Rationale and Development

Website Structure : Wave of Care Website 1.0

The website (https://wave-of-care.webflow.io/) follows a continuous narrative journey from problem statement through three core perspectives *(People on Board, Riding the Waves, and Cabin and Shared Deck)* to design framework and research foundation. This complete story explores how families could share health data, what designers can learn from their experiences, and the research approach behind these insights.



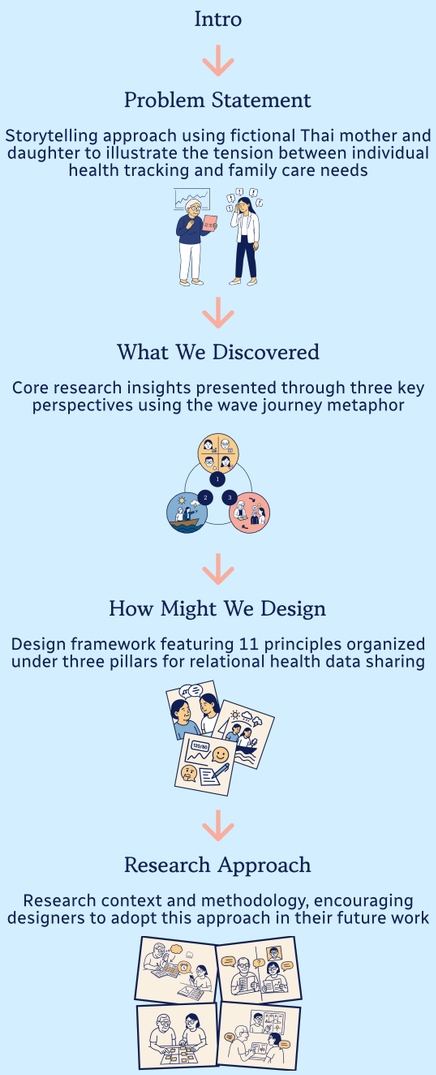


Figure 33: Website landing section (left)
Figure 34: Website content structure (right)

1. Problem Statement: Mali & Pam's Story

Introduces fictional characters Mali and Pam, based on participant stories and insights, to illustrate the gap between individual tracking systems and family care needs, showing the *"blurry space in between"* where families actually operate, navigating between sharing everything and sharing nothing at all.



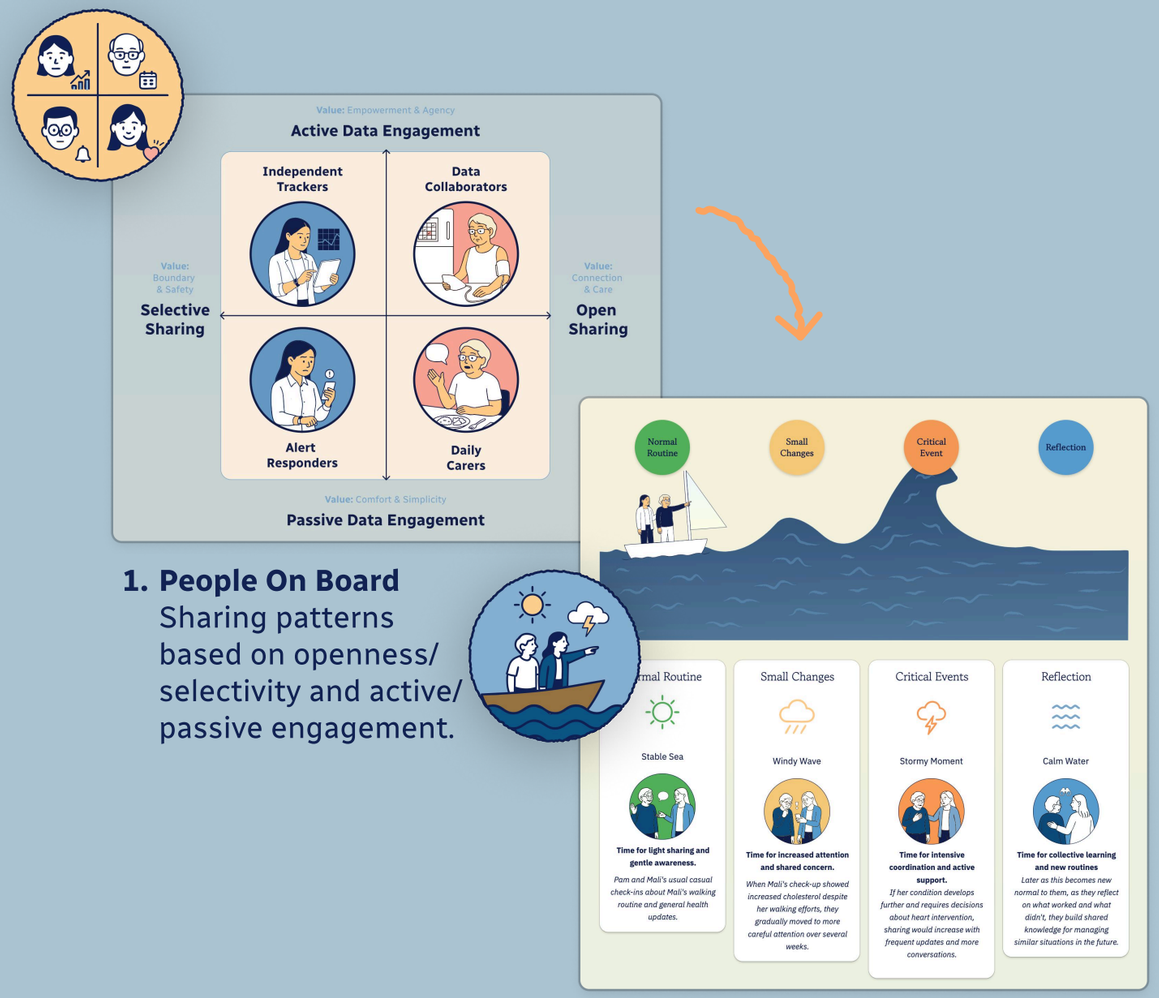
Figure 35: Problem statement section showing Pam and Mali's story about health data sharing tensions

2. Key Insights: Three Perspectives on Family Health Data Sharing

Present the core research insights through the wave journey metaphor Description: Introduces the metaphor of family health as navigating changing waters together, then explores three interconnected perspectives:

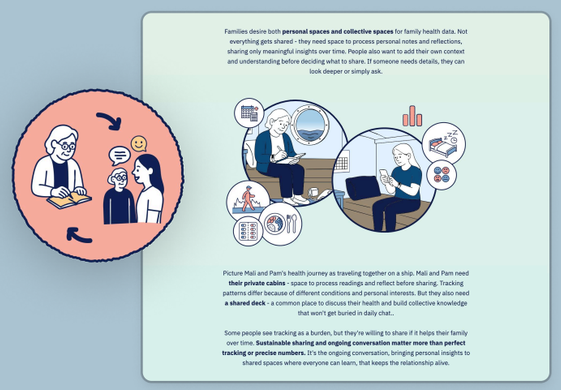


Figure 36: Introduction to Three Perspectives on Family Health Data Sharing



1. People On Board Sharing patterns based on openness/ selectivity and active/ passive engagement.

2. Riding the Waves Four health phases and how families adapt



3. Cabin and Shared Deck Balance between personal reflection spaces and shared data space

Figure 37: Three sections exploring each perspective: People on Board, Riding the Waves, and Lived Experiences

3. How Might We Design for Relational Use in Health Data?

Present the design framework derived from research insights. This section introduces and displays the eleven principles organized under three pillars **(see figure 38),** positioning them as considerations rather than checklists for designing with sensitivity to relationships which invite designers to reflect and rethink and imagine possible ways to share with relationships in mind. Each principle is presented as an interactive card that users can click to flip and reveal the design question with a short description of the principle. **(see figure 39)**



Figure 38: Eleven principles organized under three pillars (Pillar 1: Designing with Relationships, Pillar 2: Designing with Changing Health Situations, Pillar 3: Designing with Lived Experiences & Shared Memories Behind Numbers)



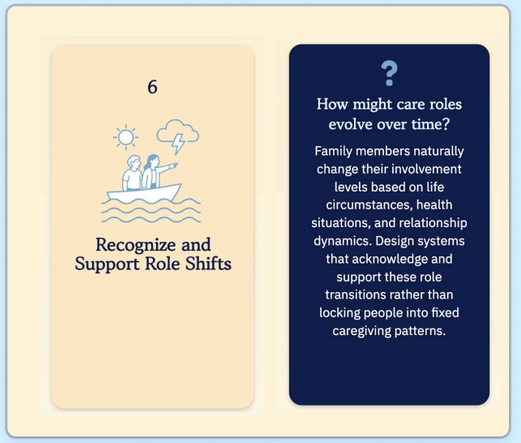


Figure 39: Principle card design showing both sides - principles (left) and corresponding "How might we" questions with descriptions (right)

4. Behind the Research

Provide research context, methodology, and encourage designers to adopt this approach in their future works. This section covers the participatory design approach conducted with Thai parent-childs, the data humanism philosophy that guided the research, key participant quotes and insights that shaped the findings, research team information, academic references, and an invitation to download the complete thesis for detailed methodology and comprehensive findings.

6.4 Conclusion

From Insights to Design Framework

This chapter translated **research insights into design framework** through eleven principles organized around three pillars: designing with relationships, adapting to changing health situations, and honoring lived experiences behind data. Rather than prescriptive solutions, these principles offer considerations for navigating the complex relational dynamics that surround family health data sharing, encouraging designers to reflect and rethink what it means to design for relationships in health contexts.

Wave of Care Website: Bringing Research to Design

The Wave of Care website artifact is designed to bridge the gap between academic research and design practice by packaging these insights into an accessible narrative experience. By using participant voices and the ship journey metaphor that emerged from sessions, the website aims to help designers understand how families naturally adapt their data sharing across different health phases and relationship dynamics.



This framework represents an approach to translating research insights into design guidance. **The next question is: How do designers engage with and make sense of this framework?**

The next chapter presents validation results with design practitioners, exploring whether these insights resonate beyond Thai families and how designers might apply these insights to reflect and ideate for health tools with relationships in mind.

Validation

Could these insights & framework work beyond Thai families? How did designers engage with and make sense of this framework?

While grounded in Thai adult-child pairs, validation with design students from diverse cultural backgrounds reveals the framework's broader potential. They shared desires for family health hubs similar to Thai participants but emphasized essential needs around emotional safety and opportunities for prevention-focused design with further development and adaptation.

7.1 Introduction
7.2 Validation Goals & Approach
7.3 Participants & Session Activities
7.4 Data Collection, Data Processing & Analysis
7.5 Validation Results
7.6 Key Design Opportunities
7.7 Website & Framework Feedback
7.8 Conclusion

7

7.1 Introduction

The research developed a framework for understanding relational dynamics in health data sharing, grounded in insights from Thai families. This framework was embodied in a website artifact designed to help designers understand these dynamics and envision health tools that work with relationships.

Having validated the framework within its original Thai family context, the next step was testing whether the insights could resonate with and be applied by designers from different cultural backgrounds. This validation phase would determine whether the framework successfully translates beyond its origins to become a useful tool for the broader design community working on family health technologies.

Design Goal: Enable designers to understand relational dynamics in health data sharing and envision designing health tools that work with relationships.

7.2 Validation Goals & Approach

Validation Goals

Primary Goal: Validate whether the storytelling website and framework helps designers understand, relate to, and envision applying this approach in health data sharing to their own contexts.
Secondary Goal: Gather feedback to improve framework communication and explore potential future applications beyond the original Thai family setting.

Validation Approach

The validation approach prioritizes personal reflection and open discussion over controlled testing. Following Sleeswijk Visser's (2009) principle that designers are "active recipients of information" who make sense through their own understanding, this validation focused on immersion and experience rather than website usability testing. Designers were invited to read and immerse themselves in the framework, then bring their reflections into group sessions where they could imagine themselves in relational roles and draw inspiration from the Thai families' stories. Since the framework aims to help designers see potential in relational health data use, the most authentic validation comes through designers experiencing the framework within their own lived relationships and co-creating from that personal understanding.

Why in group, not in pair: This validation was conducted with design students (n=5) in a group setting rather than pairs, which differs from the parent-child approach used in previous cycles. The group format serves different research goals at this validation stage: while parent-childs were essential for authentic health data sharing discussions based on existing relationships and trust, the validation phase focuses on framework clarity, applicability, and potential improvements from multiple design perspectives simultaneously and how they reflect within their own close relationship . Groups enable immediate peer feedback and collaborative sense-making about the framework's utility across different design contexts, creating more comprehensive evaluation than individual reviews would provide.

Session Structure: Participants engage with the framework by first reflecting individually on their personal relationships and health experiences through post-it activities, then apply these insights in generative group discussions. This approach reveals whether the framework genuinely resonates and proves potentially useful when grounded in real contexts, rather than given scenarios. The combination of individual reflection followed by open group discussion allows for nuanced feedback about clarity, applicability, and potential improvements that wouldn't emerge through structured interviews or isolated individual evaluations.

7.3 Participants & Session Activites

Participants

Five design students/practitioners with health design interests, all adult children representing diverse cultural backgrounds and health tracking experiences:

Code	Pseudo nyms	Age	Health Data Tracking Experience (Intensity & Type)	Cultural Background	Family Health Conversataion Comfort
D1	Yoshi	18-25	Occasional (mood, sleep, activity)	Cross-cultural	Very Comfortable
D2	Wisely	26-40	Regular (activity, symptoms)	East Asian	Somewhat Comfortable
D3	Kazu	18-25	Occasional (activity, weight)	East Asian	Somewhat Comfortable
D4	KK	26-40	Regular (activity, sleep)	Southeast Asian	Neutral / Depends
D5	Aan2297	26-40	Occasional (activity, weight)	South Asian	Somewhat Comfortable

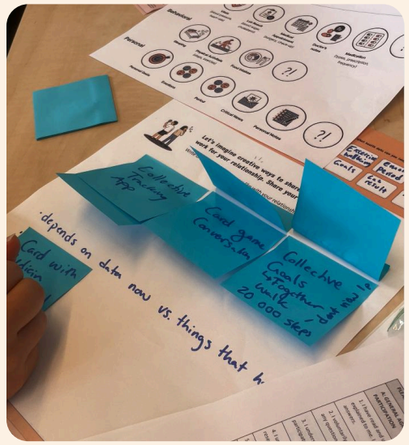
Table 9: Validation Participants (n=5): Cultural Background, Health Tracking Experience, and Family Communication Comfort

Session Structure (75-105 minutes)

- **Pre-Session:** Background survey + individual website exploration (15-30 min)
- **In-person Group session:** Website feedback, personal reflection using framework axes, collaborative ideation, and future application discussion (60-75 min)

Co-creation Session Outlines (60-75 mins)

1. **Recap from website (10-15 min**): Quick recap of website experience, feedback on framework content and UX by placing dot or smiley stickers on printed website to identify what's surprising, what's useful and what's unclear (Group)
2. **Reflect (10 min**): Personal reflection on framework - each participant imagines themselves and someone they feel close enough to share health data with, maps them both on the axis, draws connecting lines and compares their positioning (Individual)
3. **Ideate (10-15 min)**: Generate ideas using framework principles by writing or drawing on post-its - "How would you and your loved one share or use this data together?" with optional use of principle cards as hints (Individual)
4. **Situate (10 min):** Place ideas back into the wave and health phases situations and explain their ideas (Group)
5. **Final Discussion (15-20 min**): Designers share thoughts on potential applications and improvement suggestions for the framework (Group)



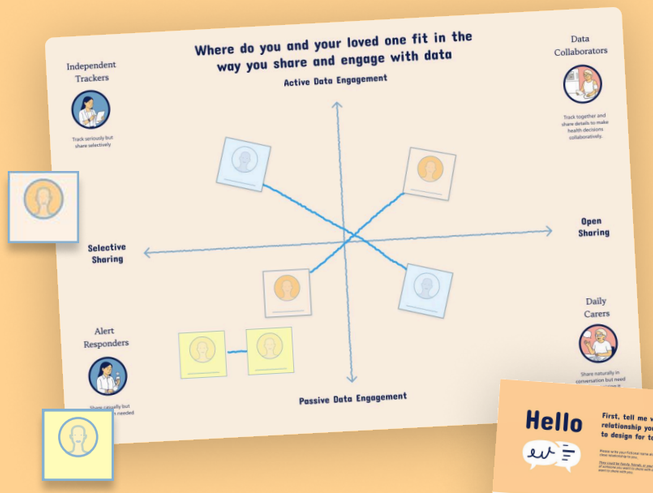
Hands-on Activities (30-45 minutes) Participants engage in reflection, ideation, and situation mapping activities to explore and apply the framework through personal contexts and design thinking.



Group Discussion (15-20) minutes) Participants discuss future applications of the framework, reflect on the validation method, and provide suggestions for framework improvements.

Figure 40: Validation session structure: hands-on framework exploration followed by group discussion.

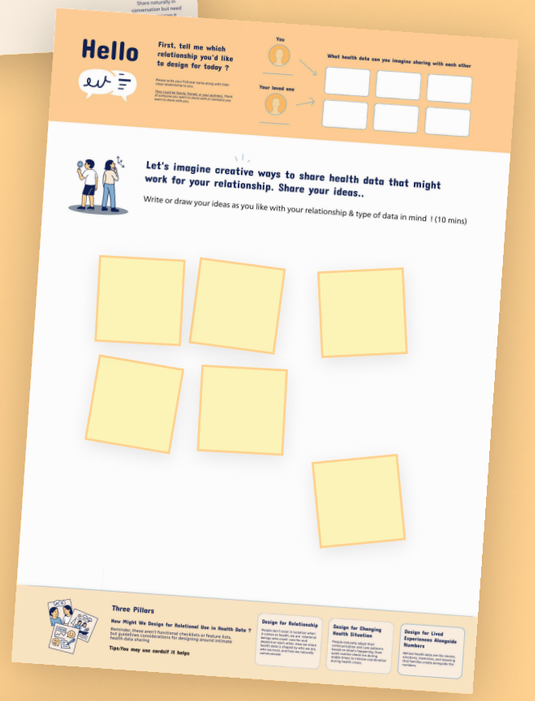
Session Materials



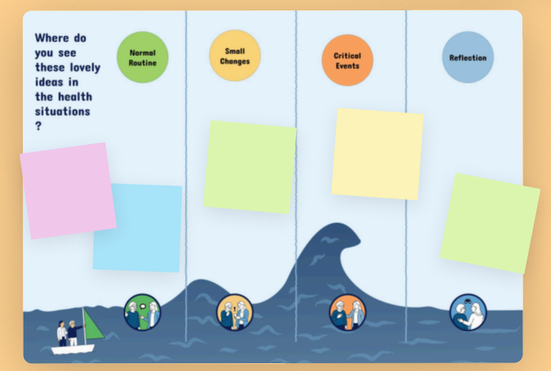
Reflection Mapping: Participants map themselves and a close person (by family role or fictional name) on sharing pattern axes, connecting and comparing their positions.



Principle Cards: "How Might We" design questions to guide ideation through a relational lens



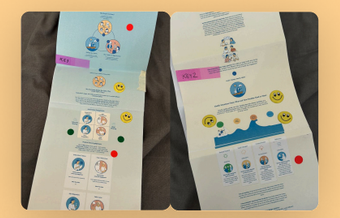
Ideation Worksheet: Template for participants to think of their own relationships and relevant health data types and ideation

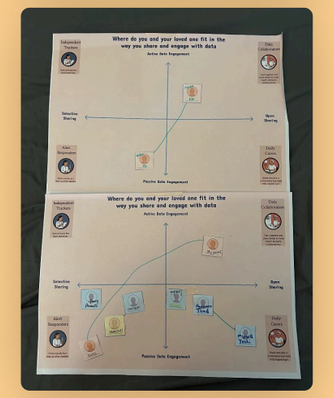


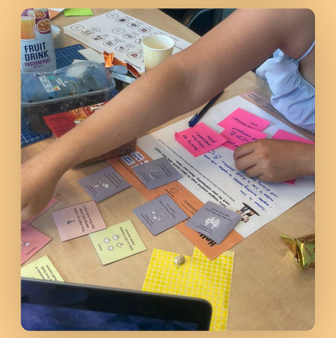
Health Phases Framework: Visual tool for placing and contextualizing ideas within different health situations and wave phases

Figure 41: Session materials: Data Sharing Pattern Axis (top), Principle Cards with design questions (left), Ideation Worksheet (right), and Health Phases Framework Template for mapping ideas (bottom).

Session Hands-on activities before discussion







For detailed feedback and insights, see Appendix

1. Participants place sticker dots on printed website pages to identify most interesting, useful, and unclear sections, then share collective feedback and personal experiences from reading the framework.

2. Participants map themselves and a close family member on sharing pattern axes, drawing connections and comparing their relational positioning within the framework.

3. Participants choose their own health data and relationship context, then spend 15 minutes ideating solutions while optionally using principle cards for guidance.



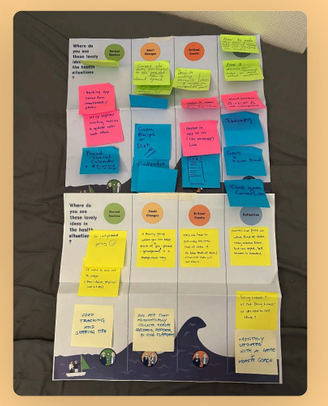


Figure 42: Showing Session Hands-on activities before discussion and

4. Participants place their ideas onto the wave framework to identify which health phases best fit their concepts, then explain their reasoning to the group. Following by group discussion,

7.4 Data Collection, Data Processing & Analysis

Data Collection

- **Pre-session Survey:** Collected participant demographics, cultural identity, design experience in health, and personal health tracking practices to understand how different backgrounds might influence framework engagement.
- **Session Documentation:** Audio recordings were transcribed with participant identification for analysis. Photos documented visual artifacts and collaborative activities throughout the session.
- **Physical Artifacts:** Materials included axis mappings (where participants positioned themselves and family members), wave situation maps (showing how ideas aligned with health phases), and post-it collections from feedback and ideation activities.
- **Privacy Protection:** Participants used pseudonyms throughout all activities to maintain anonymity while enabling consistent analysis. References to close relationships used family roles only, not personally identifiable information.

Data Processing & Analysis

- **Transcription and Coding:** Audio files were transcribed by Otter.ai and manually edited for accuracy, then organized in Google Sheets with thematic tagging corresponding to session topics. Key insights and quotes were converted into statement cards for clustering analysis in Figma boards with participant color codes to enable pattern detection. Physical artifacts were digitized for analysis and archival.
- **Visual Analysis:** Three analysis boards organized the data: website and framework feedback, participant ideation clustered by themes and connections, and method reflections. Visual artifacts were analyzed alongside thematic coding following contextmapping principles (Visser et al., 2005) to understand how participants engaged with framework components and translated insights into design ideas within their own contexts.

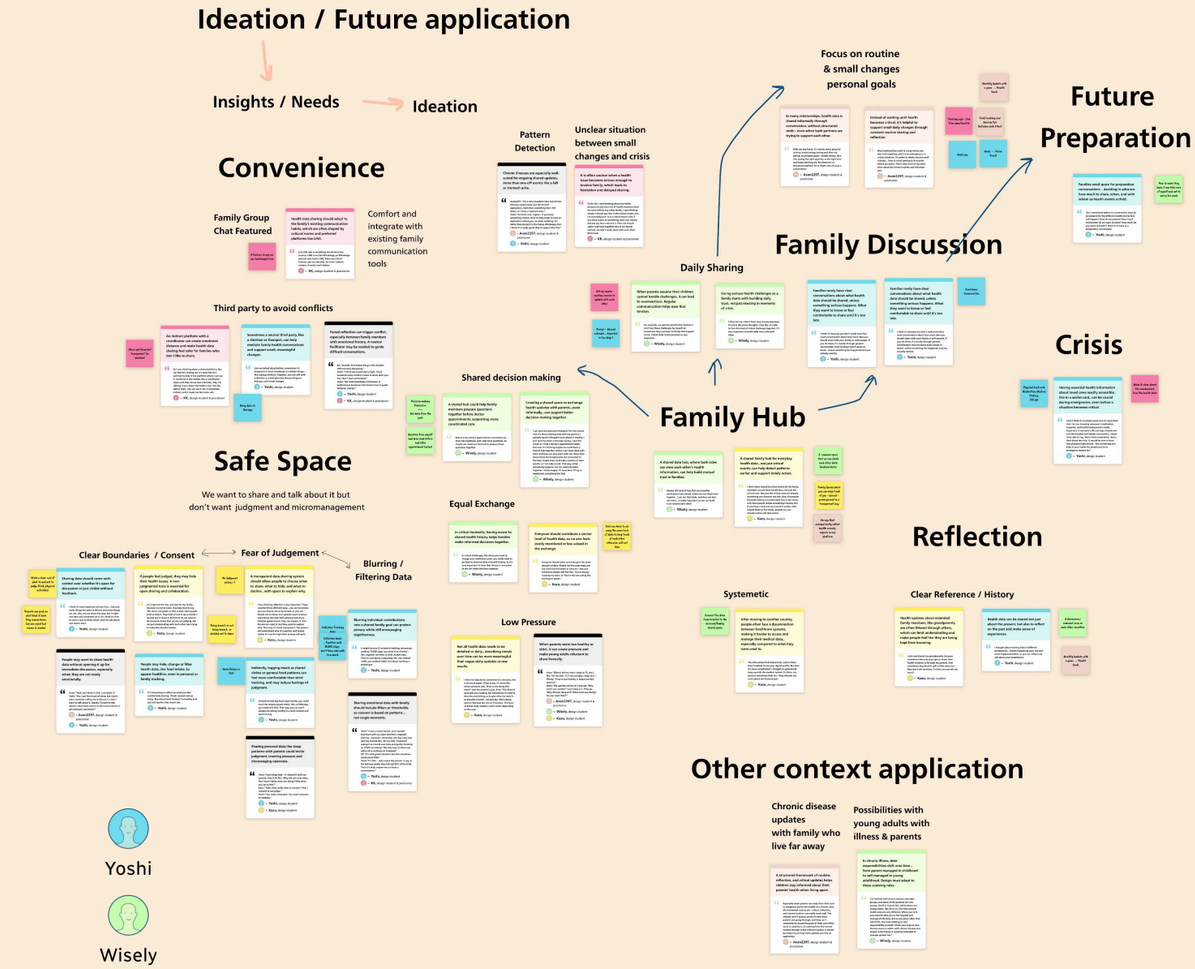


Figure 43: Statement cards from 5 participants (color-coded) clustered into 8 themes: Convenience, Safe Space, Family Hub, Family Discussion, Crisis, Future Preparation, Reflection, and Other Context Applications.

7.5 Validation Results

Success Indicators Summary

The validation session was conducted with 5 design students to assess whether the framework effectively communicated its core concepts and could be applied to real family health scenarios. Participants were asked to explore the website, reflect on the framework through the lens of their own family experiences, and generate ideas for potential applications for their own context. The validation was structured around four key success indicators that measured framework comprehension, reflective engagement, framework application, and future vision.

Success Indicator 1: Framework Comprehension

Do participants understand the three design perspectives and health phases, and can they relate these concepts to real situations?

Participants demonstrated clear understanding of the three design perspectives and health phases, often relating them to their own family contexts. The wave metaphor, in particular, helped them articulate how communication patterns around health tend to build up and release at moments of urgency.

> Summing up, I think what all of us saw is that every family goes through these waves ... you want to share something, but it gets really critical before you finally bring it up... That visual really helped me reflect on those conversations, and that's why I put a smiley there
>
> – **Avan2297**

The framework's storytelling was also well-received:

> This way of putting different kinds of people into four different dimensions, it's pretty clear, consistent, and easy to understand for me."
>
> – **Yoshi**

> I think the part about Mali and Pam is helpful... it's the way you use storytelling. It makes it a lot easier to understand
>
> – **KK**

Success Indicator 2: Reflective Engagement

Do participants connect the framework to their own personal experiences and family dynamics?

During the session, participants referred to personal experiences with their families when discussing the framework. They described real examples of delayed or avoided communication and identified emotional barriers like judgment and worry.

> I can share a bit...this shows an example of the tension... For example, my father has had high blood pressure for quite a long time, and recently he's been coughing a lot, maybe because of COVID. But my mom kind of hides these things from me. Actually, she's also been sick with a cough lately. So both of them aren't very well, but they don't really want to tell me or make me worry
>
> – **Wisely**

> My parents usually don't tell me much about their health, but they always want me to keep them updated. Every week, they ask if I've taken my medicine regularly. But when I ask them, it's just like, 'Oh, it's going well.' And then suddenly, it's like, my mom's numberl is not good anymore, and I'm just like—what? When did this even happen?
>
> – **Kazu**

Participants identified and discussed fear of judgment from family members as a significant barrier to health data sharing.

> **Yoshi:** "Even sleep data... if I shared it with my parents, they'd be like, 'Why did you only sleep four hours? What were you doing? Why were you up so late?'"
> **Kazu:** "Yeah, they really need to consent.. like, I consent to not judge."
> **Yoshi:** "You need a therapist. You need someone to mediate."
>
> – **Yoshi & Kazu**

Participants also identified gaps in proactive family health communication, noting that detailed data sharing typically only happens when health issues arise.

> I think it's because you don't really have that much conversation about how much data you should share with your family or with people.
>
> If you do share, it's usually through general conversation, but not about exact values or detail.. unless something has happened and you actually need to.
>
> – **Yoshi**

Success Indicator 3: Adaptive Application

Can participants use the framework to generate design ideas and solutions around their own personal context ?

Can participants use the framework to generate design ideas and solutions around their own personal contexts? Several participants used the framework to propose new tools and interactions—such as family-centered tracking goals, indirect data sharing, and mediated health discussions—all rooted in their own experiences. However, many ideas centered more on surfacing insights and articulating concerns and needs rather than developing specific solutions.

Collaborative Family Tracking: Shared family goals (like collective step counts) that focus on combined achievements rather than individual contributions, avoiding comparison and shame around unequal participation.

> It might be nice if, instead of tracking one person walking 10,000 steps, you track it as a family—like, together we need to walk 20,000 steps. Then it's not about comparing, like 'you walked 1,000, you walked 5,000,' but about reaching a shared goal."
>
> – **Yoshi**

Family Health Hub Concept: Two participants shared ideas of digital space where family members can voluntarily share health data and updates, moving beyond daily messaging to enable mutual sharing and collaborative decision-making when health situations arise.

> . Usually, I just send my mom a message saying, 'I got this result' or 'I had a doctor's appointment today.' But now I'm thinking maybe we could have a kind of hub together, where I can share data with them and they can also share with me... That way, when something happens, we can make decisions together
>
> – **Wisely**

Emotionally Safer Sharing Methods: Non-direct data approaches like sharing recipes or logging shared meals instead of explicit food tracking, creating a more relaxed and positive way to understand family eating patterns without the pressure of deliberate monitoring

> Instead of tracking food super strictly, you could track the recipes people make. Like, on Monday, you made this dish. That way, you can see if people are eating healthy in a more relaxed and positive way.
>
> – **Yoshi**

Success Indicator 4: Future Vision

Could participants envision how the framework could extend beyond its current scope to other contexts and applications?

Participants considered how the framework might apply beyond the current scope, bringing up use cases in chronic illness management, preparation for emergencies, and different stages of life.

Chronic Illness Management Tool with Family: Participants recognized that the framework particularly suits chronic condition management, where ongoing tracking and family communication are essential. Unlike acute incidents, chronic illnesses benefit from sustained, structured sharing that goes beyond casual family messaging. A dedicated application would provide better organization and continuity for long-term health management compared to scattered conversations in family chat groups.

> **Avan2297:** "It's a very mundane idea, but chronic illnesses would really suit this kind of application..more than something like 'I fell down' or 'I have a stomach ache.'"
>
> **Yoshi:** "So that's nice. I agree... if you have something chronic, then it really helps to have an application where you can keep updating. It's better than doing it in the family WhatsApp chat."
>
> **– Avan2297 & Yoshi**

Children with Chronic Disease Transitioning to Self-Management: Participants identified the framework's potential for supporting the gradual shift from parent-managed to self-managed health data as children with chronic conditions mature. This transition involves changing roles around health data management, suggesting the framework could adapt to support evolving family dynamics across different life stages.

> I've worked with chronic disease volunteer groups, and some of the patients are very young...like 8 or 9 years old...while others are young adults, like 20 or 23. The roles around health data are very different. When you're 8, your parents take you to the hospital and manage all the data. But as you grow older, that role shifts... maybe in the future, it could be extended to younger groups too.
>
> **– Wisely**

Future Health Preparation Through Conversation: Participants saw the framework as facilitating proactive family discussions about health data sharing preferences before health events occur. This involves preparing for different health scenarios by establishing boundaries around information sharing and determining comfort levels for what family members want to know and share, shifting from reactive crisis communication to intentional preparation.

> Like I mentioned before in conversation, how do we prepare for the different health events that will happen? How do we prepare? How much information do we want to share? How much do you want to know? I think of it more as a preparation conversation.
>
> **– Yoshi**

The validation demonstrated mixed success across the success indicators. While participants showed strong framework comprehension and reflective engagement, their responses revealed more design opportunities and insights than concrete design solutions.

Rather than generating numerous specific ideas, participants primarily surfaced fundamental challenges in family health communication and identified key areas where relational considerations could transform health technology design.

This suggests the framework's primary value lies in helping designers recognize and understand the complex dynamics that must be addressed when designing for family health contexts, opening pathways for more relationship-centered design approaches.

7.6 Key Design Opportunities

The validation revealed several design insights that emerged from participants' reflections on their own family health dynamics. Their engagement with the framework surfaced fundamental challenges in family health communication and identified specific opportunities for supporting safer, more effective health data sharing when relational considerations are prioritized in design approaches.

1. Emotional Safety is Critical for Health Data Sharing

Significant barriers to family health sharing were fear of judgment and emotional overreaction. Participants consistently described experiences where family members' responses discouraged further sharing, creating patterns of avoidance and delayed communication.

Emotional Overreaction Discourages Sharing

> I have a mood tracker, and I started sharing it with my mom. But then I stopped sharing... because I remember one day I was sad, and she reacted like, 'Oh my God.' Instead of seeing it as a trend over time and gently checking in, it felt too intense. The only way to share was either all or nothing, so I stopped.
>
> **– Yoshi**

Need for Emotional Filters:

> **KK:** "It's with good intention, but this somehow needs some filter."
> **Yoshi:** "It's like... only notice this person if, say, in the last two weeks they felt sad 60% of the time. Then it's okay, maybe we can have a conversation."
>
> **– KK & Yoshi**

Indirect Sharing for Emotional Safety: To address discomfort with direct health conversations, participants proposed mechanisms that create emotional distance while maintaining visibility and support.

> So I was thinking about a shared platform. But not like he's texting me. It's more like he's putting his data in the platform where I can see it. Someone in the middle, like a coordinator, helps with that. So we don't feel like, 'Hey, I'm talking to you about my health crisis.' But the data is there. You can see it. So it's somehow indirect, and it made me feel more safe.
>
> **– KK**

2. Family Communication Imbalances

Participants revealed asymmetrical sharing patterns where expectations for disclosure were uneven, particularly in families where parents expected regular updates from children while withholding their own health information until crisis points.

> My parents usually don't tell me much about their health, but they always want me to keep them updated... And then suddenly, it's like, my mom's cholesterol is not good anymore, and I'm just like—what? When did this even happen? It's like everything builds up quietly, until they can't say 'it's okay' anymore, and then I get the whole story all at once, with so little time to process it,
>
> **– Kazu**

3. Prevention Over Crisis Response

Participants strongly emphasized that current family health communication patterns wait too long, missing opportunities for early intervention and support. Design approaches could provide better structure for ongoing interactions between close family members rather than waiting for crisis moments.

> Most relationships work in a way where you don't tell anything until it's an emergency or a critical situation. I'd prefer to ideate around small changes... how to avoid getting to that point where you panic. That's why most of my ideas were about the normal routine and reflection part
>
> **– Avan2297**

> I mean, like, okay, I track my data and I'm open to sharing, but I don't really feel like we're tracking together or trying to be healthy together.
>
> **– KK**

4. Framework as Family Discussion Facilitator

Beyond being a framework for designing digtial health data tools for relational use, participants recognized its potential for opening difficult family conversations about health boundaries, expectations, and preparation for future health events.

> How do we prepare for the different health events that will happen? How do we prepare? How much information do we want to share? How much do you want to know? I think of it more as a preparation conversation
>
> **– Yoshi**

These design insights reveal that effective family health data sharing requires addressing emotional safety, communication imbalances, and timing issues that current health technologies largely ignore. Participants identified clear needs for emotional filters, indirect sharing mechanisms, and proactive rather than crisis-driven communication. The framework's value extends beyond designing digital tools to facilitating essential family conversations about health boundaries and preparation.

7.7 Website & Framework Feedback

Strengths

- **Storytelling Effectiveness:** The narrative approach with Mali and Pam characters successfully helped participants relate framework concepts to personal experiences and reduced abstract complexity. Participants found the storytelling made the framework easier to understand and immediately began sharing their own family stories that mirrored the examples.
- **Wave Metaphor Resonance:** The health wave visualization particularly resonated, with participants immediately recognizing the pattern of delayed disclosure until crisis points. Many participants described having experienced this exact pattern in their own families, where health issues were hidden until they became too serious or critical to conceal.

Areas for Improvement

- **Restructure content** to reduce overlap Information feels redundant across different sections, making the website feel longer and less focused than necessary.
- **Add interaction guidance** between framework types Users understand the different personality types but don't know how they should communicate or collaborate with each other.
- **Clarify terminology** with concrete examples (comprehension barrier) Terms like "data collaborator," "reciprocity," and "perspectives" are too abstract for users to understand what they actually mean in practice.
- **Move philosophy section to beginning** Participants prefer knowing the approach and philosophy in introduction to properly introduce the project positions.
- **Add clear & practical framework application guidance** While users validated that the framework makes sense conceptually, they need step-by-step guidance on how to actually use it in their own family situations. Now it’s overwhelming

7.8 Conclusion

Framework Shows Promise Across Cultural Backgrounds

Initial validation with five participants indicated the framework can help designers from different cultural backgrounds understand and engage with relational dynamics in health data sharing. Participants comprehended core concepts, connected them to personal experiences, and generated design ideas from their own family contexts.

Wave Metaphor & Stotytelling Sparked Personal Reflection

The storytelling approach and wave metaphor effectively prompted reflection on participants' family experiences and facilitated meaningful discussion about health data sharing dynamics.

Emotional Safety Emerged as Critical Design Factor

Important insights emerged around emotional safety, asymmetrical family sharing expectations, and prevention-focused approaches that warrant further investigation for future health technology design. This is less discussed in Thai adult-child pairs who are the original context of study.

Framework Functions as Both Design Tool and Conversation Starter

The framework showed potential as both a design tool for understanding relational patterns and a family conversation facilitating tools for discussing health boundaries and preparation.

However, this initial validation represents only one step in understanding how such frameworks might work across diverse contexts and whether the insights truly address universal versus culturally specific needs in family health communication.

The next chapter will reflect on these methodological considerations and situate the findings within existing literature on family health technologies and cross-cultural design research.

Discussion

Connecting insights & frameworks to existing research.

What we learned and how it connects to existing research. Situating findings within personal informatics literature, reflecting on the methodological approach of working with parent-child pairs, and examining the shift from individual to relational approaches in health technology design.

8.1 Research Recap and Validation Outcomes
8.2 8.2 Expanding from Individual to Collaborative Health Data Approaches
8.3 Health Data Sharing in Adaptive Situations
8.4 Shared Lived Experience & Memory Behind Numbers
8.5 Data Humanism and Data Intimacy: Philosophical Foundations
8.6 Initial Validation: From Thai Families to Multicultural Perspectives
8.7 Methodological Reflections
8.8 Limitations
8.9 Future Research Directions

8

8.1 Research Recap and Validation Outcomes

This research began with exploratory questions focused on what health data is meaningful to families and who within families would be willing to share data with each other. Through two cycles of participatory research with Thai parent-childs, these initial questions evolved.

Cycle I explored the "what" and "who" dimensions through the question "How and why do families track and share health data? What do they need and wish?" However, participants consistently described their sharing desires as changing based on health situations. This led Cycle II to focus on when families choose to share through the question "How might family data sharing adapt over the family journey of long-term care?"

Ultimately, these cycles informed the overarching question: **"How might we design for relational use in health data?"**

Key Insights & Outcomes: Three Interconnected Perspectives & Design Framework

The research revealed three key perspectives that challenge individual-focused health technology design:

- **The People On Board** revealed that families have different data engagement styles and sharing comfort levels, creating four distinct behavioral patterns from Independent Trackers to Data Collaborators. Importantly, this is not a fixed trait but changes in response to time and context.
- **Riding the Waves of Care** showed that sharing needs shift across four health phases: normal routine (stable periods with casual check-ins), small changes (emerging concerns requiring gentle alerts), critical events (health crises demanding intensive coordination), and recovery & reflection (building collective memory from past experiences).
- **The Cabin and Shared Deck** uncovered how families use data as memory aids and conversation starters, combining medical numbers with personal stories to create collective health knowledge & shared memory around health over time.

From these perspectives, I developed a **design framework with 11 considerations** organized around three pillars as tools to reflect and imagine design that takes relationships into consideration. This framework offers considerations, not checklists, to navigate health data sharing with attention to people's lived experiences and the relational dynamics that surround health decisions.

8.2 Expanding from Individual to Collaborative Health Data Approaches

From Individual to Relational Approaches

The field of Personal Informatics, as defined by Li et al. (2010), has traditionally centered on helping individuals collect and reflect on personal information for self-awareness and behavior change. Health technologies follow this individual-focused model—you track your steps, review your own charts, and make personal decisions about your health habits. **My findings revealed alignment with researchers who have begun to recognize potential use beyond personal informatics.** Rooksby et al. (2014) proposed "Live Informatics," arguing that tracking is often social rather than purely personal, while Rapp et al. (2016) found that self-tracking can be sustained by forming small, trusted groups where people share data and exchange insights. This represents a shift from quantified self toward more qualified self approaches that embrace social interpretation and contextual meaning.

Recent family informatics research has started exploring these dynamics specifically within families. Li et al. (2020) found that self-tracking tools with data-sharing features can strengthen communication in Chinese intergenerational families, while Vizer (2019) called for models that recognize tracking as a shared practice including family members and informal caregivers. While this existing literature primarily comes from Western and East Asian contexts, it provides groundwork for understanding family health data dynamics.

My findings supported this emerging family informatics work by revealing the behavioral diversity within families that shifts over time to respond to different moments and situations the family experiences. The four archetypes I identified—Independent Trackers, Data Collaborators, Alert Responders, and Daily Carers—showed that even within the same family, people have vastly different approaches to data sharing based on their engagement styles and comfort levels. This behavior pattern is not fixed but adapts with different family roles and situations.

Validation with design students from diverse cultural backgrounds revealed similar asymmetrical sharing patterns found in Thai families. One participant described experiencing this dynamic:

"My parents usually don't tell me much about their health, but they always want me to keep them updated…suddenly my mom's cholesterol number is not good anymore, and I'm just like…what? When did this even happen?" This experience mirrors the behavioral patterns identified in Thai families, suggesting these relational dynamics may transcend specific cultural contexts.

From Individual Tracking to Collaborative Sense-making

Originally, personal informatics assumes rational, individual data analysis leading to behavior change. However, **families operate through collaborative sensemaking that transforms health data into shared lived experience.** Building on Rooksby et al.'s concept of "lived informatics"—recognizing that tracking is embedded in day-to-day life rather than isolated analytical activity—**my findings showed how families engage in collaborative interpretation that goes beyond individual reflection.**

Early validation with international design students indicated similar collaborative preferences. Participants described wanting shared family goals and emotionally safer sharing methods, moving beyond individual performance toward mutual support. One participant noted: "*It might be nice if, instead of tracking one person walking 10,000 steps, you track it as a family…like, together we need to walk 20,000 steps."* This approach buries individual numbers within group effort to reduce shame and comparison.

In family health contexts, this collaborative approach becomes meaningful because family members bring different perspectives and experiences to shared data. Health data could work as entry points for discussing details or sensitive topics such as emotions, stress, or critical news that might affect the family and require shared decision-making. This collaborative sensemaaking approach aligns with Yan et al.'s (2025) work on reciprocal data exploration. Their PAIRcolator demonstrates how pairs can make personal data more relational through guided comparison, while Reciportrait shows how collaborative data visualization supports mutual reflection. While momentary reciprocity operates on different timescales than intergenerational care relationships, these forms complement each other—brief collaborative moments can deepen enduring bonds of mutual support over long-term care.

Participants' expressed needs for **collaborative goals, emotional safety, and family-centered approaches** reveal potential opportunities for expanding beyond individual health apps with basic sharing features.

Their preferences for low-pressure, long-term sharing, and their desire for emotional safety mechanisms, suggest **potential design spaces** that could better support relational dynamics in health data sharing They envisioned digital health tools designed around their existing and desired care relationships: how they already check in, negotiate boundaries, and respond to health concerns together. However, understanding these behavioral patterns was only the first step, these relational dynamics shift based on health situations and timing, leading to the discovery of adaptive health phases.

8.3 Health Data Sharing in Adaptive Situations

Through both research cycles, families revealed that their health data sharing behaviors adapt based on changing health situations rather than following fixed sharing preferences. This challenges current health technology models that assume static sharing patterns. Validation suggested this pattern's broader relevance, **design students immediately recognized the wave metaphor in their own family experiences**, with one noting: *"What all of us saw is that every family goes through these waves, you want to share something, but it gets really critical before you finally bring it up."*

From Thai families' shared experiences, **four distinct health phases emerged that captured different sharing needs: stable periods, concerning changes, critical events, and recovery phases**. **Importantly, these weren't sequential steps but adaptive responses** - families could skip from stable directly to crisis, stay in detection mode for years, or cycle back and forth based on health conditions, with multiple conditions sometimes co-existing within one person or family unit. This reflects the reality that chronic care *"involves changes in lifestyle and management occurs mainly in the community setting"* (Deek et al., 2016). Families naturally adapt their health management responses to changing circumstances based on their specific situations and needs

This addresses a gap identified in Sandbulte et al.'s (2019) work on family "turning points"—major events that trigger shifts in family health communication. While Sandbulte et al. identified these crisis-driven communication changes, they also called for understanding how families might share health information earlier in the process. My findings suggest both Thai families and international design participants desire to cultivate sharing before crises happen, seeing potential for data as starting points for ongoing conversation, mutual understanding, and shared decision-making rather than waiting for emergencies to force communication into family involvement in chronic care.

8.4 Shared Lived Experience & Memory Behind Numbers

Though this research began with daily health tracking, findings revealed families' interests in broader health informatics approaches that encompass meaningful health moments and long-term patterns while seeing behavioral data as background context.

Health Data as Family Narratives

Families in this study didn't view health data as isolated metrics but as anchors for memory and reflection, co-existing with behavioral patterns and personal stories. Health numbers became part of ongoing narratives participants told about themselves and their families—o*ne mom linked dropping cholesterol without medication to walking more after moving neighborhoods and cutting back on cakes, while another mom reflected on different step counts compared to a more active pre-retirement life.*

These personal contexts didn't replace medical explanations but added meaning that made health data more memorable and motivating for behavioral changes. Some participants—*particularly those who were more data-active*—brought their personal notes and tracked data to doctor consultations, using it to explain changes, ask questions, and discuss treatment options. This suggests potential for collaborative sense-making around health data that's already collected, where real-life experiences attached to numbers could invite conversations about what worked, what might have caused changes, and how families could support each other. This collaborative purpose could also provide stronger motivation for tracking itself—knowing that the data could facilitate meaningful family conversations and mutual support rather than serving only individual reflection.

Documentary Health Informatics: Data as Family Memory

Rather than viewing digital health as monitoring tools, families approached health information as documentary informatics—using data to reflect, remember, and express lived experience over time (Elsden et al., 2016). Long-term patterns mattered more than daily precision.

Families valued noticing that regular exercise continued regardless of exact step counts, while sudden drops or spikes became cues to share, reflect, or check in. One mother described shared data as a "*time capsule that captures something real in a moment, and then it goes on a journey. The data also has its own journey. From that day to today, over three months, what has changed inside that capsule?"* This metaphor reflects how families viewed health data as living, evolving records layered with context, emotion, and meaning.

Design Implications: Supporting Contextual Health Informatics

These findings suggest opportunities to design tools that support layering personal context with clinical data. Families preferred systems allowing them to highlight key health moments with headlines, related data, and personal notes rather than comprehensive tracking. Early validation indicated similar preferences across cultures—design students proposed tracking family recipes instead of strict food logging and creating emotionally safer sharing methods that moved beyond raw metrics. This aligns with qualified-self approaches that embrace subjectivity, contextual meaning, and social interpretation (Elsden et al., 2016; Rooksby et al., 2014), suggesting opportunities to design tools supporting shared understanding and relational care embedded in everyday life.

8.5 Data Humanism and Data Intimacy: Philosophical Foundations

Data Humanism and Data Intimacy: Philosophical Foundations

Building on data intimacy defined as developing closeness through sharing personal data with trust and intention, the study reveals how parent-child pairs navigate vulnerability and safety needs in health data sharing. Participants revealed that their reluctance or willingness to share often centered on **emotional safety—wanting to feel understood rather than judged, and seeking companionship in health challenges rather than surveillance or competition.** This need for emotional safety suggests potential for indirect data sharing methods and blurred data presentation that create ambient awareness without making data explicit, reducing shame, fear of judgment while maintaining family connection without daily details or specific numbers.

This finding aligns with recent research by Rentschler and Nothwehr (2024), who found that people with diabetes develop **"data intimacies"** through sharing imperfect health data as **"affective practices."** Their work on how people share glucose monitor graphs to mediate relationships and "bad feelings" around chronic conditions demonstrates that health data sharing can prioritize emotional support over clinical monitoring.

This challenges one-way monitoring approaches by revealing the importance of reciprocal engagement. As one design participant expressed frustration about being the only person sharing while their parents didn't reciprocate, wishing for *"a system that requires equal sharing and consent to share and consent to not judge."* This highlights how families seek mutual vulnerability and emotional safety rather than unidirectional surveillance, emphasizing the need for systems that support balanced, non-judgmental health data sharing.

8.5 Initial Validation: From Thai Families to Multicultural Perspectives

Cross-Cultural Validation Findings

To explore whether these insights might resonate beyond the original Thai families, I conducted validation sessions with five design students from diverse cultural backgrounds (primarily Asian and European with Asian upbringing contexts). The sessions suggested that the framework could translate across cultures, with participants recognizing similar patterns in their own family health dynamics.

The validation indicated three key outcomes: participants understood the framework concepts and related them to personal experiences; they described similar family health communication patterns across cultures, including delayed disclosure before crisis, fear of judgment, and asymmetrical sharing expectations (parents don't share but request information from adult children); and they generated design ideas using the framework, from collaborative family tracking to emotionally safer sharing approaches.

Design opportunities from validation included family health hubs where members could coordinate care together. As one participant noted: "I actually haven't thought much about it. Usually, I just send my mom a message saying, 'I got this result' or 'I had a doctor's appointment today.'

But now I'm thinking maybe we could have a kind of hub together, where I can share data with them and they can also share with me... That way, when something happens, we can make decisions together."

Participants also recognized the framework's potential beyond designing health data tools, seeing it as structure for facilitating difficult family conversations about health boundaries and preparation. This dual function could address gaps in how families navigate health communication while revealing additional design considerations around emotional safety and prevention-focused approaches.

Cultural Context and Broader Application

These insights emerged from culturally specific Thai family contexts where intergenerational caregiving is deeply embedded in family values. While existing family health informatics research primarily comes from Western and East Asian contexts, limited work has explored these dynamics within Southeast Asian family structures.
The validation with international designers suggested potential for broader application across different cultural contexts, though this would likely require thoughtful adaptation rather than direct implementation.

Data Humanism and Data Intimacy: Philosophical Foundations

This work is grounded in **data humanism** philosophy, which values subjectivity and personal meaning over objective metrics (Lupi & Posavec, 2016). Thai families demonstrated this approach when discussing their health data as background context for expressing vulnerability and seeking companionship—sharing not just numbers but the life circumstances that shaped them. Building on **data intimacy** defined as developing closeness through sharing personal data with trust and intention, the study reveals how parent-childs navigate vulnerability and safety needs in health data sharing. This challenges *one-way monitoring approaches* by showing how participants expressed desires for mutual sharing where both family members could track different data but find companionship through discussing them together.

Participants revealed that their reluctance or willingness to share often centered on emotional safety—wanting to feel understood rather than judged, and seeking companionship in health challenges rather than surveillance or competition. Despite tracking different health priorities

8.6 Methodological Reflections



Working in Pairs and Reciprocity as Method and Finding

Working with parent-childs offered an approach for researching relational dynamicsa around health data sharing, though it required addressing significant recruitment challengesFinding participants willing to engage in research with family members required extensive outreach and coordinating across time zones. However, this enabled access to family negotiation patterns that individual interviews could not capture.

The intergenerational pairing (parents 60+ and adult children 25-40) revealed both opportunities and complexities. Different generations brought varying comfort levels with technology and different communication styles, requiring constant facilitation adaptation. However, this also surfaced valuable insights about how families navigate generational differences in health data approaches.

While the reciprocal approach—where both family members tracked and shared data—was my deliberate methodological choice for generating research insights, participants were not obligated to contribute equally. They could opt out of tracking specific data types or leave certain areas blank in the sensitizing toolkit and in sharing sessions.

Though challenging to balance structure with flexibility for different tracking preferences, this approach enabled observation of how families actually negotiate sharing when both members have their own data to contribute. What emerged were insights into how they chose what to share, how they shared it, and how they negotiated these decisions in future together. This created a context for studying data intimacy within existing relationships, essential for building systems for relational use in health data, which requires understanding actual relationship dynamics rather than individual perspectives or interactions between strangers.

From Adult Child Pairs to Design Group: Different Insights, Different Methods

The methodological shift from parent-childs to individual validation with design students revealed complementary strengths and limitations. Family pairs provided authentic relational dynamics and natural comfort levels, but may have masked individual concerns participants felt uncomfortable expressing in front of family members. Individual validation sessions lacked relational authenticity but surfaced specific emotional barriers, particularly fear of judgment from family members and concerns about emotional overreaction to health data, that hadn't emerged explicitly in family conversations.

Validation participants also revealed data they considered too personal or sensitive to discuss in front of their families, such as stress, actual sleeping hours, and mood tracking. This highlighted how family pair sessions, while capturing sharing dynamics in existing relationships, might suppress discussion of data types that individuals track privately but wouldn't feel comfortable sharing with family members present.

Participatory Design and Contextmapping for Health Data Sharing

The data sensitizing activities complemented discussions about health data sharing preferences. When participants tracked their own health data for a week, they could compare their actual filtering and sharing behaviors with their stated preferences, revealing different layers of privacy comfort that emerged through experience versus direct questioning. This sensitizing process prepared participants for discussions about family health data sharing by bringing personal data into shared space. The observation that participants wrote personal notes before putting in data sheet sharing suggests that individual processing and shared communication should be designed as distinct but connected processes.

The research expanded from initial behavioral tracking data (steps, sleep, food) to discussions about sharing health records and understanding contexts for long-term, future-oriented health management involving medical information such as appointments, lab results, medication, and treatment plans. Participants moved from discussing daily tracking to envisioning adaptive sharing systems that could maintain comfort while supporting long-term family health coordination. This progression suggested that sensitizing activities can help participants build from current experiences toward more complex future considerations.

Participatory taught me letting go of control as participants adapted activities in unexpected ways. While initially structured around explicit choices about what, how, and when to share, the contextmapping process revealed latent needs that emerged through participant-led modifications and unexpected sharing patterns. Participants naturally filtered data, chose different tracking focus areas than suggested, and negotiated sharing boundaries in ways that surfaced underlying family dynamics and comfort levels. **This experience suggests that contextmapping approaches for sensitive health topics may benefit from researcher flexibility that allows participant-led adaptation, enabling the surfacing of latent needs that structured questioning about explicit preferences might not uncover.**

8.8 Limitations

Scope and Context: This research was conducted with Thai families managing stable metabolic conditions, reflecting specific cultural values around intergenerational caregiving. While validation with international design students suggested broader applicability, the findings require cultural adaptation before application elsewhere. The study focused specifically on parent-child pairs (ages 60+ and 25-40), which may not reflect dynamics in other family configurations such as siblings, partners, or chosen family relationships.

Sample and Method: The study engaged four parent-childs (n=8) for deep qualitative understanding rather than broad generalization. Participants were self-selected, likely already interested in health tracking, and comfortable discussing health with family members. Remote sessions across time zones limited real-time clarification opportunities, and the reciprocal approach required both family members to participate, potentially excluding families with different comfort levels or availability constraints.

Validation and Implementation: Framework validation involved five design students discussing the principles rather than families testing them in practice. While this provided insights about cross-cultural resonance, it didn't test whether the framework actually support improved family health data sharing when implemented. Additionally, the research captured dynamics at specific points in time rather than observing how sharing needs evolve as health conditions or family relationships change over longer periods.

8.9 Future Research Directions

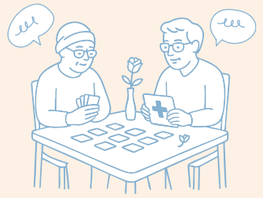
This research provides a foundation for understanding relational dynamics in health data sharing, pointing toward several key areas for future investigation.



Bringing Ideas to Life: From Framework to Toolkit

The design framework requires translation into practical tools that work effectively and communicate clearly in real-world contexts. These tools should be adaptable to different health conditions beyond metabolic care—*from data sharing approaches for families navigating dementia together, to collaborative data management during cancer treatment, to coordinated tracking during post-injury rehabilitation.* This toolkit could combine elements from the website and toolkit into comprehensive design resources that can be customized for various health contexts while maintaining the core relational principles.

Future work could involve developing prototypes that implement these framework principles across different health conditions, then testing them with diverse families to evaluate whether they actually improve health data sharing experiences. Since current findings are based on participants' expressions and desires about long-term sharing needs, longitudinal studies could observe how these aspirations translate into practice as health conditions progress and family relationships change over time. Additionally, exploring how the three pillars—designing with relationships, adapting to changing situations, and honoring lived experiences—apply across different health contexts could reveal both universal and condition-specific design.



Tools for Family Health Dialogue for Future Preparation

Future research could explore how this framework might serve as a facilitator for meaningful family health conversations—especially around boundaries, expectations, and preparation before crises force sudden decisions. Rather than waiting for emergencies to prompt difficult discussions, the framework could support proactive dialogue about how, when, and what to share across different health situations. This opens up opportunities to develop facilitation tools that guide families in expressing their sharing preferences, establishing comfort levels, and co-planning adaptive approaches over time.

One validation participant saw its value for long-distance care, noting: *“Especially when parents are away from their children and in the middle of a chronic crisis, the framework—critical, reflection, and normal routine—can really work well. Starting from the normal routine through to the critical situation, it would be really nice to have little updates.”* — Avan2297



Building Bridges: Family Data Meets Healthcare

Future research could explore how family health data sharing might connect with healthcare systems, filling gaps from fragmented health records by empowering families to own their data and bring it to hospitals rather than relying on system-to-system sharing. Current systems center individual patients, making family roles invisible, even though families act as care teams with members taking turns in caregiving roles, reinforcing long-term reciprocity over time.

This approach would move health conversations that already happen in family chats into structured, reviewable systems. Personal health data and family notes become crucial references when illnesses from decades ago resurface or when tracing patterns across years. Participants realized shared data could help them co-prepare for doctor visits and support each other, creating collective health history that travels across providers while keeping families in control.

Designing for this mutual support means moving beyond crisis-driven models toward relational, trust-based approaches that strengthen connection rather than isolate, giving families agency over their collective health narrative.



Beyond Parent-Child: Exploring Relationships

Future studies could expand beyond parent–child pairs to explore how health data is shared across a wider range of relationships, including siblings, partners, extended family, and chosen family. These dynamics may bring different rhythms, expectations, and needs into view—especially in the context of more critical or emotionally sensitive health conditions than the stable metabolic cases explored in this study.

One design participant, reflecting on their volunteer work with children chronic illness support groups, noted how care roles often shift across the life course. He observed how young children are typically cared for entirely by parents, while adolescents and young adults begin to navigate health more independently. This insight led them to imagine how the framework could also support transitions across these developmental stages, where roles around health and data evolve.

Including people who are less digitally engaged or hesitant to share health data could also surface important barriers and alternative practices not reflected in this study's self-selected sample. The framework might further extend to peer relationships—spaces where care flows laterally rather than hierarchically. As one parent put it: "*At this age, we're dealing with similar issues... It's all friends sharing casually, helping each other maintain our aging bodies—before it even gets to the point of illness.*" — Dolly (Mom)

Personal Reflection & Visions

Personal reflections on what this research means for me and what I learned as a person.

After six months of working alongside Thai families, listening to their stories, and witnessing how they navigate health together, this final chapter turns inward. It's a space to reflect on my own transformation, from a designer focused on pretty data visualizations to someone who now sees the messy, beautiful reality of how people actually live with their data. This is my journey from data design to participatory design with data, and imagining myself in a world where health technology could work with me as a relational and social being in the future.

9.1 Personal Reflection
9.2 Living in Data, Together: Envisioning What It Could Feel Like

9

9.1 Personal Reflection

Looking Back, Looking Ahead

I started this project with a curiosity about what data intimacy really means. Having worked with data design before, it was often about charts, dashboards, and statistics, pretty visuals meant to impress or inform. But I kept wondering: how do people actually think, feel, or act when they see numbers that are about their own lives?

During COVID, remote monitoring and e-health became widespread, while the idea of data humanism began to surface. This made me reflect on my own design work: was I just making data look beautiful without questioning its emotional impact? Later, during Digital for Health and eHealth electives' projects, many discussions emphasized the importance of family and community in care, yet systems rarely included them, often because of privacy concerns.

Throughout this project, I've learned so much from conversations with participants and from navigating uncertainty. The research felt messy and unclear at first, but participants helped shape and frame it into something meaningful. What I've come to value most is working with people, not just designing for them. Participatory design, especially in pairs or small groups, showed me how co-creation generates ideas that feel grounded and real.

Letting Go of Control, Learning to Listen

As a previous UX/UI designer, I'm used to working with detailed plans with clear specification and scope, which means I'm the one in control. But participatory design taught me to be adaptable and flexible, because I can't predict what people will bring. I can offer structure and format, but the content comes from them. Participatory design changed that perspective. It taught me to be more flexible and responsive, sometimes out of scope and focus. I couldn't plan verything in advance, because I had no idea what people would bring into sessions. I could offer structure and format, but the experiences came from them. That was both the challenge and the beauty.

At first, I saw this project as speculative design, a space to imagine future possibilities where people data as commons like in utopian science fiction. But participants kept grounding it in the present. They didn't want distant visions, they wanted tools they needed now but didn't yet have. That shifted my mindset from imagining futures to designing within today's realities with future in mind.

This project also changed the kinds of questions I asked. I used to focus on the what, what data to show, what chart to use, what interactions to design. But this work made me ask why and when often. Why does this data matter to someone, and when does it become useful? Health isn't a clean journey. It isn't linear. It unfolds through events, phases, and unexpected turns.

I also realized people don't care if you walked exactly 10,000 steps yesterday. What matters is whether you've been active three days a week for the past year. Data doesn't have to be precise. It can be comparative, fuzzy, reflective. It can show rhythm instead of detail. Some people track intensely for a short period, then carry what they learned into daily life.

These insights pushed me far beyond my initial assumptions about data tracking and sharing. Families showed me that meaningful data sharing is relational, contextual, and flexible. It could move with people's live..I went in thinking families needed better tracking tools. I came out understanding they need better ways to care for each other through the data they already have.

This project led me into people's lives—not as individuals but as families—which opened rich discussions I hadn't expected. They shared their family stories with me, and those stories stayed. When one friend read the website, she remembered being angry that her dad didn't tell her about her grandpa's oxygen levels at his deathbed. These moments reminded me why this work matters. I'm grateful to keep learning from the stories people trust me with.

Working with Families

Working with adult–child pairs meant navigating the emotional layers of their real relationships, especially when it came to sharing information that might otherwise stay private. I'm grateful I chose a reciprocal approach, where both family members shared their own data—but not necessarily the same data. That small design decision opened up space for genuine conversation, shaped by their lived experiences and shared history.

I came in assuming that adult children would be more tech-savvy and more serious about tracking. But in practice, many of them tracked casually, without much reflection or intention. Meanwhile, parents often tracked with a clear purpose—to prepare for doctor visits or show improvement at checkups. Neither side initially saw how their data could become something shared or relational. It wasn't about comparison or performance. What was missing was the possibility of using it as a way to understand each other.

The moments when families disagreed or had to negotiate were especially revealing. Whether they were debating different exercise choices or explaining why certain types of data mattered more at different life stages, these conversations uncovered the real dynamics behind their choices. What families wanted went far beyond sharing daily or weekly activity numbers. They were asking for something deeper: the willingness to stay connected over time, to share when it felt right, and to do so with low pressure and mutual respect.

Despite the sometimes sensitive nature of these discussions, families described the sessions as enjoyable. Many saw them as a rare opportunity to reflect on the future together—to imagine how they might support one another through different health moments, on their own terms.

Personal Growth: From Design to Research

I've worked as a designer for many years, but my research was typically applied—validating usability or conducting interviews for immediate project insights before moving on. Taking on a research-focused project was a significant shift that I'm still learning. I enjoy both worlds for different reasons. Design is about making complex things accessible and simple for people to use, while research explores what isn't yet clearly stated, what can't simply be Googled.

Being in the researcher role requires tremendous invisible work of thinking and rethinking, while I'm accustomed to making and moving forward. Translating rich lived experiences into design guidance demands careful sense-making—researchers must bridge the gap between family stories and actionable insights for designers. This project required constant reflection on how to communicate the depth of families' experiences without losing their humanity in translation.

Reflection was new to me. In design, we do, improve, and move on to the next project. Research builds ideas on foundations made by others, hoping my contributions will be relevant to broader communities in futures that don't yet exist is also new to me. It's much more thinking than doing and making, with lots of redoing to get things right, and learning to let go when time runs tight.

Working with qualitative approaches, things sometimes get messy and I get lost—there are no strict client expectations, and timelines are self-defined. But I learned that redoing doesn't mean going backward; it's part of the process. Sometimes forgetting about something and returning to it later actually helps. Overall, despite the mess and uncertainty, it was genuinely fun. I feel more confident working with participatory design approaches.

9.2 Living in Data, Together: Envisioning What It Could Feel Like

Through this project, I began to rethink what it means to live in data—not as isolated individuals tracking numbers, but as people in relationship with one another.

Gentle Coordination, Shared Responsibility

I can imagine using a system that quietly adapts over time, helping me stay connected with how my parents are doing—in their own words, with data as gentle support. It wouldn't demand daily input or attention. Maybe it's tucked into our family chat, where it blends into how we already talk. I'd see a simple timeline: my dad's upcoming bladder check-in, my mom's sugar levels holding steady, alongside a soft reminder that durian season is coming. My brother might drop in his latest sleep tip or celebrate a weight loss milestone. If I'm curious, I could ask to see more when we are driving somewhere or having dinners. Nothing urgent. Just a way to stay close, without needing to hover.

Casual Conversations, Lifelong Support

As I get older, I imagine sharing experiences not just with close friends We might log different menopause symptoms together, share small updates over time. Maybe someone would mention their ovary operation from five years ago, and I could ask about it when it's my turn. As one participant said, *"The doctor doesn't have the symptom that we have. We go to friends who had it to ask about their experiences."*

These people—friends, relatives—wouldn't replace doctors, but they would add their life context to mine. This wouldn't be about daily check-ins or something called 'monitoring.' It would be a timeline that quietly captures the long arc of our health stories, shaped by the people we already turn to when we need to make sense of things.

The Quiet Health Archive of Our Lives

Years from now, I might find myself trying to recall how I used to walk—before the pain began, before the body shifted. Or I might need to remember which side I fell on when I crashed my bike. These are small details I might misplace over time, yet they could shape decisions about how I move, how I heal, how I'm cared for. A system that holds these fragments—not as proof, but as memory—could help me understand what's changed, and what has stayed the same. This vision moves beyond apps that treat health as individual data streams. It imagines something quieter and more enduring. A shared record, unfolding over time. Not in service of optimization, but of connection. A technology that recognizes health as something lived in relationship—with others, with our pasts, and with the people who will remember us.

Living in Data, Together isn't just the title of this project.
It's a perspective I now carry forward.

Not everything needs to be tracked. Not every number needs to be explained. But what if health data could move gently through the everyday? Through chats, calendars, and shared memories—where care already lives? What if data wasn't something we had to perform or constantly report? What if it could be shared selectively, situationally, and over time? Only when it feels right. Only with the people who care for us and live with us.

That's the kind of future I'd want to live in. And design for.

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Appendices



Table of Appendices

A. Research Foundations
- **A.1** Original Design Brief
- **A.2** Ethics & Consent Documents
  - A.2.1 HREC Application
  - A.2.2 Data Management Plan
  - A.2.3 Consent Form Template
- **A.3** Recruitment Materials
  - A.3.1 Poster (Thai/English)
  - A.3.2 Survey Questions
  - A.3.3 Digital Poster and Recruitment Message (Translated)

B. Research Materials & Tools
- **B.1** Sensitizing Toolkit
  - B.1.1 Part 1: Data Reflection Sheet
  - B.1.2 Part 2: My Family Sharing & Well-Being Data Tracking Workbook
- **B.2** Digital Session Boards (Cycle I & II)
  - B.2.1 FigJam Canvas: Reflection & Data Mapping
  - B.2.2 FigJam: Digital Session Board for Sharing
- **B.3** Co-Design Tools (Cycle II)
  - B.3.1 Workshop Guides & Templates
  - B.3.2 Workshop Materials: Health Data Cards

C. Validation Materials
- **C.1** Background Questionnaire
- **C.2** Session & Instruction Slides
- **C.3** Materials: Printed Website & Workshop Templates
- **C.4** Principle Cards

D. Results & Analysis
- **D.1** Sample: Translated Quotes Table
- **D.2** Cycle I Analysis
  - D.2.1 Tracking Artifacts
  - D.2.2 Statement Card Clusters (Themes)
  - D.2.3 Framing Analysis & Models
- **D.3** Cycle II Analysis
  - D.3.1 Evolution of Workshop Template
  - D.3.2 Clustering Map
  - D.3.3 Workshop Output (Sample)

E. Design Principles & Final Outcome
- **E.1** Design Principles
- **E.2** Website Storytelling Structure

A. Research Foundations

A1. Original Design Brief

DESIGN FOR our future

TU Delft

IDE Master Graduation Project

Project team, procedural checks and Personal Project Brief

In this document the agreements made between student and supervisory team about the student's IDE Master Graduation Project are set out. This document may also include involvement of an external client, however does not cover any legal matters student and client (might) agree upon. Next to that, this document facilitates the required procedural checks:

- Student defines the team, what the student is going to do/deliver and how that will come about
- Chair of the supervisory team signs, to formally approve the project's setup / Project brief
- SSC E&SA (Shared Service Centre, Education & Student Affairs) report on the student's registration and study progress
- IDE's Board of Examiners confirms the proposed supervisory team on their eligibility, and whether the student is allowed to start the Graduation Project

STUDENT DATA & MASTER PROGRAMME
Complete all fields and indicate which master(s) you are in

Family name	Chonato	7548	IDE master(s) IPD ☐ Dfl ✓ SPD ☐
Initials			2nd non-IDE master
Given name	Pitshaya		Individual programme (date of approval)
Student number	5989302		Medisign ✓
			HPM ☐

SUPERVISORY TEAM
Fill in he required information of supervisory team members. If applicable, company mentor is added as 2nd mentor

Chair	Jacky Bourgeois	dept./section	SDE / KInD
mentor	Marieke Sonneveld	dept./section	HCD /AED
2nd mentor			
client:			
city:		country:	
optional comments			

! Ensure a heterogeneous team. In case you wish to include team members from the same section, explain why.

! Chair should request the IDE Board of Examiners for approval when a non-IDE mentor is proposed. Include CV and motivation letter.

! 2nd mentor only applies when a client is involved.

APPROVAL OF CHAIR on PROJECT PROPOSAL / PROJECT BRIEF -> to be filled in **by the Chair** of the supervisory team

Sign for approval (Chair)

Jacky Bourgeois — Digitally signed by Jacky Bourgeois Date: 2025.02.20 09:25:54 +01'00'

Name Jacky Bourgeois Date 20 Feb 2025 Signature

CHECK ON STUDY PROGRESS
To be filled in **by SSC E&SA** (Shared Service Centre, Education & Student Affairs), after approval of the project brief by the chair.
The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total	EC
Of which, taking conditional requirements into account, can be part of the exam programme	EC

★	**YES**	all 1st year master courses passed
☐	**NO**	missing 1st year courses

Comments:

Sign for approval (SSC E&SA)

L. Boot — Digitaal ondertekend door L. Boot Datum: 2025.02.24 14:59:47 +01'00'

Name Lisette Boot Date 24 feb 2025 Signature

APPROVAL OF BOARD OF EXAMINERS IDE on SUPERVISORY TEAM -> to be checked and filled in by IDE's Board of Examiners

Does the composition of the Supervisory Team comply with regulations?

YES	★	Supervisory Team approved
NO	☐	Supervisory Team not approved

Comments:

Based on study progress, students is ...

★	**ALLOWED** to start the graduation project
☐	**NOT** allowed to start the graduation project

Comments:

Sign for approval (BoEx)

Monique von Morgen — Digitally signed by Monique von Morgen Date: 2025.02.25 11:28:01 +01'00'

Name Monique von Morgen Date 25 Feb 2025 Signature

Appendix

Personal Project Brief – IDE Master Graduation Project

Name student Pitshaya Chonato **Student number** 5,989,302

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT

Complete all fields, keep information clear, specific and concise

Project title **Living in data, together:** Connecting people with chronic illness and their companions in dyadic relationship through health data sharing.

Please state the title of your graduation project (above). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

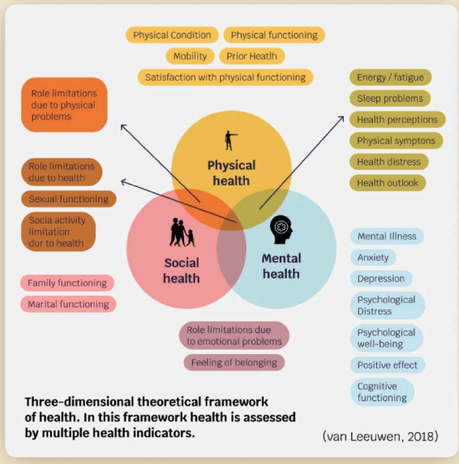
Chronic diseases burden patients, families, and healthcare systems, increasing mortality and lowering quality of life (Golics, 2013). Remote Patient Monitoring (RPM) addresses these challenges, enabling patients to continue daily activities at home while being monitored via advanced communication and sensor technologies (Malasinghe, 2019). However, RPM often excludes families from the care journey and risks disconnecting patients from their health, leading to feelings of isolation and a lack of personal engagement (Walker, 2019).

Relationship-focused family interventions benefit adult patients with chronic diseases by fostering connection over education (Hartmann, 2010). Involving families in chronic care and data sharing can create a supportive, connected experience, adding meaning to health data. This aligns with data humanism, as demonstrated by Giorgia Lupi and Stefanie Posavec's *Dear Data* (2016), which transforms personal data into expressive, context-rich visuals that foster deeper reflection and engagement (Kim et al., 2019).

A data-sharing tool based on data humanism which combines self-logging (e.g., emotions, energy) with sensor data (e.g., stress, sleep). Such a tool can turn health data into a medium for connection, emotional expression, and care, strengthening patient-family bonds and shifting RPM toward a more human-centered, meaningful tool.

➔ *space available for images / figures on next page*

introduction (continued): space for images



Three-dimensional theoretical framework of health. In this framework health is assessed by multiple health indicators. (van Leeuwen, 2018)



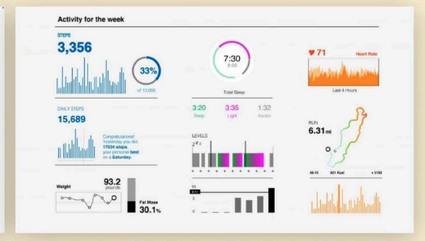
LUMC Care app



Analog self logging tools for cancer treatment (NH, Macmillan)

image / figure 1 Three-dimensional theoretical framework of health (physical, mental, social) and sample application





Giorgia Lupi's personal information design captures the richness of human lives, offering thoughtful, engaging representations that embrace complexity and spark meaningful discussions—unlike the neutral, impersonal charts typical of the data-driven world

How we can find ourselves in data l Giorgia Lupi
https://www.youtube.com/watch?v=sFIDCtRX_-o

image / figure 2

Personal Project Brief – IDE Master Graduation Project

Problem Definition

What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.
(max 200 words)

Healthcare is shifting from treatment-centered approaches to patient engagement beyond hospitals, focusing on physical, emotional, and social well-being influenced by loved ones (Bate & Robert, 2006). Rising cancer survivorship highlights the importance of addressing long-term quality of life, not just survival (van Leeuwen, 2018). Remote Patient Monitoring (RPM) supports this shift by enabling continuous tracking, reducing visits, and personalizing care (Serrano, 2023). However, the impact of illness on families remains overlooked, despite its importance in supporting patients (Golics, 2013). Current RPM systems, like LUMC's, integrate health metrics (steps, stress, sleep) with mood logging, extending beyond medical data. Such data opens opportunities for mutual care, where families can provide emotional support, share experiences, and foster connection. Data technology often prioritizes privacy but leaves individuals passive in their care journey. Jer Thorp (2016) advocates turning data into tools for people's well-being. Inspired by Data Feminism (D'Ignazio, 2018)'s using data to elevate emotions, there's potential to design tools that enable patients and companions to connect through shared emotional and well-being data, fostering dialogue and understanding. I aim to design tools for patients and companions in dyadic relationships to share and reflect on well-being data, promoting meaningful dialogue and connection while ensuring privacy and control. Insights from this project can enhance RPM systems for chronic care. **Main Research Question:**What types of personal health data are most meaningful for patients and their companions to share in a chronic care context, and in which scenarios are these data most effective?

Sub-Questions:

- What are the key needs and challenges patients and companions face when sharing emotional and well-being data in chronic care?
- How can dyadic data-sharing tools support meaningful conversations about health data between patients and companions? What are the potential benefits and concerns?
- How can these tools balance privacy with fostering personal connections?
- What value can such tools bring to enhance the current Remote Patient Monitoring (RPM) ecosystem?

Assignment

This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:

Design tool that helps chronic patients and their companions in dyadic relationships to share, reflect, and connect through well-being data, fostering dialogue, understanding, and connections while ensuring control over their personal health data.

Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)

Literature Review: Explore the context of data sharing in healthcare and data-enable design
Pre-survey: Recruit dyads (e.g., partners, family which one of them is chronic patient) for participation (online & offline), set expectation with participants that they need to fill in their data and involve actively throughout the process. Both should use health tracking devices.
Data Probes/Sensitizing Toolkits: Develop sensitizing tools and exercises to reflect on data-sharing experiences, exploring emotions and personal meanings behind the data.
Interviews/Discussion/Workshop: Facilitate conversations to uncover relational insights about sharing data with loved ones developed from data probes.
Data Analysis: Gather needs and insights from prior activities
Ideation & Design: Develop concepts for data-sharing tools based on participatory insights.
Testing & Evaluation: Test and gather feedbacks from participant
Reflection: Insights and what I learn through the design process of this project & approaches

Project planning and key moments

*To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting**, **mid-term evaluation meeting**, **green light meeting** and **graduation ceremony**. Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).*

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting	10 Feb 2025
Mid-term evaluation	21 Apr 2025
Green light meeting	25 Jun 2025
Graduation ceremony	1 Aug 2025

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	✓
For how many project weeks	24
Number of project days per week	4,0

Comments:
I will take dutch course which will take 8-10 hours per week

Motivation and personal ambitions

Explain why you wish to start this project, what competencies you want to prove or develop (e.g. competencies acquired in your MSc programme, electives, extra-curricular activities or other).

Optionally, describe whether you have some personal learning ambitions which you explicitly want to address in this project, on top of the learning objectives of the Graduation Project itself. You might think of e.g. acquiring in depth knowledge on a specific subject, broadening your competencies or experimenting with a specific tool or methodology. Personal learning ambitions are limited to a maximum number of five.
(200 words max)

I worked as an information designer in Southeast Asia, using data visuals to make complex social issues accessible. Returning to school, I'm exploring design for emerging tech, interested in apply my data and design skills in healthcare context—not just for solutions, but to ensure technology retains its human touch.

Studying Design for Interaction has taught me to view people within the context of their lives, understanding healthcare as a lifelong journey shaped by personal, social, and systemic factors. Being healthy includes emotional and social dimensions, not just clinical treatments. I hope to design solutions that involve companions, fostering human connections through data to bring compassion and meaning into healthcare.

My goal is to combine my design and data skills to create person-centered, compassionate approach in healthcare. For my graduation project, I aim to explore healthcare and data technology through humanist and feminist lenses, prioritizing human well-being and personal meanings behind the numbers. Such as: Applying data-centric approaches to design, blending quantitative and qualitative methods for participatory experiences, Building skills in data design and coding for healthcare context.

A2.1 HREC Application *Approved Date: 25-Mar-2025 Application number: 5202*

Delft University of Technology
HUMAN RESEARCH ETHICSCHECKLIST FOR HUMAN RESEARCH
(Version January 2022)

IMPORTANT NOTES ON PREPARING THIS CHECKLIST

1. An HREC application should be submitted for every research study that involves human participants (as Research Subjects) carried out by TU Delft researchers
2. Your HREC application should be submitted and approved **before** potential participants are approached to take part in your study
3. All submissions from Master's Students for their research thesis need approval from the relevant Responsible Researcher
4. The Responsible Researcher must indicate their approval of the completeness and quality of the submission by signing and dating this form OR by providing approval to the corresponding researcher via email (included as a PDF with the full HREC submission)
5. There are various aspects of human research compliance which fall outside of the remit of the HREC, but which must be in place to obtain HREC approval. These often require input from internal or external experts such as Faculty Data Stewards, Faculty HSE advisors, the TU Delft Privacy Team or external Medical research partners.
6. You can find detailed guidance on completing your HREC application here
7. Please note that incomplete submissions (whether in terms of documentation or the information provided therein) will be returned for completion **prior to any assessment**
8. If you have any feedback on any aspect of the HREC approval tools and/or process you can leave your comments here

I. Applicant Information

PROJECT TITLE:	Living in data, together: Connecting people with chronic illness and their companions in dyadic relationship through health data sharing.
Research period: *Over what period of time will this specific part of the research take place*	February 2025 – August 2025
Faculty:	Industrial Design Engineering
Department:	'Sustainable Engineering Design (SDE) / Knowledge and Intelligence Design (KInD)
Type of the research project: *(Bachelor's, Master's, DreamTeam, PhD, PostDoc, Senior Researcher, Organisational etc.)*	Master Graduation Project
Funder of research: *(EU, NWO, TUD, other – in which case please elaborate)*	–
Name of Corresponding Researcher: *(If different from the Responsible Researcher)*	Pitshaya Chonato
E-mail Corresponding Researcher: *(If different from the Responsible Researcher)*	p.chonato@student.tudelft.nl
Position of Corresponding Researcher: *(Masters, DreamTeam, PhD, PostDoc, Assistant/ Associate/ Full Professor)*	MSc Student
Name of Responsible Researcher: ***Note:** all student work must have a named Responsible Researcher to approve, sign and submit this application*	Jacky Bourgeois
E-mail of Responsible Researcher:	J.Bourgeois@tudelft.nl
*Please ensure that an institutional email address (**no Gmail, Yahoo, etc.**) is used for all project documentation/ communications including Informed Consent materials*	
Position of Responsible Researcher : *(PhD, PostDoc, Associate/ Assistant/ Full Professor)*	Assistant Professor

II. Research Overview

***NOTE:** You can find more guidance on completing this checklist here*

a) Please summarise your research very briefly (100-200 words)
What are you looking into, who is involved, how many participants there will be, how they will be recruited and what are they expected to do?

Add your text here – (please avoid jargon and abbrevations)

Research scope & Goal

This **research explores** how **adult children (aged 25–40)** and **their parents (aged 60–75)** with metabolic **health conditions—such as hypertension, diabetes, and high cholesterol**—use well-being data to support and understand each other in managing long-term health.

Participants—either individually or in parent-child pairs—will track **step counts, sleep patterns, or food log**s for one week using their own smartwatches, phone apps, or self-observation. They will also add personal reflections to contextualize the data, which will then be discussed together with their pair and the researcher during a session.

This study aims to better understand **how family members interpret and share health data in ways that reflect their needs, values, and relationships**. The insights will help inform future health data technologies that support person-centered and family-based chronic care at home, while considering the potential risks of data use and sharing.

Participant Recruitment & Eligibility

Participants will be recruited through an **online recruitment survey**. I will recruit **4-10 pairs (8-20 participants)**. Interested individuals can **voluntarily provide their contact information** if they wish to proceed. The survey will assess **age range, health condition type, family role, location, and level of comfort to discuss health with their family.**
Recruitment will prioritize broader communities (e.g., social media, public flyers, community interest groups) to minimize reliance on personal networks. Personal identifiable information is only collected if participants voluntarily agree to proceed. No pressure, obligation, or financial incentives were involved in recruitment. All participants follow a standardized consent process to prevent undue influence

Level of Participants

Participants can engage in the research at two levels:

- **Survey Participation:** Participants can provide input through an anonymous online survey with no location restrictions. They acknowledge their right to remain anonymous and understand data handling procedures.
- **Full Participation (Self-Logging & Workbook, Interviews, Discussions):** They will complete a pre-session activity, self-log their input, and fill in a workbook before attending the session yet they have freedom to fill in what is relevant to them. Introduction session, guideline and explanatory material will be provided in their participation. A signed consent form is required to participate.

Data Collection Methods

This study consists of **multiple data collection methods**:

1. **Online Recruitment Survey –** Participants will anonymously assess their eligibility before choosing to participate.
2. **Health Data Tracking (1 week) –** Participants will track their steps, sleep patterns, and food logs using wearable devices or manual logging and write their own note and reflection.
3. **Sensitizing Toolkit (Self-Logging) –** Participants will reflect on their experiences using a physical workbook or a pseudonymized Figjam board.
4. **Interviews & Discussions (Individual & Pair Sessions) –** Participants will discuss their own data individually first, then reflect on their data with their family pair, adding meaning and context.
5. **Co-creation & Evaluation Sessions (Optional) –** Participants may join design review sessions to discuss future data-sharing scenarios, visualizations, and interface mock-ups. Alternatively, they can also provide feedback anonymously via a survey.

Study Process & Session Format

During interview session, Participants will first discuss their own data individually, then in paired discussions, reflect on the meaning of their shared data. Later, they may optionally participate in a discussion session to evaluate design outcomes or future scenarios, such as data visualizations and prototypes developed from research insights.

Sessions will be conducted either in person or online, in English or Thai, based on participants' preference and they will be informed before making decision to participate. All materials will be bilingual, and participants will be informed in advance to select their preferred language. Sessions will be recorded in video/audio formats for analysis.

b) **If your application is an additional project** related to an existing approved HREC submission, please provide a brief explanation including the existing relevant HREC submission number/s.

Add your text here – (please avoid jargon and abbrevations)

c) **If your application is a simple extension of, or amendment to,** an existing approved HREC submission, you can simply submit an HREC Amendment Form as a submission through LabServant.

III. Risk Assessment and Mitigation Plan

NOTE: *You can find more guidance on completing this checklist here*

Please complete the following table in full for all points to which your answer is "yes". Bear in mind that the vast majority of projects involving human participants as Research Subjects also involve the collection of **Personally Identifiable Information (PII)** and/or **Personally Identifiable Research Data (PIRD)** which may pose potential risks to participants as detailed in Section G: Data Processing and Privacy below.

To ensure alignment between your risk assessment, data management and what you agree with your Research Subjects you can use the last two columns in the table below to refer to specific points in your Data Management Plan (DMP) and Informed Consent Form (ICF) **– but this is not compulsory**.

It's worth noting that **you're much more likely to need to resubmit your application if you neglect to identify potential risks**, than if you identify a potential risk and demonstrate how you will mitigate it. If necessary, the HREC will always work with you and colleagues in the Privacy Team and Data Management Services to see how, if at all possible, your research can be conducted.

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
A: Partners and collaboration						
1. Will the research be carried out in collaboration with additional organisational partners such as: • One or more collaborating research and/or commercial organisations • Either a research, or a work experience internship provider[1] [1] *If yes, please include the graduation agreement in this application*		✓				
2. Is this research dependent on a Data Transfer or Processing Agreement with a collaborating partner or third party supplier? *If yes please provide a copy of the signed DTA/DPA*		✓				
3. Has this research been approved by another (external) research ethics committee (e.g.: HREC and/or MREC/METC)? *If yes, please provide a copy of the approval (if possible) and summarise any key points in your Risk Management section below*		✓				
B: Location						
4. Will the research take place in a country or countries, other than the Netherlands, within the EU?	✓		**Yes.** The research will recruit participants from both the Netherlands and countries through an online recruitment survey. Since recruitment is not geographically restricted, participants may join from different location. **1. Data Privacy Risks**: Collecting personal data via an online survey platform may expose participants' information to unauthorized access or usage outside of research & recruitment purposes. **2. Language and cultural barriers:** For country outside Europe, people might not be aware of their rights on personal data.	**1. Data Privacy Risks:** To ensure data privacy and security, all data collection (including surveys, sensitizing toolkits, and interviews) will be conducted remotely via GDPR-compliant platforms such as Microsoft Forms (for surveys), FigJam Board (for anonymized data entry), and Microsoft Teams (for interviews). No in-person sessions will take place outside the Netherlands. • **For survey input:** Microsoft Forms will be used, with data stored temporarily in OneDrive. Personal information (name, phone number, email, location) is for administrative use only and will be permanently deleted after research completion. • **For full participation:** Participants will be informed about data-handling measures before sessions, with guidelines also included in the sensitizing materials they use for input. **2. Language Accessibility:** To accommodate language barriers, all participation materials (consent forms and sensitizing toolkit/ workbook) will be provided in both English and Thai. • Participant will choose to participate in either English or Thai on their preference for the survey, activity materials, and interview session. • For interested individuals, there will be an introduction meeting which researcher explain the research activities and also their rights before they make decision to participate. • All participants, including those from international locations, will be fully informed of their withdrawal rights and data handling procedures in every session to ensure transparency and ethical compliance.	3, 4, 5 17, 18, 30, 31	1, 2, 7,9, 11,12
5. Will the research take place in a country or countries outside the EU?	✓		See checklist 4	See checklist 4	See check list 4	See checklist 4
6. Will the research take place in a place/region or of higher risk – including known dangerous locations (in any country) or locations with non-democratic regimes?		✓				
C: Participants						
7. Will the study involve participants who **may** be vulnerable and possibly (legally) unable to give informed consent? (e.g., children below the legal age for giving consent, people with learning difficulties, people living in care or nursing homes,).		✓				
8. Will the study involve participants who **may** be vulnerable under specific circumstances and in specific contexts, such as victims and witnesses of violence, including domestic violence; sex workers; members of minority groups, refugees, irregular migrants or dissidents?		✓				
9. Are the participants, outside the context of the research, in a dependent or subordinate position to the investigator (such as own children, own students or employees of either TU Delft and/or a collaborating partner organisation)? *It is essential that you safeguard against possible adverse consequences of this situation (such as allowing a student's failure to participate to your satisfaction to affect your evaluation of their coursework).*		✓				
10. Is there a high possibility of re-identification for your participants? (e.g., do they have a very specialist job of which there are only a small number in a given country, are they members of a small community, or employees from a partner company collaborating in the research? Or are they one of only a handful of (expert) participants in the study?		✓				
D: Recruiting Participants						
11. Will your participants be recruited through your own, professional, channels such as conference attendance lists, or through specific network/s such as self-help groups		✓				
12. Will the participants be recruited or accessed in the longer term by a (legal or customary) gatekeeper? (e.g., an adult professional working with children; a community leader or family member who has this customary role – within or outside the EU; the data producer of a long-term cohort study)		✓				
13. Will you be recruiting your participants through a crowd-sourcing service and/or involve a third party data-gathering service, such as a survey platform?		✓	No. Participants will be recruited through direct online survey distribution (Microsoft Forms) rather than a third-party crowdsourcing platform.			
14. Will you be offering any financial, or other, remuneration to participants, and might this induce or bias participation?		✓				
E: Subject Matter *Research related to medical questions/health may require special attention. See also the website of the CCMO before contacting the HREC.*						
15. Will your research involve any of the following: • Medical research and/or clinical trials • Invasive sampling and/or medical imaging • Medical and *In Vitro Diagnostic Medical* Devices Research		✓				
16. Will drugs, placebos, or other substances (e.g., drinks, foods, food or drink constituents, dietary supplements) be administered to the study participants? *If yes see here to determine whether medical ethical approval is required*		✓				
17. Will blood or tissue samples be obtained from participants? *If yes see here to determine whether medical ethical approval is required*		✓				
18. Does the study risk causing psychological stress or anxiety beyond that normally encountered by the participants in their life outside research?	✓		1. Discussing personal health data can cause anxiety & stress, especially when family is involved, leading to potential relationship conflicts. 2. Sharing health data may also bring feelings of guilt and fear of judgment.	1. Participants will be fully informed during recruitment about the types of health data involved, research objectives, and discussion topics. They will be reminded of their right to withdraw at any time and request data deletion until the study is completed. In recruitment survey, there is	**17, 18**	**3, 4, 7, 12**

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
			3. There might be type personal health data they are not comfortable sharing and discussing. 4. To obtain tracked data by themselves might be a technical challenge and cause stress for the participants. 5. Participants may feel discomfort sharing personal reflections or find self-logging burdensome. Some may feel pressure to provide complete logs.	also one section asked about their comfort in discussing health with family. 2. The study is exploratory for their needs and wishes in the future and does not involve any judgment or assessment of participants' health conditions, opinions, or behaviors. Participation is voluntary, and participants can decide what data to share and at what level of detail. 3. At the start of each session, participants will be asked if they are comfortable proceeding and reminded that they can pause, skip questions, or withdraw at any time. 4. The researcher will provide technical assistance for data collection if needed. Monthly check-ins will address any concerns or confusion, ensuring participants feel supported throughout the process. 5. Participants can choose what data they log, and the logging period is limited to one week. Before submitting their data for discussion, they can review, edit, or filter their entries. They may skip any details they do not wish to share, and guidance will be provided for those unfamiliar with self-tracking to ensure a smooth experience.		
19. Will the study involve discussion of personal sensitive data which could put participants at increased legal, financial, reputational, security or other risk? (e.g., financial data, location data, data relating to children or other vulnerable groups)		✓				
Definitions of sensitive personal data, and special cases are provided on the TUD Privacy Team website.						
20. Will the study involve disclosing commercially or professionally sensitive, or confidential information? (e.g., relating to decision-making processes or business strategies which might, for example, be of interest to competitors)		✓				
21. Has your study been identified by the TU Delft Privacy Team as requiring a Data Processing Impact Assessment (DPIA)? *If yes please attach the advice/ approval from the Privacy Team to this application*		✓				
22. Does your research investigate causes or areas of conflict? *If yes please confirm that your fieldwork has been discussed with the appropriate safety/security advisors and approved by your Department/Faculty.*		✓				
23. Does your research involve observing illegal activities or data processed or provided by authorities responsible for preventing, investigating, detecting or prosecuting criminal offences *If so please confirm that your work has been discussed with the appropriate legal advisors and approved by your Department/Faculty.*		✓				
F: Research Methods						
24. Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g., covert observation of people in non-public places).		✓				
25. Will the study involve actively deceiving the participants? (For example, will participants be deliberately falsely informed, will information be withheld from them or will they be misled in such a way that they are likely to object or show unease when debriefed about the study).		✓				
26. Is pain or more than mild discomfort likely to result from the study? And/or could your research activity cause an accident involving (non-) participants?		✓				
27. Will the experiment involve the use of devices that are not 'CE' certified? *Only, if 'yes': continue with the following questions:*		✓				
• Was the device built in-house?						
• Was it inspected by a safety expert at TU Delft? *If yes, please provide a signed device report*						

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
• If it was not built in-house and not CE-certified, was it inspected by some other, qualified authority in safety and approved? *If yes, please provide records of the inspection*						
28. Will your research involve face-to-face encounters with your participants and if so how will you assess and address Covid considerations?	✓		Interviews, co-creation, and evaluation sessions will be conducted either in person or online.	1. I will stay informed and apply any health guideline by the time of study. 2. The in-person interaction will be optional based on the participants' preference and convenience. 3. Most sessions will be online with technical assistance from the researcher especially for older participants for safety and also technical difficulties.	**17, 18**	
29. Will your research involve **either:** a) "big data", combined datasets, new data-gathering or new data-merging techniques which might lead to re-identification of your participants **and/or** b) artificial intelligence or algorithm training where, for example biased datasets could lead to biased outcomes?	✓		The study involves collecting health data from smartwatches and personal logging/observations. This combination may increase the risk of re-identification, as patterns in the data could potentially reveal specific health behaviors or conditions. The AI or algorithms used in participants' systems may vary depending on the service they use.	**1. Short-Term Health Data Tracking:** Participants will manually record their health data for one week using their own device and filling in sensitizing toolkits, rather than downloading it directly from their smartwatch services. **2. Data Privacy & Access Control:** Personal identifiers (names, emails) will not be linked to health data. Data input through the sensitizing toolkit (structured workbook or Figjam digital board for participant to fill in their own opinion and experiences) will only be accessible to the researcher, participant, and their companion for discussion sessions. **3. Addressing biases and inconsistencies:** Participants will reflect on whether their data feels representative of their well-being. Filling in data by hand might be not accurate but accuracy is not the focus of this study. Instead, the participants will be well informed that the goal is to explore the context of data and finding needs	1, 2, 3, 11, 18, 23, 30,31	3, 8, 9, 11

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
				and wishes when it comes to sharing data for the future.		
G: Data Processing and Privacy						
30. Will the research involve collecting, processing and/or storing any directly identifiable PII (Personally Identifiable Information) including name or email address that will be used for administrative purposes only? (eg: obtaining Informed Consent or disbursing remuneration)	✓		Yes. The research will collect and process directly identifiable PII (Personally Identifiable Information), including names, email addresses, and phone numbers for administrative purposes only (obtaining informed consent, scheduling sessions, and handling withdrawal requests)	**Personal identifiers** (name, phone number, and email) will not be included in analysis or reports, and will not be collected in archive and will be deleted after the study is completed. Names, emails, and phone numbers **will not** be stored together with health-related data or findings, and won't be used in process and analysis. The access to **Signed Informed Consent** from will be restricted in TU Delft Server.		
31. Will the research involve collecting, processing and/or storing any directly or indirectly identifiable PIRD (Personally Identifiable Research Data) including videos, pictures, IP address, gender, age etc and **what other Personal Research Data** (including personal or professional views) will you be collecting?	✓		**Yes, the research will collect and process PIRD, including:** **Direct identifiers:** Name, phone number, and email (for administrative use only). **Indirect identifiers:** Age (in ranges), family role, and general type of metabolic health conditions *(high blood pressure, high sugar level, high cholesterol)* **Media:** Audio and video recordings of interviews and evaluation sessions (anonymized before use). **Personal research data:** Participants' experiences, opinions, and observations regarding health data sharing and personal health behavior and opinions.	**1.** Before participation, data collection, processing, and storage methods will be clearly explained verbally in session and in consent form. Participants can withdraw or request data deletion at any time during the project. **2.** Name will be collected in informed consent for with restricted access. Contact information (phone numbers and emails) will be stored for administration purpose and will be deleted immediately when the project is completed. 3. Age (in ranges), family role (e.g., mother, daughter), and general type of metabolic health condition (e.g., hypertension, high blood sugar, high cholesterol) will be stored anonymously or under pseudonyms separately from PIRD. This contextual information will	11, 17, 18 19, 23, 30,31	1, 2, 7, 8, 9, 10 11

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
				be used to characterize the study population while maintaining participant confidentiality. 4. **Audio and video** recordings will not be archived and will be deleted after the project is completed. **5.** Quotes and written input will be pseudonymized/ anonymized before processing and analysis.		
32. Will this research involve collecting data from the internet, social media and/or publicly available datasets which have been originally contributed by human participants		✓				
33. Will your research findings be published in one or more forms in the public domain, as e.g., Masters thesis, journal publication, conference presentation or wider public dissemination?	✓		The research is part of a graduation project and will be published in the TU DELFT repository and potentially a scientific article.	See checklist item 31 No.5	29, 31	14, 15, 16
34. Will your research data be archived for re-use and/or teaching in an open, private or semi-open archive?		✓	Not in plan, but it is possible	In consent form, participants will be asked to provide consent for sharing their data to be used in the archive under CC BY.	29, 31	16

			If YES please complete the Risk Assessment and Mitigation Plan columns below.		*Please provide the relevant reference #*	
ISSUE	**Yes**	**No**	**RISK ASSESSMENT – what risks could arise?** *Please ensure that you list ALL of the actual risks that could potentially arise – do not simply state whether you consider any such risks are important!*	**MITIGATION PLAN – what mitigating steps will you take?** *Please ensure that you summarise what actual mitigation measures you will take for each potential risk identified – do not simply state that you will e.g. comply with regulations.*	**DMP**	**ICF**
				be used to characterize the study population while maintaining participant confidentiality. 4. **Audio and video** recordings will not be archived and will be deleted after the project is completed. **5.** Quotes and written input will be pseudonymized/ anonymized before processing and analysis.		
32. Will this research involve collecting data from the internet, social media and/or publicly available datasets which have been originally contributed by human participants		✓				
33. Will your research findings be published in one or more forms in the public domain, as e.g., Masters thesis, journal publication, conference presentation or wider public dissemination?	✓		The research is part of a graduation project and will be published in the TU DELFT repository and potentially a scientific article.	See checklist item 31 No.5	29, 31	14, 15, 16
34. Will your research data be archived for re-use and/or teaching in an open, private or semi-open archive?		✓	Not in plan, but it is possible	In consent form, participants will be asked to provide consent for sharing their data to be used in the archive under CC BY.	29, 31	16

H: More on Informed Consent and Data Management

NOTE: *You can find guidance and templates for preparing your Informed Consent materials) here*

Your research involves human participants as Research Subjects if you are recruiting them or actively involving or influencing, manipulating or directing them in any way in your research activities. This means you must seek informed consent and agree/ implement appropriate safeguards regardless of whether you are collecting any PIRD.

Where you are also collecting PIRD, and using Informed Consent as the legal basis for your research, you need to also make sure that your IC materials are clear on any related risks and the mitigating measures you will take – including through responsible data management.

Got a comment on this checklist or the HREC process? You can leave your comments here

IV. Signature/s

Please note that by signing this checklist list as the sole, or Responsible, researcher you are providing approval of the completeness and quality of the submission, as well as confirming alignment between GDPR, Data Management and Informed Consent requirements.

Name of Corresponding Researcher (if different from the Responsible Researcher) (print)
Pitshaya Chonato

Signature of Corresponding Researcher:



Date: 25.03.2025

Name of Responsible Researcher (print)
Jacky Bourgeois
Signature (or upload consent by mail) Responsible Researcher:



Date: 25.03.2025

V. Completing your HREC application

Please use the following list to check that you have provided all relevant documentation

Required:

- **Always:** This completed HREC checklist
- **Always:** A data management plan (reviewed, where necessary, by a data-steward)
- **Usually:** A complete Informed Consent form (including Participant Information) and/or Opening Statement (for online consent)

Please also attach any of the following, if relevant to your research:

A2.2.1 Consent Form Template (Thai Adult Child Pairs)

Consent Form: Living in data, together [Version 25/03/25]

You are invited to participate in a research study titled *"Living in Data, Together: Connecting People with Chronic Illness and Their Companions in Dyadic Relationships Through Health Data Sharing."* This study is conducted by **Pitshaya Chonato**, an MSc student in **Design for Interaction at TU Delft**, Faculty of Industrial Design Engineering under the supervision of Dr. Ir. Jacky Bourgeois and Dr.Ir. Marieke Sonneveld.

Research Goals

This research explores how a**dult children (aged 25–40) and their parents (aged 60–75)** with **metabolic health conditions—such as hypertension, diabetes, and high cholesterol**—use well-being data to support and understand each other in managing long-term health.

You may choose to participate individually or together with a parent or adult child. You will be asked to track one aspect of your **well-being—such as step counts, sleep patterns, or food logs—for one week using smartwatch, phone app, or self-observation.** You will also be invited to add personal reflections to help explain the meaning of your data.

At the end of the week, **you and your pair (if applicable) will take part in a conversation session** with the researcher to discuss the data and your experiences.

This study aims to better understand **how family members interpret and share health data in ways that reflect their needs, values, and relationships**. The insights will help inform future health data technologies that support person-centered and family-based chronic care at home, while considering the potential risks of data use and sharing.

Participation Responsibilities

By agreeing to participate in this study, you will commit to the following:

- You will track and log selected health data (e.g., step counts, sleep patterns, food logs) using a **wearable device, applications, or manual recording** for one week. This data will be recorded in a **sensitizing toolkit** (a workbook or online board with images and text materials where you can document personal experiences and reflections related to the collected data). You may **choose the type of data** you feel comfortable sharing and discussing. Once completed, you will **review and filter your entries** to ensure you are comfortable sharing them during the session.

Health Data *(Choose from this list—no need to complete everything perfectly.)*	**Sample Data** *(These are examples of the data you will choose to record and reflect on. It's okay if they are incomplete—the goal is for reflection and discussion.)*
Step counts	Log your daily steps for 5-7 days, adding any relevant notes.
Sleep patterns	Record your sleep duration and time for 5-7 days, adding any relevant notes.
Food logging	Log your daily food in takes and meal time, adding any relevant notes.

- **Reflect and write down notes** – You will use the **sensitizing toolkit** (as defined above) to **record and reflect** on your **attitude towards health data tracking** and **family data sharing** in your current situation. You may choose to input data on a private online board, write on PDF files, or print and fill them out by hand, depending on your preference.
- **Participate in an Interview / Discussion session** – You will take part in a 60-minute interview with your family pair to discuss your data, your thoughts and feelings about sharing this information with each other. This session will be private, involving only you, your relative, and the researcher, conducted either online or in person.
- **Join Co-Creation & Evaluation Sessions (Optional)** – You may choose to participate in co-creations & evaluation sessions to provide feedback on the design outcomes from your insights, such as data visualizations and prototypes, or fill in a survey anonymously.
- **Attend Sessions & Consent to Recording** – Sessions may be conducted face-to-face or online (via Zoom/Microsoft Teams) and will be recorded and transcribed for analysis.
- **All sessions can be held in English or Thai, depending on participants' preferences.**

Data Handling

While there is always a **risk of a data breach**, we take all necessary precautions to protect your information. Only **non-identifiable health tracking data, sensitizing materials, and pseudonymized transcripts** will be securely stored on **TU Delft servers**.

- Interview, co-creation, and evaluation session recordings will be stored temporarily on TU Delft OneDrive, with quotes **anonymized** and recordings **deleted within six months** after the research is completed.
- **Personal details (name, phone number, email) are optional**, used solely for administrative purposes, and will be deleted after the study.
- Age, family role and type of chronic condition will be collected in **broad categories** to protect privacy.
- **Photos will be anonymized**, and participant quotes will be referenced in reports using **pseudonyms** (e.g., *"Apple, Mom, age 50–64 years."*).

If you have any questions or concerns, please contact: Pitshaya Chonato , TU Delft – *p.chonato@student.tudelft.nl* **– *+31 63 9565358 or +66 89 7652756***

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
A: GENERAL AGREEMENT – RESEARCH GOALS, PARTICPANT TASKS AND VOLUNTARY PARTICIPATION		
1. I have read and understood the study information dated from 25/03/25 or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	☐	☐
2. I voluntarily consent to participate in this study. I understand that I can **refuse to answer questions** and **withdraw at any time** without providing a reason.	☐	☐
3. I understand that as part of this study, I will track and log selected health data (e.g., step counts, stress levels, sleep patterns, emotions, energy levels) from my wearable device, application or by hand for one week. I will use a **sensitizing toolkit** to reflect on my data, focusing on **personal insights and discussion**, rather than medical assessment. Furthermore, I have the **freedom to choose** which types of data to track and how much detail I am comfortable sharing and discussing.	☐	☐
4. I understand that I will participate in a **60-minute private interview** with my family member/partner to discuss my collected data, thoughts, and feelings. My health condition will only be referenced as **background context**; no detailed medical information will be required.	☐	☐
5. I can optionally participate in 60-minute **co-creation and evaluation sessions** to provide feedback on design outcomes.	☐	☐
6. I understand that the study will end by August 2025	☐	☐
B: POTENTIAL RISKS OF PARTICIPATING (INCLUDING DATA PROTECTION)		
7. I understand that taking part in the study may involve potential risks, such as discomfort when discussing personal health data or conflicts with my companion. These risks will be mitigated by giving me full control over what I choose to share when logging my information and during discussions. I can also review, edit and filter the data and input before submitting it back to the researcher. I can withdraw or stop participation at any time.	☐	☐
8. I understand that the tracked health data will be anonymized and will not be linked to any personally identifiable information. I also acknowledge that some of the personally identifiable research data (PIRD), specifically health-related data, is considered sensitive under GDPR legislation.	☐	☐
9. I acknowledge that **measures will be taken** to minimize data risks and protect my identity.	☐	☐
10. I consent to **audio/video recordings**, which will be transcribed **without personal identifiers** and deleted after the project ends.	☐	☐
11. I understand that any **identifiable personal data (name, email, phone number)** will not be shared beyond the study team and will be **deleted after the research is completed**.	☐	☐
12. If I experience **technical difficulties** or feel uncertain about using the digital toolkit or participating in online sessions, I can request help from the researcher. Technical support will be available to ensure I feel comfortable during participation.	☐	☐
13. I understand that **all materials and sessions are available in English and Thai,** and I may choose the language I prefer.		
C: RESEARCH PUBLICATION, DISSEMINATION AND APPLICATION		
14. I understand that my **de-identified data** may be used in an MSc **graduation project report** or a scientific publication.	☐	☐
15. I agree that **my responses, views, or quotes** can be used anonymously in research outputs.	☐	☐
16. I understand that any written materials I provide may be included in research outputs under a **Creative Commons Attribution (CC BY)** license. This allows others to share and adapt my contributions with proper attribution. • My submitted materials may be published under a **CC BY license** in research reports. • My work will be properly attributed, but no personally identifiable information will be linked. • I have the right to withdraw my contributions before the study is completed.	☐	☐
D: (LONGTERM) DATA STORAGE, ACCESS AND REUSE		
17. I consent to the archiving of de-identified transcripts, quotes, anonymized photos, population data, and sensitizing toolkit entries in the **TU Delft repository** for future research and learning. I understand this repository is **publicly accessible.**	☐	☐

Signature:

_____ _____ _____

Name of Participant [printed] Signature Date

I, as the researcher, have clearly explained the information sheet to the participants and ensured they

Pitshaya Chonato 25 March 2025

Researcher [printed] Signature Date

Appendix

A2.2.1 Consent Form Template (Design students/Designers)

Consent Form: Living in data, together *[Version 20/07/25]*

You are invited to participate in a research study titled "*Living in Data, Together: Connecting People with Chronic Illness and Their Companions in Dyadic Relationships Through Health Data Sharing.*" This study is conducted by **Pitshaya Chonato**, an MSc student in **Design for Interaction at TU Delft**, Faculty of Industrial Design Engineering under the supervision of Dr. Ir. Jacky Bourgeois and Dr.Ir. Marieke Sonneveld.

Purpose of the Session:
You are invited to take part in **a validation sessio**n for a design research project exploring how families use and share health data. This session focuses on gathering your opinions and experiences in response to findings and framework. Your input will help refine and improve the final outcomes of this research for future application.

What You'll Be Asked to Do:
During the session, you may be asked to reflect on visual materials, comment on ideas, or share your impressions based on your own knowledge or experience. Your feedback can be general or personal—share only what you're comfortable with.

Recording & Documentation:

- The session will be audio-recorded for analysis purposes.
- Photographs may be taken of materials you interact with (e.g., your hands, post-its), but not your face.
- Quotes and materials you produce may be used in the thesis report and future presentations. However, all names will be changed—we will use pseudonyms to ensure your privacy.

Voluntary Participation:
Your participation is completely voluntary. You may choose to skip any question, stop the session at any time, or withdraw from the study without any consequences.

Confidentiality:
No sensitive personal or health data will be collected. All data will be anonymized and stored securely. Only the research team will have access to the full recordings and original files.

Contact:
If you have any questions about the research, please feel free to contact:
Pitshaya Chonato , TU Delft – *p.chonato@student.tudelft.nl* – *+31 63 9565358 or +66 89 7652756*

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
A: GENERAL AGREEMENT – RESEARCH GOALS, PARTICPANT TASKS AND VOLUNTARY PARTICIPATION		
1. I have read and understood the study information dated **20/07/25**, or it has been explained to me. I have had the opportunity to ask questions and receive satisfactory answers.	☐	☐
2. I voluntarily **consent to participate** in this study. I understand that I can refuse to answer any question and may withdraw at any time without giving a reason.	☐	☐
3. I understand I will complete a short anonymous survey, review a website in advance, and participate in a 60–90 minute discussion session.	☐	☐
4. I understand the session will be audio-recorded and photographed (excluding faces) for research purposes.	☐	☐
5. I understand that the study will end by **August 2025**.	☐	☐
B: POTENTIAL RISKS OF PARTICIPATING (INCLUDING DATA PROTECTION)		
6. understand that while no health data is collected, I may be asked **to reflect on personal or emotional experiences related to data sharing with family members**. I am free to skip any question or topic that feels uncomfortable, and I may stop participating at any time without consequence.	☐	☐
7. I acknowledge that **measures will be taken** to minimize data risks and protect my identity.	☐	☐
8. I consent to **audio recordings**, which will be transcribed without personal identifiers and deleted after the project ends..	☐	☐
9. I understand that any personally identifiable information **(name, email, phone number)** will not be shared beyond the study team and will be deleted after the research is completed	☐	☐
C: RESEARCH PUBLICATION, DISSEMINATION AND APPLICATION		
10. I understand that my **de-identified data** may be used in an MSc graduation report or a scientific publication.	☐	☐
11. I agree that **my responses, views, or quotes** can be used anonymously in research outputs.	☐	☐
12. I understand that any written materials I provide may be included in research outputs under a **Creative Commons Attribution (CC BY)** license. This allows others to share and adapt my contributions with proper attribution.	☐	☐

• My submitted materials may be published under a CC BY license in research reports. • My work will be properly attributed, but no personally identifiable information will be linked. • I have the right to withdraw my contributions before the study is completed.		
D: (LONGTERM) DATA STORAGE, ACCESS AND REUSE		
13.. I consent to the archiving of de-identified transcripts, quotes, anonymized photos, population data, and sensitizing toolkit entries in the **TU Delft repository** for future research and learning. I understand this repository is **publicly accessible.**	☐	☐

Signature:

_____ _____ _____

Name of Participant [printed] Signature Date

I, as the researcher, have clearly explained the information sheet to the participants and ensured they understand their voluntary consent to take part in this study.

Pitshaya Chonato 20 July 2025

Researcher [printed] Signature Date

A3. Recruitment Materials

A3.1 Digital Poster and Recruitment Message (English Translation from Thai)



Hello there! 🙌 I'm reaching out again to ask for your kind help.
I'm currently working on my master's thesis at the Data-Centric Design Lab at TU Delft in the Netherlands. The topic is Data Intimacy – exploring how we can feel closer through sharing personal health data. 💞
I'm looking at how everyday health data from smartwatches (like steps, sleep, stress, or moods) can support reflection and spark meaningful conversations within families—especially when one family member is managing a mild chronic condition (e.g., heart disease, diabetes, high blood pressure, or post-cancer recovery), and loved ones feel concerned but don't want to intrude.
I'm now looking for parent–adult child pairs or life partners, where one of you is managing a mild chronic condition independently. You'll be invited to track health data from your smartwatch (based on what you're comfortable sharing), then come together for a short conversation session to reflect on the data—and imagine how this kind of information could help connect family members while still respecting privacy.
🧪Why this research matters: The findings will help inform the design of future remote patient monitoring systems that better support families as part of ongoing care—not just during crisis moments. This might also help guide future tools that support shared decision-making in later life stages.
🔐Privacy note: All personal identities will be anonymized. Any data, audio, or video will be deleted after the project ends.
👉If you're interested, feel free to message me directly and fill out this quick survey:
https://forms.office.com/e/8pVatzTxwx
Even if you're not interested in participating, filling in the survey still helps me understand the broader context. 🙏
Thank you so much! 🙏 And please feel free to share this with anyone who might be interested. There's no financial incentive, but if you're curious about how the data we collect every day could open up new ways of caring in families—I'd love to hear from you.
💬What you'll do:

- Log some health data (based on your choice) for one week.
- Join a one-hour conversation session (March–April).
- Optionally, join a second session to give feedback or brainstorm together in a more creative (speculative) way.

📍All sessions with Thai participants will be held online. No prior tech or health knowledge is needed—just time, interest, and a willingness to reflect and talk with your loved one. 🧡
Sorry this message is a bit long—I just wanted to give you all the context so you can decide comfortably. 😊

A.3.2 Participant Survey & Recruitment Questions

Survey Questions

1. Consent
   - Do you agree to participate in this survey? (Yes / No)
2. Demographics & Background
   - What is your age group?
     (18–24, 25–34, 35–44, 45–54, 55–64, 65+, Other)
3. Health History
   - Do you or a family member have a history of any of these chronic diseases?
     (Select all that apply)
     (Heart disease, Diabetes, Hypertension, Cancer, Chronic respiratory disease, None, Other)
4. Data Tracking Habits
   - Do you track any kind of well-being data? (Select all that apply)
     (Physical activity, Sleep, Food, Emotions/mood, Stress, General health, None, Other)
5. Reflection Frequency
   - How often do you look back at your tracked data?
     (Daily, Few times a week, Weekly, Monthly, Rarely, Never, Other)
6. Health Conversations
   - Do you like to discuss and talk with your family about health and well-being?
     (Yes frequently, Sometimes, No, Other)
7. Comfort Level
   - How do you feel about sharing and talking with your family about health and well-being?
     (Not at all comfortable → Very comfortable, Other)
8. People You Talk To
   - Who are the family members or close ones you might discuss health with?
     (Select all that apply)
     (Partner, Parent, Sibling, Child, Relative, No one, Other)
9. Interest in Study
   - Would you be interested in participating in the research project?
     (Yes, Maybe, No)
10. Contact Information
    - If interested, please provide your email or phone number

1. Living Situation
   - What is your current living situation?
     (Live alone / Live with family / Other)
1. Current Location
   - Where do you currently live?
     (Delft / Other in NL / Other country)
1. Family's Location
   - Where is your family located?
     (Same place / Delft / Other in NL / Other)
1. Final Comments
   - If you have any comments, please specify

B. Research Materials & Tools

B0. Participant Introduction

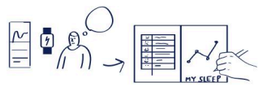
A brief meeting introduce each participant pair and researcher at the start of the session. It included background context and guide to participatory design activities to help ground the research and build trust.

Overview

Timeline &
Expected Activities

Participation

1. Sign consent form → **Complete the exercise (record data for one week and fill in the workbook).**



Submit consent form & workbook

2. **Discuss and share insights with your family**



&

3. **Join a brainstorming session (optional)**



Explore scenarios where health data could be useful and appropriate for family sharing.

Researcher has some initial ideas, just as a starting point for discussion.

4. **Participate in the upcoming design process (Optional)**



Samples

Samples of exercises you have to do before session

Part 1. Data Reflection Sheet



Part 2: My family sharing & well-being data tracking experience workbook

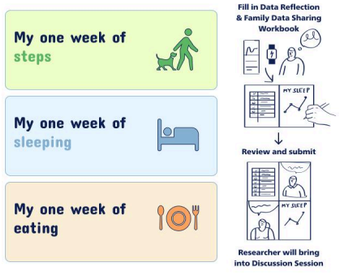


Activities

Before discussion session

Part 1. Data Reflection Sheet

For the next 5-7 days, I invite both of you to individually take 5-10 minutes each day to track each of this data.

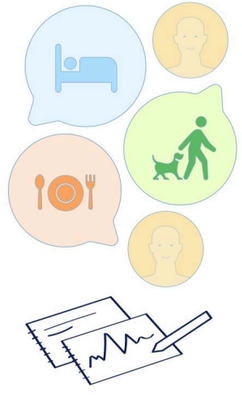


Part 2: My family sharing & well-being data tracking experience workbook

For the next 5 days, I invite both of you to individually take 5-10 minutes each day to reflect on your experience with data tracking and family sharing.

Sample of questions

- What types of health data are currently collected from you?
- What health information are you comfortable sharing with your family?
- How and when do you share health information with your family?
- In the future, how should sharing health data with your family feel, and what concerns might you have?



Checklist

Thank you for participation
If you have questions & concern, please contact me.

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NL +31 063 956 5358

- ☐ **Read and sign consent form** before submission of you fill input (data reflection & family sharing workbook)
- ☐ **18 - 24 March** Data reflection & Family sharing workbook 10-20 Mins for 5-7 Days
- ☐ **When done:** review and submit before session
- ☐ **25 March - 1 April** Discussion session with your pair
- ☐ **1 - 8 April Co-creation & Evaluation Session** round 1 (optional)
- ☐ **May April Co-creation & Evaluation Session** round 2 (optional)

Appendix

The toolkit helped participants sentisize to the topic of study by reflecting on their own experiences with health, data, and family. It included:

- **Part 1: Data Reflection Sheet** – A simple tracking sheet where participants could log data like sleep, steps, or food, and add personal notes or context. It supported reflection on how this data related to their everyday life.
- **Part 2: Family Sharing & Tracking Workbook** – A 5-day activity to reflect on their experience with data tracking and family communication. Participants could skip or remove anything they didn't want to share. The workbook was later used in a shared session with a family member.

This toolkit supported participants in bringing their lived experiences into the sessions and feeling more prepared to reflect and share.

B1.1 Part 1: Data Reflection Sheet – A lightweight activity to log health data (e.g. sleep, steps, food) alongside personal context.



p.1

My one week of steps

My (unreal) name is .....

Start date ... / ... / ...

My daily step goal is

.....

I tracked this data with

.....

for example, what device or what application..

Why I chose to track and share steps:

Anything I want to watch out in my steps

Your Data

Date ..... Date ..... Date .....

Day 1 | Day 1 | Day 1

6K 5K 4K 3K 2K 1K 0K

My step counts | My step counts | My step counts

Your story

Activities that make me most active today

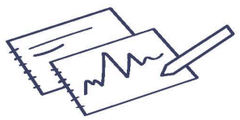
Today I feel

Additional notes..

Part 1. Data Reflection Sheet

What is this?

In this activity, for 5-7 days, select your data—track daily habits like steps, sleep, or eating (choose 1, 2, or all 3). Tracking every 2-3 days is fine, but daily tracking keeps details fresh! It doesn't have to be perfect, and you have all the rights to leave anything blank.



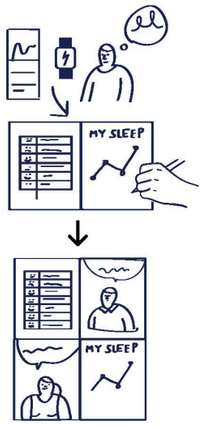
Why?

Every day, data is collected from you. But what truly matters is understanding what data is important to you and how you choose to share it. This insight could help shaping and re-imagining data technology that fits your needs.

My one week of steps

My one week of sleeping

My one week of eating



How to do this ?*

1. **Write basic information –** Briefly explain how you tracked your data and why you chose to track and share it.
2. **Log your data** – Record your daily numbers. You can also create a graph if you'd like and take notes to help you remember each day.
3. **Reflect & review** – After tracking, answer a few reflection questions. Did you notice any patterns or factors influencing your habits? Please review, and you can always remove any parts you prefer not to share with me or your family in session Bring this to discuss in session.
4. **Share & Discuss –** Share only what you're comfortable with, we will focus on understanding rather than judgment.

Important* What you fill in will remain anonymous. Note: For your privacy and your family's, avoid sharing personally identifiable information such as your full name, address, phone number, workplace, or specific medical conditions.



p.2

Your data

Date ..... Date ..... Date ..... Date .....

Day 1 | Day 1 | Day 1 | Day 1

6K 5K 4K 3K 2K 1K 0K

My step counts | My step counts | My step counts | My step counts

Your story

Activities that make me most active today

Today I feel

Additional notes..

Final Notes: Time to Review and Reflect

Important: Please review the information you've provided. You may remove any sensitive details and ensure you're comfortable sharing it in the upcoming session.

After one week, I see these patterns in my steps:

Factors that seemed to affect my daily steps:

Interesting things I'd like to share with family:

My one week of sleeping

My (unreal) name is .....

Start date ..../..../.....

My usual sleeping hour is

.....

I tracked this data with

.....

for example, what device or what application..

Why I chose to track and share my sleep:

.....

Anything I want to watchou about my sleep.

.....

Your Data

Date ..... Date ..... Date .....

Day 1		Day 2		Day 3	
I went to bed at ..	I woke up at ...	I went to bed at ..	I woke up at ...	I went to bed at ..	I woke up at ...
Sleep time ..... Hr.		Sleep time ..... Hr.		Sleep time ..... Hr.	
Sleep quality ..... %		Sleep quality ..... %		Sleep quality ..... %	

Your story

My sleep notes..

.....

When I woke up, I felt
circle or write your own

😴 😌 😐 😊

Sleeping factors?

.....

Your data

Date ..... Date ..... Date ..... Date .....

Day 4		Day 5		Day 6		Day 7	
I went to bed at ..	I woke up at ...	I went to bed at ..	I woke up at ...	I went to bed at ..	I woke up at ...	I went to bed at ..	I woke up at ...
Sleep time ..... Hr.		Sleep time ..... Hr.		Sleep time ..... Hr.		Sleep time ..... Hr.	
Sleep quality ..... %		Sleep quality ..... %		Sleep quality ..... %		Sleep quality ..... %	

Your story

My sleep notes..

.....

When I woke up, I felt
circle or write your own

😴 😌 😐 😊

Sleeping factors?

.....

Final Notes: Time to Review and Reflect

Important: Please review the information you've provided. You may remove any sensitive details and ensure you're comfortable sharing it in the upcoming session.

After one week, I notice these sleep patterns:

.....

Factors that seemed to affect my sleep:

.....

Interesting things I'd like to share with family:

.....

My one week of eating

My (unreal) name is .....

Start date ..../..../.....

My eating goal is

.....

I tracked this data with

.....

for example, what device or what application..

Why I chose to track and share eating:

.....

Anything I want to watch out in my diets:

.....

Date .....

Your data

Day 1		
Time What time did you have it?	**What did you have?** Write down the food name or category	**Additional notes** Anything you want to remember

Your story

My satisfaction for food today

☆ ☆ ☆ ☆ ☆

Why ?

.....

Additional notes, or factors:

.....

Final Notes: Time to Review and Reflect

Important: Please review the information you've provided. You may remove any sensitive details and ensure you're comfortable sharing it in the upcoming session.

After one week, I see these patterns in my eating habits:

.....

These factors seemed to improve or worsen my eating habits:

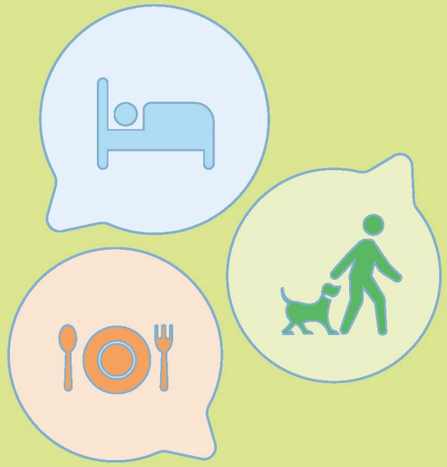
.....

Last note, interesting things I'd like to share with family:

.....

B1.2 Part 2: My Family Sharing & Well-Being Data Tracking Workbook – A 5-day guided workbook inviting reflection on tracking habits and communication styles within the family.

Part 2: My family sharing & well-being data tracking experiences



Introduction:

Thank you for you participation.
Hi, I'm Sai. I'm a designer who is interested in family role in healthcare journey. Every day, our lives are captured by sensors and technology, turning into numbers and charts that we rarely reflect on. For this project, I'm exploring how these health data can help support family care in a meaningful way, in the context of metabolic conditions like hypertension and diabetes.

By participating, your valuable insights will help me understand how families share health information and how data fit into our daily life. Your contribution will help open door to new ways of sharing between family members in the future.

My contact: Pitshaya Chonato (Sai)
p.chonato@student.tudelft.nl
TH +66 089 765 2756
NL +31 063 956 5358

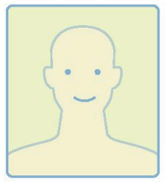
Instruction:



1. For the next 5 days, I invite you to individually take 5-10 minutes each day to reflect on your experience with data tracking and family sharing
2. There is no right or wrong answer, feel free to leave any part blank , and if you have any questions, you can always reach out to me !
3. When you're done, you can review and delete parts you are not willing to share with me or family.
4. By the end, you will bring this to talk with your pair in family.

Important: What you share will remain anonymous. For your privacy and your family's, please avoid including personally identifiable information such as full names, addresses, phone numbers, workplaces, or specific medical conditions. **By filling out this booklet**, your de-identified responses may be used in my graduation project report and potential scientific publications.

First, tell me a little bit about yourself ...



My (unreal) name is

I am a ○ Daughter ○ Son ○ Mom ○ Dad ○ Other

I live ○ with ○ apart from **my pair**

Your health concerns that I'm keeping an eye on

Check ✕ what applies to you but don't go into details

- ○ I don't have any
- ○ Hight Blood Pressure
- ○ High Blood Sugar Level
- ○ Cholesterol (HDL, LDL)
- ○ Weight / BMI
- ○ Heart Health (Heart rate, ECG)
- ○ Stress
- ○ Others

Day 1

Everyday, your health data can be collected from you, both with and without your awareness.

Mark **circle** around the ones most relevant to your well-being now. **Additionally**, If you find any connection between these data you can draw lines to connect them.

Vital signs

- Heart Rate
- Blood Pressure
- Blood sugar level
- Oxygen
- Weight
- Menstrual Cycle
- Temperature
- Breathing
- _____
- _____

Activities / Habit

- Sleeping
- Daily Steps
- Exercise
- Food logging
- Medication
- Alcohol counts
- Water counts
- Meditation
- _____
- _____

Mental

- Mood Logging
- Stress Level
- Personal Goal
- _____
- _____

Others

- Screen time
- Search history
- Social media use
- Location
- Chat Messages
- _____

Day 2

If you suddenly lost all the health data you've been tracking—no step counts, no sleep records, no food logs. What data would you miss the most? ans why?

And If you feel like losing all of it wouldn't matter, you can also share why :)

Data I don't want to lose



Why ?

Day 3

From the health data you chose earlier, which do you find important to share with your family?

Write down most important information you selected from Day 1 and rank then check ✕ how often you'd like to share it ...

How often would you like to share ?

More important

		Real time	Daily	Weekly Summary	Monthly Summary	History Log	Highlight only	Never	Others
1		☐	☐	☐	☐	☐	☐	☐	
2		☐	☐	☐	☐	☐	☐	☐	
3		☐	☐	☐	☐	☐	☐	☐	
4		☐	☐	☐	☐	☐	☐	☐	
5		☐	☐	☐	☐	☐	☐	☐	

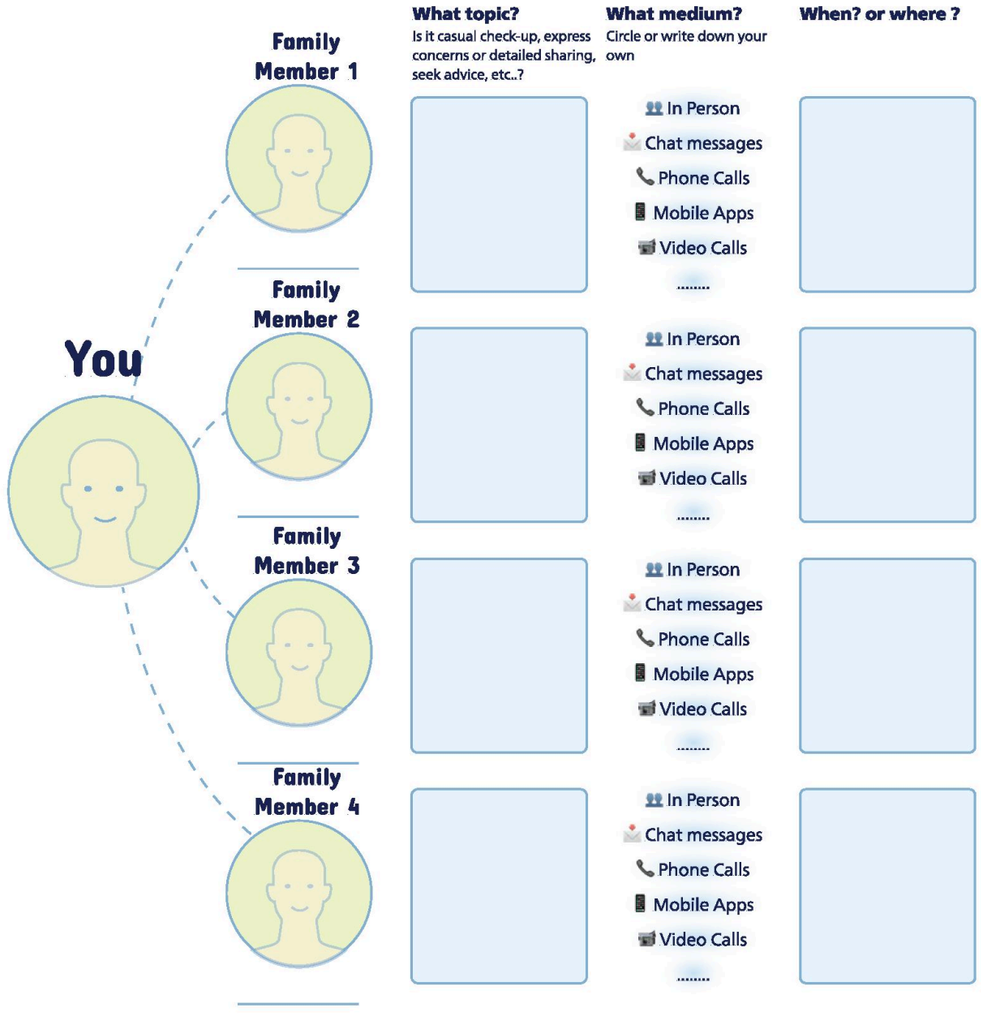
Less important

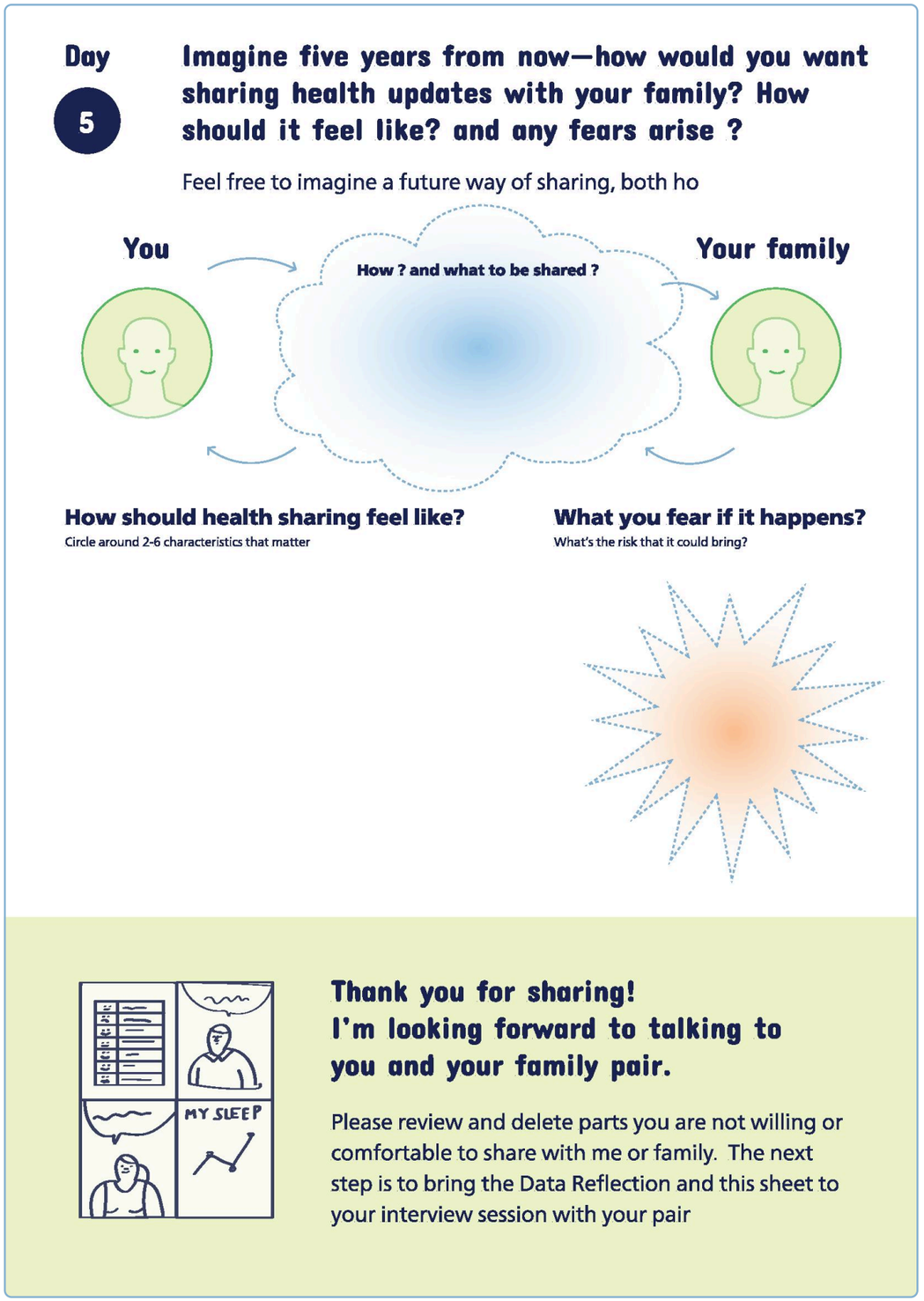
Day 4

Think about your family and how you share health information now. What do you usually talk about? How do you share updates? And how often do these conversations happen?

Describe your family member's role, the health topics you discuss, the way you communicate (e.g., in person, messages, apps), and when or where these conversations typically take place

With this person I discuss about ....





B2.1.1 FigJam Canvas: Reflection & Family Health Data Sharing Workshop

Used in Cycle I to explore participants' current data practices, family dynamics and context of study.

1. Before starting, participants were reminded of the session's purpose, their rights, and asked for consent—with an emphasis on creating a safe and comfortable space for sharing.
2. The interactive board helped participants build on insights from earlier sessions (Cycle I) by making choices about what health data to share, how to share it, what it felt like, and what concerns they had. It turned reflections into shared decisions.

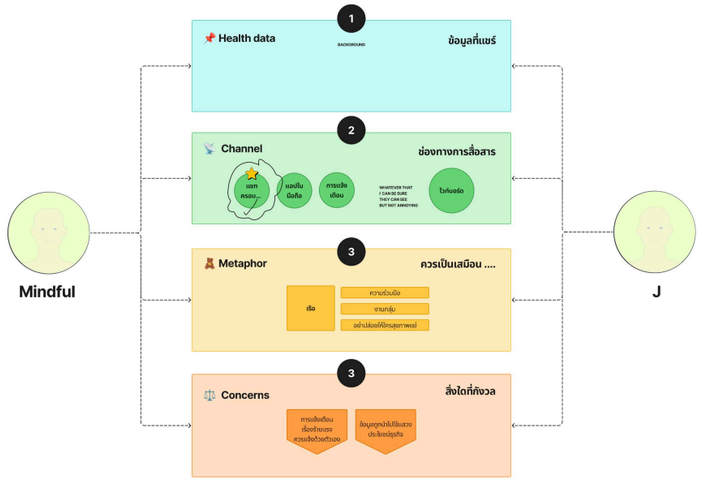


Future of Family Health Data Sharing Workshop

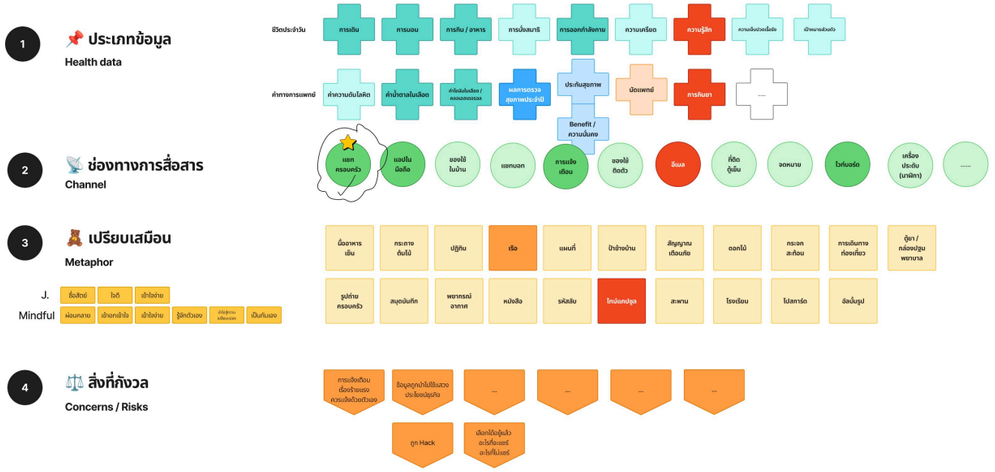
15 Mins

If you and your family had to decide a "health data sharing" system that fits your needs...
Let's think and explore together.
Try to answer these questions:

- 📌 **What kind of information should we share ?**
- 📡 **How should we share it—with what channel is most useful ?**
- 🧸 **If this system were "a thing," what would it be ?**
- ⚖️ **What concerns do we have about sharing health information in this system ?**



คุยกันและ ลากตัวเลือกไปใส่ในแต่ละกล่อง โดยร่วมกันตัดสินใจ ... (เลือกกี่อันก็ได้)



The interactive board is made of

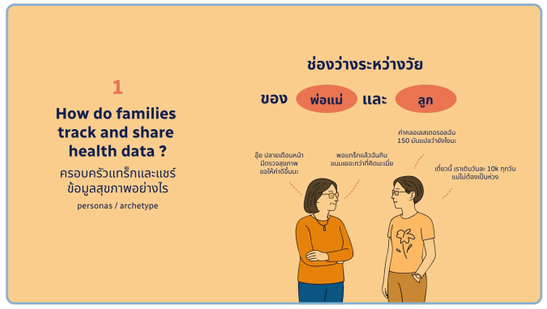
- What data to share
- How to share it (channel)
- What it feels like (metaphor)
- What concerns they have

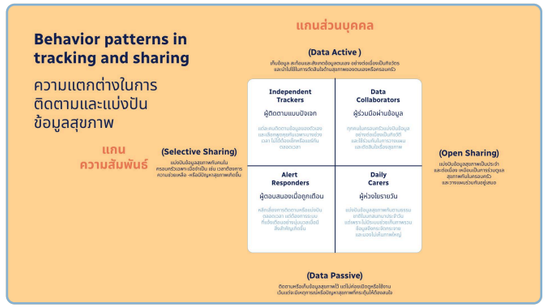
Cycle II

B2.2 FigJam: Digital Session Board for Sharing

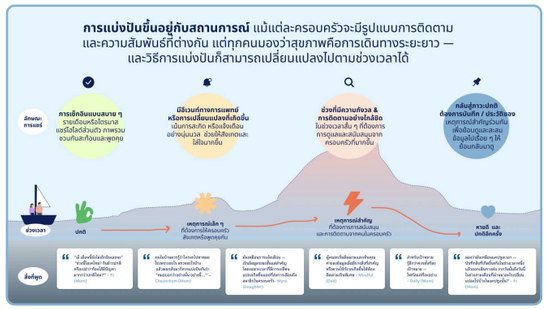
B.2.1 Initial Insights Sharing

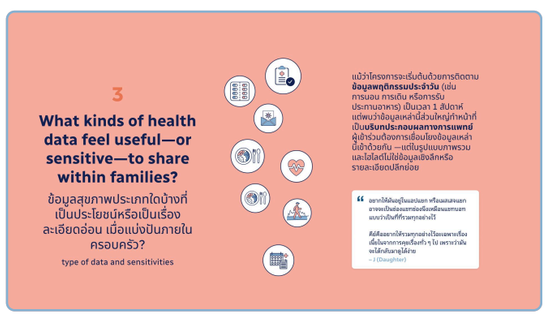
Visual materials used to present key insights from Cycle I as prompts for discussion and reflection (translated to Thai)







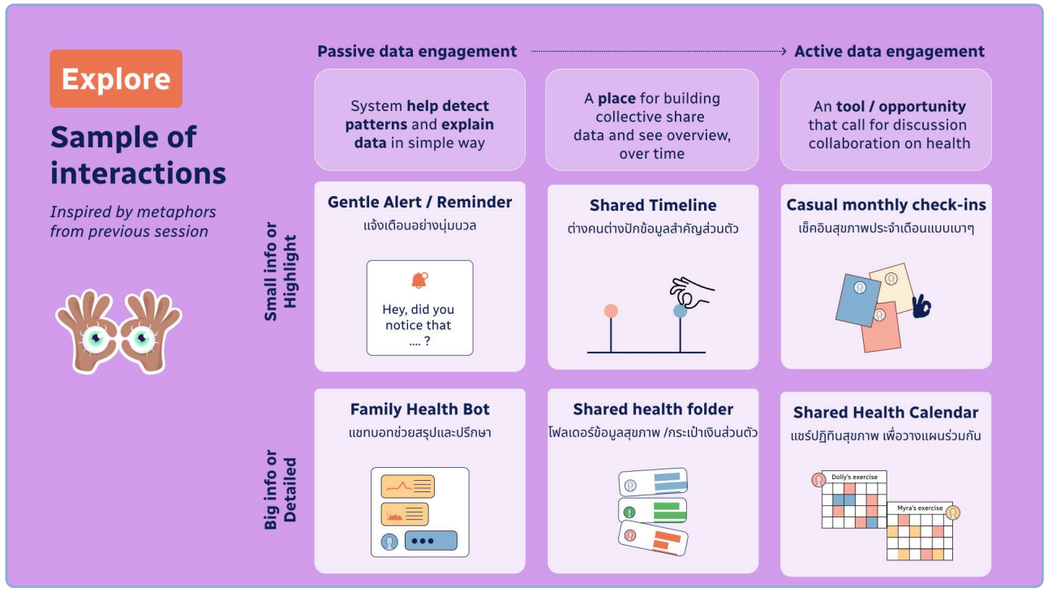




Appendix

B.2.2 Sample of Interactions

Scenario-based examples illustrating possible ways to share and relate to health data.



1

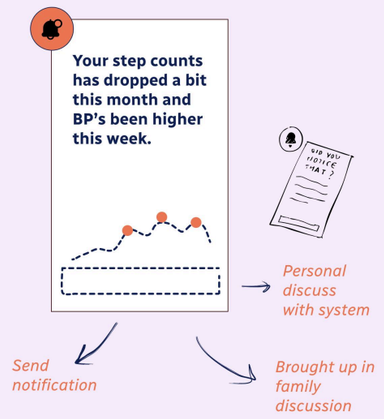
Gentle Alert

Why

For those who don't often check their own data and nor actively analyse own data, it's easy to miss early signs and critrical trends.

What

Gentle notices/alerts about important health changes or events that asks people to reflect before sharing with family.



How

Instead of pushing updates to family automatically, people can first review and reflect on what the data means to them before deciding to share.

Situation - System detects change in blood pressure and ask member to review before sending updates to other member



2

Family Health Bot

Why

For families who aren't used to analyzing data, they need simple summaries and gentle prompts that encourage reflection or tracking.

What

A **simple chatbot** that checks in with gentle questions like "How are you feeling lately?" or "Did you notice any changes?" — helping users reflect and decide what to track or share.



How

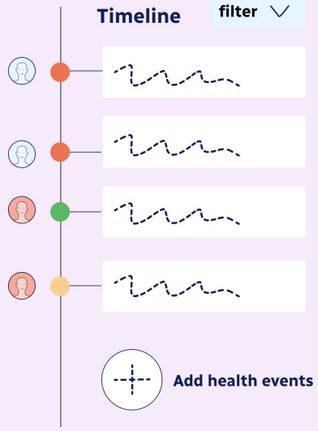
Through casual, dialogue-based prompts, the chatbot supports self-awareness and sharing at one's own pace, help translate data to key takeways — making the interaction feel personal, not clinical.

Situation - Joe just had a health checkup, he uploaded it to the system then the system discuss the result about higher sugar level, then it suggest him to track about diet, then he discussed with mom, she suggested reducing snacks or improve sleep.



3

Shared Timeline



Why

For families who want to collect health data over time in a non-intrusive way, without requiring immediate responses.

What

A shared space for the family to quietly post health updates, events, and key information—like pinning milestones along their health journey.

How

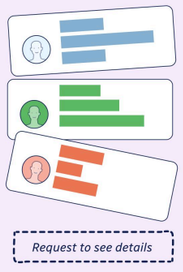
Instead of automatically pushing updates to the family, individuals first record their own data and reflect on its meaning—then choose what to share in the collective space.

Situation - A mother and son quietly track their own health updates in a personal and shared timeline, using it to reflect on own check-ups, and patterns over time without needing to directly notify each other. They can look what others share.



4

Shared Health Folder / Wallet



Why

To make it easier for families to stay informed without needing constant updates—especially when they want to check in at their own pace.

What

Health foldercthat stores key documents, summaries, and reports in one organized place. It offers both high-level overviews and deeper details if requested.

How

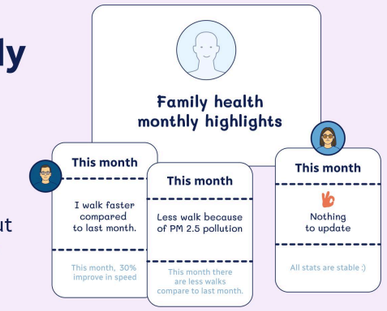
Information is added over time—such as check-up results, medication updates, or habit notes—and organized for easy understanding. Family members can **browse the folder** or **request access** to see details when they feel curious or concerned.

Situation - A son compares his recent health check-up results with his dad's by uploading both result into shared folder, leading to a conversation between them. If he wants moredetails he need to ask for consent from dad.



5

Casual monthly check-ins



Why

Families want to stay in touch about health—without having to ask or knowing in details. They want to know everyone is okay, without pressure.

What

A light way to regularly stay updated on each other's well-being that could be starting point for in-person check up.

How

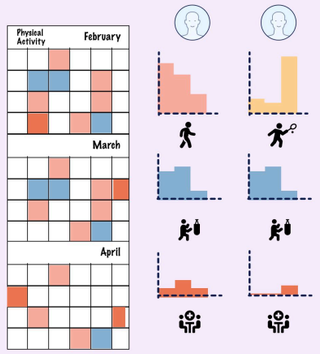
Each month, highlights updates, shared by choices, help them stay connected, see the overview, and stay aware—gently and without worry.

Situation - Family member agree to check in once a month using simple "status cards." as highlight. If needed, they can view trends or compare changes over time.



6

Shared Health Calendar



Why

In families that actively share and engage with data, there's a need for shared awareness and planning—making health routines visible so everyone.

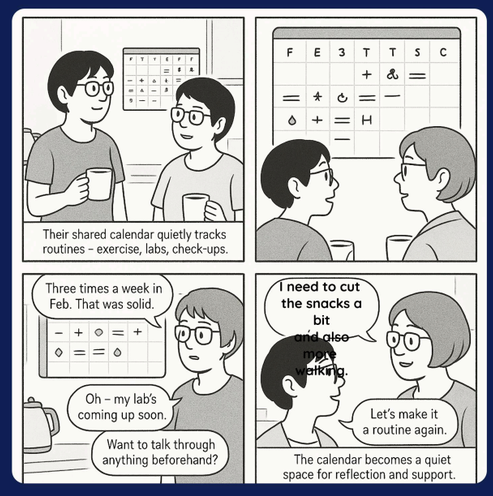
What

A shared calendar—digital or physical—that shows medical appointments and healthy routines, helping families stay aware, involved, and plan together.

How

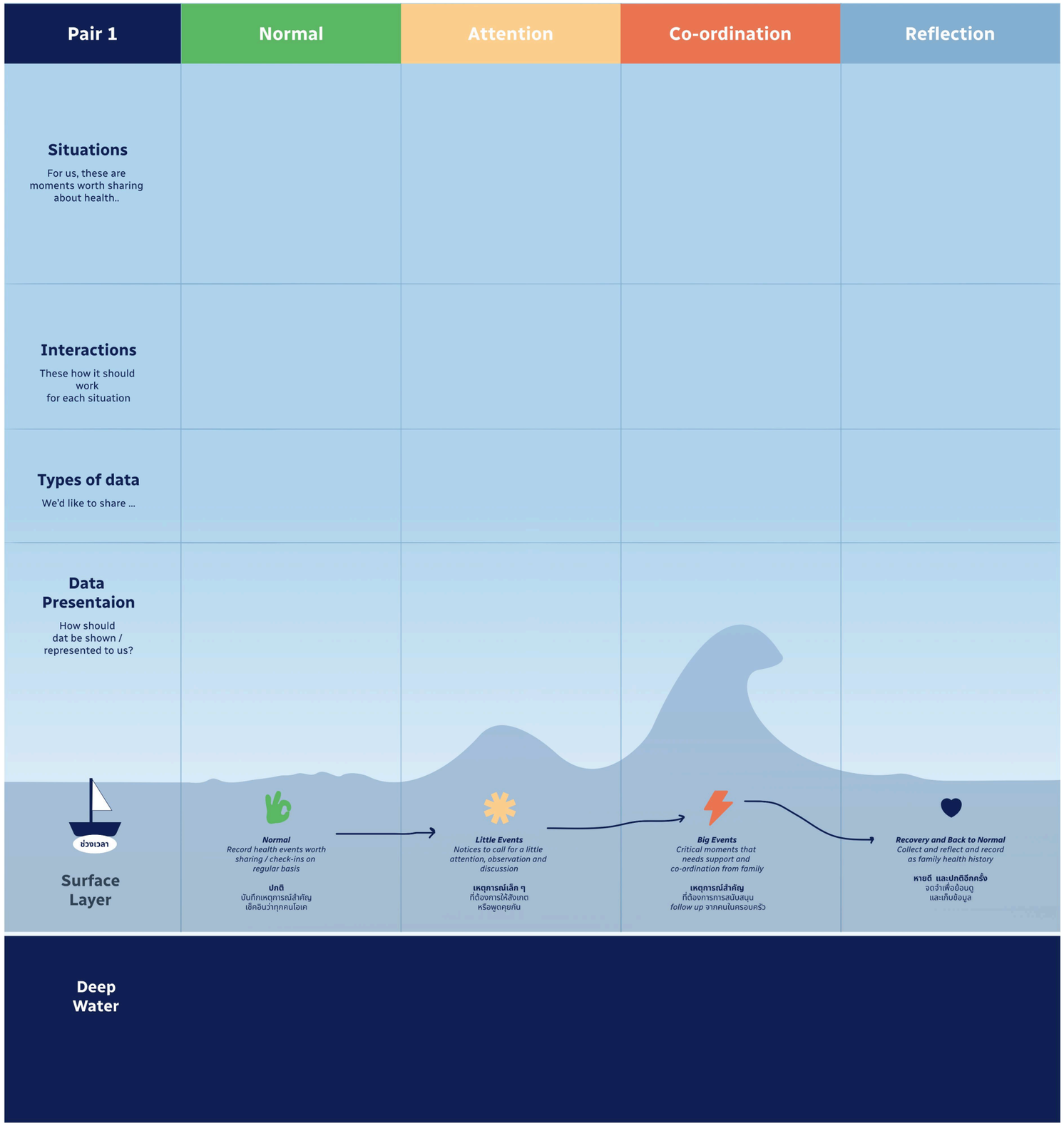
In the kitchen, a shared 3-month calendar displays health routines and upcoming plans from the family's synced calendars. It naturally invites observation and casual conversations about what's coming up.

Situation - Dolly notice her own regular workouts in February, but fewer in March. While looking at the calendar, Myra notices her mom's upcoming check up and brings it up casually.



B.2.3 Co-Design Canvas with Health Data CardsTemplate

he main interactive board featuring a wave structure and draggable Health Data Cards, used to explore who shares, what data, how it's shared, and why/why not.



A. Reflect

Step 1: (Who) Discuss you are and how you track and share health data in family พูดคุยเพื่อปักว่าครอบครัวคุณมีนิสัยแทร็กและแชร์ข้อมูลแบบใด

Answer these 2 guide questions to help you guide your archetypes and also discuss

(5 mins)



1

Who

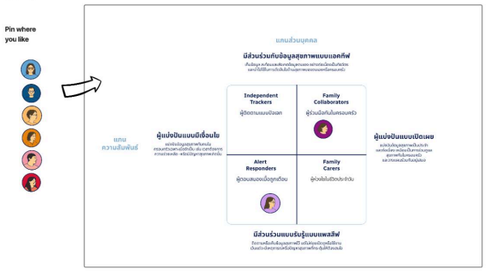
Our archetypes

How our family see ourselves?

Drag your avatar into place that fits you

ลากไปวางในจุดที่คิดว่าตัวเองอยู่

Pin where you like



2

When

The **moment(s)** we'd like to design for

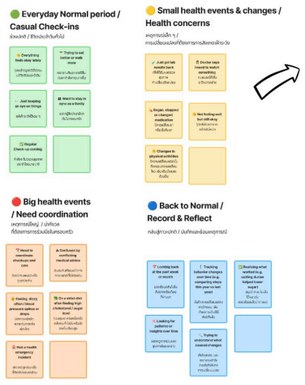
Step 2: (When) Look at the health journey and decide which situation / scenario that is relevant for sharing in family เมื่อมองกลับไปที่ Health Journey ในช่วงต่างๆ เลือกว่าสถานการณ์ใดที่ควรต่อการแชร์ในครอบครัว สามารถเพิ่มเติมได้จากประสบการณ์ส่วนตัว

Talk together and **choose moments** you want to explore sharing with in the future sharing system.

(15 mins)

Moment Cards

Samples



B. Create

✨ Now let's imagine a health sharing system that truly fits your family. Feel free to mix, adapt, or create something entirely your own.

Where do you picture it being part of your everyday life and how might the way you use it shift over time?
คุณมองเห็นระบบนี้อยู่กับชีวิตคุณอย่างไร และเปลี่ยนแปลงอย่างไรในแต่ละช่วงเวลา

Step 3:

3

How

Channels / Mediums

ช่องทางการสื่อสารที่เหมาะสม

✌️ Everday tools
เครื่องมือใช้ในชีวิตประจำวัน

⌚ Wearables & Tangible
สมาร์ทวอช หรืออุปกรณ์สมาร์ทโฮม

💬 System / Service Formats
ระบบ หรือ บริการ



Step 4 & 5:Interaction: Decide together how it should work ระบบนี้ควรทำงานอย่างไรในแต่ละช่วงเวลา

Choose one or more cards—feel free to mix, adjust, or come up with something new that fits the moment and your family's way of sharing.

Then, imagine how you want the system to feel when using it.
(15 mins)

4

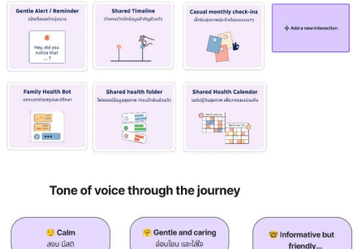
How

Ways of Interaction

Interaction
การปฏิสัมพันธ์

Pick idea you like, combine or make your own :)

These are how it can work for each situation



Tone of voice through the journey

For us, each moment should feel like ..



Choose the medium for family sharing, what data and how the data should be communicated.

Based on the moment or situation you chose, **what kind of data is relevant—and how would you like to see it?**

(10 mins)

5

What

Data Presentation

- How should the information be shown to us?

ประเภทข้อมูล
ข้อมูลใดบ้างที่สำคัญในแต่ละช่วงเวลา ?



ข้อมูลควรแสดงอย่างไร ในแต่ละช่วงเวลา

Use this as inspiration, it focuses on Blood pressure.



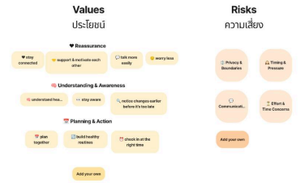
C. Reflect

Next, the facilitator will briefly sum up your design—now it's your turn to reflect on what feels good, and what concerns you might have.

Step 5: (Why and why not) Reflect values and risks and wrap-up !

- What value do you see in it? And what risks or concerns might come up?
- Give your system a name :)

(10 mins)



5

Why
😊 Values / Benefits

Why not
🧐 Risks / Concerns

ชื่อระบบของเรา

Final : Wrap up & closing
(5-10 mins)

- *Overall feedback, how are you feeling now?*
- *If this session can be done better for the future, how would you change it?*
- *Which part is helpful for ideation / co-design?*
- *Which part is confusing and overwhelming?*

Appendix

C3.4 Workshop Materials: Health Data Cards

Participants used health data cards on a shared canvas to co-design their ideal sharing setup. Through three steps (reflect, create, reflect again) across four stages of the health journey, they explored who to share with, what data to share, how to share it, and why or why not.

C. Validation

These materials were used during the validation phase to gather feedback from designers and researchers. The goal was to assess the clarity, relevance, and applicability of the proposed frameworks and design principles.

C1. Validation Materials

C1.1 Background Questionnaire

A short form to understand participants' backgrounds, roles, and familiarity with health data

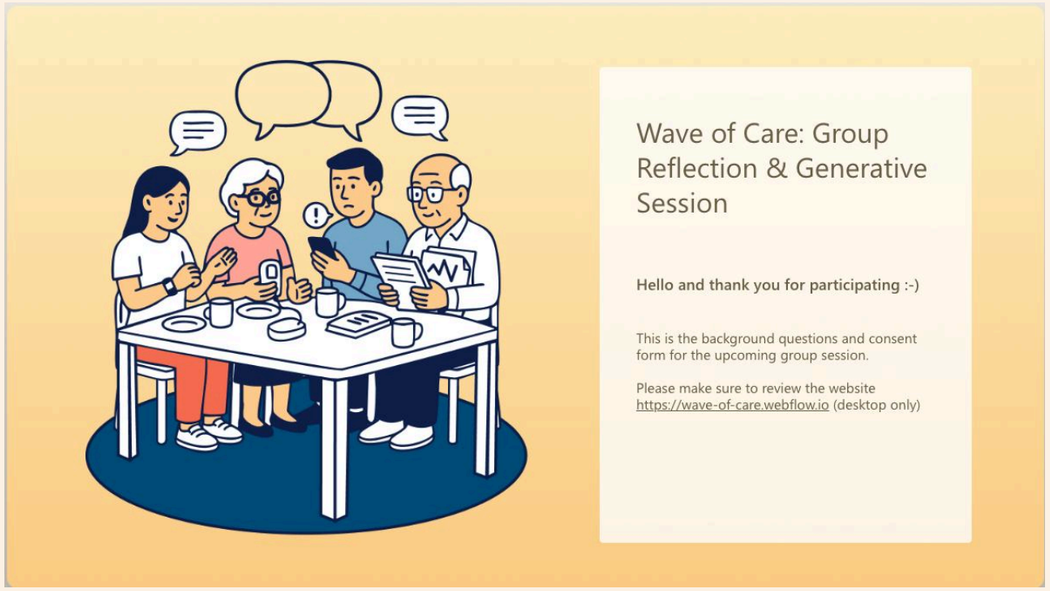


Figure: Microsoft Forms survey to gather participant background and provide instructions for exploring the Wave of Care website before the group session.

Background Questionnaire

1. Consent
   - Do you agree to provide your background responses anonymously? (Yes / No)
   - Do you agree to participate in the upcoming group session? (Yes / No)
   - Do you consent to the session being recorded and photos of group work taken? (Yes / No)
2. Pseudonym
   - Please choose a name you'd like us to use when referring to your responses. (Open text)
3. Age Group
   - What is your age group? (18–25, 26–40, 41–59, 60–75, 76+, Prefer not to say, Other)
4. Family Role
   - Which family role do you identify with? (Child / Adult child, Parent, Other, Prefer not to say)
5. Professional Background
   - What is your professional background? (Designer / Practitioner, Design Student, Healthcare Professional, Researcher / Academic, Health App Developer, Public Health / Policy, Other)
6. Health Design Experience
   - How much interest or experience do you have in health-related design? (No interest, Some interest, Took related courses, Short-term projects, Work experience, Other)
7. Data Tracking Habit
   - Do you currently track any personal data? (Yes regularly, Yes occasionally, No, Other)
8. Types of Tracked Data
   - What types of data do you track? (Physical activity, Sleep, Vitals, Weight, Mood / Mental health, Nutrition, Symptoms / Conditions, None, Other)
9. Cultural Background
   - What cultural background do you identify with? (Open text)
10. Comfort with Health Conversations
    - How would you describe sharing and talking about health in your family? (Very comfortable, Somewhat comfortable, Neutral, Somewhat uncomfortable, Very uncomfortable, Other)

C1.2 Session & Instruction Slides

Slides used to guide participants through each part of the session: intro, recap, reflection, ideation, and discussion. The goal was to bring in culturally grounded insights (Thai family context) and receive diverse feedback.

In this session, we will ...

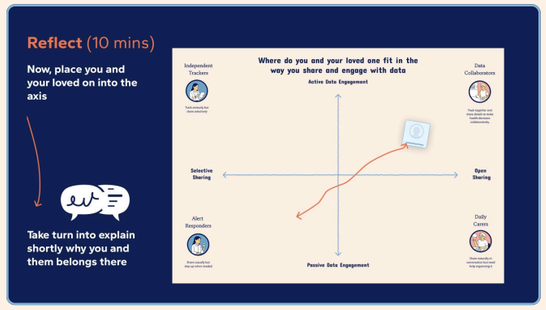
Intro ⟶ Recap ⟶ Reflect ⟶ Ideate ⟶ Situate & Discuss

5 min | 10 min | 10 min | 15 min | 20 min

Goal

Bring **cultural situated findings & principles (Thai family context)** to gain perspectives from you, d*esigners with diverse backgrounds to improve the framework and website.*



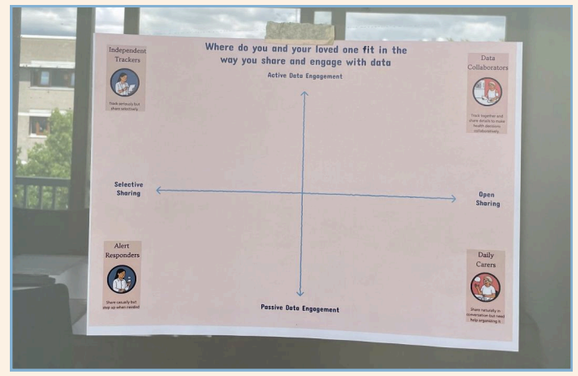




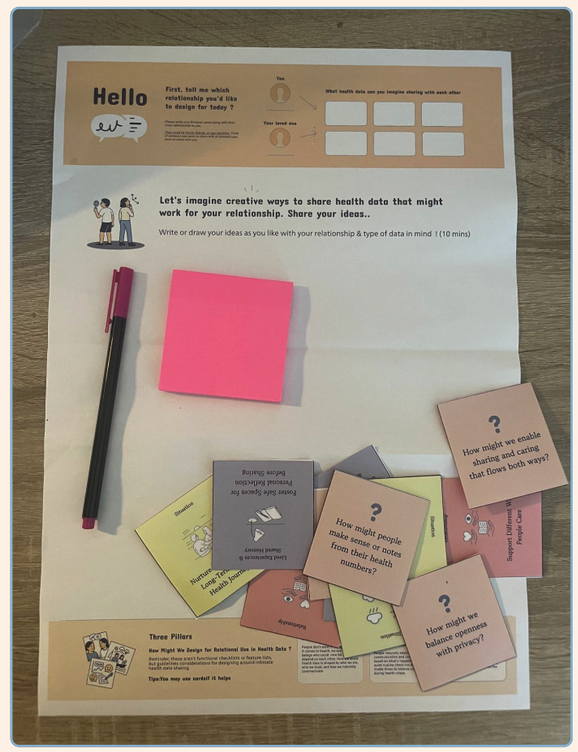


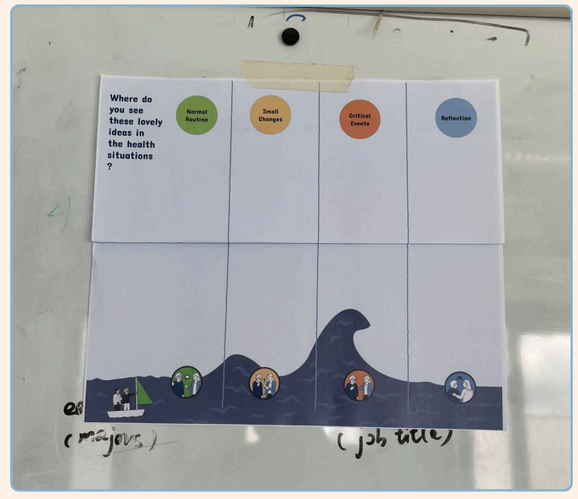
C1.3 Materials: Printed Website & Workshop Templates

Printed version of the storytelling website and tools like the axis sheet, wave canvas, and ideation templates.









C1.4 Principle Cards

A set of relational data-sharing design principles, used to support participants during the ideation phases. Each card represented each principle from the framework with “how might we?” question, helping participants reflect on its relevance and potential application.



D. Results & Analysis

This section includes raw and intermediate materials that supported analysis across both research cycles. These outputs capture participants' voices, shared artifacts, clustering maps, and evolving templates that informed key themes, metaphors, and research directions.

D1. Original Design Brief

A view of original Thai transcripts and their English translations, showing how participants' words were interpreted and prepared for statement card and analysis.

Speaker	Time Stamp	Importance	Thai	EN (google translated)	Paraphrase (Chat GPT natural english and edited)	Note
Mindful	19:21	☑	เพราะเสียยอดเป้าหมาย เพราะเสียยอดเดี่ยวนับตอนเดินเดินถึงแล้วเดี่ยวเสียเลยครับ เดี่ยวค่ามันจะช้า	Because the target amount is lost. Because the amount is lost, sometimes counting when you reach it, sometimes losing it right away. Otherwise, the value will be slow.	Because I don't want to miss the step goal — I need to keep walking until it counts, or else the number might lag and I'll lose the progress.	Data Tracking
Mindful	19:23	☑	อีกอย่างหนึ่งก็คือว่าถ้าเกิดถ้าเกิดไปใช้ระยะทางจากบ้านเลยเนี่ยใช้การเก็บแผนที่ที่ดูเส้นทางที่เราเดินเนี่ยมันจะไกลมากแล้วมันจะไม่เห็นในส่วนในส่วนที่เราเดินถ้าในส่วนที่เราเดินเราเดินวนอยู่แต่ใช้ระยะทางยาวเนี่ยมันจะมาจากไอการนั่งรถก็คือเรามีนั่งรถด้วยไง ก็จะกดเริ่มลำบากไง	Another thing is that if we use the distance from home, collecting a map showing the route we're walking will be very far and we won't be able to see the part we're walking on. If we're walking in circles, the long distance will come from taking the car, which means we're taking the car, so it's difficult to press start.	Another thing is, if I start tracking from home, the route map ends up showing a really long path that includes when I'm in the car. So the walking part — where I'm actually doing loops — doesn't really show clearly. It makes it hard to know when to start recording.	Data Tracking
J.	20:48	☑	คือพ่อสนใจพวกเรคคอร์ดข้างเคียงด้วยเช่นสปีดและระยะทางใช่ปะ ก็เลยเหมือนต้องเก็บให้มันละเอียด	Dad is also interested in side records like speed and distance, right? So it's like he has to keep them in detail.	You're interested in things like speed and distance too, right? That's why you try to record everything in detail.	Data Tracking, Family Sharing
Mindful	21:07	☑	ส่วนหนึ่งเค้าบอกว่าการเดินที่จะให้ได้ผลเนี่ยมันต้องเดินเร็วอย่างน้อยครึ่งชั่วโมงขึ้นไปแล้วก็ speed เนี่ยควรจะไม่เกิน 13 ไม่เกิน 12 13 นาทีต่อกิโล	Some say that to be effective, you have to walk fast for at least half an hour or more, and your speed should be no more than 13, no more than 12, 13 minutes per kilometer.	They say for walking to be effective, you need to walk fast for at least half an hour. The speed should be no more than 12 or 13 minutes per kilometer.	Health Goal
Mindful	21:09	☑	ผมเลยพยายามทำตรงนั้นแล้วดูว่าที่ผ่านมาร่างกายมันโอเคขึ้นไหม่	So I tried to do that and see if my body was okay again.	So I've been trying to follow that — and seeing whether my body has improved over time.	Health Goal, Data Tracking
J.	24:23	☑	ไม่ได้เห็นแพทเทิร์นในเชิงแบบความสัมพันธ์กับอารมณ์หรือคนอื่นคือไม่ได้รู้สึกว่าเดินแล้วทำให้ทำงานดีขึ้นแต่เดี๋ยวทำให้นอนดีขึ้นหรือว่าเดินเยอะทำให้อารมณ์ดีขึ้นอย่างงี้ไม่เห็นแพทเทิร์นแบบนั้น	I don't see any patterns in terms of how it relates to mood or other people. I don't feel like walking improves my work performance, but then it improves my sleep, or that walking a lot improves my mood. I don't see any such patterns.	I haven't really noticed any patterns linking walking with my mood or interactions with others. Like, I don't feel that walking helps me work better, sleep better, or feel happier. I haven't seen those kinds of connections	Analysis, Value
Mindful	29:32		แต่ส่วนใหญ่ถ้าอาจจะลงในกรุ๊ปเพื่อนเพราะลง	But most likely, they'll post it in	Most of the time, I post in my friend group — I	Family Sharing

Session 01 | Session 02 | Session 03 | Session 04 | Summary | Total Filled In | Desired System | Sheet5

D2. Cycle I

D2.1 Tracking Artifacts

Photos and materials voluntarily shared by participants to illustrate their health routines and tracking habits. While not requested by researchers, these helped participants explain how they currently track and collaborate, offering a glimpse into the messy, everyday reality of health data in their lives.

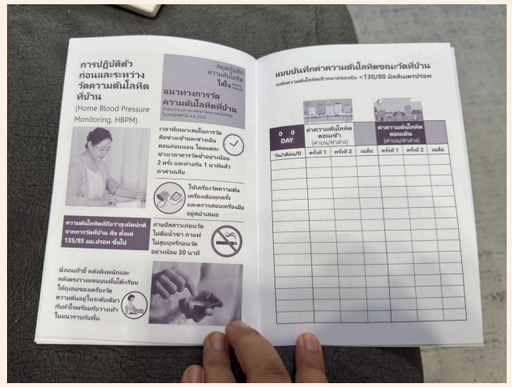


Figure: Blood pressure booklet provided by a Thai hospital, used for daily tracking with tips inside.

Date	LDL
20201201	129
20211207	133
20221201	146
20231207	178
20240402	157
20240806	131
20250207	138

Figure: Personal LDL spreadsheet created by a participant to monitor their main health concern over time.

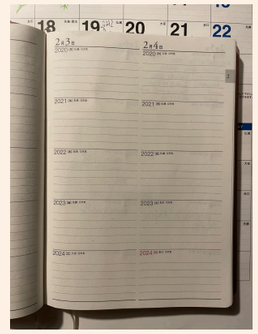


Figure: Japanese Notebook with layout comparing entries on the same date across 6 years as a way to look back.



Figure: Paper calendar one family used to note down health-related events and shared exercise reminders.

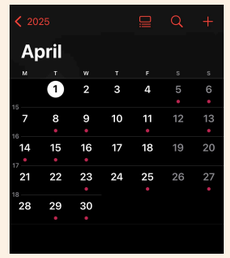


Figure: Instagram story archive shown by a participant to illustrate how like t look back over time—offering a reference for how they'd like health data to feel

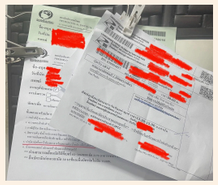


Figure: One family clustered **printed appointment slips on a mirror (so they don't miss)** to keep upcoming health visits visible and remind each other.

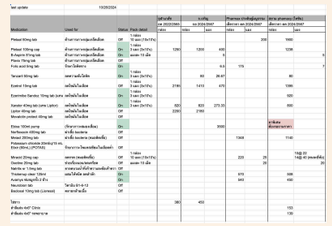
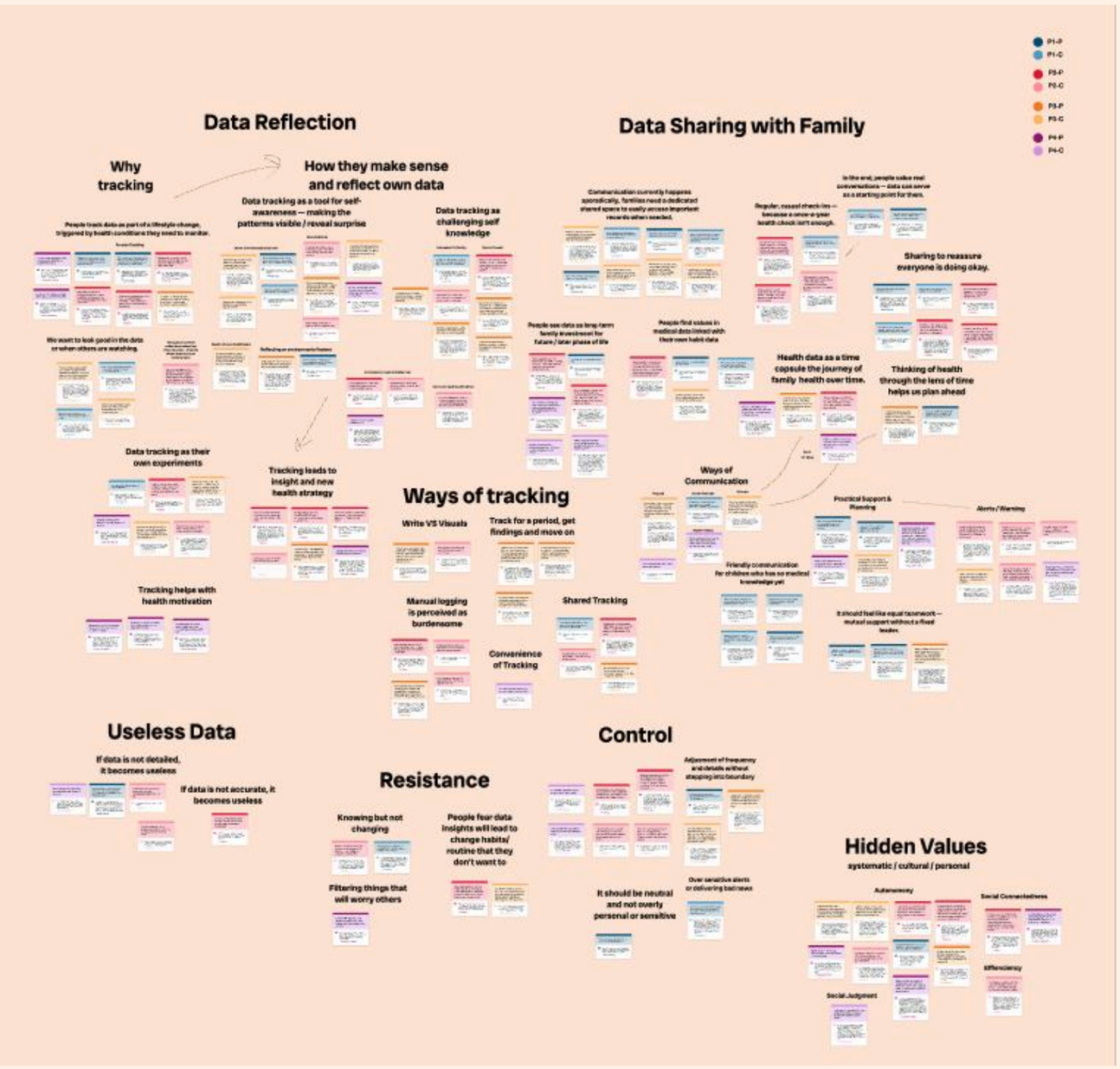


Figure: Medication spreadsheet one family created to track dosage changes, brand switches, on-off usage, and long-term expenses.

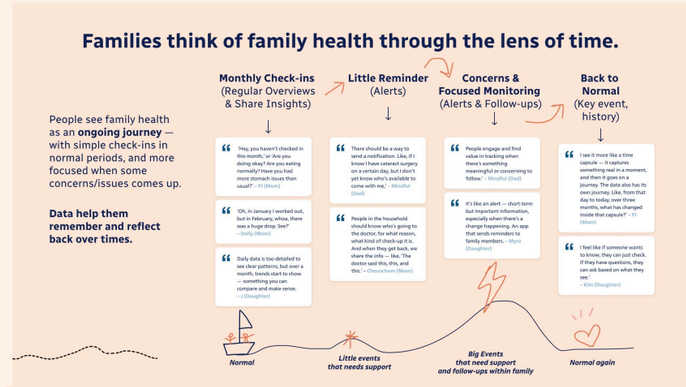
D2.2 Statement Card Clusters (Themes)

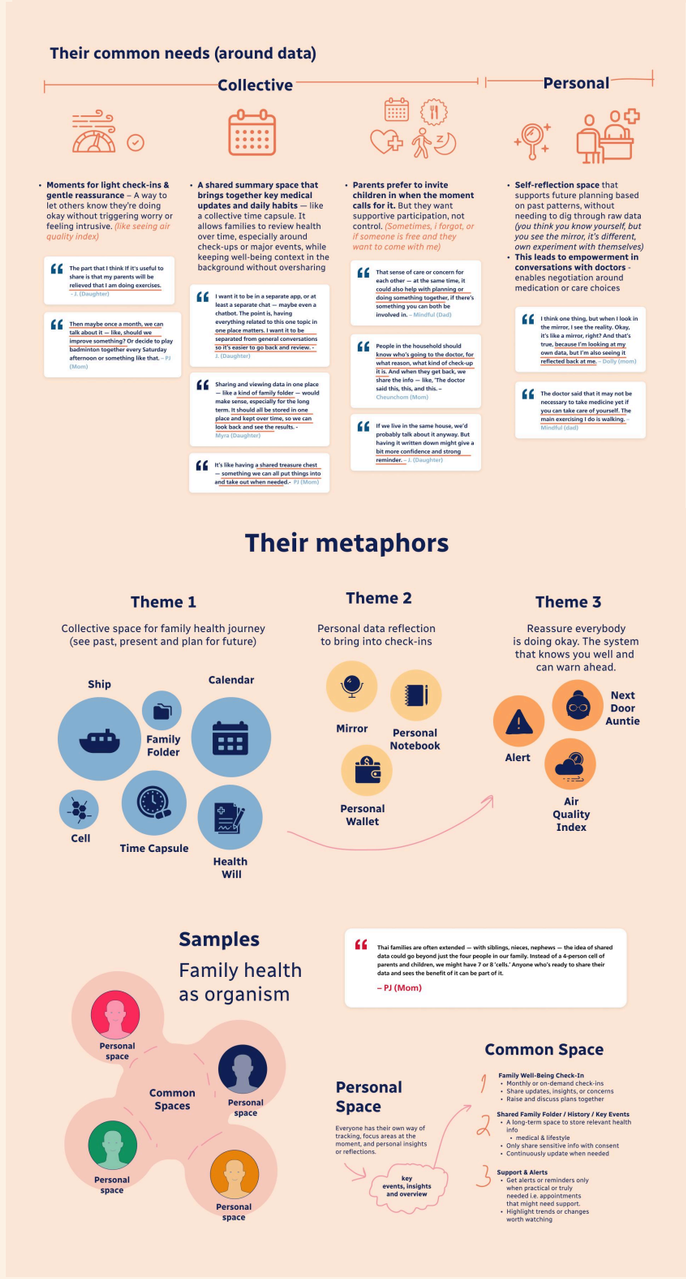
Statement card clusters from Cycle I, organized into emerging themes such as Data Reflection, Data Sharing, and Hidden Values. These reveal participants' reasons for tracking, ways of making sense of data, sharing practices, and deeper cultural or emotional needs surrounding health data.



D2.3 Framing Analysis & Models

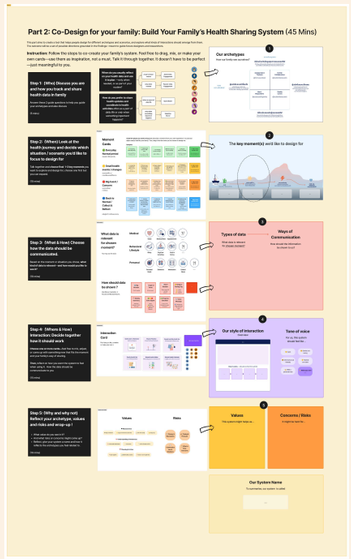
This section presents alternative ways of organizing and interpreting insights from Cycle I. By shifting perspectives—from individual to collective, from literal to metaphorical—these framings helped shape the core models used in later framework development converged to key insights.



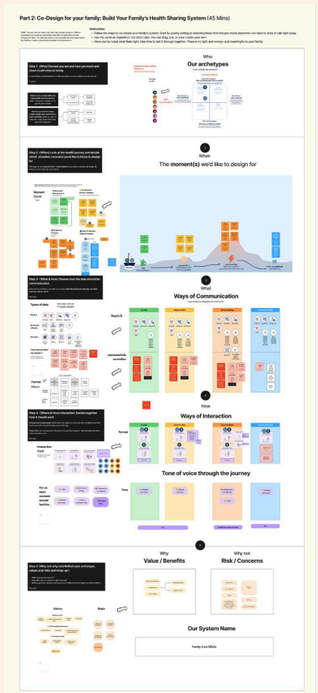


D3.1. Evolution of Co-creation Template

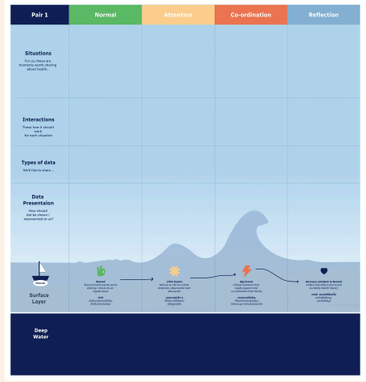
The first workshop design separated “who,” “what,” and “how” into different steps—but it felt too rigid. Participants wanted these elements to adapt depending on their health situation. This led to a new canvas centered around health journey stages, making it easier to explore sharing in context. Over time, the layout was simplified and adjusted for better flow and proximity, making it more natural to use during sessions.



See it as separated, not reflecting key findings.



Difficult to go up and down

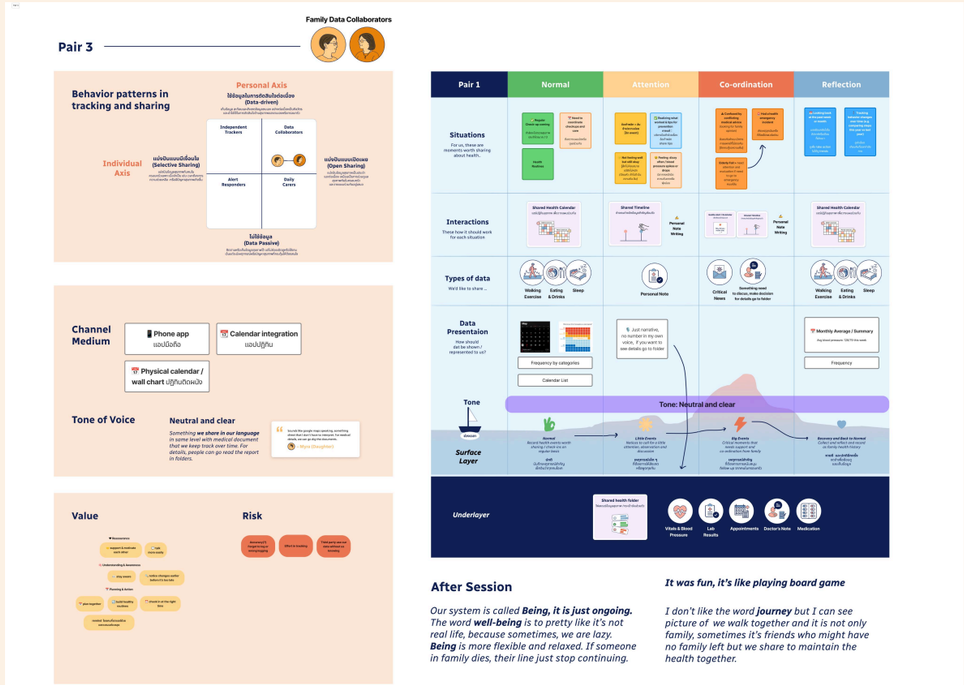


Final Canvas

D3.3 Clustering Maps

This sectionrepresents **the analysis phase** of Cycle II. After each session, a summary map was created for each pair to get an overview of what they designed and agreed upon during collaborative co-creation. These individual maps then informed multiple rounds of re-clustering to explore patterns across participants

The goal was to make sense of not just what participants designed, but why—by identifying shared values, needs, and mapping those decisions back to the health journey. These thematic clusters directly informed the final key insights and design principles.



After Session

*Our system is called **Being, it is just ongoing.** The word **well-being** is to pretty like it's not real life, because sometimes, we are lazy. **Being** is more flexible and relaxed. If someone in family dies, their line just stop continuing.*

It was fun, it's like playing board game

*I don't like the word **journey** but I can see picture of we walk together and it is not only family, sometimes it's friends who might have no family left but we share to maintain the health together.*

Design Values for Family Health Data Sharing

Data Sharing Adapts to Care Journey Stages

flexibility assurance and contextual awareness

Information sharing evolves based on health situations, from casual updates to crisis coordination and the situation doesn't follow linear progression, each member might be in different condition

For normal period showing to family, people desire to share headlines if someone shows interest they can look into details



During health concerns, people opens up more to keep family involved in their journey



Health recovery doesn't always follow linear progression and may skip expected stages



People are willing to share and know more when it's critical times



Design Implication
Provide different sharing modes and interactions that adjust granularity (how much details) and urgency based on events and health situation severity

The Journey

Relationships Shape What and How Data Gets Shared

emotional safety and consent

Trust, closeness, and family roles determine what gets shared and how

With highly individual families, they want clear signals whether they're sharing for information, making announcements, or asking for support



People need control over who sees what health information.



Families already involved in caregiving and coordination around care share sensitive health data comfortably by default



Care is not one-sided

Design Implication
Build granular privacy controls and clear communication signals (info vs. announcement vs. support request)

Archetypes

Data as Lived Experience, Not Just Metric

meaning-making and personal agency

People relate to health data through stories, patterns, and personal context rather than raw numbers

People prefer describing health events in their own words when talking to family



People want to filter own data before sharing with families.



People use their own data to discuss with doctor in consultation



People want to be able to disclose how much detailed they share.

People compare data and personal experienced to make sense of own weeks and adjust their habits



Numbers help people reflect their daily acitivies and factors through the weeks that affect health outcome



The data should be materials for conversation not replace it.



Data don' replace the healthcare professional but should work with



Data can help make care visible and become more concrete



Design Implication
Enable personal storytelling, custom language, and contextual notes alongside data points

The Cabin

Data Tools Must Feel Familiar and Unforced

(comfort and natural integration)

echnology should blend into existing communication patterns without adding complexity

Elderly prefer simple notebook to keep record own health week by week



People wants something flexible and non-demanding for different life rhythms and not constant notification



For immediate action, people desire to directly contact through phones, this app doesn't need real-time input





Design Implication
Integrate with existing communication patterns and tools while avoiding demanding interfaces, constant notifications, or forced interactions

Value Must Justify Effort

(empowerment and long-term benefit)

People will track and share data when they see clear benefits like emergency preparedness or early detection

Families view health data as a long-term collective resource that complements daily care, conversations, and doctor visits while bridging gaps between different healthcare providers



When parents share caregiving experiences, it prepares younger family members for future health management



Design Implication
Demonstrate clear benefits through insights, emergency preparedness features, and pattern recognition that people can act on

Emergency prepared ness

People wants to share all relevant datas for future emergency such as health insurances



Alert or chatbot will work if they understand the history and average of the family



People expect data to help assess the critical of the symptoms



Proactive health management

People want system to remind them of important event they might miss



People want the system to help them detect serious conditions before it's too late



System can help bring systems / guideline into helping family sync and work as team in critical times



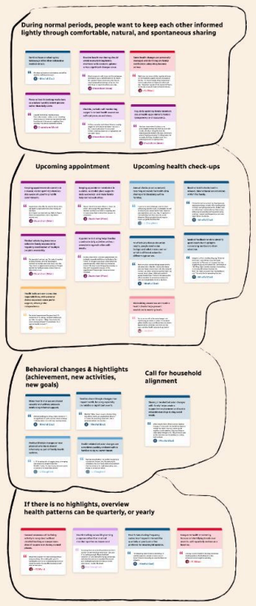
Health Bot



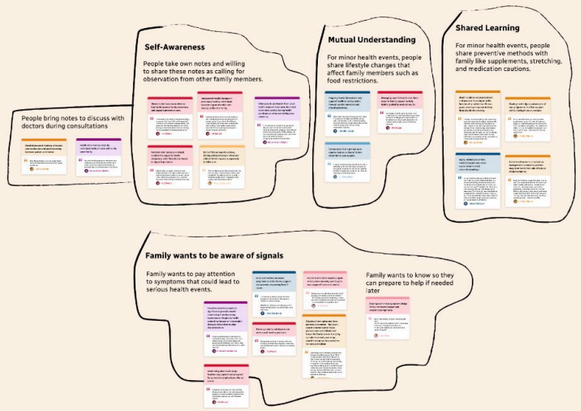
The Deepwater - not everyone wants to dive (Data engagement varies)

Cluster By 4 Phases

Normal situation
Light, maintaining connection

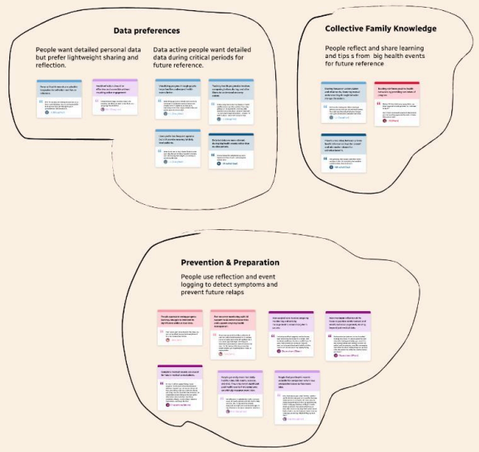


Small Health Events
Awareness, getting ready



Critical Health Event
Active collaboration and support

Recovery
Reflection and knowledge building



Appendix

D4. Validation Feedbacks & Insights

This section presents the outcomes of the validation session, combining the collected artefacts and a thematic analysis of participant input. These results helped refine the design principles and storytelling approach.

D4.1 Session Artefacts (Digitalized from physical for analysis)

- **Printed website pages** marked with dots to show which parts worked or caused confusion
- **Mapped axis template(digitalized),** where participants placed their own relationships to reflect personal positioning
- **Input** indicating where ideas came from—such as health data types
- **Post-it ideas** placed directly on **the wave framework** to show where each idea or insight belonged within the health journey stages

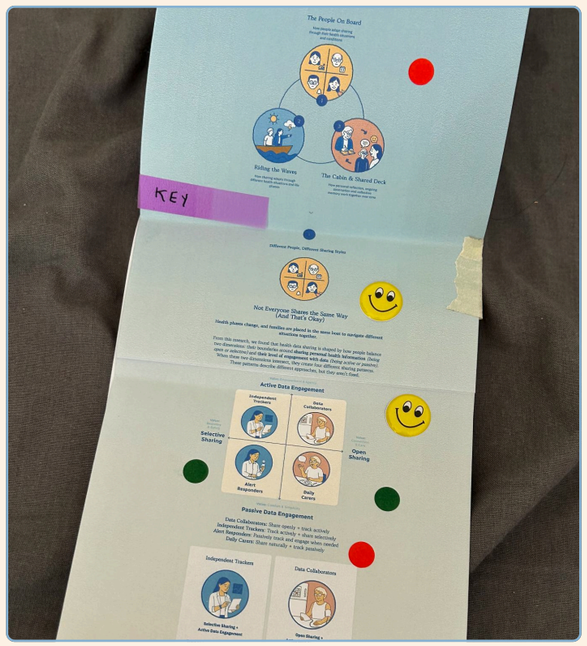
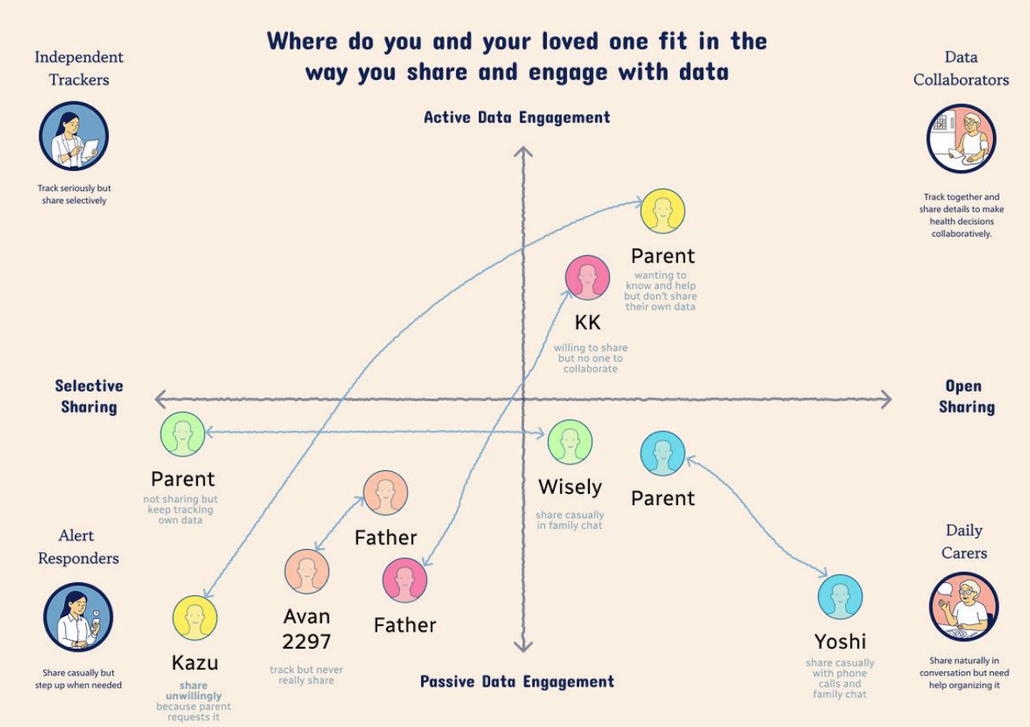


Figure: **Printed website pages** marked with dots to show which parts worked or caused confusion







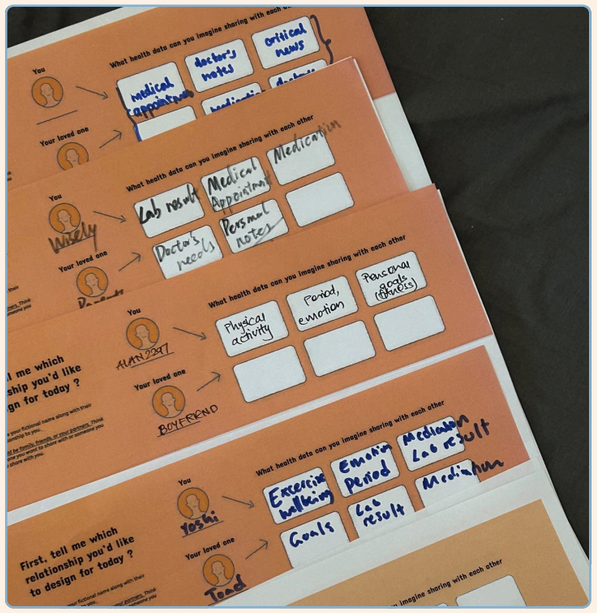


Figure: **Mapped axis template(digitalized)** where participants placed their own relationships to reflect personal positioning

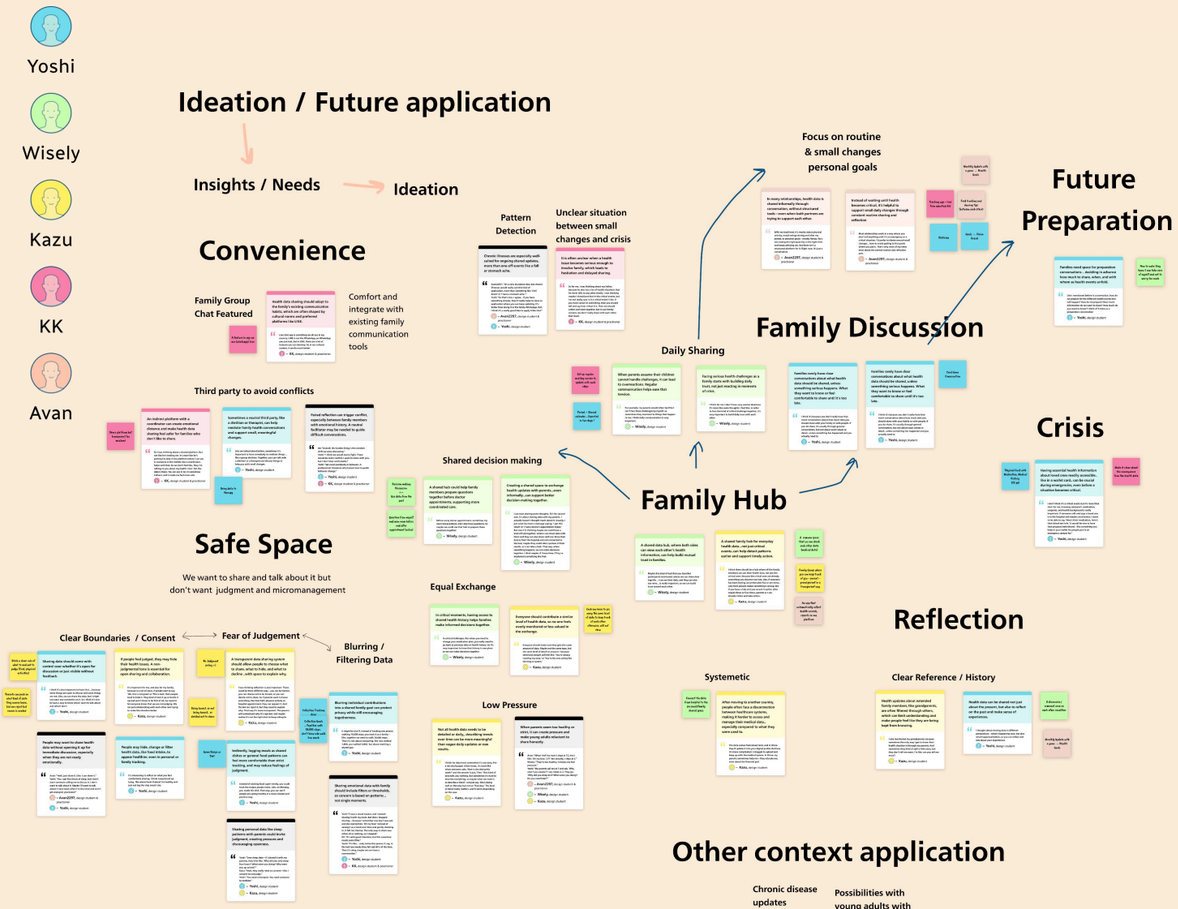
Figure: **Input** indicating where ideas came from—such as what relationship and what health data types



Figure: Post-it ideas placed directly on **the wave framework** to show where each idea or insight belonged within the health journey stages

D4.2 Validation Analysis Mapping

Participant quotes and notes from the validation session were transcribed and clustered on a digital board. The mapping brought together reflections on health data sharing and new design ideas (from Post-its) to explore how the framework was received and reimagine



E. Design Principles & Final Outcome

E1. Framework Synthesis

E1.1 Connecting Key Insights to Design Principles

This appendix presents the eleven design principles shaped by insights from co-creation sessions. Each principle links to specific key insights (KI) drawn from participants' experiences with family health data sharing. Grouped into three pillars, these principles guide the design of relational, flexible, and context-aware health tools.

Pillar 1: Designing with Relationships

1. Design with Reciprocity in Mind

Key Insights:

- KI1.1: Trust and care shape what and how data is shared
- KI1.3: Sharing is often uneven and reciprocal — and that's okay
- KI2.2: Families move from privacy to openness during uncertainty

2. Support Different Ways People Care

Key Insights:

- KI1.4: Different people engage with and share data differently
- KI2.5: Health journeys are non-linear and perceptions differ
- KI3.4: Personal data space coexists with shared space

3. Respect Different Communication and Information Styles

Key Insights:

- KI1.2: Sharing is not just for monitoring, but for mutual understanding
- KI1.4: Active and passive data engagers prefer different levels of detail
- KI3.3: Data can lead to emotionally sensitive discussions

4. Build Trust Through Clear Signals and Boundaries

Key Insights:

- KI1.1: Families interpret sharing boundaries differently based on past experiences
- KI1.4: Passive data engagers need clarity and simplicity
- KI3.4: Families need flexible control over what's shared and when

Pillar 2: Designing with Changing Health Situations

5. Adapt to Life's Changing Health Moments

Key Insights:

- KI2.1: Families share highlights, not constant updates
- KI2.2: Sharing shifts with health uncertainties and crises
- KI2.5: Health journeys aren't linear — and that's normal

6. Recognize and Support Role Shifts

Key Insights:

- KI1.3: Sharing and care roles shift naturally within families
- KI2.3: Shared experiences build family knowledge for the future
- KI3.2: Data is used to compare past, present, and future self

7. Nurture Sustainable and Long-Term Health Journeys

Key Insights:

- KI2.4: Routine sharing builds readiness before crises
- KI3.5: Sharing should build collective memory without pressure
- KI3.2: Data serves as a memory aid, not a performance tracker

Pillar 3: Designing with Lived Experiences Behind Numbers

8. Foster Safe Spaces for Personal Reflection Before Sharing

Key Insights:

- KI3.3: Reflection on data can surface emotions and concerns
- KI3.4: People want space to make sense of data before sharing

9. Add Life Context Alongside Health Numbers

Key Insights:

- KI3.1: People contextualize medical data with lived experiences
- KI2.3: Families learn from past health events with emotional memory

10. Embrace Imperfect Tracking Methods

Key Insights:

- KI3.2: Tracking is often inconsistent but still meaningful
- KI3.5: Families value sustainability and low-pressure systems

11. Let Data Start Reflection and Conversation

Key Insights:

- KI1.5: Data should spark conversation, not replace it
- KI3.3: Data opens up difficult but necessary health talks

E1.2 Putting It All Together: Toward the Final Framework

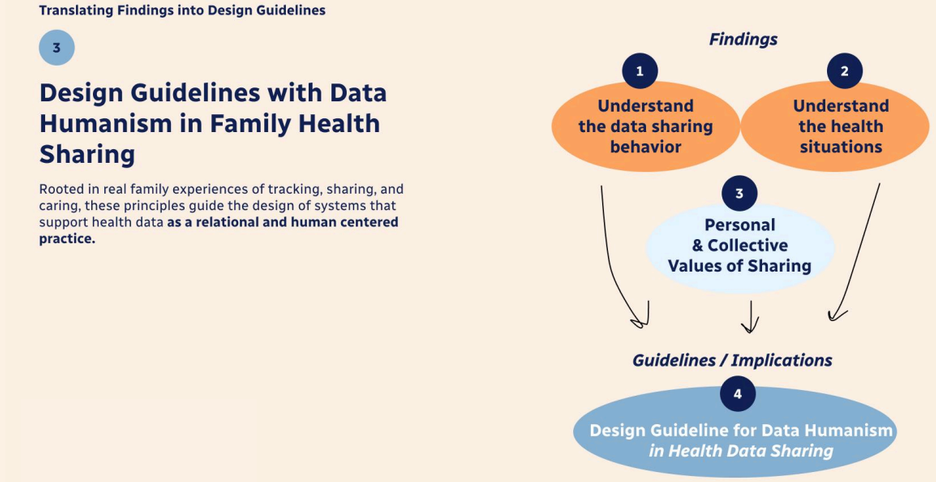


Figure: Formation of Three Pillars towards Guideline / Framework

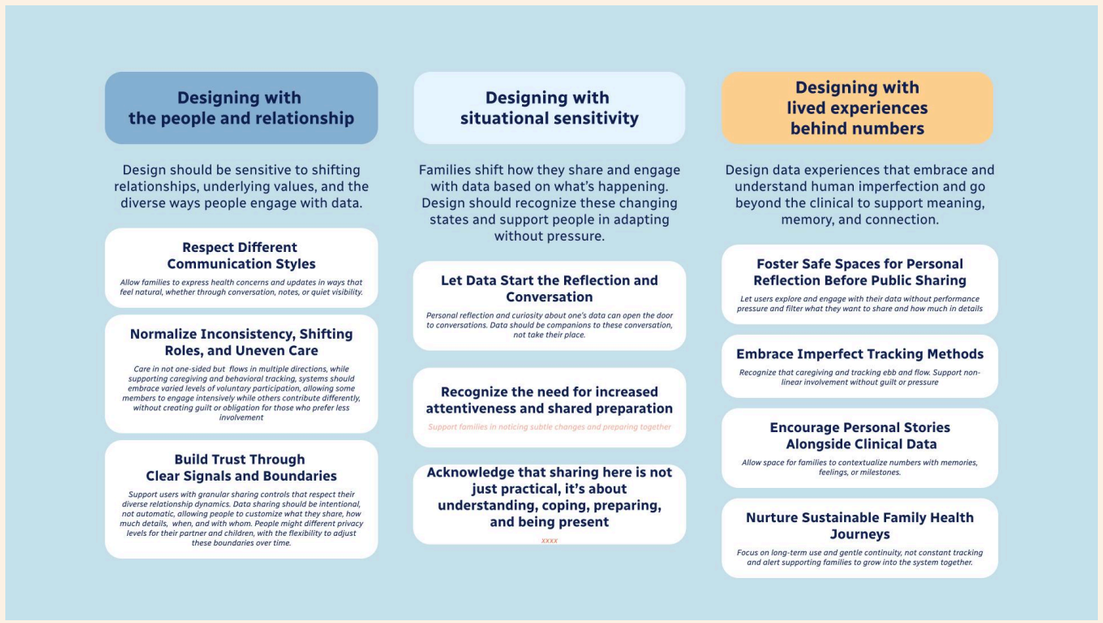
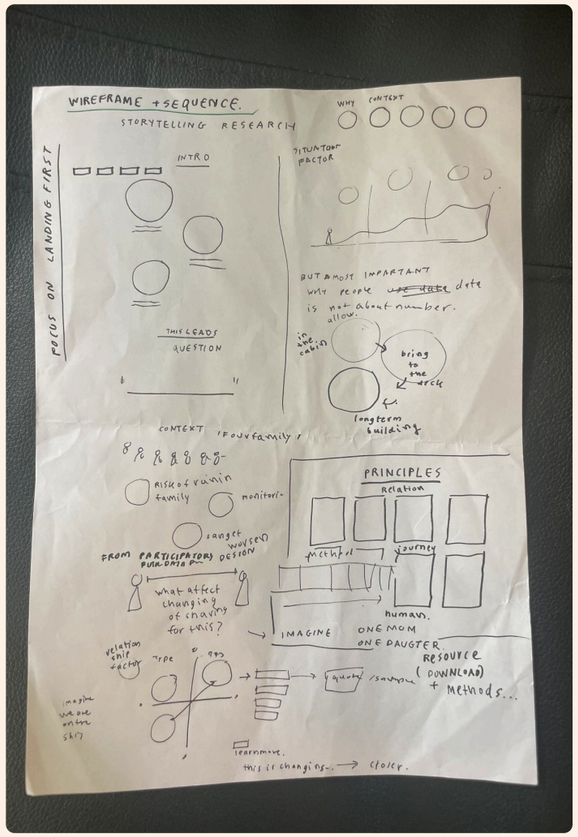


Figure: Early conceptual frameworks helped surface three core perspectives—relationships, changing health situations, and lived experiences—that later guided the development of design implications and principles

E2.Storytelling Website Wireframe

Because the website was designed and developed directly in Webflow, the structure moved straight from paper sketches to live prototyping, skipping static wireframes. This appendix presents key layout & content structure that shaped the storytelling format, translating the research framework into an interactive website to bring this research forward.



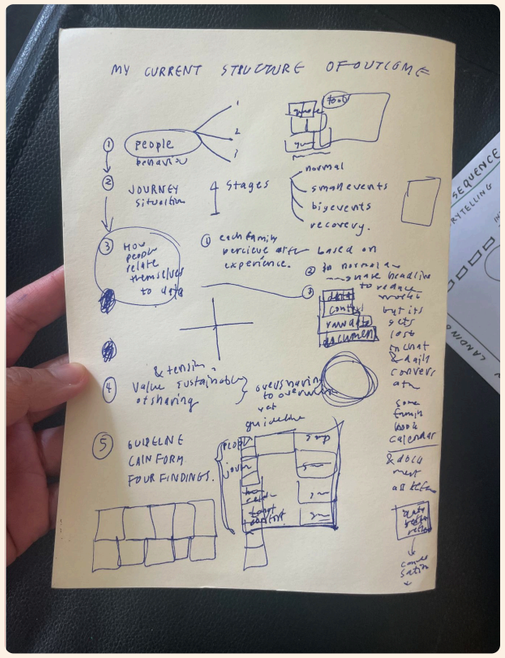


Figure: Quick handsketch Wireframe and content structure before moving to prototyping on Webflow