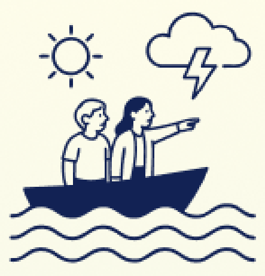
Living in Data, Together



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

Key Findings

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

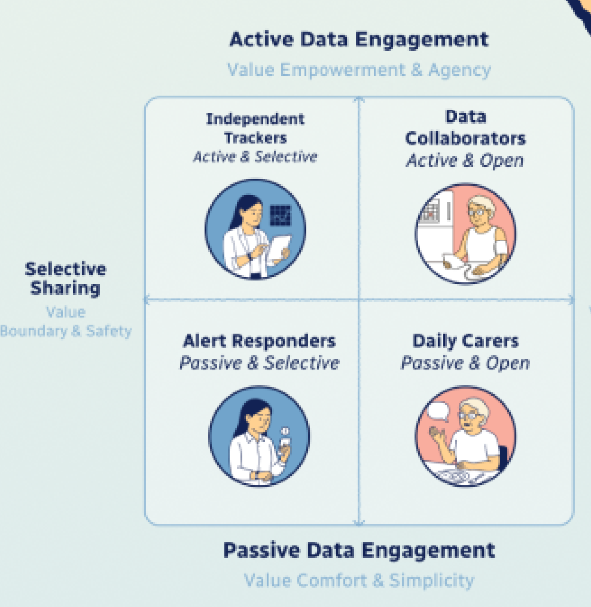
Three Perspectives on Family Health Data Sharing

1

The People On Board

Not Everyone Shares the Same Way (And That's Okay)

Health phases change, placing families in the same boat to navigate different situations together. We found that health data sharing is shaped by two key dimensions: **data intimacy** *(open vs. selective)* **and data engagement** *(active vs. passive)*. When these intersect, they create **four distinct sharing patterns** that describe different family behaviors. **These patterns aren't fixed—**families continuously adapt their health data sharing practices to changing health situations and life transitions.



Active Data Engagement
Value Empowerment & Agency

Independent Trackers
Active & Selective

Data Collaborators
Active & Open

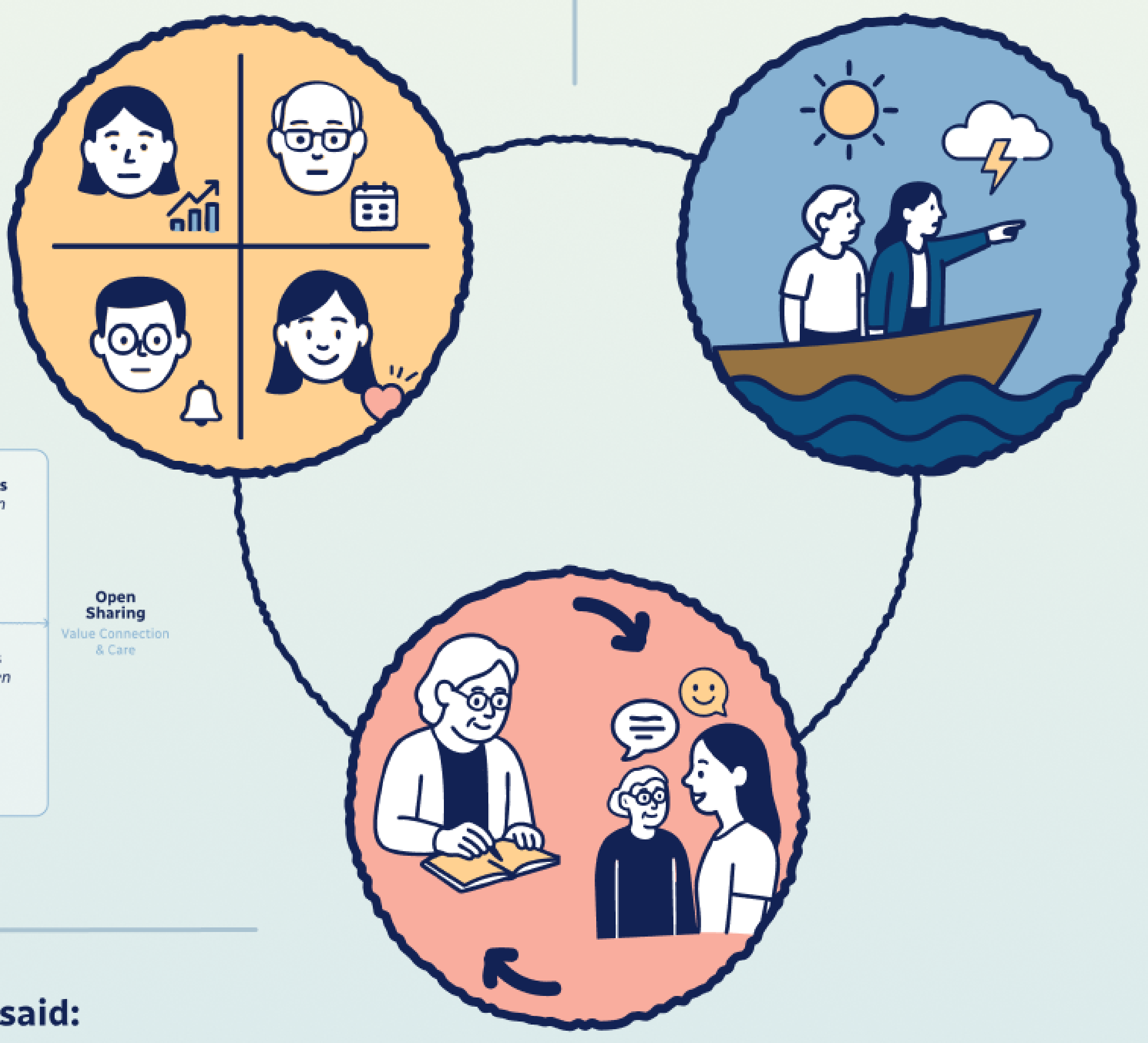
Alert Responders
Passive & Selective

Daily Carers
Passive & Open

Selective Sharing
Value Boundary & Safety

Open Sharing
Value Connection & Care

Passive Data Engagement
Value Comfort & Simplicity



2

Riding the Waves

Health Situations Shape What and How Families Need to Share

Second, health unfolds over time. Families navigate chronic conditions as a journey with four phases, *each requiring different levels of attention and involvement.* These phases don't follow a straight line—families move back and forth as circumstances change. ***Health Changes Over Time, Shouldn't Data Sharing Adapt Too?***

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

3

The Cabin & Shared Deck

Lived Experiences Alongside with Numbers: From Personal Reflection to Shared Health Data

Third, health data becomes meaningful by bringing personal reflection from private spaces into shared spaces. Sharing health data isn't about perfect tracking—it's about sustaining ongoing conversations and mutual understanding that evolves with long-term relationships and chronic health conditions.

What participants said:

> *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**

> *I think one thing, but when I look in the mirror, I see the reality. Okay, it's like a mirror, right? And that's true, because I'm looking at my own data, but I'm also seeing it reflected back at me.*
> **– Dolly (mom)**

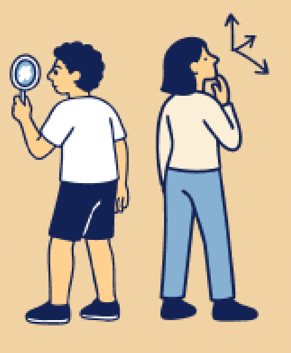
> *"The point is, having everything related to this one topic in one place matters. I want it to be separated from general conversations so it's easier to go back and review."*
> **– J. (Daughter)**

How Might We Design For Relational Use in Health Data?

Pillar 1: Designing with Relationships

Pillar 2: Designing with Changing Health Situations

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



Reflect Imagine

These three perspectives revealed key design implications, leading to eleven principles organized under three pillars for relational use in health data design.

Use them as lenses for reflection—consider your experiences with current digital health tools, then imagine how we might share data differently with relationships in mind.

While grounded in Thai adult-child pairs managing metabolic conditions, these principles have potential for broader application across different cultural settings and close relationships.

Approach & Methodology

This work builds on the philosophies of data humanism (Lupi, 2017) and data intimacy. **Data humanism** challenges the idea that data is neutral or universal, exploring instead how health data becomes meaningful through the relationships and contexts families create together. For this project, **data intimacy** means a sense of closeness that emerges when personal data is shared with intention and trust, with potential to support family members to connect, understand, and care for one another.

This research explores **how Thai adult-child pairs** (n=8) **managing metabolic condition**s like *diabetes, high blood pressure, and high cholesterol* share health data and how they could share it better. Working with adult children and their parents through **participatory design sessions with context mapping methods,** we looked at how they currently share health data and co-designed possible ways to share health data with each other across the changing phases of chronic care.

Particpatory Design Activities within Two Cycles

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

Explore Waveof Care Website

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Living in Data, Together:
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Design for Interaction, Medi

Committee
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