Human-centered design

Introduction and examples

Presented to: CCCR-CTRIS NIAMS P30
Presented on: Nov 15, 2022
Presented by: Andrew Berry, Assistant Professor, Medical Social Sciences
Outline

• Brief introduction to human-centered design
• Examples of HCD in my research
  – Co-design workshops with patients with multiple chronic conditions, caregivers, clinicians
  – Iterative paper prototyping with patients with multiple chronic conditions
Introduction to Human-Centered Design

• Why is HCD needed?
• What is HCD?
• How does one do HCD?
Why is human-centered design needed?

• Design is everywhere, and it has serious implications for people’s well-being
  – People who use technologies, products, services
  – Other direct and indirect stakeholders who aren’t users
  – Examples: Facebook, medical billing, highway infrastructure

• Design enables us to examine an existing situation, and change it into a preferred one

• HCD provides principles and methods to ensure we do this capably and responsibly
Why is human-centered design needed in health-related research and practice?

• When key stakeholders are not included in the design, development, and evaluation of products (e.g., health information technologies), end users perceive those technologies as less usable and acceptable
  – E.g., many, many papers from the 2000s and 2010s examining EHRs and documenting workflow disruptions, patient safety issues, and provider burnout, and more.

What is HCD?

Courage & Baxter. Understanding Your Users: a practical guide to user requirements.

• “…a product development approach that focuses on the end users of a product.” (p. 3)
• “…the product should suit the user, rather than making the user suit the product.” (p. 3)
• Principles of user-centered design (p. 4)
  – An early focus on users and tasks; involve users from the product’s inception
  – Empirical measurement of product usage
  – Iterative design; product is designed, modified, and tested repeatedly
What is HCD?

• An iterative approach to designing products and/or services that engages potential users and other stakeholders in the design process
  - understanding the context of use
  - defining design requirements
  - generating possible solutions
  - evaluating solutions with feedback from stakeholders (e.g., users)

Anticipating consequences (benefits and harms) and planning accordingly
The dark arrows show a general tendency toward a cyclical process, with the color coding of the titles indicating activities of similar types. In real life, as is illustrated by the project shown in the green sequence, the pattern is complex and less orderly than a clockwise cycle.
What is HCD?

...ever evolving

• A set of ethical commitments
  - Ensuring accessibility and inclusivity
  - Facilitating voice and building power among people who are marginalized
  - Surfacing and challenging systems of oppression, including race, class, gender

  e.g.,
  Design Justice (Sahsa Costanza-Chock)
  Inclusive Design (Kat Holmes)
  Critical Fabulations (Daniela Rosner)
Multiple chronic conditions: a major public health concern

Buttorff, Ruder, & Bauman, 2017
Multiple chronic conditions: a major public health concern

71% of all healthcare spending
93% of Medicare spending
Multiple chronic conditions: a major public health concern

Diminished quality of life
Increased physical disability
More adverse drug events
Higher rates of mortality

(compared to single chronic conditions)
Gijsen et al., 2001; Patrick et al. 2000; Stewart et al. 1989
Competing demands and the importance of values

Competing demands
Difficult choices for health care priorities
Disease-specific guidelines may conflict
Bayliss et al 2003, Fried 2010

Discordant priorities
Patients and providers decide differently…
Zulman et al 2010, Junius-Walker et al 2011
…resulting in poorer health outcomes.
Patients’ values inform their health priorities.

To reach shared priorities for care, providers need to understand patients’ personal values.

How might we design support for patient-provider communication about patients’ personal values?
How might we design support for patient-provider communication about patients’ personal values?

**Understand key actors’ perspectives**

- Patient interviews
- Provider interviews
- Observations of clinic visits

**Design, build, evaluate, iterate**

- Co-design to frame the design space
- Iterative design and build of a working tool
### Personal values

**What a person considers important for their well-being and health**

<table>
<thead>
<tr>
<th>Abilities</th>
<th>Activities</th>
<th>Emotions</th>
<th>Possessions</th>
<th>Principles</th>
<th>Relationships</th>
</tr>
</thead>
<tbody>
<tr>
<td>mobility, mental</td>
<td>walking the dogs, reading</td>
<td>serenity, joy,</td>
<td>photographs, letters, home</td>
<td>spirituality,</td>
<td>family, friends,</td>
</tr>
<tr>
<td>sharpness</td>
<td></td>
<td>accomplishment</td>
<td></td>
<td>independence</td>
<td>social groups</td>
</tr>
</tbody>
</table>

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Lim et al. JGIM 2017, Berry et al. AMIA 2017
Takeaway:
Communication boundaries are mutually reinforced by patients and providers

- **Patients** withhold values they perceive as not pertinent to their health
- **Providers** aim to understand patients’ values, but employ values to serve medical priorities

...it takes **work** for patients and providers to establish the pertinence of values to health care and operationalize them in care planning
How might we design support for patient-provider communication about patients’ personal values?

Understand key actors’ perspectives
- Patient interviews
- Provider interviews
- Observations of clinic visits

Design, build, evaluate, iterate
- Co-design to frame the design space
- Iterative design and build of a working tool
Part I: Envisioning ideal futures

- Future workshop
  - 5 groups patients/caregivers
  - 3 groups of providers
- Storyboarding workshop

Part II: Scrutinizing ideal futures

- Thematic analysis
- Design of concepts
- Focus groups
  - 3 groups patients/caregivers
  - 3 groups of providers
“Future” Workshop

understand what is most important to patient’s well-being and health?

AGE

✓ Ice Breaker
✓ Reflection
✓ Problem Brokering
✓ Work on Themes

Ideation:
critiquing the present and envisioning ideal futures

Affinity diagramming and summary of themes
Storyboarding Workshop
Scenario sketches

Patient's home

Team member following up with phone call from patient

KP nursing home visit

2 hours

Script: 1. Scribe is entering inputting info in the computer.

Script: 2. Patient + Family

Script: 3. Relationships + Emotions + Abilities

Script: 4. For care record
Future workshop
Storyboarding workshop

Part I: Envisioning ideal futures
5 groups patients/caregivers
3 groups of providers

Part II: Scrutinizing ideal futures
Design of concepts
Focus groups
3 groups patients/caregivers
3 groups of providers
Design dimensions

Explicitness
Deliberate and direct elicitation vs. values emerging spontaneously in conversation

Scale
The number and type of people engaged in the conversation about values.

Synchrony
Real time discussion or segmented

Intimacy
Values shared and heard in a personal, caring context vs. impersonal one.

Guidance
Level of support and direction given to patients to spur patients to share values.

Effort
Burden patients or care team members associate with how values are shared, collected, or reviewed.

Disclosure
Degree to which patient controls what information is elicited or collected, and with whom that information is shared.
Future workshop + Storyboarding workshop → Thematic analysis → Design of concepts → Focus groups

Part I: Envisioning ideal futures
- 5 groups patients/caregivers
- 3 groups of providers

Part II: Scrutinizing ideal futures
- 3 groups patients/caregivers
- 3 groups of providers
In his last visit with Pete’s doctor, she mentions that she would like to learn about what he considers important to his well-being and health. She gives him a wearable clip and asks him to wear it for one month.

The clip can track Pete’s location, movements, and capture video and photographs of how he spends his day. The clip records everything Pete does, who he spends time with, and what he says.

Pete can also push buttons on the clip to create audio recordings, short videos, and photos of anything he definitely wants to share.

Everything the clip records is analyzed by an automated system, and this information is visualized to depict Pete’s values.

Based on the information presented to her, Pete’s doctor and the rest of the care team are able to get a sense of what is most important to Pete’s well-being and health.

Pete and his doctor discuss his values together. This discussion helps them plan Pete’s care to best meet what is important to his well-being and health.
Focus group findings

**Explicitness**  
Deliberate and direct elicitation vs. values emerging spontaneously in conversation

**Scale**  
The number and type of people engaged in the conversation about values.

**Synchrony**  
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Level of support and direction given to patients to spur patients to share values.

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Takeaways

• Design dimensions characterize the design space for supporting communication about values.

• They are a generative resource for further systematic exploration of the design space.

• Need to develop multiple ways of supporting communication about values to cater to varying preferences.
Supporting Communication About Values Between People with Multiple Chronic Conditions and their Providers

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ABSTRACT
People with multiple chronic conditions (MCC) often disagree with healthcare providers on priorities for care, leading to worse health outcomes. To align priorities, there

KEYWORDS
Co-design, multiple chronic conditions, multimorbidity, patient-provider communication
How might we design support for patient-provider communication about patients’ personal values?

Understand key actors’ perspectives

- Patient interviews
- Provider interviews
- Observations of clinic visits

Design, build, evaluate, iterate

- Co-design to frame the design space
- Iterative design and build of a working tool
Supporting Collaborative Reflection on Personal Values and Health

Andrew Berry, Catherine Lim, Calvin Liang, Andrea Hartzler, Tad Hirsch, Dawn Ferguson, Zoë Bermet, and James Ralston
Outline

Exploring how to support **collaborative reflection** on relationships between personal **values** and health for people with **multiple chronic conditions**

- PROBLEM & MOTIVATION
- PROTOTYPE DESIGN & FUNCTION
- KEY EMPIRICAL FINDINGS
- DESIGN GUIDELINES
Key gaps and research question

• Need to help patients see connections between personal values and health
• Reflective conversations help (Catherine Lim et al. CHI 2019)
• Not clear how to design interactive systems to support this reflection, and how to balance this with human facilitation

Research question

How can collaborative reflection, supported by interactive information systems, enable patients to identify and articulate relationships among personal values and health?
What do we mean by reflection on values and health?

**Reflection**: a process through which people with MCC gain self-knowledge about their personal values, self management of health, and associations among topics from these categories (draws on Baumer et al. 2014)

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**Personal values**
What a person considers important for their well-being and health, including abilities, activities, emotions, possessions, principles, and relationships (Lim et al. JGIM 2017, Berry et al. AMIA 2017)

**Self-management work**
Work to prevent or attenuate the course of illness complications, including illness work (e.g., taking meds), everyday life work (e.g., keeping a job), and biographical work (e.g., coping with life changes due to illness) (Corbin & Strauss 1985, 1988)

**Health status indicators**
Common outcome measures that clinicians use to gauge how well a chronic condition is being managed and/or how it is progressing (e.g., blood sugar, blood pressure, cholesterol level, foot sensitivity)
Approach, Methods, and Prototype Design
### Design process: ideation, analysis, iteration
Grounded in our prior research involving people with multiple chronic conditions (e.g., Berry et al. CHI 2019, Lim et al. CHI 2019)

### Implemented three paper prototypes
Paper-based interactive wireframes. Rationale for choosing 3 is included in the paper.

### Tested prototypes with 12 people with MCC
Personalized each prototype with data elicited from participants prior to testing session: personal values, self-management duties, health status indicators
Prototypes

Three approaches to collaborative reflection on values and health

My List:
Create a list of topics to discuss with your doctor, aligned with your values

Conversation Canvas
Talk through an important topic with a facilitator and a shared visual space

Time Machine
Reflect on your values and health today, in the past, and in the future
### Personal values

**PART 1**

**What is most important to your well-being and health?**

Understanding what you consider most important to your well-being and health is central to this study. To help guide your thinking, we include below examples we have heard from others. There are no right or wrong answers. Please write your responses below and use your own words to tell us what is most important to you.

<table>
<thead>
<tr>
<th>Activities: pursuits or things that you do (ex: vegetable gardening, working, reading sci-fi novels, or resting)</th>
<th>Possessions: things that belong to you (ex: your car, pictures of family members, letters from friends, or your home)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationships: connections with other people or groups (ex: family, companions, or church group)</td>
<td>Emotions: feelings or moods your experience (ex: comfort, joy, relief, or accomplishment)</td>
</tr>
<tr>
<td>Principles: beliefs, standards, or virtues you live by (ex: independence, honesty, faith)</td>
<td>Abilities: physical or mental capacities or skills (ex: mental sharpness, mobility, vision)</td>
</tr>
</tbody>
</table>

### Self-management work

**PART 2**

**What do you do in your daily life to manage your well-being and health?**

Understanding what you do to manage your health is also important to this study. To help guide your thinking, below are examples we have heard from others. There are no right or wrong answers. Please use your own words to tell us what tasks you do to manage your health.

**Examples of tasks for managing health**

- Keeping track of your health conditions, such as measuring your blood sugar level or blood pressure.
- Housekeeping, preparing meals, running errands.
- Exercising, such as walking outside, yoga, or water aerobics.
- Following a specific diet.
- Taking medications, such as pills, insulin, using an inhaler.
- Taking care of others, raising children, tasks you do for family.
- Managing emotions, such as coping with anger, fear, frustration, or depression.
- Discovering new ways of finding fulfillment.
- Adjusting how daily tasks are done due to health or other changes.

Write your responses below.

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Approach to facilitation

Participants used each prototype in the presence of a facilitator

• Each session facilitated by two research team members
  - Lead: informed consent, explained prototype, asked participant to think out loud, offered guidance about how to operate prototype; depending on prototype, may ask probing questions to encourage reflection
  - Supporting: mostly focused on operating the prototypes (swapping in screens, storing data to “database”, etc., but also may ask probing questions
• We expected different prototypes to require different types of facilitation
  - Generally, facilitation was flexible to each participant’s perspectives and needs
  - Some prototypes were more participant-led, while others were more facilitator-led
• See Methods for details; see Discussion for facilitation as a key consideration in designing support for collaborative reflection on values and health
<table>
<thead>
<tr>
<th>ID</th>
<th>Prototypes in order used</th>
<th>Education</th>
<th>Race, Ethnicity</th>
<th>Age</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>My List</td>
<td>High school or less</td>
<td>Black or African American</td>
<td>86</td>
<td>Man</td>
</tr>
<tr>
<td>P2</td>
<td>My List, Conversation Canvas</td>
<td>More than high school</td>
<td>White or Caucasian</td>
<td>75</td>
<td>Man</td>
</tr>
<tr>
<td>P3</td>
<td>My List, Conversation Canvas</td>
<td>More than high school</td>
<td>Black or African American and Hispanic</td>
<td>63</td>
<td>Woman</td>
</tr>
<tr>
<td>P4</td>
<td>My List, Time Machine, Conversation Canvas</td>
<td>High school or less</td>
<td>White or Caucasian</td>
<td>58</td>
<td>Woman</td>
</tr>
<tr>
<td>P5</td>
<td>My List, Conversation Canvas, Time Machine</td>
<td>High school or less</td>
<td>Asian</td>
<td>78</td>
<td>Woman</td>
</tr>
<tr>
<td>P6</td>
<td>My List, Time Machine</td>
<td>More than high school</td>
<td>Asian</td>
<td>76</td>
<td>Woman</td>
</tr>
<tr>
<td>P7</td>
<td>My List, Time Machine, Conversation Canvas</td>
<td>More than high school</td>
<td>White or Caucasian and Native Hawaiian or Pacific Islander</td>
<td>79</td>
<td>Woman</td>
</tr>
<tr>
<td>P8</td>
<td>Time Machine, Conversation Canvas</td>
<td>More than high school</td>
<td>White or Caucasian</td>
<td>72</td>
<td>Woman</td>
</tr>
<tr>
<td>P9</td>
<td>My List, Time Machine</td>
<td>More than high school</td>
<td>White or Caucasian</td>
<td>72</td>
<td>Man</td>
</tr>
<tr>
<td>P10</td>
<td>My List, Time Machine</td>
<td>High school or less</td>
<td>White or Caucasian</td>
<td>66</td>
<td>Man</td>
</tr>
<tr>
<td>P11</td>
<td>My List, Conversation Canvas</td>
<td>More than high school</td>
<td>White or Caucasian</td>
<td>75</td>
<td>Man</td>
</tr>
<tr>
<td>P12</td>
<td>Time Machine, Conversation Canvas</td>
<td>High school or less</td>
<td>White or Caucasian and Hispanic</td>
<td>65</td>
<td>Woman</td>
</tr>
</tbody>
</table>
**My List**

Create a list of topics to discuss with your doctor, aligned with your values

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### Adding an item
**What do you want to discuss with your healthcare provider?**

- Item name: 

**Which of the topics below are related to this item, if any?**

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#### A PERSONAL VALUES

Which of your personal values are affected by or connected to this item? Select any number that apply.

- Losing 60 lbs after better nutrition and exercise
- Silver sneakers

---

#### B SELF-CARE DUTIES

Which of these self-care duties are related or affected by the item you’d like to discuss? Select any number that apply.

- Taking medication for blood pressure
- Measuring blood pressure with cuff
- Biking
- Water aerobics

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#### C HEALTH STATUS INDICATORS

Which of these indicators are related or affected by the item you’d like to discuss? Select any number that apply.

- Retinal exam
- LDL cholesterol level
- Blood pressure

---

**Save item to list**
MY LIST

Create a list of concerns to discuss at your next appointment with your healthcare provider.

Make sure your list honors the things you consider most important for your well-being and health.

Create a new list
Create a list of topics to discuss with your doctor, aligned with your values

• Supports visit preparation, a familiar activity
  – Helps organize thinking and develop health priorities
  – Could serve as a memory aid during visit
  – Could help anchor the conversation with doctor, boost patient agency

• Did not overcome well-documented communication boundaries (Lim et al. 2016)
  – People still filtered down what they shared based on what they thought doctors wanted or needed to hear
“...once I write it down on paper or on the computer screen, once it’s there in front of me, then I can think about **enlarging the thought**, adding to the concept...it’s there and I’m thinking about it. Because I forget everything, and for me, something that’s written down allows me to not forget, or **even if I do forget, it’s still written down** and I can use this before I go to the doctor’s.” (P9)

“I think that lets them know I’m interested in retiring but I don’t want to sit around and do nothing...we want to **stay as active as possible**...I think that’s important. I think doctors sometimes **set in their mind what they think you want** but they don’t know what you want...but I think it’s important that they know what you would like to do or what you would like to keep doing.” (P4)
Conversation Canvas
Talk through an important topic with a facilitator and a shared visual space

You connected with: Michael
Michael is a registered nurse at a primary care clinic in Madison, WI. He also has five years of experience as a volunteer social worker. He loves spending time with his family, painting, and having friends over for board game nights.

Choose a topic
- I'm thinking through an important life decision
- I'm not able to do something important to me because of my health
- Something major changed in my life

Figure 2 shows the most important screens from the interaction described above. At the top left is a description of one of the two facilitator personas, Michael, which includes his clinical experience and a few details about his hobbies. Below that is the pop-up inviting the user to select a conversation topic. At the right are three screens the user will see as the facilitator guides them through selecting items related to the conversation topic; there is one screen each for personal values, self-care duties, and health status indicators.

4.4 Prototype 3: Time Machine
Time Machine invites patients to assess how their attitudes toward values, self-care duties, and health status indicators have changed over time. It uses information visualization to plot changes over time and invite reflection on those changes.

4.4.1 Rationale.
We chose this prototype primarily because of its explicitly temporal nature. It allowed us to understand how patients react to prompts to reflect on values and health in the past, present, and future. Additionally, this prototype draws on techniques used in personal informatics applications intended to foster reflection. The flow of this activity is inspired by Li et al.'s stage-based model of personal informatics systems, including preparation, collection, integration, reflection, and action. Time Machine maps to these stages as follows: preparation is completed...
Conversation Canvas

Living with long-term health conditions can make life complicated. Sometimes talking through what's on your mind with an active listener can bring some clarity.

In this activity, you will have a live video conversation with a trained health worker. They will help you talk through something that has been on your mind, and help you understand how different aspects of your life and health care are involved.

During this conversation, the health worker will add items to a virtual canvas that you can see. At the end of the conversation, the canvas will show how different aspects of your life are related. This will help you see the big picture and reflect on how things are going for you.

Connect with a health worker
Conversation Canvas - Findings

Talk through an important topic with a facilitator and a shared visual space

• Externalization supported participant and facilitator
• Emotionally satisfying to talk through and be heard
  - But for some, this generated difficult emotions
• Helped people reach clarity about situation and priorities
  - But some lamented lack of clear conclusion
• Deeper reflection facilitated by probes
  - Helpful when personalized and contextualized
“[I] got a lot off [my] chest about this damn liver transplant. . . [It] let me set everything straight. And it also made me think, ‘What more can I do?’” P3

“It’s like getting your feelings out. Like when you have troubles and they say it lifts a burden off your shoulders or off your mind?” P12

“I’m digging into my own thoughts deeper than I normally would, and then sharing that. Not quite like going to confession but maybe close. . . But I liked the [My List] system a little better.” (P11)

“I’m looking for advice. I am looking for some validation. . . I am amazed that this would allow me that kind of time with a medical professional to go through my problem...But I’m also amazed that I didn’t get [something more].” P2
bone-to-bone in my legs. don't want liver transplant - want at least one of my knees fixed

risk of bleeding platelets
kidney liver transplant dialysis

cadillac (walker) trying to start swimming

explaining the decision to my kids
taking my medications keeping track of all these appointments

liver for someone younger being able to dance

last foot exam: hemoglobin alc: 4.5%
Time Machine

Reflect on your values and health today, in the past, and in the future.

Let's start with TODAY.
Select a PERSONAL VALUE you’d like to spend time thinking about.
- Losing 50 lbs after better nutrition and exercise
- Silver sneakers
- Water aerobics
- Moving things to my apartment
- Health coach
- Riding my bicycle
- Do more at home

Select a SELF-CARE item you’d like to spend time thinking about.
- Taking medication for blood pressure
- Measuring blood pressure
- Cleaning the house, doing the dishes
- Being careful, tire marks
- Preparing meals, planning ahead
- Bike ride

Select a HEALTH STATUS indicator you’d like to spend time thinking about.
- Hemoglobin A1c
- Blood pressure
- Foot exam
- HDL cholesterol level
- LDL cholesterol level
- Retinal exam
+ add new

Northwestern Medicine
Feinberg School of Medicine

11/14/22
Welcome to your personal time machine.

Think about what is important to your well-being and health today, yesterday, and tomorrow.

Get started
Looking across time

- Preparing meals, planning ahead
- Helping others (ex: giving rides)
- Staying away from tough emotions
- Hemoglobin A1c
- Keeping busy, healthy; bending, stooping, stretching
- PHQ9 score

What do you notice?

my depression keeps getting worse, but meals and helping others are steady.
Most change:
- Exercising hard and often
- Nutrition
- Blood pressure

Least change:
- Being a spiritual person
- Being careful about too many meds
- LDL cholesterol level

What do you notice?

I'm proud of big improvements to my nutrition and blood pressure.
Time Machine - Findings

Reflect on your values and health today, in the past, and in the future

- Some evidence of transformative reflection
  - Hope for the future
  - Considering changes to behavior, self-management
- Strong resistance to reflecting on the past
- Unsuccessful visualization
Discussion: Key Takeaways
## Design guidelines

Supporting collaborative reflection on personal values and health

<table>
<thead>
<tr>
<th>Explore</th>
<th>Open with exploratory, reflective conversation (patient + facilitator)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Map</td>
<td>Map the conversation as it progresses (externalize, visualize)</td>
</tr>
<tr>
<td>Conclude</td>
<td>Conclude by identifying key takeaways</td>
</tr>
<tr>
<td>Align</td>
<td>Align with established practices (clinical workflow)</td>
</tr>
</tbody>
</table>
### Key roles for interactive systems

Supporting collaborative reflection on personal values and health

<table>
<thead>
<tr>
<th>Personalized repository</th>
<th>Stores key information, including personal values, self-care duties, health status indicators, that can be consulted, selected from, added to as needed.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared information space</td>
<td>Scaffold collaborative reflection by creating a shared space for person with MCC and facilitator to progressively map out connections between values and health.</td>
</tr>
</tbody>
</table>
Choose a topic

Choose a conversation topic from the list below:

- I'm thinking through an important life decision
- I'm not able to do something important to me because of my health
- Something major changed in my life
Should I give up my home and move in with my daughter in Eastern Washington?
Catherine Lim
Design Researcher
KPWHRI (now 98point6)

Tad Hirsch
Professor, Design
Northeastern University

Andrea Hartzler
Associate Professor, BIME
University of Washington

James Ralston
Senior Investigator
KPWHRI

Linda Kiel
Project Manager
KPWHRI

Zoë Bermet
Project Manager
KPWHRI (now UW)

Dawn Ferguson
Design Researcher
KPWHRI (now Meta)

Evette Ludman
Researcher
KPWHRI
Questions?
Thank You