

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.

Ash JS, Berg M, Coiera E. Some Unintended Consequences of Information Technology in Health Care: The Nature of Patient Care Information System-related Errors. *Journal of the American Medical Informatics Association*. 2003 Nov 21;11(2):104–12.

Karsh B-T, Weinger MB, Abbott PA, Wears RL. Health information technology: fallacies and sober realities. *J Am Med Inform Assoc*. 2010 Nov;17(6):617–23.

What is HCD?

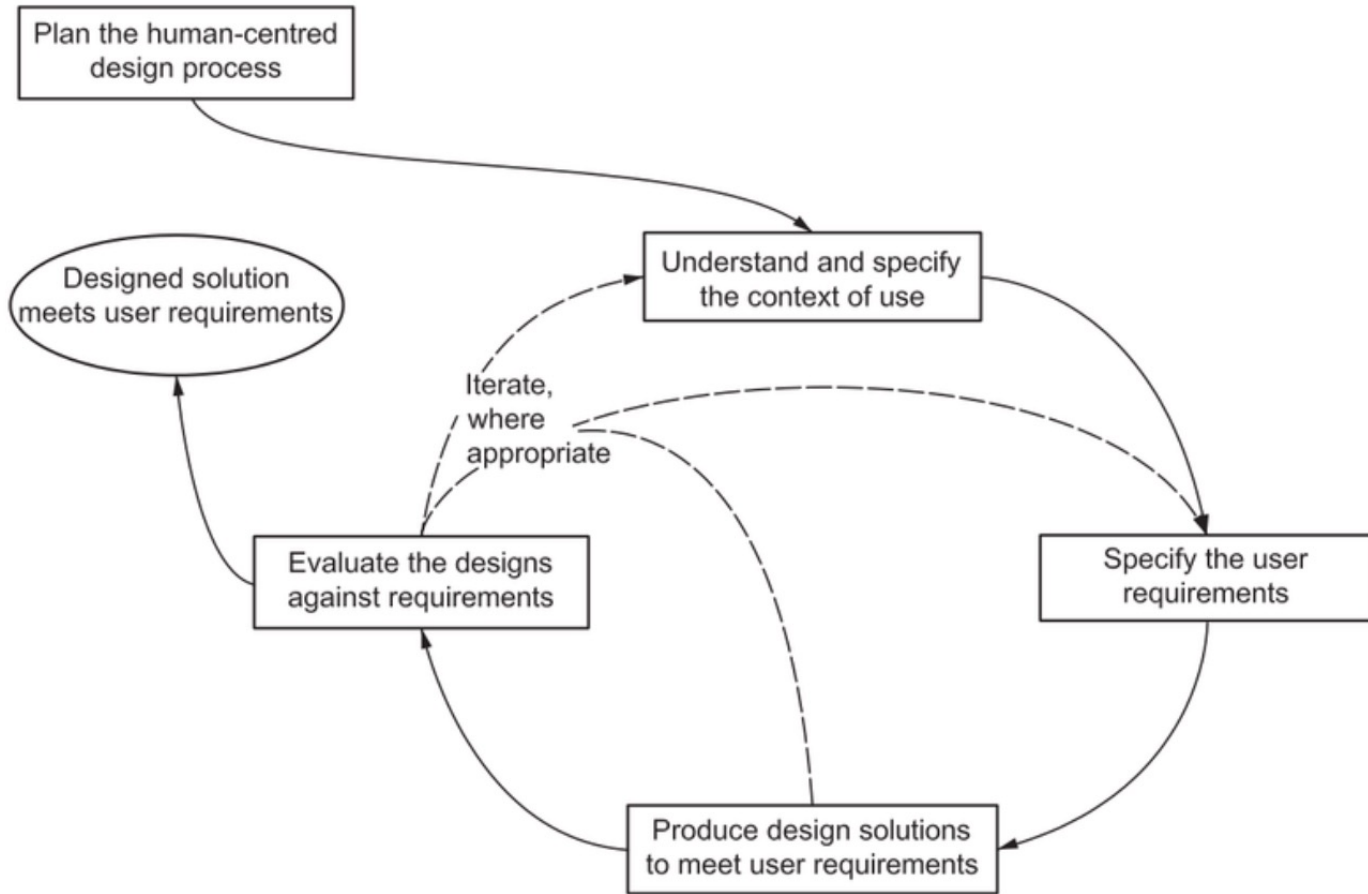
Courage & Baxter.: Understanding Your Users: a practical guide to user requirements.

- “...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



1. Concept

Competitive analysis
User requirements activities
Functional specification
Usability/UI development plan
Persona development

2. Design

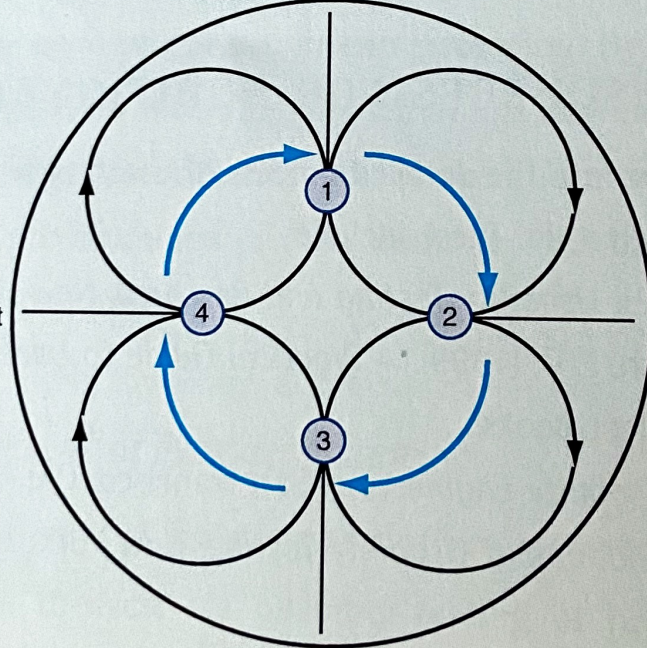
Information architecture
Graphics creation
Design specifications
Taskflows
Iterative UI design
Paper/pencil prototype
Realistic prototype (e.g. html)
User requirements activities
User evaluation
Heuristic evaluation

3. Develop

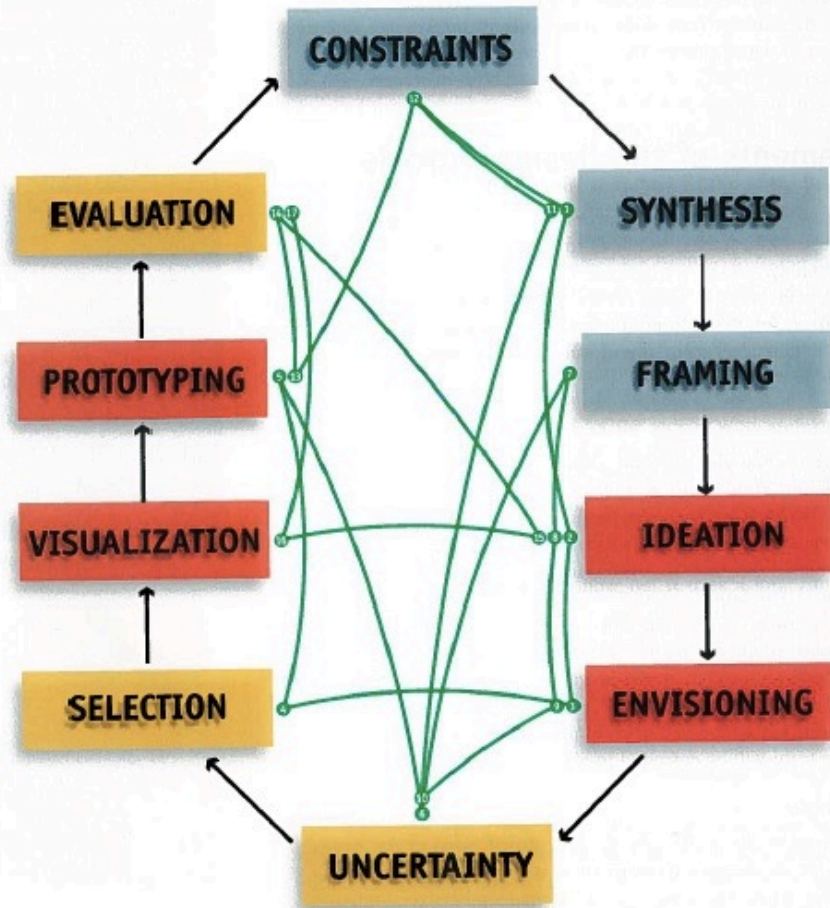
Formal usability test
Formal design review
Heuristic evaluation

4. Release

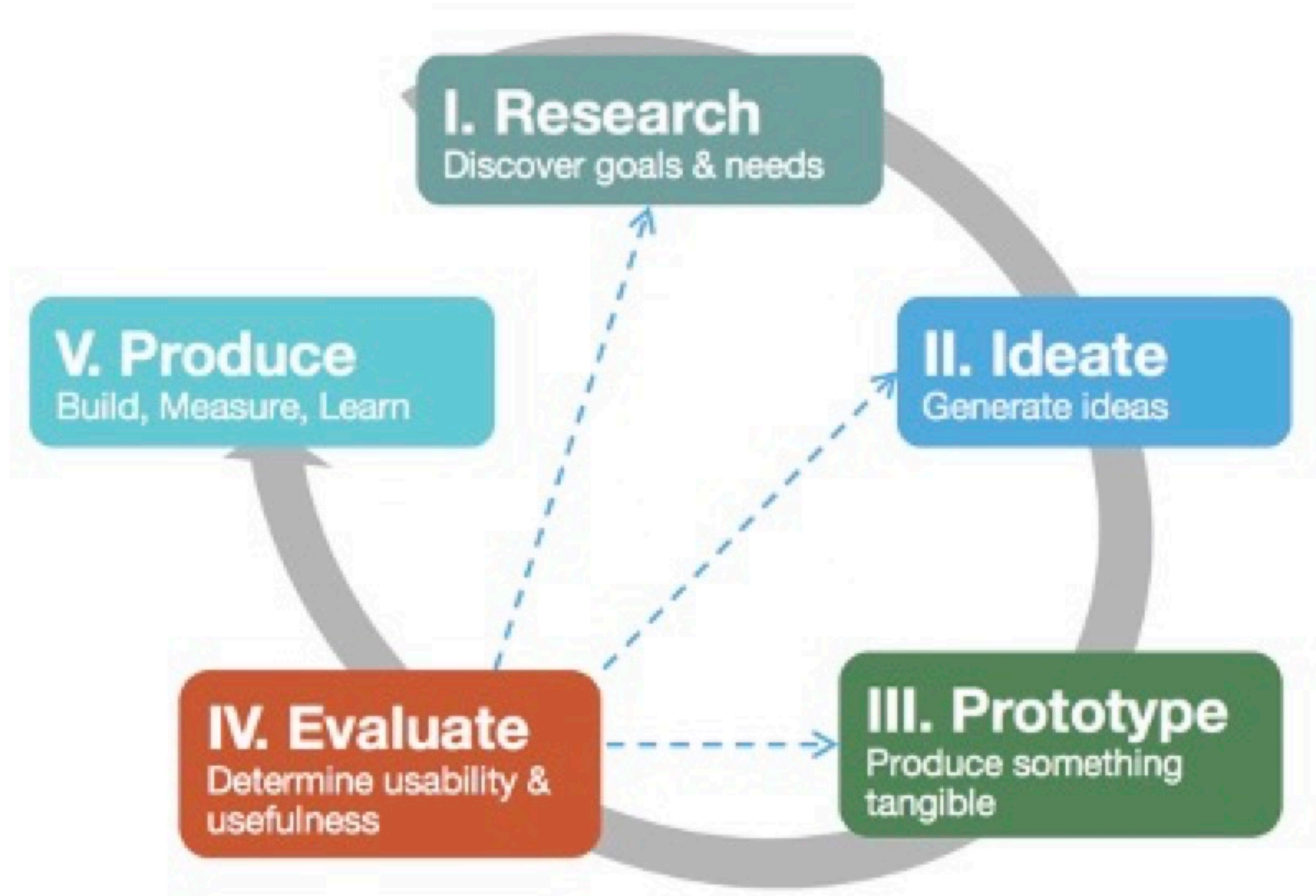
Competitive usability test
Benchmark test



Courage C, Baxter K.
Understanding your users: A
practical guide to user
requirements methods,
tools, and techniques. Gulf
Professional Publishing;
2005 Jan 11.



Moggridge B,
Atkinson B.
Designing
interactions.
Cambridge: MIT
press; 2007 Oct.



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.,

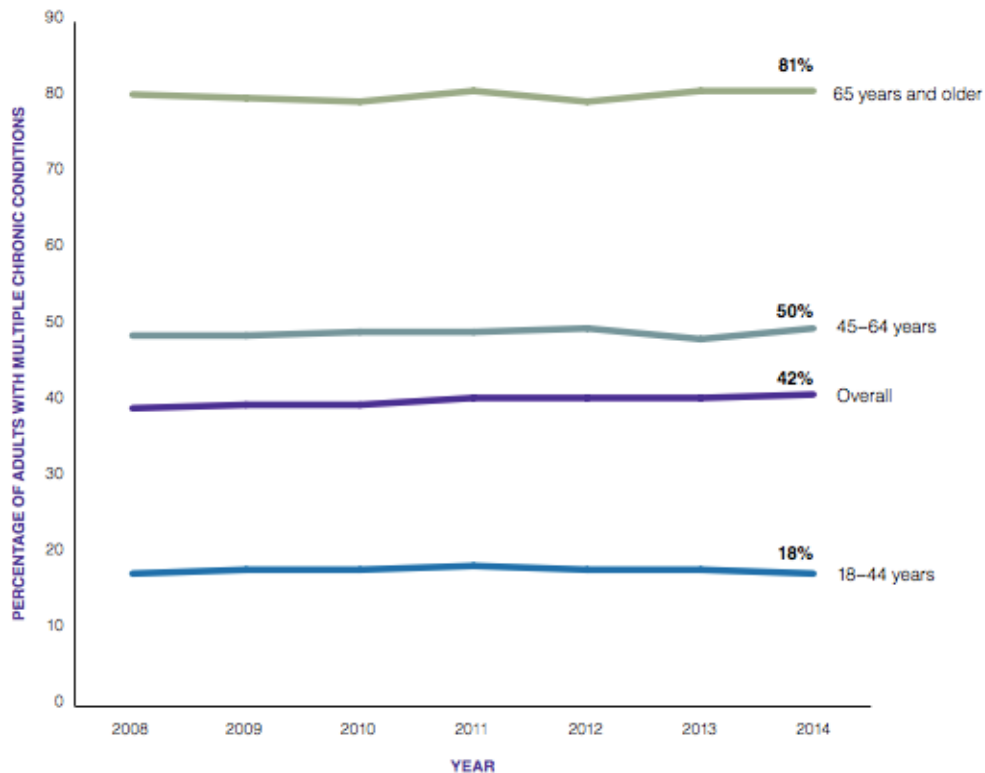
Design Justice (Sahsa Costanza-Chock)

Inclusive Design (Kat Holmes)

Critical Fabulations (Daniela Rosner)

Multiple chronic conditions: a major public health concern

Figure 1.2. Prevalence of Multiple Chronic Conditions, by Age (2008–2014)



Multiple chronic
conditions:
a major public
health concern

71% of all health
care 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



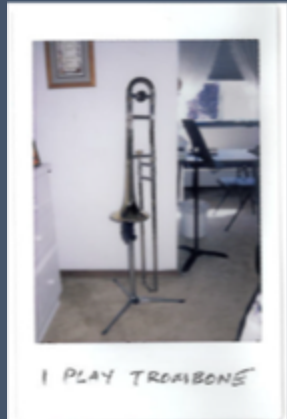
Co-design to frame the design space



Iterative design and build of a working tool

Personal values

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



Abilities

mobility, mental sharpness



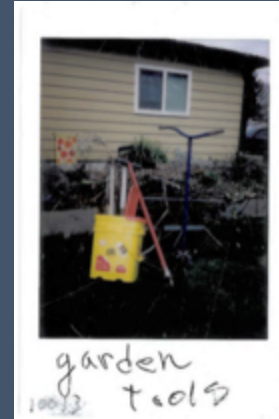
Activities

walking the dogs, reading



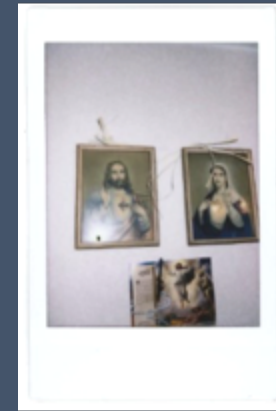
Emotions

serenity, joy, accomplishment



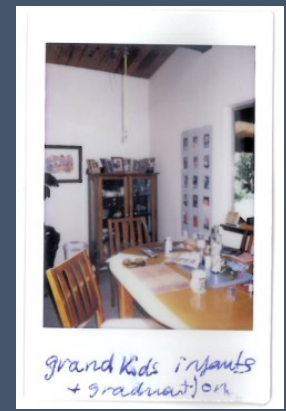
Possessions

photographs, letters, home



Principles

spirituality, independence



Relationships

family, friends, social groups

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

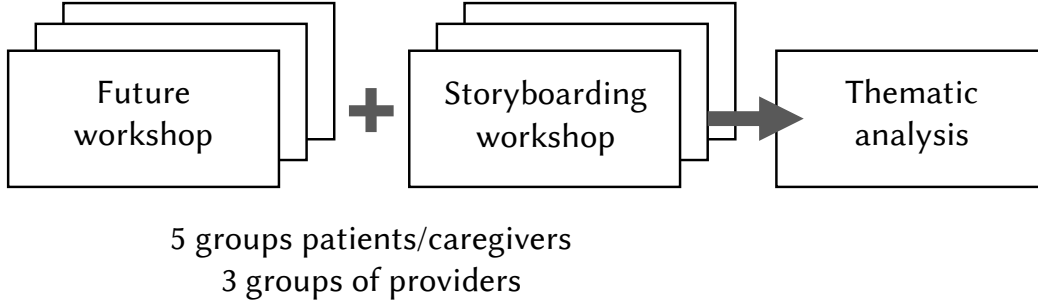


Co-design to frame the design space

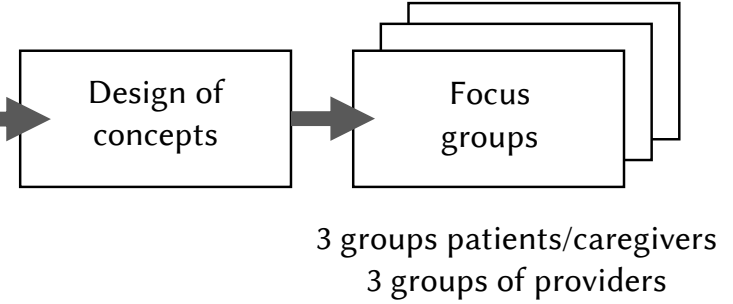


Iterative design and build of a working tool

Part I: Envisioning ideal futures



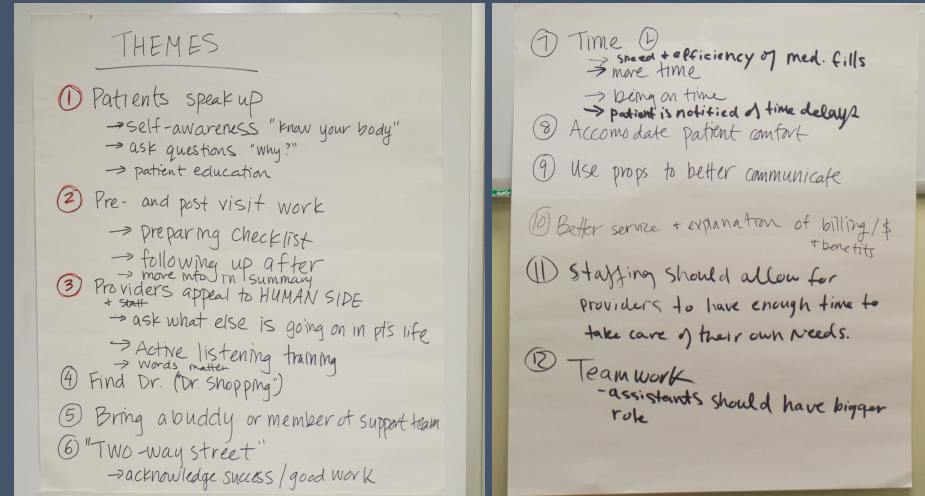
Part II: Scrutinizing ideal futures



“Future” Workshop

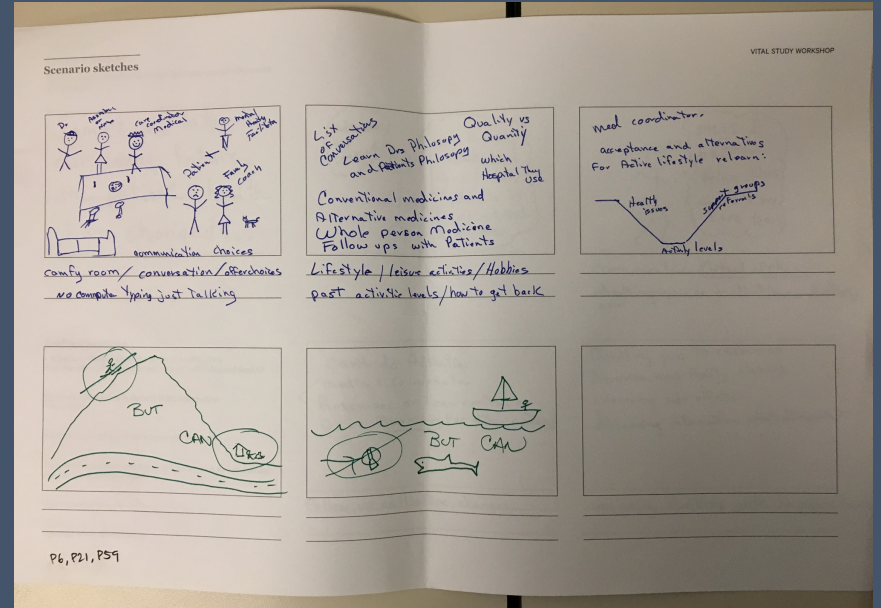


Ideation:
critiquing the present and
envisioning ideal futures

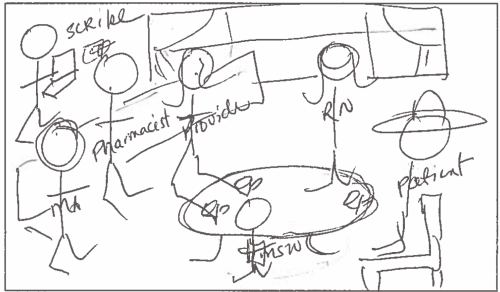


Affinity diagramming and
summary of themes

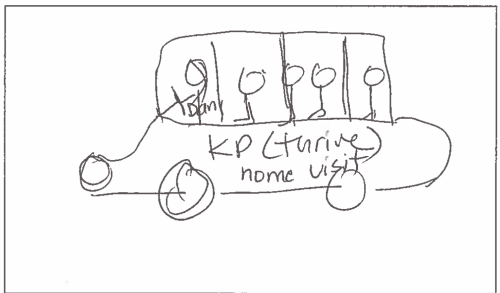
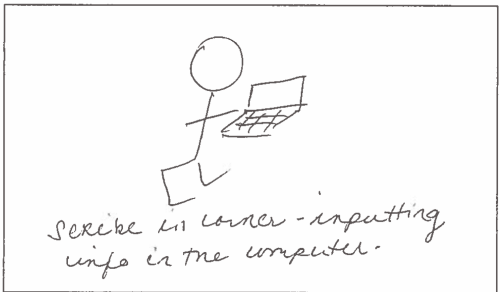
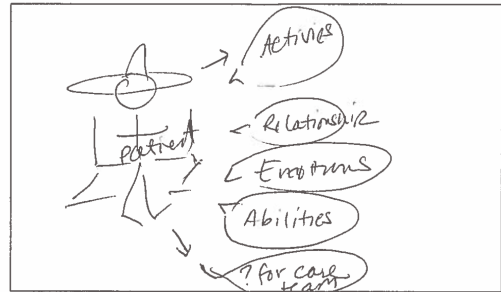
Storyboarding Workshop



Scenario sketches



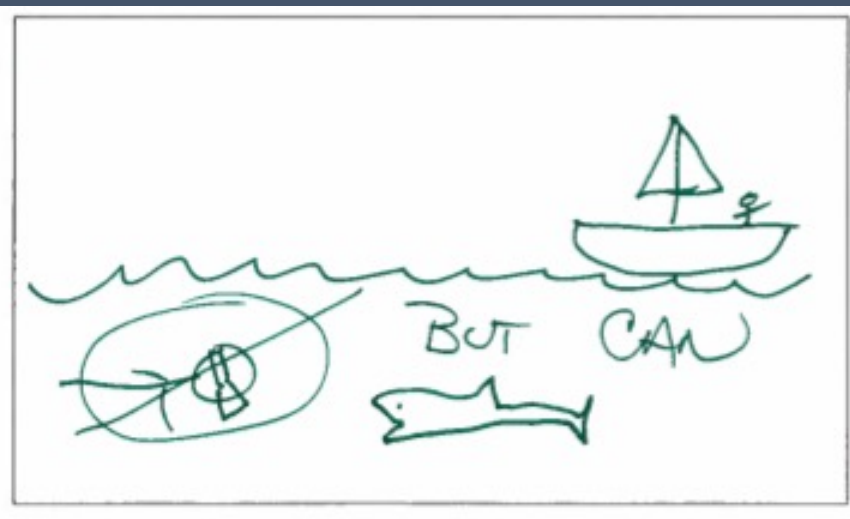
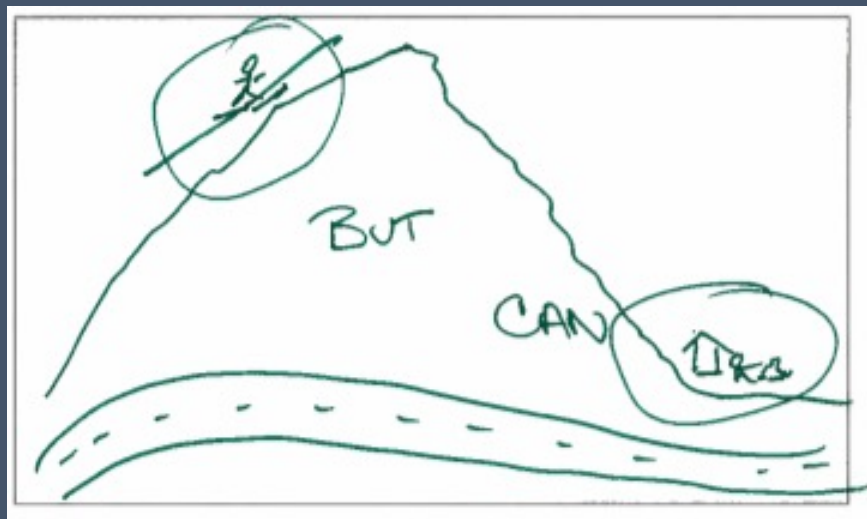
Patient's home

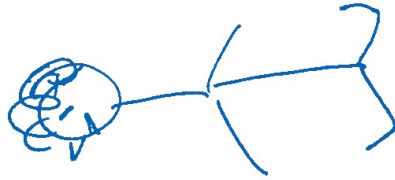


2 hours



Team member following up with phone call/ email

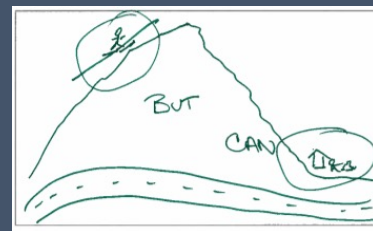
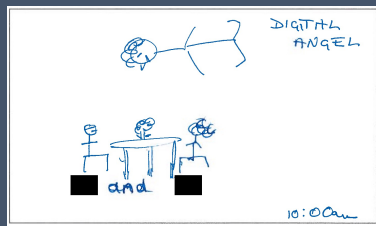




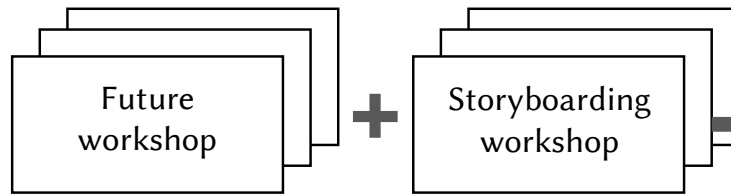
DIGITAL
ANGEL



10:00am



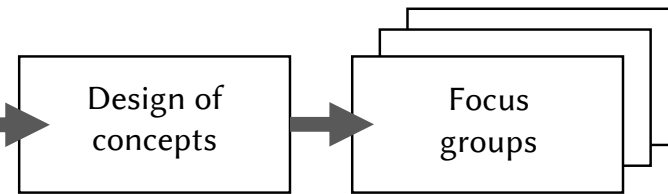
Part I: Envisioning ideal futures



5 groups patients/caregivers
3 groups of providers

Thematic
analysis

Part II: Scrutinizing ideal futures



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.

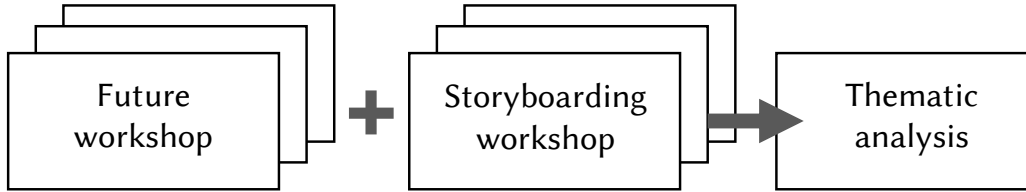
Effort

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

Disclosure

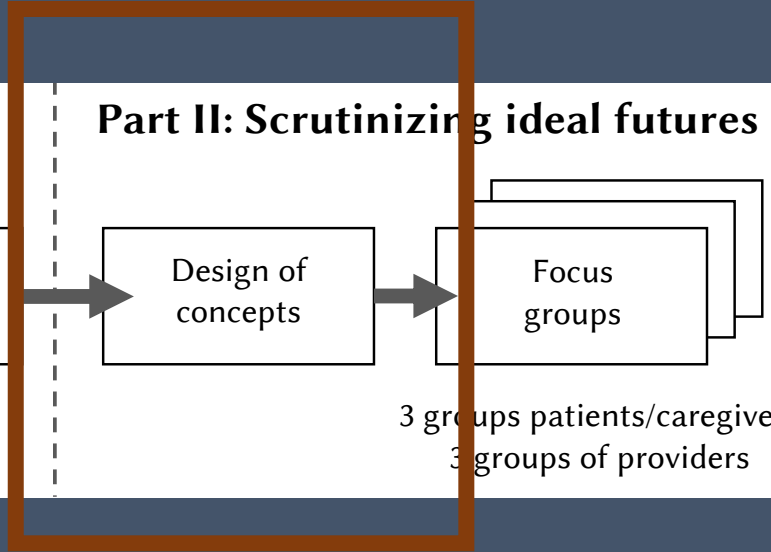
Degree to which patient controls what information is elicited or collected, and with whom that information is shared.

Part I: Envisioning ideal futures

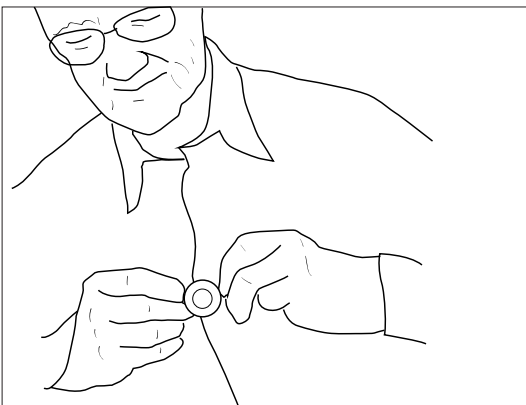


5 groups patients/caregivers
3 groups of providers

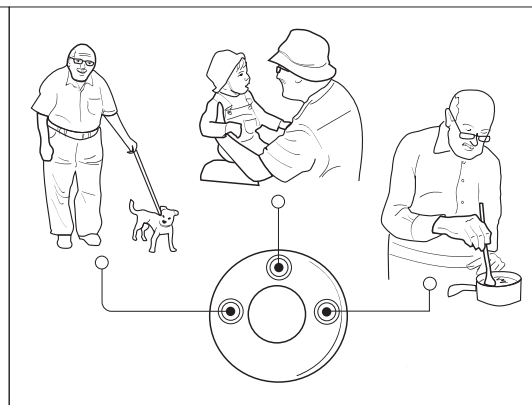
Part II: Scrutinizing ideal futures



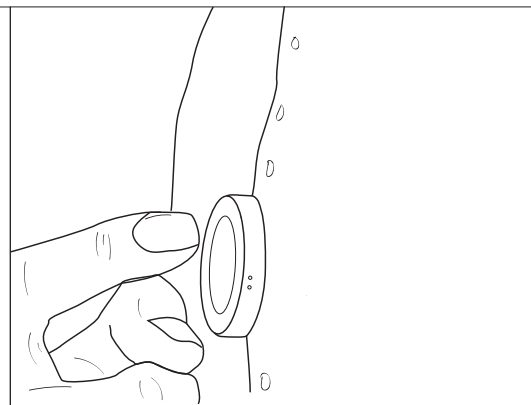
3 groups patients/caregivers
3 groups of providers



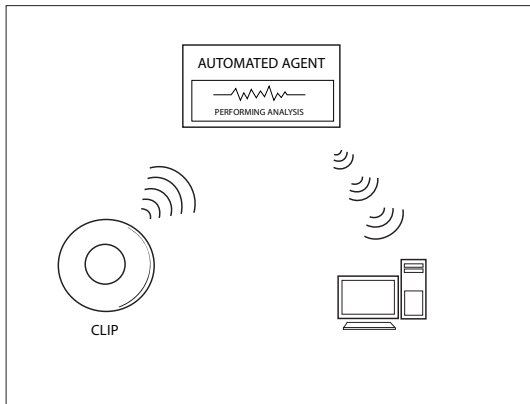
In his last visit with Pete's doctor, she mentions that she would like to learn about what he considers important to his well-being and health. She gives him a wearable clip and asks him to wear it for one month.



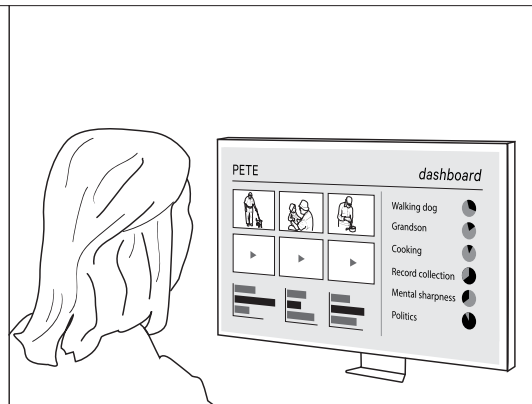
The clip can track Pete's location, movements, and capture video and photographs of how he spends his day. The clip records everything Pete does, who he spends time with, and what he says.



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

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.

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.

Berry ABL, Lim CY, Hirsch T, Hartzler AL, Kiel LM, Bermet ZA, et al. Supporting Communication About Values Between People with Multiple Chronic Conditions and their Providers. In: Proceedings of the 2019 CHI Conference on Human Factors in Computing Systems - CHI '19 [Internet]. Glasgow, Scotland Uk: ACM Press; 2019 [cited 2019 Jul 23]. p. 1–14. Available from: <http://dl.acm.org/citation.cfm?doid=3290605.3300700>

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



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Supporting Collaborative Reflection on Personal Values and Health

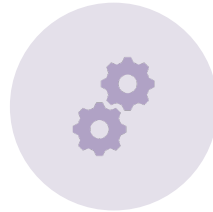
Andrew Berry, Catherine Lim, Calvin
Liang, Andrea Hartzler, Tad Hirsch, Dawn
Ferguson, Zoë Bermet, and James Ralston

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)



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)

An aerial photograph of Northwestern University's campus in Chicago. The image shows several large, modern buildings with glass facades and flat roofs. In the background, the blue waters of Lake Michigan are visible under a clear sky. A large, semi-transparent purple triangle is overlaid on the left side of the image, containing the university's logo and text.

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Approach, Methods, and Prototype Design

Approach and Methods



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

Personalization of data

Each participant used prototypes personalized with their own data

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.

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

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	Discovering new ways of finding fulfillment
Exercising, such as walking outside, yoga, or water aerobics	Following a specific diet	Adjusting how daily tasks are done due to health or other changes
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

Write your responses below.

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 1. Participant demographics and prototype use

ID	Prototypes in order used	Education	Race, Ethnicity	Age	Gender
P1	My List	High school or less	Black or African American	86	Man
P2	My List, Conversation Canvas	More than high school	White or Caucasian	75	Man
P3	My List, Conversation Canvas	More than high school	Black or African American and Hispanic	63	Woman
P4	My List, Time Machine, Conversation Canvas	High school or less	White or Caucasian	58	Woman
P5	My List, Conversation Canvas, Time Machine	High school or less	Asian	78	Woman
P6	My List, Time Machine	More than high school	Asian	76	Woman
P7	My List, Time Machine, Conversation Canvas	More than high school	White or Caucasian and Native Hawaiian or Pacific Islander	79	Woman
P8	Time Machine, Conversation Canvas	More than high school	White or Caucasian	72	Woman
P9	My List, Time Machine	More than high school	White or Caucasian	72	Man
P10	My List, Time Machine	High school or less	White or Caucasian	66	Man
P11	My List, Conversation Canvas	More than high school	White or Caucasian	75	Man
P12	Time Machine, Conversation Canvas	High school or less	White or Caucasian and Hispanic	65	Woman

My List

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

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?

A PERSONAL VALUES

Explore

B SELF-CARE DUTIES

Explore

C HEALTH STATUS INDICATORS

Explore

D NOTES

Explore

Save item to list

A RELATED 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 RELATED 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
- Biking
- Measuring blood pressure with cuff
- Water aerobics

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 sugar

How are these values affected by or connected to this item?

Back

Save

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

My List - Findings

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

My List - Findings

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

“...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)

① BACK PAIN

Back exercises
 Exercising via walk
 Staying busy

Morning routine

DISCUSS POSSIBLE SURGERY

Treating others the way I'd like to be treated

Bulldozing + excavating

SLOW DOWN (PAIN) DISPOSITION

MAKE OR APPOINTMENT

DR LIST

List name

Date of next appointment

Provider name

Add item

② DIABETIES

Controlling blood sugar
 Testing blood sugar

* Weighing myself
 Taking meds
 Insulin injections

Following a diabetic diet
 * A1c test

Testing / highs
 lows

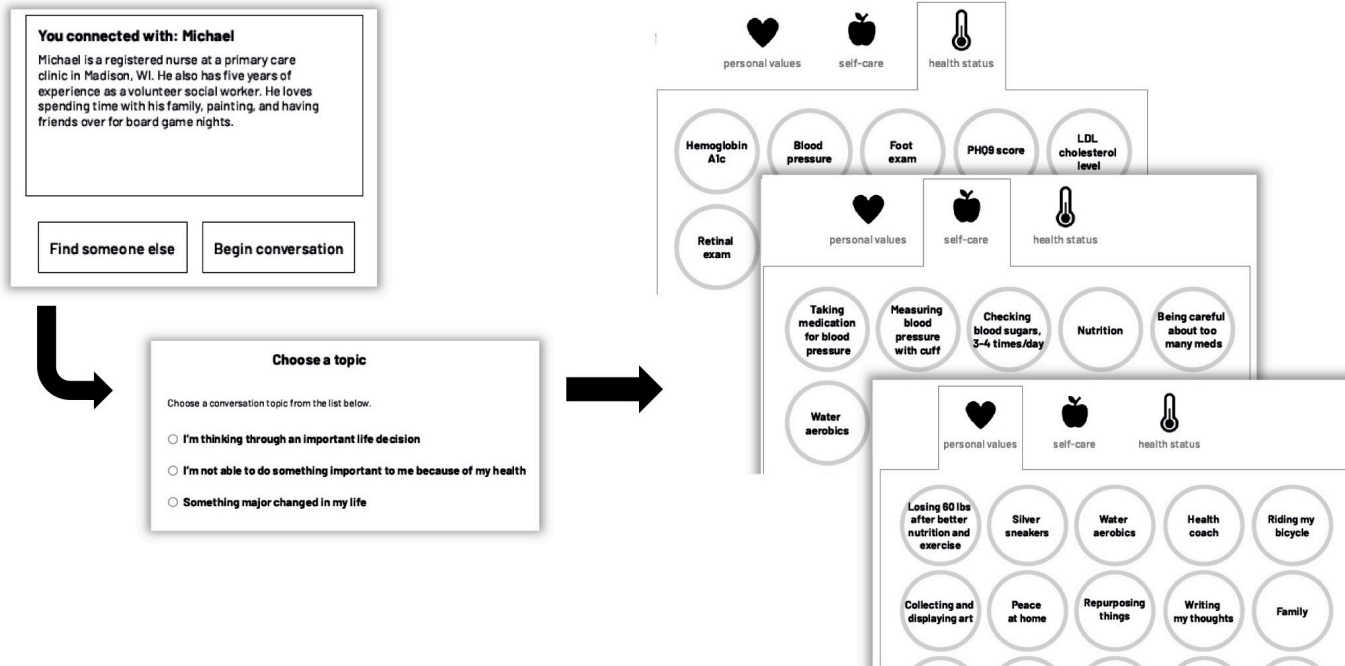
Weight - Goal
 diet - Food

③ Left thumb/hand

My list is complete

Conversation Canvas

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





my info

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, 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

Conversation Canvas - Findings

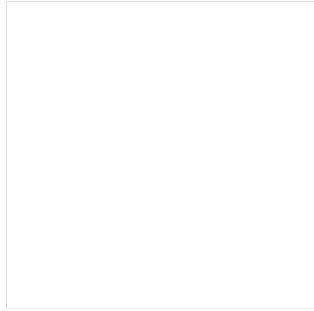
Talk through an important topic with a facilitator and a shared visual space

“**[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



my info

Working on my computer

Walking, getting fresh air

Independence

Walking

cadillac (walker)

Trying to start swimming

Taking my medications

Keeping track of all these appointments

liver for someone younger

being able to dance

explaining the decision to my kids

risk of bleeding

platelets

Last foot exam: [redacted]

Hemoglobin A1c: 4.5% [redacted]


kidney

liver transplant

dialysis

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. Surprise me

Losing 60 lbs after better nutrition and exercise	Silver sneakers	Water aerobics
Moving things to my apartment	Health coach	Riding my bicycle
		Exercise at home

Select a **SELF-CARE** item you'd like to spend time thinking about. Surprise me

Taking medication for blood pressure	Measuring blood pressure with
Cleaning the house, doing the dishes	Being careful not to overexert
Preparing meals, planning ahead	Biking



Select a **HEALTH STATUS** indicator you'd like to spend time thinking about. Surprise me

Hemoglobin A1c	Blood pressure	Foot exam
PH09 score	LDL cholesterol level	Retinal exam
+ add new		

Next



×

How do you feel about this today?

 ○ ○ ○ ○ ○ 



Write your thoughts in your own words.

write a note

 **Looking back**  **Looking forward**

×

How did you feel about this ____ years ago?

 ○ ○ ○ ○ ○ 

Write your thoughts in your own words.

write a note

predict you will feel about this in ____ years.

○ ○ ○ ○ ○

our thoughts in your own words.

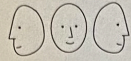
note



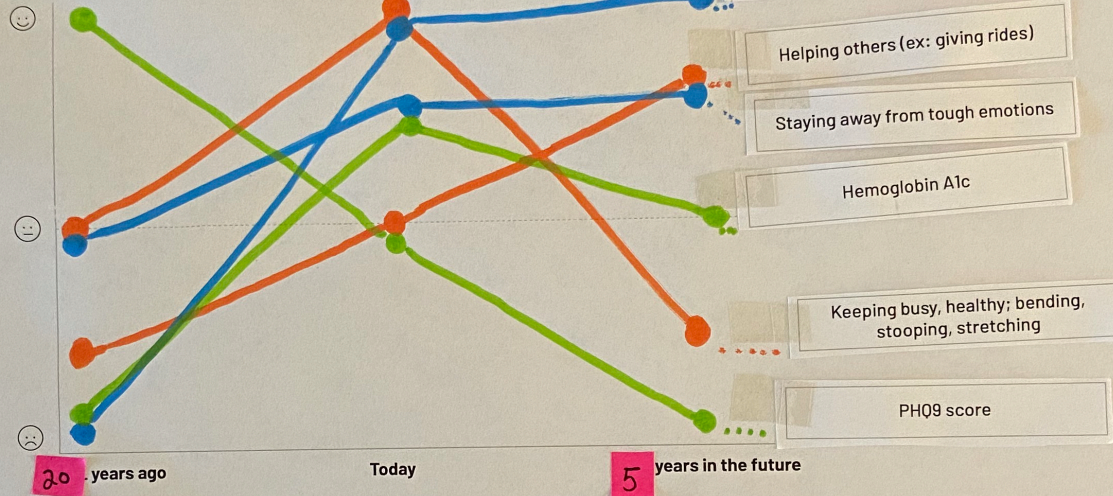
Welcome to your personal time machine.

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

Get started



Looking across time



What do you notice?

my depression
 keeps getting
 worse, but
 meals and helping
 others are steady.

Next

20 years ago versus today

Today versus 5 years forward

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.

Next

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

The image shows the exterior of a modern, multi-story building with a curved glass facade at dusk. The building's interior lights are on, and the sky is a deep blue. A large, semi-transparent purple graphic element is overlaid on the left side of the image. In the foreground, there is a glass-enclosed walkway with a white structural frame and a person in a white coat walking. A street sign above the entrance reads "303 E Superior".

M Northwestern Medicine
Feinberg School of Medicine

Discussion: Key Takeaways

Design guidelines

Supporting collaborative reflection on personal values and health

Explore	Open with exploratory, reflective conversation (patient + facilitator)
Map	Map the conversation as it progresses (externalize, visualize)
Conclude	Conclude by identifying key takeaways
Align	Align with established practices (clinical workflow)

Key roles for interactive systems

Supporting collaborative reflection on personal values and health

Personalized
repository

Stores key information, including personal values, self-care duties, health status indicators, that can be consulted, selected from, added to as needed.

Shared
information space

Scaffold collaborative reflection by creating a shared space for person with MCC and facilitator to progressively map out connections between values and health.



personal values



self-care duties



health conditions

Choose a topic



Choose a conversation topic from the list below:

I'm thinking through an important life decision

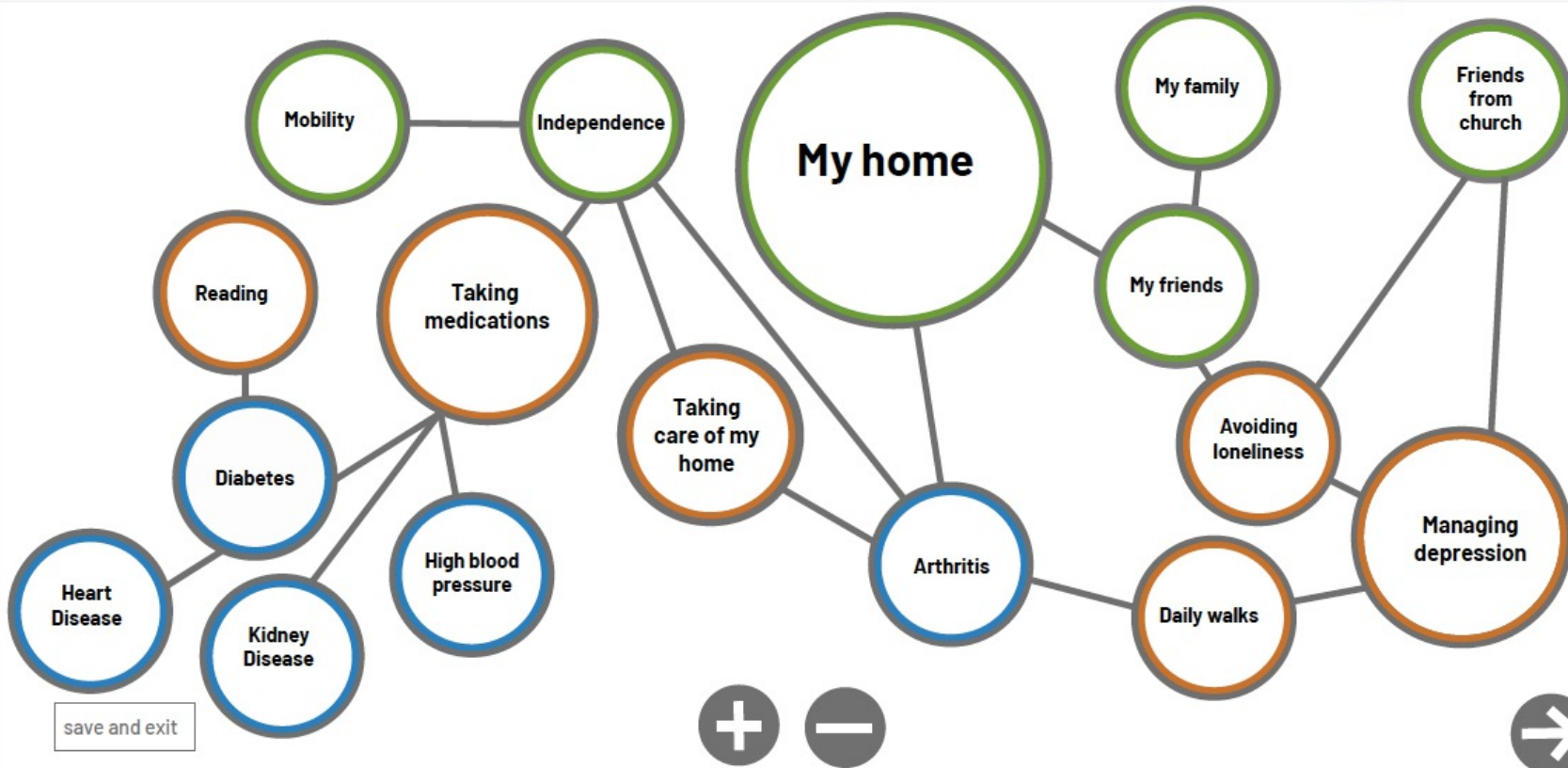
I'm not able to do something important to me because of my health

Something major changed in my life

save and exit



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



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Associate Professor, BIME
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KPWHRI (now
Meta)



Evette Ludman
Researcher
KPWHRI

Questions?

Thank You