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## Supporting collaborative reflection on personal values and health

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### Abstract

People with multiple chronic conditions (MCC) need support to identify and articulate how their personal values relate to their health. We drew on previous research involving people with MCC to develop three prototypes for supporting reflection on relationships between values and health. We tested these prototypes in a qualitative study involving 12 people with MCC. We identified benefits and limitations to building on patients' existing visit-preparation practices; revealed varying levels of comfort with deep, exploratory reflection involving a facilitator; and found that reflection oriented toward the future could elicit hopeful attitudes and plans for change, while reflection on the past elicited strong resistance. We discuss these findings in relation to previous literature on designing for reflection in three areas: shifting between self-guided and facilitator-guided reflection, balancing between outcome-oriented and exploratory reflection, and exploring temporality in reflection.

### Additional Keywords and Phrases:

multiple chronic conditions; reflection; concordance; patient-clinician communication

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## 1 INTRODUCTION

People with multiple chronic conditions (MCC) face competing demands for their health care [6,7,60]. Choosing to address the symptoms or complications of one condition may come at the expense of addressing those for another condition [7,45,69]. So, people with MCC often have to prioritize treatment for one or more conditions over others.

For example, a person may want to exercise to manage depression, hypertension, and diabetes, but if that person has chronic pain, exercising might be very painful. This person would face difficult decisions about whether to exercise and exacerbate pain symptoms or not to exercise and risk long-term complications of the other conditions.

Patients and healthcare providers often do not agree on which health conditions and treatment options to prioritize [36,45,79,82]. This is a problem because when patients do not agree with their providers on priorities for health care, patients are less likely to follow through with recommended health care and are more likely to experience worse health outcomes [71,72].

Patients' priorities for health care are shaped by many factors. For example, patients often prioritize symptomatic conditions (e.g., chronic pain) over asymptomatic ones (e.g., hypertension) [44,69,82]. One critical factor shaping patients' priorities for health care is what they consider important for their well-being and health (i.e., patients' personal values, including abilities, activities, emotions, possessions, principles, and relationships [10,52]). A patient's personal values influence their priorities for health care [26,27].

One avenue to concordant priorities between patients and providers is for patients to articulate how their personal values influence their health priorities. But, this is difficult to achieve in practice. Recent research in CSCW documented how some types of values are discussed often in clinic visits while others are not, and how patients and providers had to work to establish the relevance of values within the context of care planning [9].

From the perspective of patients, there are many reasons why establishing the relevance of values to health care can be challenging. Patients may not know how their values relate to their health care, and they may not see how health care can support their values. Patients also may perceive boundaries regarding which values they can or should discuss with providers [54]. There is a need to help patients engage with these perceived barriers and ultimately articulate personal values in conversation with providers.

Recent research has shown initial promise to address this need. Lim et al. [53] reported on the types of reflection patients engage in when asked to describe relationships between their values and their health. Additionally, those findings were generated through a combination of individual reflection and collaborative reflection (i.e., reflection guided by a facilitator during interviews). Still, it is not well known how interactive information systems can play a role in supporting this reflection, and how to balance support from interactive systems and human facilitation. In this paper, we sought to advance understanding of how best to support this reflection by investigating the research question:

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

We approached this research question by designing three prototype reflection activities and testing them with 12 people with MCC. (Hereafter, we refer to these prototype reflection activities as “prototypes.”) Each prototype engaged people with MCC in identifying and articulating relationships among personal values and health-related topics (i.e., self-care duties, such as taking medications or exercising, and indicators of health status, such as laboratory test values or symptoms). Each prototype involved using an interactive information system while engaging with a human facilitator. All three prototypes contained the same basic information, but each one represented a distinct approach to reflection on values and health.

By testing these different approaches, we generated empirical findings regarding activities and features that supported patients in identifying relationships between values and health. We translated these findings into design guidelines for supporting collaborative reflection on values and health. These findings and guidelines move us closer to enabling patients to overcome well-documented barriers to articulating how their personal values influence their health priorities. Enabling patients to articulate their values and health priorities will better prepare them to identify and resolve discordant priorities with health care providers. This is a critical step forward in improving the health of people with MCC. Additionally, we add to previous literature on designing for reflection by discussing shifts between self-guided and facilitator-guided reflection, the need to balance outcome-oriented and exploratory reflection, and the potential for reflection across temporalities.

## 2 BACKGROUND

### 2.1 Definition of personal values

In this paper we use the term *personal values* to refer to what a person considers important for their well-being and health [52]. This definition is intentionally broad and intentionally patient-centered. We allow people with MCC to define for themselves what they consider important, and we use the term personal values to refer to those topics.

This definition of personal values was informed by research on the relationship between values and design, including the definition of values used in the Value Sensitive Design literature [30]: “what person or group of people consider important in life” (p. 70). We acknowledge many different perspectives on the definition of values and the relationship between values and design (c.f., designers adopting discursively-defined values of moral and ethical import [30,50]; designers seeking values as rooted in local contexts and lived experience [50]; designers viewing values as enacted and re-enacted in practice, not fixed and stable entities [39]; designers working with values as hypotheses, dialectically, rather than identifying values and applying them in the design process [43]). Our definition aligns most closely with perspectives that allow for values to be personal and/or local and for values to change and develop through action in practice.

This definition of personal values is also rooted in empirical research involving people with MCC. Six categories of personal values illustrate the breadth and overlap of topics people with MCC consider important for their well-being and health: abilities (e.g., vision, walking), activities (e.g., volunteering, bicycling), emotions (e.g., comfort, satisfaction), possessions (e.g., letters from family, musical instruments), principles (e.g., self-sufficiency, religious faith), and relationships with family and friends [10,52].

## 2.2 Study context: health care for multiple chronic conditions

Patients bear most of the responsibility for managing MCC care in daily life. Care for chronic conditions in general requires ongoing self-management work [11–13] to prevent or attenuate the course of complications like nerve, eye, and kidney damage in people with diabetes. Corbin and Strauss identified three categories of self-management work [16,18]: illness work, everyday life work, and biographical work. Illness work can involve activities like taking medications, monitoring blood sugar, and exercising [11,18,56,57]; everyday life work involves activities like holding down a job, raising children, spending time with a spouse; and biographical work involves coping with changes in one's life and identity due to illness. Often informal caregivers support this self-management [16,17]. Depending on patients' needs, caregivers might help with activities such as dressing, eating, and finances, and provide emotional support [70]. This work may include changing diet and eating habits, exercising, taking medications, and monitoring health status (e.g., blood glucose levels or blood pressure). Good self-management and healthcare of chronic conditions avoids or delays complications of those conditions [11–13].

Health care for chronic conditions is carried out by a number of actors, including patients (in the form of self-management work), informal family caregivers (supporting self-management), and members of the patient's health care team (e.g., primary care physician, medical assistant, diabetes nurse, behavioral health specialist, etc.). The Collaborative Care model outlines a commonly-used approach for patients and healthcare team members to work together as partners to manage chronic illness [80].

In a collaborative care approach, patients meet with providers to assess the patient's health and adjust the patient's care plan as needed. These conversations typically involve 1) collaborative problem definition, 2) targeting specific problems, and 3) planning care. In collaborative problem definition, patients and providers discuss and define health-related problems. For example, a provider may ask patients about challenges and successes following their prior care plan, or a patient may raise concerns about new symptoms or disruptions to life due to illness management [80]. If multiple problems are defined, as is common for people with MCC, patients and providers select specific problems to target. This can involve focusing on one problem, often prioritizing some problems over others. After targeting problems, patients and providers set realistic goals and plan actions for pursuing them.

However, as discussed in the introduction, collaborative care can break down for people with MCC. Patients and providers often do not agree on priorities for health care, leading to worse health outcomes for patients. In order to enable collaborative care for MCC, there is a need to support patients in articulating their priorities for health care. As a step toward this

ultimate aim, this paper examined how to enable people with MCC to identify and articulate relationships between what they consider important for well-being and health (i.e., personal values), what they are doing to manage their health (i.e., self-care duties or self-management work), and health information that indicates how well health conditions are being managed.

### 3 RELATED WORK

In this section, we review two threads of relevant scholarship from computer-supported cooperative work (CSCW) and adjacent research communities: aligning perspectives and concerns between patients and health care team members, and supporting reflection through interactive systems design. Our paper's contributions build on and extend this prior work by illustrating how interactive systems can support collaborative reflection for people with MCC.

#### 3.1 Aligning concerns, perspectives, and priorities between patients and providers

In CSCW, there is sustained interest in supporting coordination and collaboration among key actors in health care. These actors include patients, informal and formal caregivers, and healthcare team members (e.g., doctors, nurses, and medical assistants). One thread of research has illustrated the distinct perspectives these actors bring to the experience and management of illness.

Tariq Andersen and colleagues articulated “alignment of concerns” as a design rationale for information technologies that aim to support patient participation and agency in their health care [1,2]. This rationale is informed by the germinal work of S. Kay Toombs [75]. Toombs studied patients' and providers' perspectives on health and health care from a phenomenological perspective and demonstrated that patients and healthcare providers think about illness and disease differently.

In articulating “alignment of concerns” as a design rationale, Andersen et al. [1] called attention to the need for designers of patient-centered technologies to explicitly account for and reconcile these differences in perspectives. Similar to “alignment of concerns” as a design rationale, Naveen Bagalkot and colleagues [3,34] called for concordance as a design ideal: promoting concordance between patients and providers can enable patients to play a more active role in their health care.

Alignment of concerns and patient-provider concordance are especially important in the context of multiple chronic conditions. When patients and providers disagree on priorities for health care, patients tend not to follow through with care recommended by the provider [14], and patients tend to experience worse health outcomes [71,72]. Patients with MCC prioritize health conditions that are symptomatic [44,82] and disabling [69], and prioritize conditions that disrupt life priorities and values [69]. Providers prioritize conditions based on medical aspects of disease, including symptoms, severity, and prognosis [49].

We build on this prior work to contribute new design concepts and empirical findings regarding how to support patients in clarifying their concerns and articulating those in conversations with healthcare providers. We explored how to support patients' reflection on

how their personal values relate to aspects of their health care, including self-care duties they perform and indicators of their health status. Supporting this reflection will prepare patients to advocate for their priorities in conversations with health care providers.

This study also builds on related work in health services research to prepare patients to share their priorities with their doctor. Typically, at the beginning of a visit the doctor will ask the patient what they want to cover that day [48]. Responding to limitations to this approach (e.g., time constraints), Richard Grant and colleagues identified requirements for eliciting visit-related priorities from patients with diabetes prior to a visit [33] and tested a tablet-based application for eliciting priorities in the waiting room prior to the visit [32]. Mary Tinetti, Anand Naik, and colleagues have similarly identified requirements for eliciting health-related priorities from patients with multiple chronic conditions [59], and have begun evaluating interventions to elicit these priorities in pre-visit conversations between a patient and a social worker [74]. These studies leave a gap in understanding regarding how to overcome patients' perceived boundaries between values and health through reflection, and how to support this reflection through interactive systems design. This study addresses these gaps through a design-based exploration of possibilities for supporting reflection on associations between values and health.

### 3.2 Designing interactive systems to support reflection

We define reflection as 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. This definition is inspired by a review of the literature on designing systems to support reflection conducted by Eric Baumer and colleagues [5].

In the context of CSCW and health care, one dominant approach to supporting reflection is through the design of personal informatics systems [4]. In an early and influential paper on this topic, Ian Li and colleagues [51] included reflection as one of the stages in their model of personal informatics systems: preparation, collection, integration, reflection, and action.

Since that paper, there has been ongoing conversation and debate regarding the relationship between personal informatics and reflection. There have been calls to attend to the lived experience of collecting and interacting with information about the self, including Rooksby et al.'s [67] articulation of lived informatics, Elsdon et al.'s [22,23] documentary informatics, Epstein et al.'s [24] lived informatics model, and a journal issue on the lived experience of personal informatics [19]. Scholars have also critiqued the nature of reflection and personal informatics systems by calling attention to the infrastructure behind such systems and inviting users to generate new relationships to personal data [46], and by exploring people's assumptions about the authoritativeness of affective biosensing technologies [40].

In this paper, we are addressing a problem from the healthcare domain in which it is important for people to reflect on health information, lived experience, and personal values together: as discussed in the Introduction, people with MCC may not understand how their values relate to their health or how their health care could be improved if their doctors better understood their personal values. This prevents people with MCC and their

healthcare providers from reaching concordant priorities for health care. To better prepare people with MCC to articulate and advocate for their personal values in conversations with healthcare providers, people with MCC need support to identify associations among their personal values and their health care. Lim et al. [53] described reflective behaviors exhibited by people with MCC while they visually explored and articulated connections among values and health-related activities. We build on this prior research by exploring how to design support for reflection through the design of interactive systems and through human facilitation.

## 4 DESIGN OF PROTOTYPES

Our objective in this study was to better understand how we might support patients to identify and articulate relationships among personal values and health. We began with divergent ideation to explore a range of possible forms of support, analyzed those to identify dimensions to explore further, and generated three prototypes to evaluate those dimensions empirically with patients. Below we describe the iterative design process we followed. Then, for each prototype we describe its overall concept and purpose, its interaction flow, and the rationale for key decisions about its design.

### 4.1 Design process

The design process began in June 2018 and concluded in March 2019. In June 2018, our research team met to review initial findings from ongoing interviews with patients with multiple chronic conditions and discuss how to approach the design process. The methods and findings from those interviews have been reported in Lim et al [51]. The interviews involved eliciting values and self-care duties from patients and then asking them to talk through associations among those topics.

Between June 2018 and October 2018, we completed these interviews. Analysis of those interviews generated four types of reflection that patients exhibited as they talked through associations between personal values and self-care duties: (a) heightened patient awareness of personal values, (b) evolving patient perspectives on personal values and how those related to health and health care, (c) recognition of misalignments between personal values and self-care duties, and (d) considering changes to self-care duties. These findings are discussed in depth in our previous paper led by Catherine Lim [52].

In October 2018, our team met again to continue generating ideas for reflective activities. We used the themes from patient interviews to frame our ideation approach and generated ideas for how to support reflection from each theme. Looking across the ideas we generated, we identified the following dimensions to help decide on which prototypes to develop and test with participants. These dimensions are also supported by prior research, especially a review of the use of reflection in interactive systems design by Baumer et al [5]. We included additional relevant references below, and later in the Discussion section we bring our findings into conversation with this literature.

- These prototypes can be guided in different ways, including self-directed by the patient, guided by the information system, guided by a facilitator, or combinations thereof (e.g., [5,28,68,73]).
- These prototypes can be fully exploratory and open-ended, constrained and oriented toward a tangible outcome, or in between (e.g., [5,8,31,55,61,62,65]).
- These prototypes can engage with change over time to varying degrees, including changes to values and health from the past and into the future (e.g., [4,5,15,22,25,41,58,63,81]).

Based on these dimensions, we decided to move forward with three prototypes: My List, Conversation Canvas, and Time Machine. We describe these in detail in sections 4.2–4.4 below. There is not a one-to-one mapping from the prototypes to the dimensions above; each prototype can be located at a different point along each dimension. Varying the prototypes in this way created many opportunities for empirical exploration and comparison of how these dimensions influenced the nature of participants' reflection. The prototypes map to the dimensions as follows:

- We designed My List and Time Machine to be more self-directed, while Conversation Canvas was mostly facilitator-directed.
- Conversation Canvas was designed to be the most open-ended and exploratory, while Time Machine and My List both built toward tangible outcomes.
- Time Machine was designed specifically to explore reflection across the past, present and future, while My List and Conversation Canvas did not have explicit temporal components.

In addition to the dimensions above, we agreed on a set of constraints for the prototypes:

- We wanted to develop several prototypes in order to explore different techniques and approaches to promoting reflection on values and health.
- We wanted prototypes to require less than 45 minutes to complete so we could test more than one activity with a participant in a two hour session.
- We planned for the prototypes to fit with existing care practices for people with MCC (see discussion of collaborative care above). We envisioned a scenario in which a patient would have an upcoming visit with a healthcare provider, the provider would invite the patient to carry out the reflection activity, and the patient and provider would discuss the outcomes of that reflection during the visit.
- We aimed to support users who could speak English, read large text, and operate a computer.

The prototypes had several common features. Each one aimed to enable the user to reflect on what they considered important for their well-being and health (i.e., personal values), what they were doing to manage their health (i.e., self-care duties), and their health status indicators (e.g., blood glucose level). Each prototype was supported by a unique interactive information system, implemented as an interactive paper wireframe. We included the same



patient information in all three wireframes. We wanted participants to reflect on their own personal values and health information, so we populated the wireframes with personalized information for each participant. We describe the process of personalizing the wireframes in the “Personalization” subsection of the Methods.

We produced the wireframes in Adobe XD and printed them on paper. We chose paper instead of digital prototypes for two reasons: (1) to invite critical feedback, we wanted participants to perceive the prototypes as provisional and unfinished, and to feel comfortable suggesting changes, and (2) hardware constraints and requirements around the protection of personal health information (PHI) were barriers to storing and presenting PHI in standard digital prototyping tools that use cloud-based storage that is not HIPAA-compliant.

## 4.2 Prototype 1: My List

In My List, the user is invited to prepare a list of topics to discuss with their primary care provider at an upcoming clinic visit. As the user adds topics to the list, they are invited to link those topics to personal values, self-care duties, and health status indicators. The purpose of this prototype is to encourage people to discuss topics with their primary care provider that reflect their personal values.

**4.2.1 Rationale**—We chose this prototype because it aligns with and extends existing practices for preparing for clinic visits, and it has a tangible outcome. My List extends existing practices because health care providers often ask patients for their priorities for the visit. As discussed earlier, approaches to eliciting priorities for a visit are limited in that they may not explicitly consider patients’ values, and when they do, they may not do enough to overcome some patients’ existing perceptions that personal values are not pertinent to raise with healthcare providers. With My List, we wanted to explore whether making values, self-care duties, and health status indicators visible during familiar list-making practices could contribute to patients identifying and articulating relationships between values and health, and ultimately to patients sharing values with healthcare providers. In terms of facilitation, My List is primarily patient-driven but a facilitator is present and available to answer questions and encourage the patient to consider potential associations between values and health.

**4.2.2 Features and interaction flow**—My List’s interaction flow begins by asking the user to input their primary care provider (PCP) and the date and time of an upcoming clinic visit. The prototype then invites the user to begin constructing a list of items to discuss during the upcoming visit.

For each discussion item the user adds to the list, the user is invited to explore how the item relates to topics from the user’s pre-populated inventory of personal values, self-care duties, and health status indicators. For example, the user might add “back pain” to the list, then indicate that the self-care duty of “back exercises” is related to back pain, and write a short explanation that “back exercises help reduce back pain, but I don’t have the motivation to do my exercises every day.” The user might also indicate that the personal value of “independence” is related to “back pain,” and explain that “when back pain is worse, I am less able to live independently.”

Once the user is finished associating topics with the first discussion item on their list, the user can repeat this process, adding as many discussion items to the list as they choose. For each discussion item, they can associate topics from their list of personal values, self-care duties, and health status indicators. Once the user is satisfied with their list of discussion items, they can send the list to their doctor and save or print the list for their own use.

Figure 1 shows the most important screens of the My List prototype. At left is the screen inviting the user to add an item to the list and to explore which personal values, self-care duties, and health status indicators are related. At center is an example of three different pop-up screens, each containing a list of potentially related topics that are personalized for the user. After the user selects associated topics, the rightmost screen is a pop-up inviting the user to explain how those topics are related to the discussion item.

### 4.3 Prototype 2: Conversation Canvas

In Conversation Canvas, the user has a guided conversation about their personal values and health with a human facilitator. If this prototype were deployed in actual clinical practice, we envisioned the facilitator being a member of the user's health care team, such as a social worker or behavioral health specialist. In terms of feasibility, this is work that social workers and behavioral health specialists already do in some clinics, albeit not supported by interactive systems. In other clinics, this work is not done currently.

The purpose of Conversation Canvas is to help a person talk through a topic that concerns them at that time, and for an active listener to guide the user toward reflection on associations between their personal values and their health care. Both the user and the facilitator can view and manipulate a shared "conversation canvas." This canvas serves as a visual record of the conversation, with a focus on visualizing connections among topics from the user's lists of personal values, self-care duties, and health status indicators.

**4.3.1 Rationale**—We chose this prototype because it allows for extensive exploration of a topic of the patient's choosing. Patients often only see health care providers for brief visits, sometimes as short as 10 minutes. This prototype provides space for a patient to talk through issues and concerns that they aren't able to discuss during time-constrained visits with a doctor. We also chose this prototype because it is primarily facilitator-driven, as opposed to patient-driven. This provides a point of contrast with the other two prototypes, which are primarily patient-driven, but supported by a facilitator as needed.

**4.3.2 Features and interaction flow**—The interaction flow in Conversation Canvas begins with the user being introduced to the purpose of the tool and connecting with the conversation facilitator. We provided the user with two options for the facilitator, each with a different persona, to invite the user to express preferences for the person with whom they would want to have this type of conversation.

Next, the facilitator invites the user to select a topic for the conversation from three pre-set options: "I'm thinking through an important life decision," "I'm not able to do something important to me because of my health," or "Something major changed in my life." We chose

these topics to be specific enough to scope the conversation to values and health, but generic enough that most participants could identify with one and steer the conversation.

After topic selection, the facilitator asks the user to explain more about the topic and writes the user's response on the canvas. For example, a user might choose, "I'm not able to do something important to me because of my health," and explain, "I'm not able to ride my bicycle because of pain radiating down both legs."

Then the facilitator asks the user to review the pre-populated lists of values, self-care duties, and health status indicators and select any that are associated with the conversation topic. For example, on the topic of not being able to ride their bicycle due to pain in their legs, the user might select the items "bicycling," "independence," and "staying busy" from their personal values, "exercising" from their self-care duties, and "blood pressure" from their health status indicators.

As the user selects related items, the facilitator adds them to the canvas. Whenever possible, the facilitator will probe on how each item is related to the conversation topic. For example, the user might explain that they chose "blood pressure" as related to the topic of pain while bicycling because riding their bike helps manage their cardiovascular health, and blood pressure is a health status indicator related to this.

Once the user is finished adding items to the canvas, the facilitator guides the user in looking over the canvas, reflecting on its contents, and identifying items of particular significance (e.g., items that make the situation easier or more challenging). Finally, the facilitator demonstrates active listening by summarizing the conversation back to the user.

Figure 2 below shows the most important screens from the interaction flow 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 [51] 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 prior to use of the tool to populate the lists of personal values, self-care duties, and health status indicators; collection is completed during

the first portion of the tool, when users enter ratings for items from those lists; integration is completed by the prototype in the form of an information visualization that combines and summarizes the user's ratings, and reflection and action are invited as the user views the information visualization. Because personal informatics systems are so widely researched in CSCW, we thought it important to explore how this style of application could support reflection on personal values and health.

**4.4.2 Features and interaction flow**—The user starts by selecting two personal values, two self-care duties, and two health status indicators on which to focus. Then, for each item selected, the user indicates how they feel about that item today and writes a brief comment explaining their rating.

Next, the user is prompted to reflect on the same topics in the past. The user chooses a number of years to look back in time and follows the same rating and commenting process, but now in terms of how they felt about each item at the specified time in the past. Additionally, the user is invited to select additional values, self-care, and health status items that have changed the most over time, and ones that have changed the least.

Then, the user repeats this process, but looking toward the future. The user chooses a number of years to look forward and follows the same process of rating and commenting. They also predict which items will change the most and which will change the least.

This process of reflecting on a set of values, self-care duties, and health status indicators culminates in a final integration stage. The ratings the user entered throughout this process are displayed in an information visualization. The visualization shows the user how their ratings for each item vary across the past, present, and future. The integration stage also includes a list of the items the user indicated would change the most and least. While viewing these screens, the user is invited to write a note reflecting on what they notice as they look across time.

Figure 3 shows screens collecting the user's attitudes in the present. These screens would be repeated for the past and the future. At left, the user selects personal values, self-care duties, and health status indicators to focus on that day. At right, the user rates how they feel about each selected item that day, and then writes a short note explaining that rating.

## 5 METHODS

The purpose of this qualitative study was to examine how people used the prototypes described above, with a focus on how well each prototype enabled people to identify and articulate relationships between personal values and health (i.e., self-care duties and health status indicators). As discussed in the previous section, these prototypes were designed to enable us to explore further the design dimensions and questions that emerged in our early design iterations. By inviting people with MCC to engage with these prototypes, we created contexts in which we could explore what aspects of the prototypes worked best, and what aspects did not. In particular, we examined which prototypes best enabled patients to connect their personal values with aspects of their health and health care, and we examined which prototypes elicited positive and negative reactions from patients.

This study was completed between March 2019 and July 2019. The study activities described below received research ethics approval from Kaiser Permanente Washington Health Research Institute. In this section we report methods in four parts: participant recruitment, personalization of prototypes for each participant, prototype testing sessions, and analysis.

## 5.1 Participants

We recruited 12 people with multiple chronic conditions from an integrated healthcare system in the Pacific Northwest region of the United States. To be eligible, participants had to have diabetes (type I or type II) plus two more of these chronic conditions: osteoarthritis, depression, and coronary artery disease. For recruitment, participants received an invitation letter in the mail and a follow-up phone call. Participants gave oral consent for a phone interview during the recruitment phone call. Later, written informed consent for prototype testing was obtained in person.

Participants had a mean age of 72.5 years ( $SD=7.73$ , range=58–86). Eight identified as women and four as men. Eight identified as white, two as Black or African American, two as Asian, and one as Native Hawaiian/Pacific Islander (participants could select more than one). Two identified as Hispanic and ten as not Hispanic.

## 5.2 Personalization of information in prototypes for each participant

To pre-populate the prototypes with personal information, we mailed participants a worksheet to complete at home, collected worksheet responses in a phone interview, and added the information to each prototype. This information included personal values and self-management work (in the prototype, this was labeled as “self-care duties”).

Worksheet questions asked participants to write down what they considered to be most important to their well-being and health. We included the worksheet in Appendix A. As guidance, six categories of personal values were provided—abilities, activities, emotions, possessions, principles, and relationships—with short definitions and examples [10,52]. Questions also asked what participants did in daily life to manage their well-being and health. Domains of self-management work were provided. These came from research on chronic illness in medical sociology (e.g., illness work, everyday life work, biographical work [16,18]) and health services (e.g., World Health Organization Disability Assessment Schedule 2.0 [76]).

In a phone interview before the in-person prototype testing session, a research team member asked the participant to share their responses to the worksheet. Phone interviews lasted 30–60 minutes. The interviewer recorded audio and wrote participants’ personal values and self-care duties in a spreadsheet. Then, the interviewer added the information to a personalized version of each prototype in Adobe XD, resulting in pre-populated lists of values and self-care duties.

In addition, we obtained permission from participants to collect from their medical record six health status indicators for the chronic conditions we focused on: hemoglobin A1c, LDL cholesterol, blood pressure, PHQ9 score (depression questionnaire), date of foot exam, and

date of retinal exam. These data were added to the prototypes in pre-populated lists of health status indicators.

### 5.3 Prototype testing session and facilitation approach

Each participant attended a two-hour prototype testing session in a private room at a primary care clinic. Each session was facilitated by two research team members. The lead facilitator obtained informed consent and explained the purpose of paper prototypes. Next, facilitators presented one prototype and asked the participant to think out loud as they used it. As needed, facilitators offered guidance about how to operate the prototype.

We expected the prototypes to require different degrees of facilitation. For My List and Time Machine, we expected the facilitator to intervene at times to help with the prototype or probe for deeper reflection. Thus, for those prototypes, collaborative reflection meant an activity paced by the participant and supported as needed by the facilitator. For Conversation Canvas, we expected the facilitator to lead the process, so collaborative reflection in this case meant an activity paced mostly by the facilitator.

In general, across the three activities, we adopted a facilitation approach that was flexible to each participant's perspectives and needs. So, if a participant got stuck or was unsure about how to use a prototype, the facilitator could step in to guide the process. As the participant used the prototype, the lead facilitator focused on following the participant's actions, swapping in screens as the participant took actions in the paper prototype, answering questions about the prototype's function, and asking probing questions to facilitate reflection on values and health. The other facilitator played a supporting role, typically managing prototype functions like searching for and producing information stored in the prototype's "database" (i.e., paper cutouts of the patient's lists of values, self-care duties, and health status indicators).

The first author of this paper was the lead facilitator, while other authors and support staff played the role of supporting facilitator. The lead facilitator drew on five years of experience interviewing people with MCC about similar topics in previous studies (e.g., [9, 10, 52]). These experiences gave the facilitator background knowledge about the nature of patients' personal values, the nature of the chronic conditions at issue, the typical work involved in managing those conditions, and patients' lived experiences balancing the competing demands of multiple chronic conditions. The facilitator drew on this knowledge and experience when deciding what questions to ask and what areas to probe on that might drive reflection. The facilitation approach was also informed by a member of the research team who had training and research expertise in behavioral health and motivational interviewing.

After a participant finished using a prototype, facilitators conducted a brief, semi-structured interview about the prototype. This interview covered questions like, "What, if anything, did you learn or discover while trying this prototype?", "How likely is it that you would want to use this prototype?", and "If you could make changes to this prototype, what would you change?"

As time allowed, facilitators repeated this process for the second and third prototypes. Because most participants weren't able to use all three prototypes in two hours, the facilitators balanced which prototypes were used to ensure that each prototype was used by roughly the same number of participants by the end of the study.

At the end of the session, facilitators conducted a short semi-structured interview to hear participants compare their experiences across the prototypes. This interview covered questions like, "Of the options we showed you today, which would you most prefer to use?", "Which helped you slow down and think about your well-being and health?", and "If you were to use a tool like this, how might it open up new conversations with a healthcare provider?"

Following each session, the lead facilitator took short field notes to capture any salient insights or reactions they had during the session.

Participants received \$100 upon completing the session. These sessions were audio recorded and professionally transcribed. Paper prototype materials were retained and scanned digitally.

#### 5.4 Analysis

Two authors conducted thematic analysis of the interview transcripts [35], including open coding, focused coding, and organizing codes and coded data into themes. As needed, authors referred to scanned images of the completed prototypes to clarify ambiguous references in the transcripts (e.g., if the participant referred to "this group of items" in the transcript, the researcher viewed the image of the prototype to identify the items to which the participant was referring). Additionally, authors referenced the field notes taken by the lead facilitator as needed; these field notes were not coded.

To begin, two researchers coded the same transcript using an open coding approach, labeling what they saw in the data. Next, authors compared codes and definitions, refined these into a revised codebook, and coded a second transcript. Following another round of discussion and clarification, the authors finalized the codebook, divided the remaining interviews, and coded them independently. All authors met regularly to discuss data associated with each code and relationships among codes. This iterative process of comparing data to data, data to codes, and codes to codes generated the themes presented in the findings below. During manuscript preparation, the primary author returned to the data frequently to clarify themes and select representative excerpts.

## 6 FINDINGS

Each prototype was used by at least eight participants. Ten participants used My List, eight used Conversation Canvas, and eight used Time Machine. Three participants were able to complete all three prototypes in one two-hour session. Due to time constraints, eight participants completed two out of three prototypes.

One participant (P1) started My List and Time Machine but did not complete either one. During the prototype testing session, P1 told several long stories about his past

and discussed his views on topics in the news at the time. These stories and views did incorporate some health-related topics, but they mostly focused on his personal values. Facilitators attempted to redirect his attention to the prototype, but after several tries decided to listen to the participant's stories. This serves as a reminder that structured reflection activities may not work well for all people with MCC.

Table 1 below shows participant demographics and the prototypes they used. Below we report themes in findings for each prototype.

## 6.1 My List

All participants who used My List were able to construct a list of topics to discuss with a doctor at an upcoming visit, and all were able to associate personal values and self-care duties with those topics (with the exception of P1 as explained above). Some participants associated health status indicators with those topics, but not all. Below we discuss the most salient themes in how participants used and responded to the My List prototype.

**6.1.1 Augmenting a familiar practice of visit preparation**—The My List activity supported the practice of preparing for an upcoming visit with a doctor. Several participants said they already prepared for visits this way, although the step of explicitly incorporating personal values was novel. Several participants thought that the My List activity would improve their existing list-making practices. P9 described My List as a “thought enhancer:”

“...because 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, whatever. Because 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)

By externalizing topics for the doctor and associating values and health-related information, P9 was able to remember and expand on those topics. P11 made a similar statement about how externalizing his thoughts could help him organize his thinking and improve on the list:

“I don't know how to describe it, but it's kind of nice to have a way to organize these things. I tend to be helter-skelter, whatever—chaotic. This seems to bring it back together. I'll be honest with you, I was a bit skeptical of what had been described to me [about My List]. I didn't know what the mechanics of this would be. But I can see the value in it, and that surprises me. I wasn't expecting that... [It helped] sort out things and focus more. So I can see this as being something useful for me personally.”

(P11)

Figure 4 shows what My List looked like after P11 finished. Each numbered item represents an item P11 added to his list. The text underneath each item represents the related values, self-care duties, and health status indicators he related to that item, along with his explanations of those relationships.



At the end of the My List activity, participants had the option to print the list they created and/or email the list to their doctor. These two features were both valued by participants, in part because they supported participants' existing list-making practices.

Some participants (P2, P4, P7, and P10) indicated they would bring the printed list to their next visit with the doctor. For some (P4, P7, P9), this was to aid their memory of the topics to discuss, including nuances and context behind those topics. P10 said bringing the list would help him "establish a baseline" during the visit, anchoring the conversation with the doctor to the topics he wanted to discuss. Bringing the list would help P10 maintain agency over the course of the conversation with his doctor. Similarly, P4 said she would use the list to focus the visit on topics she cared about.

A few participants wanted to add to the list over time rather than complete in a single sitting. Two said (P9, P2) they would print the list, display it in a prominent place in their home (e.g., at their desk or on their refrigerator), and several said they would return to it over time as new issues came up (P2, P9, P10, P11). Describing this, P11 said:

"Well, the first thing that comes to mind about making a list is it's probably not something I could do start to finish in one sit down. Over the course of time I'm going to think about things and I would probably want to prioritize some of that, because the doctor's time is limited, and I don't want to go on and on. So I would probably start with a list, and then I would want to go through and prioritize, and then just do the things that are really the most important."

(P11)

While explaining his decision to print the list, P10 expressed a desire to carry the list with him in daily life. He said he would prefer that this be accomplished through a mobile application.

"Well, yeah, I could do this. It would be nice that I'd have this electronically done and if I had an app on my phone to be able to do it as I run around and make sure that I'm able to keep—I don't have to use this as much as I could use my phone to keep track of it on an app is nice. I like the idea of keeping track of things in my own life and not depending upon other people to do it. So this helps me do that, it helps me get it organized and in a place that I can understand and find it without having to go search for it."

(P10)

Participants had mixed reactions to the option of sending the list directly to their doctor. P3 said she often talks with her doctor via text-based chat, so she thought if she emailed her list to the doctor, the doctor would reply right away. Other participants said they would not email the list to the doctor, including people who said they would bring the printed list with them to the visit.

P11 explained this, saying, "I think the doctor's too busy to spend a lot of time looking through this silliness." This resistance to sending the list to the doctor demonstrates that participants perceived boundaries in communication between patients and providers, echoing those reported in prior research [54].

Others thought sending the list in advance could help orient their care and the visit to items on the list. P4 thought the doctor could review the list ahead of time and make sure to cover those topics during the visit. Additionally, P4 thought the doctor and the rest of the care team could potentially address some items from the list before the visit started.

P10 thought that if the doctor read the list of items in the patient's own language, this would support communication between the patient and the doctor about the patient's priorities. Similarly, P4 thought that sharing personal values with the doctor would help the doctor understand what the patient wants and keep the doctor from adopting too narrow an understanding of the patient's health care needs.

P4: "I think that lets them know I'm interested in retiring but I don't want to sit around and do nothing. I have things that we still want to do, we want to stay as active as possible, things like that. 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. They look at you and they think well, she must – you know. I think that's just human nature in a way, but I think it's important that they know what you would like to do or what you would like to keep doing, maybe."

Interviewer: "So not just making assumptions but actually really investigating what's specific to you?"

P4: "Yes. If I told you I've been diabetic and take medication for my legs, and my legs hurt, would that make you think well, maybe she doesn't walk as much or it's not important or she's not doing anything to try to help that or something."

Overall, the My List activity aligned well with many participants' existing list-making practices. Participants felt that the activity would help them organize their thoughts and develop their priorities for an upcoming visit over time. Additionally, participants thought that bringing the printed list with them to a visit would help them remember the topics they wanted to discuss with the doctor, and that it would help structure the visit around their own priorities without getting sidetracked by other topics the doctor may raise. Participants shared mixed opinions about sending the entire list to the doctor electronically; some participants thought that this would be too much information while others thought it could provide useful context.

**6.1.2 Orienting toward clinic visit with doctor can reinforce communication boundaries**—Despite creating lists with personal values attached, we found that participants resisted the prospect of sharing those values with their doctor. My List did not go far enough to overcome patients' perceived boundaries between values and health. Participants' reactions to My List suggested that focusing the activity on preparing for an upcoming visit with their doctor may reenact and reinforce those boundaries instead of disrupting them.

The following example from P9 illustrates two reasons participants gave for not sharing values with providers: not wanting to burden health professionals with issues one can deal with on one's own, and not raising issues with the doctor that one doesn't believe the doctor can address. For P9, one reason for not wanting to burden his doctor was his perception

that doctors have limited time to spend on any given patient. P9 said he would not waste a doctor's time unless he had reached a roadblock analyzing solutions on his own:

“I know how busy [they] are...they get a lot of baloney ...and I don't wish to burden him with things that either I think I can take care of myself or I don't think he can help me with...until I reach a roadblock or can't come up with a solution, I'm not going to waste his time. [...] He likes to have one item [to focus on during a visit], and I understand that, so I try to do that. And then I'll ask him a quick question that's unrelated that he can answer in a sentence or a paragraph so that it doesn't waste his time.”

(P9)

Other participants resisted explaining connections they identified between values and list items, reasoning that these expanded explanations should not be shared with the doctor. P2 said he didn't want to share these explanations with the doctor because doing so would waste the doctor's time. He explained that the notes he took in My List to document his thought process were for his use only. Even though he thought that identifying connections between values and health was useful for helping him identify topics to raise with his doctor, he would share those values with the doctor.

Similarly, P11 wrote down connections between values and health but then decided those were not topics he would share with the doctor. He saw back pain as related to two personal values: his bulldozing and excavating business (an example of the “everyday life work” of managing chronic conditions), and treating others as he'd like to be treated. P11 had been given exercises to manage back pain, but he had not been doing them unless his back pain became extreme. P11 felt that his ongoing pain was his responsibility, and thus not something he'd bring up with the doctor, even though the pain was impacting his personal values. He said,

“...So the things that are connected, this is in reference to back pain, is that correct? So obviously a connection there would be the bulldozing and excavating. Probably treating people the way I'd like to be treated as it relates to my business. Taking care of the equipment, I had a major problem with that this morning. I think those three are the ones that come to mind...But as I look at this now that it's on paper, I'm thinking this isn't something to waste a doctor's time with, this is something that I have to do.”

(P11)

These examples illustrate a pattern exhibited across several participants: My List successfully prompted participants to consider how personal values were associated with their health concerns but it did not overcome patients' perceived boundaries around sharing values with health care providers.

## 6.2 Conversation Canvas

All participants who used Conversation Canvas were able to select a conversation topic, select values, self-care duties, and health status indicators related to that topic, and then respond to the facilitator's inquiries about relationships among those items. Below we

discuss several themes that stood out about participants' actions with this prototype: many participants described dual benefits of Conversation Canvas as a process that felt emotionally satisfying and a process that helped generate clarity around a topic important to them; some participants experienced difficult emotions during the process, and others expressed dissatisfaction at not reaching a clear conclusion after completing the process; personalized and contextualized probes from the facilitator enabled deeper reflection; and participants sought alignment between their choice of conversation topic and their choice of the facilitator persona.

### 6.2.1 Dual benefits: reaching clarity and appreciating the process—

Conversation Canvas enabled participants to think through an important topic in depth and ultimately reach greater clarity about that topic. Additionally, it produced positive and even cathartic feelings for some participants.

To illustrate these dual benefits, we include a vignette from P3's discussion of several interrelated decisions she faced. Figure 5 shows the topic P3 chose and the related items she added to the canvas.

P3 talked through a disagreement between her doctor, her family, and she. She said her knees were “bone on bone,” causing pain and limited mobility and preventing her from doing things she enjoys, like going for walks with family members or going out dancing with friends. These are examples of everyday life work that are critical for living with and managing chronic conditions over time. She wanted to have knee surgery, but her doctor would not allow it because P3 would “bleed to death.” (The risk of excessive bleeding during surgery is related to poor diabetes control.) Instead of knee surgery, P3's doctor recommended that she have a liver transplant, and her daughters and granddaughter also advocated for this direction.

Talking through this disagreement in Conversation Canvas, P3's focus shifted and her perspective evolved. Initially she focused on how knee surgery would help her enjoy valued activities like dancing and maintain relationships with friends. Later, P3 also explained why she doesn't want the liver transplant:

“I feel like there's somebody younger that really might need it. Someone has to die [because of a scarcity of livers available for transplant], and I'm up in age, so can't do much, so what the hell? They [my family and my doctor] say, ‘Oh, you'll feel better.’ Well, I don't know about that. If you can't walk... [...] All my friends are dead. I've been through three husbands and a girlfriend, but I've had a beautiful life.”

(P3)

Later, when P3 was reflecting on her experience using the Conversation Canvas prototype she said,

“[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?’ Go back on

the computer and think of something else...[It] gave me some things to organize and...look at and really think.”

(P3)

These statements about Conversation Canvas demonstrate benefits at two levels. First, P3 achieved an outcome: she clarified for herself why she did not want a liver transplant and why she wanted to pursue knee surgery. She felt she was able to “set everything straight” and discover novel next steps to convince her doctor and family that she should have knee surgery. Second, this reflection process gave P3 a sense of relief, having gotten “a lot off [her] chest.” P3 experienced the process of reflection itself as positive and cathartic.

Other participants echoed this dual benefit of Conversation Canvas: reaching greater clarity and appreciating the reflection process. For example, Conversation Canvas helped P4 clarify important factors associated with the decision to get an insulin pump, which would transform how she self-manages diabetes (i.e., the illness work of administering medication). She was unsure if a bulky pump would prevent her from continuing yoga, one of her valued activities and another aspect of self-management (i.e., exercise is illness work that helps manages blood sugar, blood pressure, and weight). Talking through factors like these, P4 had a realization that she did not know why her doctor was so insistent that she should get an insulin pump. As a result, P4 decided on a question to ask her doctor at her next visit: “Why do you think it is so important to get an insulin pump?” Looking back on her experience with Conversation Canvas, P4 said,

“It helped clarify what I was really thinking...what I wanted to ask [doctor]. Did you plan this, knowing that I [laughter]...Yes, I think it did help me.”

(P4)

P4 laughed because the insights from Conversation Canvas materially helped her prepare for an actual upcoming visit with her doctor.

In another example, Conversation Canvas lifted a burden that P12 had been feeling and boosted her motivation to tackle a problem that had overwhelmed her for a long time. Over many years, the floors in every room in P12’s home had collected piles of boxes, furniture, and other belongings. This had occurred while her husband was still alive, and he had recently passed away. P12 wanted to take on the massive effort of decluttering her home, but she was unable to do it without becoming overwhelmed with difficult emotions. Talking about what she appreciated about Conversation Canvas, P12 said,

“I think it would help quite a bit. 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 gestures to the conversation topic of decluttering and cleaning up her home It helps you want to do this when you get home...ask my friend to help me.”

(P12)

These examples show how participants appreciated Conversation Canvas for its dual benefits. The activity supported participants as they talked through a complex topic and ultimately reached a point of clarity. And, participants experienced the activity as cathartic.

**6.2.2 Emotional discomfort**—Not all participants experienced the deep thinking of Conversation Canvas positively. Some participants expressed emotional discomfort with the process, indicating they were not used to thinking in this way. This contrasts with the positive emotions illustrated in the section before this one.

For example, after completing Conversation Canvas, P11 acknowledged engaging in a deeper level of thinking than he was used to. He said it gave him an opportunity to “sit down and digest” the topics we covered, saying “this was a good exercise for me.” Despite calling it a “good exercise,” P11 did not show positive emotions that would suggest this “good” exercise was enjoyable. P11 said he would prefer to use My List because his experience with Conversation Canvas was “a little more stressful:”

“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...So the digesting, from that perspective this was a good exercise for me. But I liked the [My List] system a little better.”

(P11)

This presents a design challenge, which we address in the Discussion: talking through the competing demands of multiple chronic conditions—as well as related life challenges, personal values, self-care duties, and health status indicators—can be unfamiliar and emotionally challenging. This defamiliarization and affect can facilitate reflection, but clearly it is important to handle these difficult emotions with care.

**6.2.3 Dissatisfaction with lack of follow-up**—After a lengthy reflective conversation, Conversation Canvas did not generate clear next steps for some participants. Some participants expressed disappointment that the conversation facilitator did not close the activity with clear suggestions. This dissatisfaction was articulated most clearly by P2 and P11. P2 felt unsatisfied that he didn’t receive clear advice after exploring factors related to establishing an advanced directive and do-not-resuscitate order. P2 expected he’d get some advice or action out of the activity.

“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, ‘Well, we can do this, let’s see if we can make an appointment for you—we have a booklet, we’ll send you one...’ I’m amazed that that wasn’t suggested.”

(P2)

P11 echoed a similar sentiment when describing what he’d want to achieve through Conversation Canvas, saying he would expect the facilitator to make suggestions, such as to see a psychiatrist or another specialist:

“I’m going to have to assume [the facilitator is] going to be taking some notes and information and I would expect he might have the ability to make some suggestions to dig further.”

(P11)

These findings suggest participants perceived limits to the open-ended, exploratory discussion involved in Conversation Canvas. Participants appreciated when this process resulted in tangible outcomes.

#### **6.2.4 Importance of personalized and contextualized probes from facilitator**

—One stage of the Conversation Canvas process was confusing for many participants. After the facilitator asked the participant to identify values, self-care, and health status indicators associated with the conversation topic, the facilitator then sought to identify factors that made the conversation topic more or less challenging for the participant to think through.

At this stage, the facilitator would typically ask about those factors directly with questions like, “Looking at all of the items you added to the canvas, which of these items make [*the conversation topic*] more challenging to think through?” or, “...which of these make [*the conversation topic*] less clear?”

Participants responded to these questions with confusion. P2 said, “I don’t follow the question;” P12 said, “Could you explain that better for me?”; P4 said, “I guess I maybe don’t know what to add or what to pick, even;” and P7 said, “All of the items made the situation more challenging.”

The facilitator typically responded to this confusion with ad-libbed probes about particular items on the canvas and how they played a role in the conversation topic. These more personalized and contextualized probes enabled participants to delve deeper into the conversation topic.

The level of experience of the facilitator is likely to have played a role in how this adaptive facilitation approach influenced participants’ reflection. For more on the facilitator’s experience with this type of reflection, limitations of this approach, and opportunities for future work, please see Methods (section 5.3) and Limitations (section 7.5).

#### **6.2.5 Preferences for matching conversation topic to facilitator persona’s expertise**

—The first step in the Conversation Canvas activity invited the participant to select a fictitious persona who would facilitate the conversation. We offered two personas for selection: one was a man and one was a woman, both had long-term experience working in health care, and neither was a doctor. Descriptions of the personas also included unique interests and hobbies outside their job.

At this step, several participants explained the type of facilitator they preferred. Some were adamant that they would only talk to a doctor, while others saw value in having this discussion with someone who could devote more time to the conversation than a typical primary care doctor could.

We also found that participants wanted to fit the topic they intended to discuss to the expertise of the facilitator. P4 had a strong preference for speaking with someone with training in managing diabetes:

“She’s a volunteer? ...we’re going to say no right there. [...] I don’t want to see a physician’s assistant, I don’t want to see a nurse practitioner, I want to see a doctor. I have a health condition [type 1 diabetes] that requires a doctor, not a volunteer...It’s not like I’m trying to decide, ‘Should I tattoo my eyebrows on?’ or something like that where I think I could talk to anybody...I need the advice of a doctor.”

(P4)

This example illustrates how participants sought fit between their concerns and the person facilitating reflection. In other examples, P2 planned to discuss an advance directive and a do-not-resuscitate order and didn’t want to waste his doctor’s time with that conversation. After completing the activity, P11 remarked that based on the nature of the conversation, which delved deeper into personal topics than he was used to, he might expect a psychiatrist to facilitate the conversation. These findings suggest that it matters to patients with whom they discuss relationships between values and health, and they seek to fit the conversation topic with the expertise of the facilitator.

As Conversation Canvas is currently defined, the participant selects the conversation topic after they select the conversation facilitator. Our findings about participants wanting to match the facilitator’s expertise to the conversation topic suggest that the current interaction flow of Conversation Canvas is out of order. It would be better to allow participants to either select the conversation topic first and then select the facilitator, or to allow them to select the topic and the facilitator at the same time.

### 6.3 Time Machine

Time Machine prompted reflection on the past, present, and future. One of the strongest and most surprising findings of this study was that people resisted reflecting on the past, often expressing negative emotional reactions. When prompted to reflect on the future, some participants adopted optimistic perspectives and experienced transformative reflection. Fleck and Fitzpatrick [29] identified transformation as one of the more advanced levels of reflection: “Revisiting an event or knowledge with intent to re-organise and/or do something differently. Asking of fundamental questions and challenging personal assumptions leading to a change in practice or understanding.” [p. 218] Baumer et al. [4] identified transformation as a key conceptual dimension of reflection: “Transformation involves change to the fundamental, basic conceptualization of a situation.” [p. 591]

**6.3.1 Strong resistance to reflection on the past**—Nearly all participants resisted looking back in time at personal values, self-care duties, and health status indicators. After early participants had negative emotional reactions to this step, we changed the Time Machine design to give participants the option not to look back in time. When given the choice, no one chose to look back. These quotes illustrate several participants’ strong reactions to reflecting on the past:

P8: “Oh...oh, there’s so many things. If I’d gotten sober earlier, if I didn’t have ADD, if I hadn’t consumed so much alcohol, if I’d followed through on my college in the 60s, if I’d taken care of myself...I don’t like this one...It’s all the ‘what



ifs'...there's a saying that you've got one foot in the past and one foot in the future...you're peeing all over today. Looking back at my past is what got me sober...Going back to my past shows me all the F'd up things I did in my life...I can't deal with it right now. So can we just postpone it?"

P2: "Looking back is a waste of time as far as I'm concerned. We make decisions and we go forward. Whether that decision's right or wrong, it was the decision for ourselves. So I think everything that we do moves us forward—if we choose to make it a forward move—or we can spend a lot of time living in the past."

P4: "Take yourself back...what was important to you then?...Do I want to? ...I don't know if I want a journey back...Honestly, I think I would just skip it."

These strong reactions to the prospect of reflecting on the past are a clear signal that the current design of Time Machine was not working. While reflecting on difficult topics from the past may be beneficial, Time Machine's current design did not handle this adequately. We explore this further in the discussion.

**6.3.2 Hope for the future and considering change**—Multiple participants enjoyed the future-oriented thinking involved in Time Machine and talked about their futures in positive terms. Several participants often chose to look much farther into the future than we expected (e.g., two people chose to look 17 years ahead, one of whom was in her upper 70s).

Time Machine invited participants to speculate on their possible future in terms of values, self-care, and health status. In many cases they adopted a hopeful perspective toward the future. P8 was surprised that when she looked forward, she was able to adopt a hopeful outlook. However, she saw an opportunity for the tool to go farther to give "positive affirmations:"

"Put some positive spins on, because I know that I'm not the only one that would be negative, especially when you don't have very much time left, you think, 'Why bother?' ...[Give] some positive affirmations... about what we could do to change ourselves."

(P8)

As indicated at the end of that quote, some participants exhibited signs of transformative reflection [4,29], including considering changes to their behavior going forward. Along these lines, P2 said:

"...if I see something in the future that looks negative, [I] try to overcome it with a positive...I have the neuropathy in my feet, which is painful, and if I could look in the future and see what the future would entail, then maybe it would make some differences...change my ways for a healthy lifestyle...Maybe I would work a little faster to go on more vacations sooner..."

(P2)

Many participants responded positively to the prospective reflection component of Time Machine. Some participants considered making changes based on these reflections, a sign of transformative reflection.

**6.3.3 Unsuccessful visualization of values, self-care, and health status over time**—In Time Machine, after participants entered ratings and explanations about how they feel about values, self-care, and health status in the past, present, and future, participants viewed screens that integrated all of those data points. One of these screens displayed a graph-like timeline with three time points (past, present, future), and plotted the ratings for each value, self-care duty, and health status indicator across these time points.

Participants did not react positively to this visualization, and most participants had trouble interpreting its meaning. Some participants found it difficult to interpret the meaning of subjective ratings across different categories (i.e., values, self-care, health status) on the same graph. Other participants were confused when the patterns they saw in the graph did not match their understanding of how their values and health were changing (or would change) over time. For example, P10 said,

“I’m not sure what these lines mean. [...] I don’t think it reflects how I feel. That means I’d feel less productive ten years from now? I’m not sure that that’s what I said. If it is, it’s not what I meant to say, and this says I’m not looking at things differently ten years from now?”

(P10)

In this quote, P10 was reacting to seeing his ratings for the present and future plotted on a graph. What he saw in the graph did not align with how he actually thought about his future. He predicted he would feel more productive and that he would look at things differently in the future compared to the present. However, the visualization—which was based on his ratings earlier in the Time Machine activity—did not show this. Thus, P10 had a clear negative reaction to this visualization step.

Worse still, many participants did not share any distinctive reactions or reflections at this step. This is likely evidence that the way we collected and visualized subjective, numerical ratings of values, self-care duties, and health status indicators was not a successful approach.

Overall, Time Machine may have been a valuable reflection exercise in some regards (e.g., articulating a hopeful view for the future), but the prototype needs substantial improvement to support more focused reflection on associations among values and health.

## 7 DISCUSSION

This study was motivated by the need to help people with MCC understand the relevance of personal values to health-related topics. Supporting reflection on values and health can help people with MCC clarify their health priorities and prepare them to advocate for their priorities in conversations with healthcare providers. We described our process of designing three prototype reflection activities and shared findings from testing these prototypes with people who have MCC. These findings illustrate aspects of each prototype that best supported reflection on values and health, as well as aspects that did not support this reflection. In subsection 7.1, we call attention to the key takeaways from these findings and translate these into design guidelines for supporting collaborative reflection on values and health. This paper also makes a contribution to CSCW by bringing these findings into

conversation with previous research on designing for reflection. In sections 7.2–7.4, we build on and extend previous work in three areas: dynamically shifting across self-guided and facilitator-guided reflection, balancing outcome-oriented and exploratory reflection, and exploring temporality in reflection. Finally, in section 7.5 we discuss limitations of our study and directions future work.

### 7.1 Key takeaways and design guidelines for supporting collaborative reflection on values and health

One of the principal contributions of this paper to CSCW is a set of empirical findings from these prototype testing sessions. The findings can be summarized as follows:

- My List supported a familiar activity of preparing a list for a visit to the doctor’s office and enabled people to identify relationships between values and health. It also produced output that patients could bring to the doctor’s office to use as a memory aid, and as support for steering the conversation with the doctor toward topics they had prioritized. However, participants still felt pressure to prioritize their list according to previously-documented [54] perceptions of what was appropriate to share with the doctor (i.e., not taking too much time, and not sharing values).
- Conversation Canvas created space for participants to talk through and think deeply about important, complex topics involving personal values and health. Some participants experienced this as cathartic, while others experienced difficult emotions. Externalizing relevant topics on the shared canvas supported the patient and the facilitator. Several pre-planned facilitator questions elicited confusion from participants, but personalized and contextualized questions were effective at eliciting deeper reflection. As the conversation closed, a lack of concrete next steps or recommendations left some participants dissatisfied.
- Time Machine elicited hopeful visions of the future from participants, including concrete plans for changing behaviors. In contrast, participants strongly resisted reflecting on the past. The visualization component of the prototype was not successful, as it was difficult for participants to compare across information of different types, and the visualization did not match participants’ understanding of the ratings they had given earlier in the activity.

Looking across these findings, it is clear that no single prototype will be sufficient. Each has limitations in its current form. To guide future work that builds on these findings, we propose the design guidelines below. These guidelines build on the strengths of the prototypes we tested and overcome some of their weaknesses.

1. Begin with exploratory, reflective conversation between the patient and an active, empathetic listener. Offer initial guidance for the general topic of the conversation (e.g., “I’m not able to do something important to me because of my health”) and allow the patient to steer the conversation as desired.
2. Map the conversation as it progresses. Externalize key topics (i.e., personal values, self-care duties, health status indicators) and visualize relationships

among them. This externalization supports both the patient and the facilitator, enabling each to identify patterns and avenues to explore further.

3. Conclude with a step to identify and articulate takeaways. In the context of reflection on values and health for people with MCC, these takeaways can be a list of topics to discuss with the doctor at an upcoming visit. Takeaways could also include personal decisions, such as committing to new self-management activities or asking for help from a family member.
4. Align this concluding step with familiar and established practices. Patients are familiar with the practice of making a list of topics to discuss with the doctor at an upcoming clinical encounter. Clinicians are familiar with a workflow in which patients declare one or a few topics to focus on in an upcoming clinical encounter.

These guidelines provide a framework for future design to support collaborative reflection on values and health. Guidelines 1 and 2 build on strengths of the Conversation Canvas prototype. This open-ended, exploratory approach provides many opportunities to overcome existing communication boundaries that My List did not overcome. Guidelines 3 and 4 build on strengths of the My List prototype. This outcome-oriented approach overcomes the dissatisfaction some participants felt about Conversation Canvas by ensuring that exploratory reflection concludes with clear outcomes. Delaying this outcome-oriented component until after the exploratory component creates space for the patient and facilitator to consider relationships between values and health without the pressure to focus or filter the scope of the conversation based on expectations about what is pertinent to share with the doctor.

These guidelines could be accomplished by composing together Conversation Canvas and My List. We imagine a system that begins with a Conversation Canvas-like activity and interface. The existing design could be extended by adding additional visual support for sorting, grouping, and connecting topics on the canvas. After that, an activity like My List could be used to document key insights from the conversation and translate those into topics or questions to raise during an upcoming clinical encounter.

More generally, these guidelines clarify two roles that interactive systems can play in supporting collaborative reflection on values and health. First, interactive systems can serve as personalized repositories of key topics relevant to this reflection, including personal values, self-care duties, and health status indicators. As repositories for this information, information systems provide starting points for patients and facilitators to build from as they identify and articulate relationships between values and health.

The information included in such a repository is critically important. As discussed in section 5.2, each of our prototypes was pre-loaded with information specific to each participant. This information was organized in three domains: personal values (elicited from six categories developed in previous research with people with MCC), self-care duties (elicited from three lines of self-management work developed in previous research involving people with chronic conditions[18]), and health status indicators (measures used by clinicians to track chronic disease management).

Once established, this repository acts as scaffolding. It can be consulted, selected from, and added to as needed. Concepts that are typically held distinct by patients and clinicians, such as personal values and self-management duties, can more easily be discussed in relation to each other.

Second, interactive systems can support collaborative reflection on values and health by providing a shared visual space for mapping relationships among key topics. By providing this shared space, the patient and the facilitator can work together as they progressively develop a representation of the relationships among the patient's values and health. As currently designed, Conversation Canvas fulfills this role to some extent. It could be redesigned to provide more explicit support for sorting, grouping, and connecting topics in the shared visual space.

Our findings from Time Machine clarified much about how not to support reflection on values and health and revealed less about what does work. We see promise in the future-oriented reflection of Time Machine. The combined Conversation Canvas and Time Machine activity is well-suited to preparation for a particular clinical encounter, but this does not account for longer-term and over-time reflection on values and health. The future-oriented aspects of Time Machine could be used as inspiration for an activity to invite patients to establish longer-term goals for health and well-being that extend beyond the timeframe of a particular clinical encounter.

These guidelines resulted from looking across findings from the three prototypes and consulting previous scholarship in CSCW and adjacent fields on designing for reflection. In sections 7.2–7.4, we elaborate further on how our findings resonate with and extend this previous scholarship.

## 7.2 Dynamically shifting across self-guided and facilitator-guided reflection

The different prototypes we tested allowed for exploration of self-guided and facilitator-guided reflection. In prior research, many interactive systems for reflection have addressed reflection as an “individual, largely mental or cognitive activity” (p. 98), while others have treated reflection as a social process [5]. In one recent example of social reflection, Saksono et al. [68] discussed how parental caregivers' beliefs and life experiences influenced how they reflected with their children on physical activity tracking data. Other examples of social reflection include SenseCam, a system used by teachers and tutors to support ongoing professional education [28] and BinCam, a system to promote reflection on waste management habits through social persuasion [73]. Additionally, other research has explored interactive reflection on health data supported by conversational agents, which exhibits individual and social modes of reflections in a single intervention [47].

Individual and social modes of reflection are relevant to health care for multiple chronic conditions. Managing chronic conditions requires individual self-management by the patient as well as communication and coordination with informal caregivers and healthcare providers [80]. Lim et al. [53] showed that people with MCC can reflect on personal values on their own, and that discussing values with an active listener can aid reflection. In this study, we explored the nature self-guided and facilitator-guided reflection further.

Our findings demonstrated that having a facilitator who listened actively and responded dynamically to participants' reflections was a key factor in guiding participants toward identifying associations between values and health. Participants' use of Conversation Canvas most clearly demonstrated the usefulness of flexible and adaptive facilitation. The value of this adaptive facilitation was evident in My List and Time Machine as well, as the facilitator could step in when participants' self-guided reflection stalled.

Thus, classifying our prototypes as either facilitator-guided or self-guided does not accurately capture participants' actions with the prototypes. In practice, agency for guiding the reflection process shifted dynamically between the participant, the facilitator, and the prototype. This was clear when participants expressed confusion or uncertainty and the facilitator stepped in to clarify, reframe, and probe deeper. At the same time, this confusion or uncertainty could reflect unskilled or unhelpful support from either the facilitator or the prototype. There is a significant opportunity for future work to balance the support patients get through interactive systems with support they get from facilitators. One important step will be to involve trained facilitators as users and stakeholders in the design process. An example of this approach is provided by Hougard & Knoche [38], in which they involved an experienced occupational therapist and stroke patients to iteratively design a tool to support interpretation of patient progress in cognitive training.

Overall, these findings highlight an important implication for the design of interventions to support reflection on values and health: designers should aim to support both the patient and the facilitator. In addition, designers should acknowledge and support shifts in agency between the primary user and the facilitator. Our findings suggest that less is more in this regard. Highly constrained processes of reflection leave little room for the patient or the facilitator to ask questions and explore.

One way to do this is expressed in the second design guideline above: externalizing and visualizing relationships among values, self-care duties, and health status indicators supported the patient and the facilitator. This supports patients by making relationships among values and health visible, allowing them to name, elaborate, and further develop those relationships. It allows them to look across those topics and relationships and reflect on them further. It also supports the facilitator, enabling them to track the relationships the patient described, reflect back to the patient what they were hearing, confirm their understanding, and identify areas on which to probe further. And, it provides these supports without dictating that either the patient or the facilitator is the primary driver of the process. It minimizes constraints and allows for both participants to follow along and contribute on their own terms as the conversation unfolds.

Looking ahead to how prototypes like ours might be implemented in health care practice, it is important for future research to define the capacities and training required to facilitate this reflection. It is likely people with training as behavioral health specialists or social workers would be prepared to facilitate with care. Because this study focused primarily on testing different approaches to reflection with patients, we did not engage people in these possible facilitator roles. This is an important next step, and we discuss this limitation further in section 7.5 below.

One of the functions of facilitation in our prototypes was to hold space for participants as they talked through emotionally-charged topics. Emotion and defamiliarization can be important ingredients of reflection, but how facilitators handle challenging topics is critical. Our experiences in this study resonate with Tad Hirsch's [37] recent paper calling attention to the therapeutic nature of participants' experiences in design research, and the need to handle these experiences with care. At the very least, facilitators of reflection on values and health must be prepared to pause or end reflection if it becomes too distressing for participants.

### 7.3 Balancing outcome-oriented and exploratory reflection

Interactive systems for reflection vary in the degree to which they are open-ended and exploratory versus outcome-oriented [5]. For example, the Drift Table was exploratory, supporting "ludic activities...motivated by curiosity, exploration, and reflection rather than externally-defined tasks" (p. 885) [31]. Other systems are designed with particular outcomes in mind, such as those promoting healthy behavior change through increased exercise (e.g., [8,65]) or changes to diet (e.g., [55,62]). Systems may blend outcome-oriented and exploratory reflection, such as those with purposes the user can adapt. For example, Oinas-Kukkonen [61] proposed behavior change support systems with user-specified goals. Such systems are outcome-oriented but adaptable.

Our findings show that in the context of MCC care, how the purpose of a reflection activity is framed can influence the nature of reflection. My List had the express purpose of generating a list of topics to discuss with the doctor. With this purpose, My List reinforced communication boundaries regarding what information pertinent to share with healthcare providers. This is problematic because the objective of all three prototypes was to intervene in and overcome these perceived boundaries.

In contrast, Conversation Canvas was open-ended and exploratory; it was not oriented toward a particular outcome. Conversation Canvas contributed to deep reflection for many participants, enabling them to discover and articulate connections between values and health. However, some participants wanted this process to result in a clearer outcome (e.g., suggestions for next steps in their health care).

Therefore, this study highlights the need to balance outcome-oriented reflection with exploratory reflection. Outcome-oriented reflection can ensure that patients' expectations are met, but if that stated outcome is visit preparation, this can have the undesirable effect of reinforcing participants' perceptions of boundaries about what they can or should communicate with doctors about. In section 7.1 above, we discussed how the design guidelines could balance outcome-oriented and exploratory reflection by creating a system that starts with an activity like Conversation Canvas and concludes with an activity like My List.

### 7.4 Exploring temporality in reflection

Many systems have been designed for users to reflect on data from their past (e.g., [15,25]). Elsdon et al. [22] explored how systems might support people in documenting, curating, and reflecting on lived experiences over the long-term, coining the term documentary

informatics. Prior work on interactive systems for reflection used recordings, visualizations, or documentation of past events to prompt reflection on the past [4,5]. Visualizations of web browser bookmarks [58] and online communication [81] enable users to identify patterns and bring awareness to their behaviors. Wandering Mind is a journaling tool that allowed users to reflect on patterns in their thinking by analyzing keywords, emotions, or the chronology of their journal entries [63]. Similarly, Isaacs et. al. [41] explored how people experienced in-the-moment reflection compared to retrospective reflection. One group of participants recorded events and experienced benefits from writing their thoughts and feelings at the time of each recording; a second group recorded events over time and later reflected back on these events. They benefited by recognizing patterns and learning from past events.

Temporality is important in the context of MCC care because managing chronic conditions is a long-term endeavor, requiring adaptation and adjustment to practices and identity over time [16]. In particular, Time Machine may be well equipped to support biographical work. Corbin and Strauss [16,18] identified biographical work (sometimes called identity work) as one of the three lines of self-management performed by people living with chronic conditions. The temporal character of Time Machine invites reflection on how one's life has changed due to illness, and how one might adjust behaviors now to put their life on a different course for the future.

Prior work has approached retrospective reflection as an activity that follows personal data collection, with a focus on recordings of past daily events and emotional states. This study's findings fill a gap in understanding in the context of MCC care about how different focuses on the past, present, or future might facilitate reflection on values and health.

Our study adds a new perspective on retrospective reflection. Time Machine generated strong resistance to reflecting on values and health in the past. Retrospective reflection can be beneficial even if it isn't enjoyable, and designers have supported reminiscence in other contexts like care for people living with dementia [20,21]. But in the context of MCC care we have shown the need to tread carefully and allow people to reflect on the past on their own terms. At minimum, this means not building systems that require the person with MCC to reflect on their past. More research is needed to understand the risks and benefits to encouraging people with MCC to reflect on values and health in the past, and how interactive systems and facilitation can help maximize these benefits and minimize the risks.

Time Machine also explored reflection on values and health into the future. We found that people with MCC can experience hope and optimism when thinking through possible futures in terms of personal values, self-care duties, and health status indicators. Reflection on values and health in the future opens up possibilities for people with MCC to clarify their health care priorities and articulate those with health care providers.

We see potential for future work to explore how an activity like Time Machine could support people with MCC in learning about relationships between values and health over time. Recent research by Herman Saksono and colleagues [68] provides a useful point



of departure. In their study of reflection on physical activity by parental caregivers and children, Saksono et al. argued, “learning how to be active is a negotiation between prior and new knowledge about ways to be active” (p.10).

Our paper focused on people with multiple chronic conditions and didn’t focus on specific behavioral goals like being active. Yet, findings from Time Machine illustrated that future-oriented reflection on values and health led some participants make goals to align their behaviors with their values. Future work could explore how an activity like Time Machine might result in a person deciding on a new goal and tracking new information associated with the goal. Then, in a subsequent reflection session, looking back on this tracked information in the context of personal experiences and personal values could support the patient in learning how to make changes in their life in accordance their values. Saksono et al.’s [68] Experience-Reflection-Insight framework provides a useful conceptualization for how designers might support people with MCC in experiential learning from reflection on values and health over time.

## 7.5 Limitations and Future Work

We tested prototype reflection activities that were supported by paper-based wireframes. This low-fidelity approach is likely to have influenced the nature of participants’ reflection, and this potentially limits the credibility and transferability of this study’s findings. However, viewing these prototypes as flexible interventions into participants’ practices and preferences for reflecting on values and health, this study generated rich findings into how designers can approach designing for reflection on values and health in the future.

We didn’t evaluate these prototypes with people who might play the facilitator role in clinical practice. The primary facilitator in this study was a research team member who had significant domain knowledge (e.g., knowledge of three lines of self-management work involved in living with chronic conditions), experiential knowledge (e.g., experience interviewing people with MCC about values in several studies the past), and qualitative interview skills. The secondary facilitators had similar knowledge and experience. Future work should evaluate reflection tools like ours with health coaches, medical assistants, social workers, and others who are candidates for facilitating this kind of reflection in clinical practice. Our study has provided critical understanding of how patients respond to different approaches to reflection on values and health, providing a foundation for future studies to understand and support the needs of facilitators. How best to support facilitators is an open question that should be explored empirically.

In addition to understanding how best to support the facilitator, future work should explore how else prototypes like ours could be implemented in health care practice. People with MCC receive much of their care in primary and specialty care settings. In the United States, where this study was conducted, these settings are highly routinized, a result of a combination of economic, policy, and practical considerations. We believe that the most likely route to initial implementation of prototypes like ours is integration into primary care through the models like the Patient Centered Medical Home (PCMH), where a health coach can act as a facilitator and coordinate care from the conversation within a larger healthcare team [42,66]. A collaborative reflection session could be held before an upcoming clinic

visit, and the output of that reflection could be a list of topics or insights that the patient can use to guide their conversation with the doctor and other PCMH care team members including nurses, dieticians, community resource specialists and social workers. However, more research is needed to understand exactly what that output should look like and how it should be communicated with healthcare providers.

Another limitation of our approach is that we engaged participants at a single point in time (as opposed to multiple engagements over weeks or months) and we did not incorporate data collected from participants' daily lives beyond what they chose to share. Additional research is needed to understand how people's reflection on values and health may evolve over time. Research on values and design illustrated that values are not fixed entities [39] and research from sociology has illustrated that people's experiences of illness shift over time [16]. There is an opportunity for future work to build on this study's findings to examine the nature of reflection on values and health when informed by lived experiences, and when continued over time.

Our study was a design-based inquiry into ways that different prototype features influenced patients' experiences with reflection. Our flexible approach enabled collection of rich qualitative experiences with our prototypes. We did not account for potential ordering effects, although our findings for each prototype were mostly consistent across participants. Although all participants did not see all three prototypes and we did not counterbalance the order they saw them, we carefully balanced which prototypes participants used to ensure that each prototype was used by roughly the same number of participants by the end of the study.

Based on our experiences with participants, a few potential considerations related to ordering could limit our findings. First, using paper prototypes was unfamiliar for our participants and their use of the first prototype typically required some basic explanation and guidance about how to interact with the prototypes (e.g., tap on a button to "select" it, write with a pen to input information). By the second or third prototype participants understood how to interact with the paper prototypes, meaning their experiences with later prototypes may have been smoother and less encumbered by ease of use issues. Second, each prototype contains the same personalized information for each participant: personal values, self-care duties, and health status indicators. This same information was represented in different ways in different prototypes. By the second or third prototype, the participant was familiar with the information stored in the prototypes, and this could have influenced how they use the prototypes. Third, reflection takes cognitive and emotional work, so by the second or third prototype, participants were not as mentally fresh as they had been for the first prototype. Fourth, insights that a participant generated through reflection in one prototype could influence their reflection in later prototypes.

Despite the potential for ordering effects, participants were mostly consistent in their feedback on prototypes, and our flexible approach allowed for rich qualitative insights.

Participants were recruited from the same integrated health care system and all had health insurance. This means that our study likely did not account for important social influences on health (e.g., limited access to health care), nor did it explicitly consider underlying

structural inequities like racism and environmental health. Tiffany Veinot and colleagues [78] have called attention to the need to engage people from historically marginalized populations in the design of health informatics interventions, and they have called for scholars to “level up” by targeting interventions to address structural inequities [77]. Thus, this paper’s findings are limited in that they do not address these important factors. More research is needed to engage people facing additional social challenges beyond the competing demands of multiple chronic conditions. Indeed, recent research has shown the need to approach the design of personal informatics systems differently for people from low-resource communities [64]. Additionally, it’s possible that other related factors could have influenced the findings and their transferability, such participants’ illness severity, availability of support, and experience managing their illnesses. Future work can explore how factors like these demand different forms of support for reflection on values and health.

## 8 CONCLUSION

There is a need to help people with multiple chronic conditions and healthcare providers align their priorities for health care. In this study, we addressed gaps in understanding regarding how to design interactive systems to support people with multiple chronic conditions in identifying and articulating what’s important to their well-being and health (i.e., personal values), and how that relates to the activities they do to manage their health (i.e., self-care duties) and measures of their health status. We developed and tested three prototypes—My List, Conversation Canvas, and Time Machine—and illustrated how these different approaches to reflection influenced participants’ abilities to connect their values with their health care. We found that there were benefits to self-guided and facilitator-guided reflection, and that systems to support this reflection should enable patients and facilitators to shift between these modes dynamically. Our findings also illustrate the need to balance outcome-oriented reflection (e.g., preparing for a visit with the doctor) with exploratory reflection (e.g., digging deeper into the competing demands of multiple chronic conditions). Finally, our findings showed that inviting reflection on values and health across the past, present, and future can generate a range of positive and negative emotions. These emotions can be integral to reflection, but reflection facilitators must handle emotionally charged topics with care. Overall, these findings move us closer to enabling patients to articulate and advocate for their health priorities in conversations with healthcare providers. Supporting patients in advocating for their priorities will ultimately help people with MCC and providers reach concordant priorities for health care and improve health outcomes for patients.

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# APPENDIX A: WORKSHEET ELICITING PERSONAL VALUES AND SELF-CARE DUTIES

## Worksheet instructions

This worksheet will help you prepare for your phone interview. Please fill out both sides of this sheet before your phone interview. You are welcome to discuss these questions with family members, if it will help you think through your answers

### 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.

<b>Activities:</b> pursuits or things that you do (ex: vegetable gardening, working, reading sci-fi novels, or resting)	<b>Possessions:</b> things that belong to you (ex: your car, pictures of family members, letters from friends, or your home)
<b>Relationships:</b> connections with other people or groups (ex: family, companions, or church group)	<b>Emotions:</b> feelings or moods you experience (ex: comfort, joy, relief, or accomplishment)
<b>Principles:</b> beliefs, standards, or virtues you live by (ex: independence, honesty, faith)	<b>Abilities:</b> physical or mental capacities or skills (ex: mental sharpness, mobility, vision)
<b>Other:</b> anything else that does not fit the descriptions above	

### 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.

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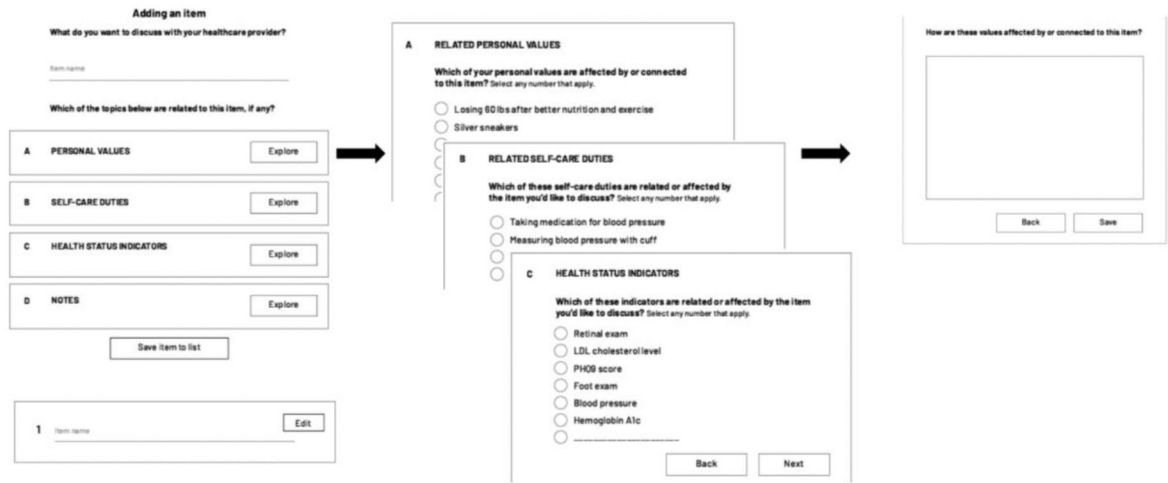


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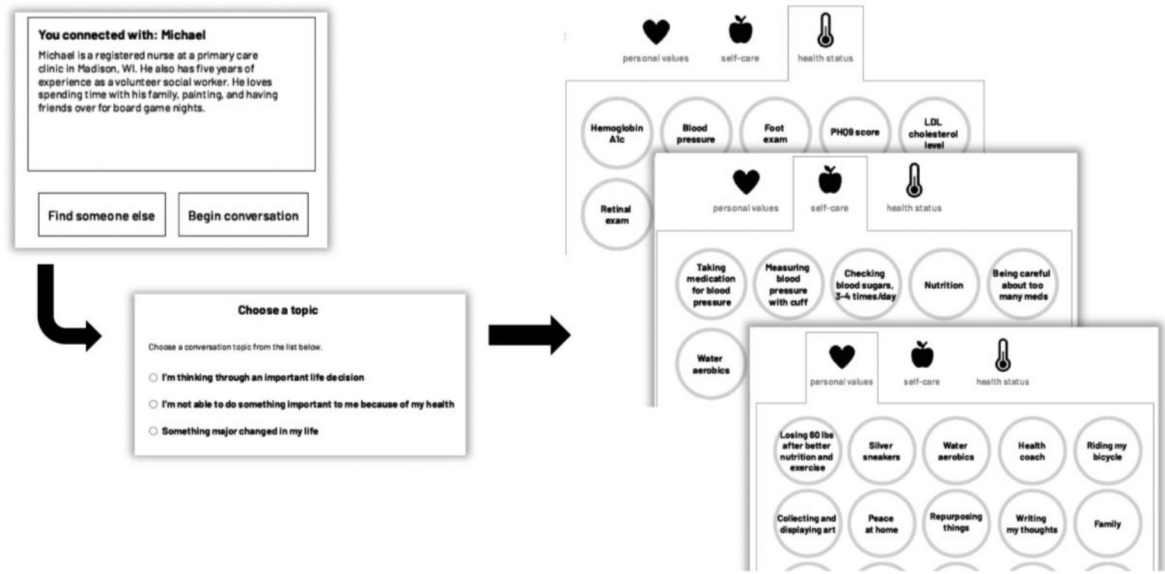
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**CCS CONCEPTS**

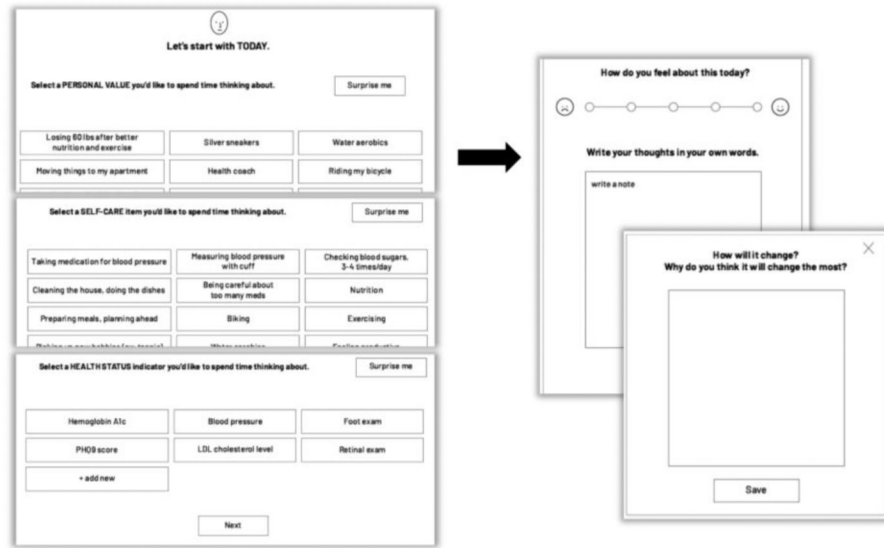
•Human-centered computing~Human computer interaction (HCI)~Empirical studies in HCI •Human-centered computing~Human computer interaction (HCI)~Interaction paradigms~Collaborative interaction •Human-centered computing~Interaction design~Empirical studies in interaction design •Applied computing~Life and medical sciences~Health care information systems •Applied computing~Life and medical sciences~Health informatics



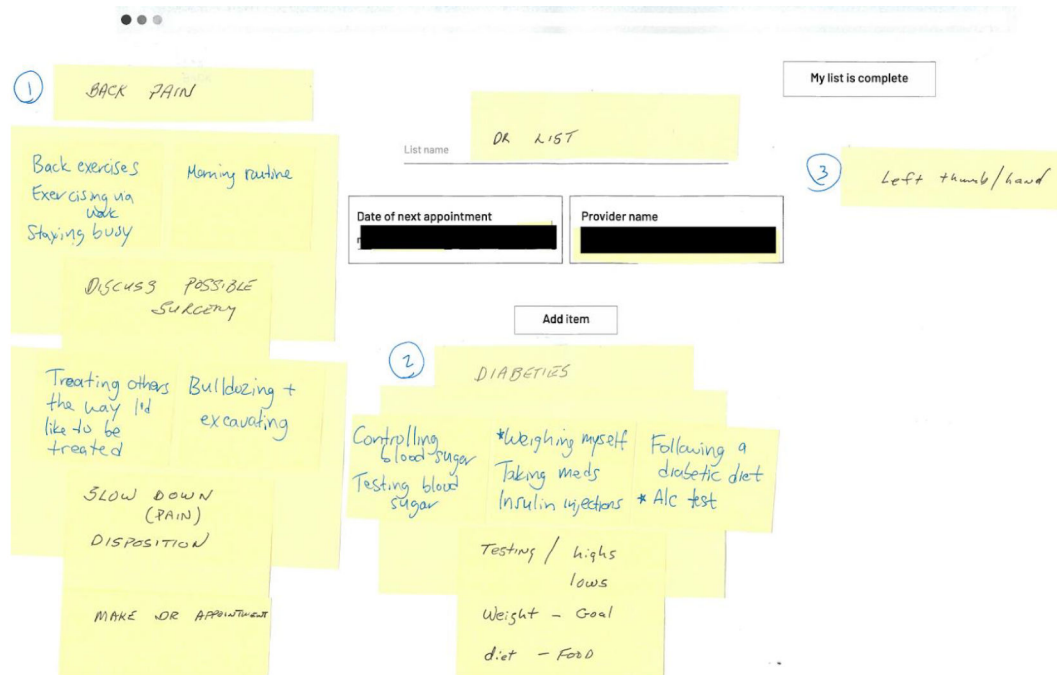
**Figure 1.** Screens from My List, including the invitation to add an item to the list (left), pop-ups containing values, self-care duties, and health status indicators (center), and pop-up asking for explanation (right).



**Figure 2.** Screens from Conversation Canvas, including the facilitator persona description (top left), options for the conversation topic, and screens for selecting values, self-care duties, and health status indicators related to the conversation topic (right).



**Figure 3.** Screens from Time Machine, including selection of personal values, self-care duties, and health status indicators to reflect on (left), rating of each selected item in the present (top right), and explaining how items will change in the future (lower right).

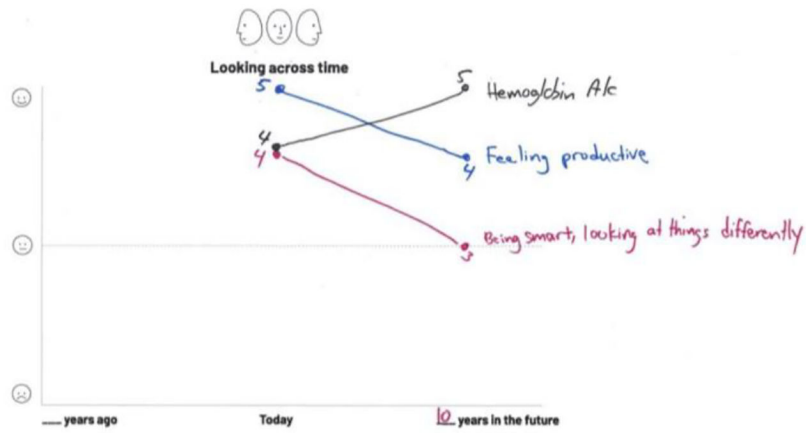


**Figure 4.** My List prototype completed by P11. He added three items to the list—back pain, diabetes, and left thumb/hand—and listed several related personal values, self-care duties, and health status indicators for the first two items.



**Figure 5.** Conversation Canvas prototype completed by P3. The canvas shows an image of Michael, the facilitator persona chosen by P3, the conversation topic and its description (i.e., “bone-to-bone in my legs...”), and a variety of personal values, self-care duties, and health status indicators P3 and the facilitator added to the canvas.





**Figure 6.**

Time Machine prototype completed by P10. This is one of the final screens of the prototype, in which the participant's ratings collected earlier in the process are visualized on a timeline. P10's timeline shows changes in ratings over time for Hemoglobin A1c (increasing), Feeling productive (decreasing), and Being smart, looking at things differently (decreasing).

**Table 1:**

## Participant demographics and prototype use

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