



## “It’s a little bit like cardiomyopathy Tinder”: Toward designing to facilitate locating peers and learning self-care ideas in online health communities

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### ABSTRACT

Users of online health communities have difficulty finding others with similar health experiences. They are often asked to use keywords when searching for their peers, but it is not uncommon for them not to know the right terms. This becomes particularly complex when unsure what or whom they are looking for. Moreover, the richness of patient perspectives is lost in the volume of discussion threads. In this paper, we investigate how to design to facilitate locating peers and learning self-care ideas from them. We created a prototype mimicking a mobile application for an online health community. The application recommended other community members to connect with and suggested self-care ideas based on what they had tried. Following a user-centered qualitative evaluation, we explore what ten people with cardiovascular disease and three clinicians thought of the prototype. Our findings reveal the preponderance of the lifestyle profile in locating peers. In light of this, we argue that, as individuals seek to lead as normal a life as possible, the most helpful suggestions in their quest may come from peers most similar to them in terms of habits and activity level. We translate the research findings into recommendations to inform future design.

### 1. Introduction

Expert by experience. In health-related contexts, this term designates an individual who has acquired expertise in coping with a particular disease from direct experience (Castro et al., 2019; Hollins, 2019). Such experiential knowledge is gradually built upon dealing with illness in everyday life, accessing healthcare services, fulfilling roles at home, at work, and in the community, and relating to peers — other people in a similar health situation (Castro et al., 2019). Authors such as Hartzler and Pratt (2011) call this type of knowledge “patient expertise”, a term we adopt in this paper.

Since it encompasses know-how and coping strategies, patient expertise is arguably better placed than clinical sources to meet certain information needs (Hartzler and Pratt, 2011). Indeed, patient-expertise sharing in peer-support settings has been linked to benefits in chronic disease self-care, including enhanced coping skills and understanding of one’s illness(es) (Campbell et al., 2004, as cited in Hartzler and Pratt, 2011).

Nowadays, anyone on the Internet can share their lived experiences and explore those of others. In particular, online health communities facilitate opportunities to learn about one’s condition (Hartzler and Pratt, 2011; Nunes et al., 2015), engage in collective sense-making activities (e.g., Huh and Ackerman, 2012; Mamykina et al., 2015;

Young and Miller, 2019), and obtain and provide various types of social support (e.g., Gui et al., 2017).

Nevertheless, two challenges warrant attention when it comes to facilitating the sharing of patient expertise in online health communities.

The first challenge concerns locating others with similar health experiences. Members of online health communities are often asked to use keywords when searching for their peers (e.g., see Fig. 1(b)), yet it is not uncommon for them not to know what terms to use (Pang et al., 2015). To top it all off, the search becomes particularly complex when the seeker is unclear about what or whom they are looking for (Levonian, 2022; Pretorius et al., 2020).

Not only is searching by keywords a frustrating experience when trying to locate supportive peers (Pretorius et al., 2020), but unmet information needs are one of the reasons why users withdraw from online health communities (Gatos et al., 2021).

The second challenge pertains to the prominence of and accessibility to patient expertise. The richness of consensus and dissensus among users and the diversity of patient perspectives are often lost in the volume of discussion threads (Hartzler and Pratt, 2011; Mamykina et al., 2015). Therefore, there is a need to explore alternatives for archiving, indexing, and recommending patient expertise so that users

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can readily find the information they seek (Gatos et al., 2021; Gui et al., 2017; Hartzler and Pratt, 2011; Young and Miller, 2019).

In view of the above, we set out to investigate how we may design to facilitate locating peers and learning self-care ideas from them in online health communities. We created a low-fidelity prototype mimicking a mobile application and recreating salient features of an existing community. In particular, the application recommended other community members to connect with and suggested self-care ideas based on what they had tried. Following a user-centered qualitative evaluation, we explore what ten people with cardiovascular disease and three clinicians with experience treating this group of heart or blood vessel conditions thought of the prototype.

Our findings reveal the preponderance of the lifestyle profile in choosing peers. In light of this, we argue that, as individuals seek to lead as normal a life as possible, the most helpful suggestions in their quest may come from peers most similar to them in terms of habits and activity level. We conclude the paper with design implications derived from the study findings.

## 2. Background

### 2.1. Cardiovascular disease: Definition(s), facts, and self-care

Cardiovascular disease (CVD) is an umbrella term for disorders or conditions of the heart or blood vessels (World Health Organization, 2023). To illustrate, the buildup of fat on the inner walls of the coronary arteries—an abnormality known as atherosclerosis (National Health Service, 2023)—can cause a decrease in the flow of oxygen-rich blood to the heart. Thus, an individual whose heart muscle does not receive enough oxygen and nutrients to function is diagnosed with coronary artery disease (National Health Service, 2020).

Situations in which the blood supply to the heart is severely reduced or blocked often precede a heart attack—a major adverse cardiovascular event known medically as myocardial infarction (Cleveland Clinic, 2022). When the lack of blood is chronic, the myocardium weakens, thereby leading to heart failure (National Health Service, 2020; WebMD, 2022). The latter denotes the inability of the heart to pump the oxygen-rich blood the body needs (National Health Service, 2022).

Figures from the World Health Organization show that CVD is the leading cause of death in the world, with 17.9 million deaths per year (World Health Organization, 2023). In addition to the loss of human life, the cost of this group of heart or blood vessel conditions is in the order of hundreds of billions of US dollars in the United States alone. More specifically, the expenses of caring for 28.6 million cardiovascular patients amount to \$407.3 billion, of which \$9 billion (2.2%) is allocated to treat coronary artery disease and \$30.7 billion (7.5%) to treat heart failure (Tsao et al., 2023). It is worth noting here that the financial cost does not always correlate with the prevalence of the disease. For every individual over 20 years old with heart failure in the United States, there are three with coronary artery disease (Tsao et al., 2023).

Although CVD is irreversible, interventions that enhance self-care through promoting a healthy lifestyle have been linked to improvements in clinical outcomes (Riegel et al., 2017). And yet, there is still a belief among patients and healthcare providers that pharmacological interventions are more effective than engaging in regular physical activity, quitting smoking, and following a healthy diet, to name a few cardiovascular health behaviors (Riegel et al., 2017). To counter this misconception, it is necessary to emphasize self-care in the current healthcare system so that the individual takes greater responsibility for their own health (Riegel et al., 2017).

Self-care is a naturalistic decision-making process in which the individual engages to maintain their physical and emotional health and manage their disease(s) (Riegel et al., 2017). Practicing adequate self-care involves adhering to cardiovascular health behaviors, such as those

mentioned above, learning about one's disease, and following medical guidelines for treatment. This process also involves self-monitoring to detect early signs and symptoms of complications or worsening of the disease. Equally important is self-management, which outlines how to act when signs and symptoms occur (Riegel et al., 2017).

In this study, we chose to focus on CVD for the following reasons. The first has to do with the fact that CVD self-care also occurs at the community level (Riegel et al., 2017). We, therefore, see an opportunity to advance our understanding of how design can enable awareness-raising and knowledge-acquisition processes in online peer-support settings that help individuals engage in adequate self-care.

Next to this is the fact that CVD has received, at best, little attention in HCI and CSCW research on online health communities (see Gatos et al., 2021). Hence, our research adds to the literature considerations people with CVD have regarding locating and choosing peers and learning self-care ideas from them in online peer-support settings.

### 2.2. Facilitating peer connections

Peer matching often connects people with similar experiences to help them support each other's health journeys. For example, in mentoring programs, a newcomer is usually matched with a seasoned member as long as they share a diagnosis and are contemporaries (Long et al., 2012, as cited in Hartzler et al., 2016a). In e-health contexts, individuals have expressed a preference for the prospective mentor's posts due to the interpersonal cues embedded therein (Hartzler et al., 2016a). Since what is meant by "optimal match" varies from one person to another, authors such as Fang and Zhu (2022) and Hartzler et al. (2016a) suggest allowing individuals to adapt matchmaking to their needs and wishes.

In online mental health communities, peer matching enables support-seeking and support-providing processes. Yet the way in which the seeker is matched with the provider is rather rudimentary, such as on a first-come, first-served basis (Fang and Zhu, 2022). In contrast, people would find it more useful if they were matched on the basis of experience level and demographic attributes (Fang and Zhu, 2022).

When people are confronted with gaps in their understanding of their health status, they turn to their peers to make sense of their own situation (Genuis and Bronstein, 2017; O'Kane et al., 2016). In this context, the sense-maker devotes a great deal of effort—both cognitive and behavioral (see Athukorala et al., 2016; Wildemuth and Freund, 2012)—to information search tasks to validate their experiences (Genuis and Bronstein, 2017). Thus, information retrieval systems enable locating peers in the digital realm.

Typically, these systems require users to enter keywords when searching for their peers (e.g., see Fig. 1(b)). But more than a few times, people do not know what keywords to use, perhaps because they are unfamiliar with medical terminology (Pang et al., 2015). On top of that, the seeker may be uncertain about what they are looking for, let alone how to go about it (Levonian, 2022; Pretorius et al., 2020; White and Roth, 2009). More specifically, when it involves uncertainty, its goal is amorphous, and there is no specific answer to it—as is often the case with health information searches (Pang et al., 2015)—peer finding could be better conceptualized as an exploratory search task (Wildemuth and Freund, 2012). In this paper, we adopt such conceptualization.

People employ the so-called "broadcasting" strategy to overcome the limitations of information retrieval systems (Hartzler and Pratt, 2011). For example, "Has anybody else got any ideas about what I can do?". As one might expect, this strategy is effective as long as those who meet the search criteria notice and respond to the call. Incidentally, unanswered questions or unhelpful responses may anticipate withdrawal from online health communities (Gatos et al., 2021).

Recently, Levonian (2022) proposed that recommendations could facilitate locating peers without the individual having to articulate their information needs into a query statement. In line with this, we think

peer recommendations—an instance of social matching systems—can support individuals in exploratory search tasks. Yet how to design peer recommendations is an open question that warrants attention from researchers and industry practitioners, as it is well-known that human factors play a prominent role in accepting technology (De Croon et al., 2021; He et al., 2016). What is more, peer recommendations are an underexplored topic in the health recommender systems literature (see De Croon et al., 2021).

All things considered, two issues remain underexplored in the context of peer matching within online health communities. The first pertains to the target population. Significant attention has been given to cancer patients (e.g., Hartzler et al., 2016a; Levonian, 2022), single-caregiver mothers (e.g., Saksono et al., 2023), and mental health support seekers and providers (e.g., Fang and Zhu, 2022). However, the specific needs for peer support of people with CVD, due to the challenges associated with managing this condition, have been largely unaddressed.

The second issue concerns research-induced expectations. For example, whether to choose a peer mentor (e.g., Hartzler et al., 2016a) or a mental health support provider (e.g., Fang and Zhu, 2022) or to facilitate behavioral modeling (e.g., Saksono et al., 2023), each other's roles were clear. However, a lack of formal roles or expectations is common in peer relationships (Simoni et al., 2011, as cited in Levonian, 2022). This somewhat aligns with our conceptualization of peer finding in that the individual may be unsure of what or whom they are looking for or what they expect to achieve.

Given the above, we seek to understand what people with CVD value in exploratory peer search and why. For this purpose, we designed user-controllable peer recommendations, whereby the individual tailors recommendations to their notion of likeness. Our approach is informed by prior research highlighting the interplay between this exercise of control and user satisfaction (He et al., 2016).

With the notion of likeness, we pursue a two-fold purpose. First, it is the measure of “fit” by which our design matches peers with each other (see Levonian, 2022). Second, it seeks to operationalize homophily, a concept that denotes the predisposition of individuals to relate to others based on commonalities such as shared experiences, personality, and interests (McPherson et al., 2001, as cited in Hartzler et al., 2016a).

We identified seven attributes widely used in peer matching or about which individuals have expressed a preference (see Levonian, 2022). We then grouped the attributes into three distinct categories, as described below.

**Demographic profile.** Matching peers based on gender and race positively influences the intention to engage in healthy behaviors, such as physical activity (Saksono et al., 2023). Along with gender, age is another demographic attribute widely used in peer matching. For example, support seekers prefer peers who are contemporaries to avoid generational gaps potentially hindering support provision (Fang and Zhu, 2022). In this work, an individual's gender and age comprise their demographic profile.

**Clinical profile.** The more similar their health experiences, the more likely people are to adopt each other's advice offered in peer support settings (Wang et al., 2008, as cited in Hartzler et al., 2016a). While people seek out peers with shared health conditions, a common diagnosis is not a prerequisite for peer communication (Levonian, 2022). In this work, diagnosed conditions, experienced symptoms, and prescribed treatments constitute the individual's clinical profile.

**Lifestyle profile.** The fact that people share similar lifestyles can make their mutual support more helpful (Dunn et al., 1999, as cited in Hartzler and Pratt, 2011). And yet, work on peer matching has paid little attention to attributes that describe people's way of living (see Levonian, 2022). In this regard, Bussone et al. (2020) and Cerón-Guzmán et al. (2022) suggest that individuals are likely to share their activity level and smoking status with their peers within online health communities. Hence, we propose to leverage these attributes to match peers based on them.

### 2.3. On the prominence of and accessibility to patient expertise

Hartzler et al. (2016b) provide an illustrative example of how to make patient expertise prominent in online health communities. Specifically, they explore the enrichment of user profiles by including topics about which members have shown themselves knowledgeable. Although this is intended to bring out the individual's experiential knowledge, its contribution to the accessibility to patient expertise may be limited, as the information seeker still has to navigate around the community and jump from one user profile to another.

In contrast, collaborative filtering recommender systems may have the potential to aggregate and synthesize patient expertise in the form of ratings or assessments, thus helping users to share and benefit from each other's opinions and experiences (Hartzler and Pratt, 2011). Broadly speaking, collaborative filtering recommender systems cluster users based on a measure of similarity to offer recommendations from like-minded people (Burke, 2010, as cited in He et al., 2016). Yet, how to operationalize such systems in the context at hand is a question worth asking. What follows is our take on this.

The first concerns the purpose. With collaborative filtering recommender systems, we seek to facilitate the learning of self-care ideas from peers by aggregating individual treatment evaluations—an instance of patient-reported outcomes and, in our view, a way to operationalize patient expertise (Huh and Ackerman, 2012; Weldring and Smith, 2013). Self-care ideas encompass practical know-how and coping strategies (Hartzler and Pratt, 2011).

The second pertains to what to recommend. In the context of living with diabetes, self-care ideas learned from peers include strategies for keeping blood glucose levels at bay (e.g., Huh and Ackerman, 2012). When it comes to cardiovascular disease, it is not well-known what people want to learn about self-care from their peers. That is why we have set out to explore this question in the present study.

While people with CVD are enthusiastic about learning self-care ideas from their peers, they are also aware of each condition's complexities and idiosyncrasies and the need to validate with healthcare providers the appropriateness of any ideas for their situation (Cerón-Guzmán et al., 2022). This awareness brings up the imperative to reflect on the extent to which design seeks to foster the individual's autonomy in self-care (Nunes et al., 2015). We therefore decided to involve clinicians in this study and thus gain further insights into designing to facilitate the learning of self-care ideas from peers.

The third aspect of operationalizing collaborative filtering recommender systems has to do with forming groups of similar users. In this sense, a phrase with which one may already be familiar across e-commerce or streaming platforms is worth quoting: “People who bought/watched this also bought/watched...” Just as this simple sentence alludes to the origin of the recommendation, it can also trigger a cognitive heuristic about the distinctive value of the suggestion (Liao et al., 2022).

Collaborative filtering often clusters users based on commonalities, such as movies watched or items purchased (Thorat et al., 2015). In this way, it seeks to make inferences as to an individual's tastes based on what like-minded people have liked or consumed before.

More interestingly, according to Liao et al. (2022), collaborative filtering elicits a bandwagon perception in users—the notion that if others have found something good, one should also find it good (Sundar, 2008, as cited in Liao et al., 2022). Notably, the elicitation of the bandwagon heuristic may explain why individuals trust collaborative filtering more than other types of filtering in recommender systems (Liao et al., 2022).

In summary, this paper proposes to derive recommendations on self-care from others in similar health situations. We believe that, to the extent that individuals perceive an optimal match between their health experiences and those of their peers, they will find the recommendations most relevant and applicable to their situation.

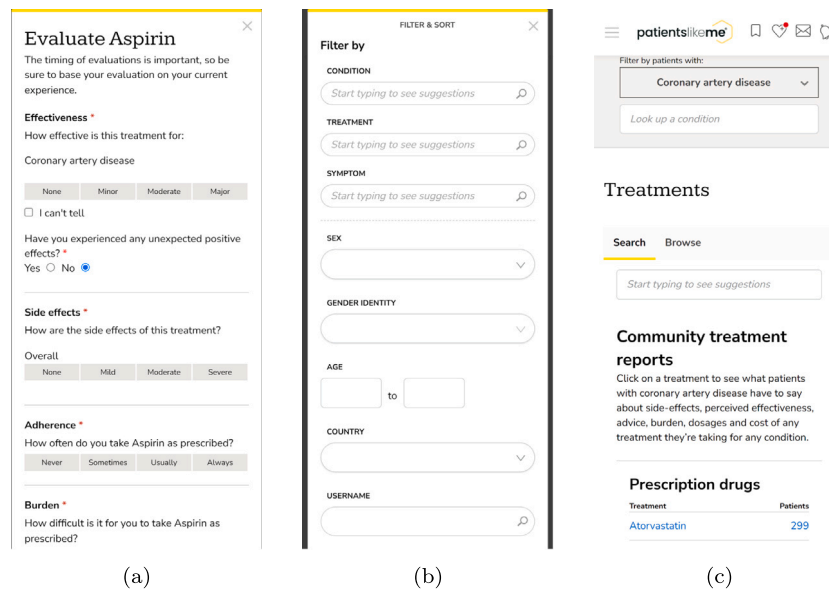


Fig. 1. The PatientsLikeMe interface (screenshots taken on 05 January 2024). (a) Multidimensional, yet subjective, evaluation of treatment (i.e., Aspirin). (b) Search for community members by keywords across criteria such as condition, treatment, and symptom. (c) Community treatment reports are filtered by condition (i.e., coronary artery disease) and sorted by frequency.

### 2.4. PatientsLikeMe

Launched in 2006, PatientsLikeMe ([patientslikeme.com](https://patientslikeme.com), accessed on 05 January 2024) is a for-profit online health community of more than 850,000 members with over 2800 conditions (PatientsLikeMe, 2023; Wicks et al., 2018). Its members can track their body weight, mood, and lab results there. Further, they can list the diseases they suffer from, the symptoms they experience, and the treatments they are taking. Of particular interest is a mechanism that, as we suggested earlier, operationalizes patient expertise: treatment evaluation (see Fig. 1(a)).

As of 2011, PatientsLikeMe evolved from hosting “vertical”, disease-specific communities to becoming a “generalized” platform, where members can track multiple conditions through generic user- and community-level features (Wicks et al., 2018). In terms of social features, this community allows one to locate other members through a keyword search system (see Fig. 1(b)), follow them to subscribe to their updates, and interact with them through private chats or public discussion forums. No less important are the community treatment reports, which aggregate individual treatment evaluations (see Fig. 1(c)).

We chose to prototype after PatientsLikeMe because of its information architecture and existing social and user-level features, which we found inspiring when designing our prototype. Hence, the prototype described below should be understood as a hypothetical new iteration of an existing technology (Nunes et al., 2015). Of particular note is that the present research study was conducted without collaboration from PatientsLikeMe.

### 3. Research prototype: A mobile application for an online health community

The prototype consists of interactive wireframes created in Balsamiq ([balsamiq.com](https://balsamiq.com), accessed on 08 January 2024), which users can click on to navigate between. With each wireframe, we recreated a screen of a mobile application for an online health community with a low-fidelity look and feel. The fact that the prototype’s look and feel were low-fidelity was deliberate. Typically, this level of fidelity allows for provisional and incomplete artifacts to be communicated such that users can feel less constrained in voicing criticism and suggesting changes.

We organized the prototype into four sections. The user profile section is where the individual can self-disclose demographic information,

such as gender identity and age, and lifestyle information, including activity level, smoking status, and health and personal interests. To allow for non-disclosure, they can choose “prefer not to say” from the response options. Health conditions, symptoms, and treatments supplement this section. The individual can also evaluate each treatment according to its perceived effectiveness, side effects, burden, and affordability.

Research on data sharing in online peer support settings emphasizes a consent model whereby the individual chooses which data to share and to whom (Bussone et al., 2020; Cerón-Guzmán et al., 2022). The consent model should be flexible enough to support an ongoing decision-making process. In line with these insights, the individual can use the features provided in the privacy control section to manage which data will be visible and to whom it will be visible. They can adjust their data-sharing preferences to make individual data items visible only to themselves, their followers, or all community members. In addition, the individual can decide how others find and connect with them.

There are two sequential flows when it comes to peer recommendations. Initially, the prototype makes no recommendations but asks about one’s notion of likeness. It breaks likeness down into demographic, clinical, and lifestyle profiles. With a brief description of their scope, it asks to rate, using a Likert-type scale, the importance of peers being like oneself in each profile (see Fig. 2(a)). The purpose of this feature is two-fold. First, it allows for user control over recommendation generation. Second, it should alleviate the cold start problem, i.e., not knowing what to recommend to newcomers (He et al., 2016).

Our approach to controllability in peer recommendations is inspired by the similarity functions formulated by Jiang and Yang (2017) and Narducci et al. (2017). These functions, which resemble a weighted average, are given  $n$  pairs of vectors, for example, to represent demographic, clinical, and lifestyle profiles, and  $n$  different weights. Then, they calculate the similarity between each pair of vectors (one vector per person or user), using cosine similarity or the Jaccard similarity index. Finally, the functions multiply each resulting similarity by the weight assigned to the corresponding pair of vectors and sum up all the weighted similarities to measure the overall likeness between two people.

We break down the concept of likeness or similarity into three profiles: demographic, clinical, and lifestyle. To assign weights to each



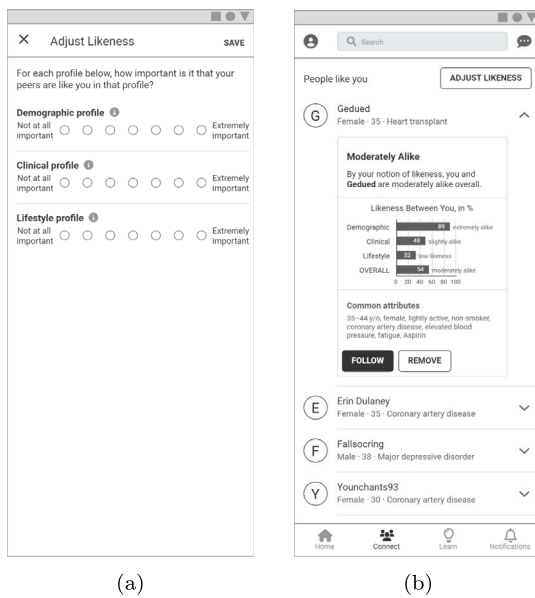


Fig. 2. Peer recommendations. (a) The individual is first asked to rate, using a Likert-type scale, how important it is that their peers are like them in demographic, clinical, and lifestyle profiles. (b) Then, the prototype makes recommendations and explains each “on-demand”.

of these, we involve the individual by asking them how important it is that their peers are like them in each profile. We used a slider widget in early iterations, common in designing interactive recommender systems (He et al., 2016), to capture profile weights. Yet we decided on a Likert-type scale since we found it more intelligible to serve the intended purpose.

In the second flow, the prototype makes peer recommendations and provides an explanation of each (see Fig. 2(b)): it calculates an overall likeness between the individual and the recommended peer — according to the former’s notion of likeness— and breaks it down into demographic, clinical, and lifestyle similarities; it also lists attributes common to both. In doing so, we intend to enhance the user’s perceived understandability of recommendations.

The learning section comprises a main screen and a detail (treatment) screen. The former shows an aggregate-level report of treatments taken or used by others in similar situations (see Fig. 3(a)).

Once the individual distinguishes relevant content, the detail screen shows the treatment’s purposes and side effects, as reported by other members. It also lists individual evaluations and related treatments, for example, that meet criteria of high affordability and little or no burden (see Fig. 3(b)).

Drawing upon the principles that what works for one may not work for another (Cerón-Guzmán et al., 2022; O’Kane et al., 2016) and, equally important, that not all self-care technologies should be used in complete autonomy (Nunes et al., 2015), the prototype invites dialogue with healthcare providers about the appropriateness of treatment for one’s situation through a discussion list (see Fig. 3(c)).

## 4. Methods

### 4.1. Ethical considerations

The local Ethical Review Board of the Department of Industrial Design at the Eindhoven University of Technology approved the research study presented herein (reference code ERB2022ID114). All participants gave informed consent before any data were collected. With the exception of the clinicians, they received a compensation of 30 GBP each for time devoted to the study.

Table 1  
Participants’ demographics. F: Female. M: Male.

ID	Gender	Age
P01	M	58
P02	F	65
P03	M	47
P04	M	76
P05	M	72
P06	F	67
P07	M	43
P08	F	46
P09	F	40
P10	F	63

### 4.2. Participants

We recruited ten people who self-reported CVD through Prolific (prolific.com, accessed on 09 January 2024) —an online platform that connects researchers with participants. Participants were English-speaking, 18 years or older, and diagnosed with coronary artery disease or heart failure, two common types of CVD (Tsao et al., 2023). We purposively recruited them based on diagnosis, sex, and age range to cover a broad spectrum of perspectives.

The sample was gender balanced: half of the participants were male, and half were female. The youngest was 40, and the oldest was 76 (mean = 57.7, SD = 12.9). All participants identified themselves as white. Seven had bachelor’s degrees, and the others (three) had a high school diploma or equivalent. In terms of diagnoses, there were equal numbers of cases of coronary artery disease and heart failure. Multicomorbidity was prevalent in our study’s participants, with seven reporting living with multiple chronic conditions. In this regard, not in all cases did CVD correspond to the participant’s primary condition (the one that caused the most problems or discomfort). Table 1 describes each participant’s demographics.

Three clinicians from two major hospitals in the Netherlands participated in this study. Two were cardiologists with a Ph.D. and six to over 20 years of clinical experience. The other clinician was a doctoral candidate and cardiologist in training.

### 4.3. Data collection

Data collection with individuals with CVD occurred at two points in time: a pre-evaluation survey and the prototype evaluation. With clinicians, the prototype evaluation was the only data collection moment.

#### 4.3.1. Pre-evaluation survey

Potentially eligible participants were directed to Qualtrics (an online survey software), where we administered a survey that informed them of the study procedures and then asked for their consent to participate. Since we wanted them to reflect on their situation when testing the research prototype, we asked the participant to provide us with their health data to personalize it prior to the evaluation. Thus, in the survey, they listed their diagnoses, symptoms, and treatments.

Participants were asked to specify their primary condition if they reported living with multiple conditions. With regard to treatments, we made it clear that, by this term, we meant all the various ways that helped them cope with their condition(s), including, but not limited to, medications, exercise, and lifestyle modifications. We asked participants to indicate the purpose of each treatment and whether a physician prescribed it.

In the survey, we also asked about lifestyle. More specifically, participants responded to how active they were on a typical day and whether they were smokers. Lifestyle-related questions also covered personal and health interests.

Last, we asked participants for their gender identity, age, and highest level of education. They also selected time slots to conduct the prototype evaluation at their convenience. In this respect, we asked participants to join the subsequent session from a laptop or desktop. The mean time to complete the survey was 17.84 min (SD = 12.71).

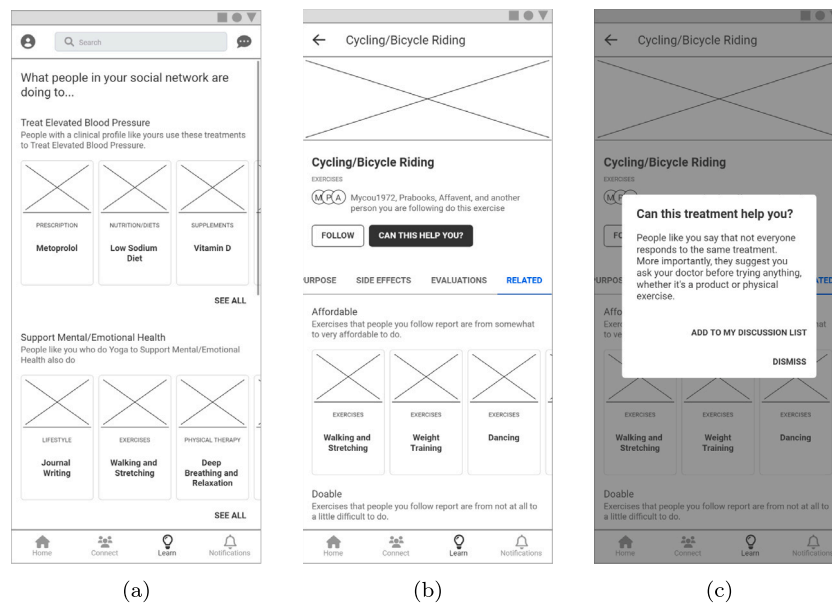


Fig. 3. Learning section. (a) Aggregate-level report of treatments taken or used by peers. (b) Page of treatment and others related to it that, for example, meet high affordability and low burden criteria. (c) Dialogue to inform about the appropriateness of the treatment for one's situation and to invite discussion with healthcare providers about it.

### 4.3.2. Prototype evaluation

Participants joined the prototype evaluation session via Microsoft Teams. To set clear expectations, we informed them that we were going to present them with a prototype of a mobile health application and ask them to use it and give us feedback. Video recording started only after the participant authorized it.

Initially, we asked participants about their past or current experiences with mobile health applications and health communities, either online or in person.

Subsequently, they were introduced to the prototype and the evaluation procedure. At this point, we asked participants to share their screens and sent them the link to the prototype via the session chat. The evaluation consisted of four activities that involved interacting with the prototype, as explained below.

First, participants were asked to evaluate a medication they had listed in the pre-evaluation survey. Second, they were directed to find out what information they were sharing and adjust who could follow them. Third, they were to find peers and learn why a particular user was being recommended (see Figs. 2(a) and 2(b)). Last, participants were to learn what their peers were doing in similar situations (see Fig. 3(a)) and whether “cycling/bicycle riding” was appropriate for their situation (see Fig. 3(c)).

To suggest potential matches with the participant, we directed ourselves to PatientsLikeMe to search for users diagnosed with the same type of CVD and who had similar symptoms or treatments. Hence, the list of recommendations could include peers whose primary condition bore no relation to the participant's diagnosis(es). In this community, we also looked for treatments for one symptom the participant experienced. The rest of the aggregate-level report (i.e., “Support Mental/Emotional Health”, “Maintain Normal Body Weight”, and “Exercise”; see Fig. 3(a)) was the same for all participants.

Although they could ask questions during the activities, we encouraged them to do what they would typically do. We gave them hints about what they could do if they got stuck. A brief, semi-structured interview followed each activity. Participants were asked what they thought about doing the activity, what had been the easiest or most difficult, and how the application features they had evaluated could be helpful in their situations. We closed the session with another brief interview. The questions revolved around what they thought about the prototype, what changes they would make, and how using a tool like

this could open up new conversations with their healthcare providers. The sessions lasted between 1.33 and 2 h (*mean* = 1.7, *SD* = 0.19).

In contrast, the sessions with the clinicians lasted one hour. Another difference was that we populated the prototype with data of a user persona, whom clinicians were to assume was their patient. For the rest, we kept the structure of the prototype evaluation, in terms of activities and follow-up questions, as intact as possible to fit it into one hour. Nevertheless, the session facilitator did the activities, while clinicians were encouraged to comment.

The lead author facilitated all prototype evaluation sessions.

### 4.4. Analysis

The reflexive thematic analysis method informed us in identifying and interpreting patterns of meaning from the dataset we collected from the prototype evaluation (Braun and Clarke, 2006, 2013; Byrne, 2022). We began by familiarizing ourselves with the dataset while revising transcripts of the recordings generated by Microsoft Teams. Subsequently, we followed an inductive, bottom-up approach to coding the dataset. At this point, we focused on describing and interpreting participants' and clinicians' perspectives on locating peers, learning self-care ideas, and our design.

After a couple of rounds of coding, we clustered codes around a central organizing concept to form themes. This phase involved splitting, combining, and discarding candidate themes until we had a story that helped us answer the research question. The lead author conducted the coding and theme generation using NVivo. The co-authors engaged in the analysis through discussion and review of the manuscript.

## 5. Results

To guide the reader in contextualizing the results, we provide a Venn diagram that depicts the relation between the themes below and the subjects under inquiry (see Fig. 4).

### 5.1. Considerations in choosing peers

The present theme explores underlying values that influence people's choices of peers. The control mechanisms provided in peer recommendations were helpful in eliciting participants' values and decision-making processes.

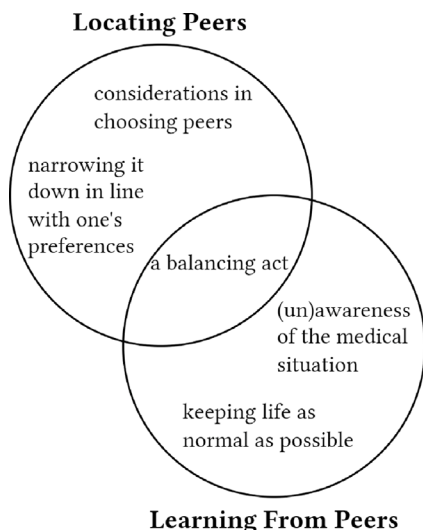


Fig. 4. Representation of the relation between the five themes and the two subjects under inquiry.

For the majority of our study’s participants, the demographic profile was of little relevance. To illustrate, one participant (P01) argued that “the age criteria, the gender, the sort of social class, [and] education wasn’t [sic] important” to him. “It was the diagnosis”. In this regard, his conceptualization of peers may have influenced his rating. Often, he referred to his peers as people who “were in the same situation”, but at no time that they were like him. Under this assumption, we hold that one’s notion of peers might be related to the importance one attaches to the demographic profile: If one thinks of peers in terms of shared situations, one might downplay the role of demographic commonalities in choosing peers, as opposed to thinking in terms of likeness.

For its part, forming a concept of peers around likeness, or, in other words, thinking of them as people like oneself, seems to make sense when (presumably) there is a link between one’s medical condition and one’s age and gender.

“The demographic profile is important. ... I don’t know enough about gender with diabetes [the participant’s self-reported primary condition], [or] whether there [are] dramatic differences. ... I’m not being sexist, but this discounts the ladies because I believe their metabolism will be entirely different to the male, and possibly there’s no point of comparison there”. (P05)

“I think the demographics would be the least important for me. But obviously, there [are] lots of conditions that are gender reliant or often linked with age. ... For instance, you know, if I wanted to go on and find people going through menopause, that would be more important”. (P08)

As might be expected, participants echoed the importance of the clinical profile when choosing peers. What is more, “it’d be a bit daft if you didn’t take the medical condition because there was no point at all” (P01). Nevertheless, it was in the perspectives held on this profile where we found nuances. More specifically, while for one participant, “the clinical profile is probably the most important of all” (P05) —in other words, for him, conditions, symptoms, and treatments were at the top of the hierarchy of commonalities— for another, these attributes corresponded to the basis of commonalities.

“I don’t just want the clinical thing. So, I was glad that I could look at it and go, well, they’re in a similar position to me. But it’s not just about clinical things. It’s about lifestyle [and] demographics. ... I’m not sort of meeting up with somebody ... just because they happen

to have cardiomyopathy. It’s a little bit like when you have a baby, and, you know, there are these antenatal classes, and you sort of look at people and think, well, the only reason we’re in the same room is we’re all having a baby. And I don’t want to say, well, the only reason I’m talking to this person is they’ve got cardiomyopathy. It’s a little bit like cardiomyopathy Tinder”. (P10)

For this participant, if “the clinical thing ... [were] the end of everything” in the community, she would not find it uncommon if her peers limited themselves to sharing “terrible stories”, such as “how they sort of had a cardiac episode ... [and] bloody operations”, or to “pointing out what could potentially go wrong”, which would make her realize what could happen to her and, consequently, increase her distress.

Conversely, what participants like P10 sought in their peers related more to optimistic and constructive perspectives. Optimistic perspectives in that the experiences of others in similar situations could lighten the burden of uncertainty that complex chronic conditions seem to impose on one’s shoulders.

“If they’re the people who have gone through it, maybe a bit ahead of you, you got an idea [of] what’s coming. If possibly they’re a little bit behind you in the process, [you] provide some reassurance to them and say, look, I’ve had it for 15 years, [and] it’s perfectly livable to have it and carry on as normal!”. (P01)

And constructive perspectives as for adjustments one could make to fit the condition into the life one aspires to lead, and not the other way around, i.e., where the condition “dictate[s] everything ... [one is] doing in their life” (P10). On this point, one participant made the following reflection:

“What kind of adjustments you can make so that you can carry on just living your life? Some of that is accepting that there are things that you can’t do anymore. But ... there are tiny tweaks that you can make, [as] other people will have already come across that problem before”. (P08)

Perhaps the practicality of these perspectives helps us understand why participants associated the lifestyle profile with such preponderance in choosing peers. Namely, we are inclined to think that the more similar one is to their peers in, for example, habits and level of physical activity, the more useful the constructive perspectives would be. The following excerpts illustrate the meaning that people with CVD attach to the lifestyle in the context at hand.

“Activity level was the other one [that mattered to me]. I will probably lean more towards the ones that are similar to me there in terms of body weight, smoking, habits, [and] activity level. But that would be because if I ride the bike, I’d wanna compare my experiences to someone who does at least a little bit of exercise, who isn’t a couch potato. If you were a bit of a couch potato, you might be quite happy to only speak to people who are similar to you”. (P01)

“Activity level, I like that. You don’t wanna feel guilty talking to someone who climbs mountains every weekend. So, that’s important to me. I want to associate with someone who’s low activity”. (P06)

Lastly, participants’ responses reinforce the relevance of the geographic location of peers (see [Levonian, 2022](#)). As shown below, P09 maintained that, given the differences that may exist from one country to another in treatments, it would not serve any purpose to establish new connections with peers abroad, especially if one is interested in exchanging views and experiences on therapies.

“If you could choose the countries they come from, just so that if I talk about the medication, I know they can get the medication that I’m talking about because there’s nothing worse than you talking to someone, and they can’t get the medication you’re on, and it’s really working for you. And you feel bad that you’ve mentioned it to them because it’s not available in their country”. (P09)

## 5.2. Narrowing it down in line with one's preferences

This second theme intends to report participants' impressions of the peer recommendation method we designed to facilitate locating others in a similar situation. For example:

"Generally, you know, if you're searching on the Internet, it's very broad information. It's too much. So, this [method] is [like] fine-tuning it to like-minded people. ... [Here] you've got like-minded people. Not millions. I'm not assuming there's going to be millions on the app. So, it's going to be more focused, useful information that I can talk to my GP about. That's very important: usability. It makes it more focused [and] more accessible. Often, you get very confused if you're trying to find it on the general Internet. So, personal recommendations are useful". (P06)

"[This method is] a very quick way [to find peers], rather than a lot of sites [where] you were purely looking for people based on conversations going on in the community, which often means you're trawling through pages and pages to find somebody who is on the same medication as you or is on the same medication for the same condition as you [be]cause a lot of medications treat 20 different things. So, being able to narrow it down without having to go through the community pages is really helpful". (P08)

These first impressions, on the one hand, show how laborious it can be to locate peers, either by using traditional search methods or by searching oneself. On the other hand, they suggest that the proposed method seems promising in helping to narrow down the list of potential peers to (a few) like-minded people.

In what follows, we describe how user control and presentation of outcomes influenced how participants interacted with peer recommendations. This account of experiences offers practical implications to guide the design of user interfaces for peer recommendations.

### 5.2.1. On controllability

Feedback from participants on the control mechanisms reinforces prior research findings in that users may be more satisfied when they are allowed to exercise control in generating recommendations (He et al., 2016). To illustrate, regarding what it meant that the application (research prototype) asked him to rate how important it was that his peers were like him in demographic, clinical, and lifestyle profiles, P05 responded that this fact showed genuine interest on the part of the application in his preferences.

"It shows that the app is actually considering the most beneficial stuff for me because it's asking what I, as an individual, consider to be important. ... It's placing me as the number one matter in the app. What is important to me is important to the app". (P05)

Of particular interest is that expressing their notion of likeness on the application proved straightforward for participants. It may be the case that the Likert-type scale —perhaps more intelligible and familiar than the widely used slider (He et al., 2016)— contributed to the perception of low cognitive load.

"It's simple and straightforward. There are a total of seven circles, and the fourth circle is the neutral zone. ... Anything to the left of the fourth circle, you're placing little or no importance on it. Everything to the right of the fourth circle is increasing the importance of the matter to your good self. So, very straightforward to use. Anybody who's ever used any kind of form should have no problem comprehending the importance of this aspect here". (P05)

"I don't think it was challenging at all. I like that you could [adjust your preferences], and I think it was done quite easily. You don't have to type in. What's it takes? You just had to select things to make sure that you got a list of people you could follow". (P09)

Finally, the following excerpts explain a trial-and-error approach to obtaining desired outcomes while constructing a mental model of the peer recommendation method.

"So, just those three criteria [referring to the demographic, clinical, and lifestyle profiles]. That's enough there ... to narrow down the people you'd like to come up with when the search is finished. And you could say not important against all of them. In fact, you probably would. If you were playing with the app, you might click not important to all of those three options and see what comes up. Just to try and understand how the system works. ... That 'adjust likeness' process lets you decide how to narrow it down in line with your own preferences rather than just look[ing] through the whole lot". (P01)

### 5.2.2. Misleading labeling

The primary condition on the list of recommendations (see Fig. 2(b)) might mislead users in different ways. At least, that is what we took away from observing participants interact with the research prototype. To elaborate on this point, we start by saying that it seemed clear to our study's participants that the primary condition corresponded to the "main problem" the recommended peer had put. Not the only one. Even so, if the peer's condition bore no relation to the participant's diagnosis(es), the participant dismissed an eventual new connection because there appeared to be nothing in common between the two.

"I noticed in the final selection there were three or two with diabetes. So, they were pretty, I would say, outside my field of interest or requirements. So, I was a bit surprised they came up because I did tick the condition, and the diagnosis was very important, and diabetes is a bit of a different track to the condition I've got. So, that was a little bit ... disappointing or a bit misleading. I don't think there [will] be many sorts of areas of common discussion with diabetes patients". (P01)

This sense of disappointment, referred to by P01, concerns the notion that the application behaved randomly. "You thought, well, this system isn't picking the people that are similar to me". Had it not been for the fact that participants were asked to find out why the first peer on the list was recommended, they would not have further considered the recommendations.

"By the time you drop down and get a little bit more information, and you see the common attributes, you can see that there are certainly two or three things there that are a good match. So, you'd have to bear that in mind and think, okay, [a] heart transplant is one thing, but the other bit, tachycardia and ICD [implantable cardioverter-defibrillator], those are definitely an excellent match. And that would be worth clicking the follow button. ... It would certainly be worth dropping down and seeing what other information is there". (P01)

Another adverse effect of the primary condition label on the list of recommendations is the potentially harmful inferences the individual would make about their own health. More specifically, a clinician postulated that if a number of peers had the same condition in common, the individual might conclude that they also suffered from it.

"I think it's important to prevent people [from] think[ing], well, I found someone with depressive disorder. Am I also depressive? Something like that. There should be a why this person is found because otherwise, if they get a list of 20 people, and they see five times 'depressive disorder', they [could] think, ... I have a depressive [disorder]". (C01)



Although not due to adverse effects, another clinician questioned the value of the primary condition label since it was a way of oversimplifying the individual. “It’s like your label is ‘heart transplant.’ ... [But] she’s not her heart transplant, ... she’s probably so much more” (C03). Reducing individuals to a single diagnosis can be problematic, especially when the diagnosis carries a social stigma, as is often the case with mental health conditions. For example: “[There] is [one with] major depressive disorder. I suppose it’s not very nice, but I’m not sure that I would like ... someone with major depressive disorder. I want someone ... who would be encouraging” (P04).

### 5.2.3. Explainability without transparency

The explainability component contributed to the understandability of individual recommendations (e.g., “it was quite good because it’s telling you why it has suggested this person, why they’re like you” —P09). However, based on which criteria the entire set of recommendations was presented or organized was unclear. And even if their intuition suggested that recommendations were ordered by similarity, the lack of transparency affected how participants engaged with them.

“I don’t know how it orders people on the list or who might be most similar to you. ... I’m looking at it, and I don’t know if this is a list of everyone that came up, and it’s up to me to go through and work out who’s most similar. Or if they are ordered in that these are the people who are most similar at the top and going down the bottom. So, it doesn’t tell me that anywhere. ... I’m not sure whether I would need to scroll right through them all. ... I might be missing somebody who’s exactly the person I wanna connect with, who’s at the bottom of the list, because I’m ignoring that”. (P08)

Regarding the understandability of individual recommendations, participants indicated that the list of common attributes was the most informative feature. So much so that they suggested placing this list above the likeness graph (the bar chart in Fig. 2(b)), considering the former a “must” and the latter a “nice to have”.

“I think the more useful part for me was the common attributes. That’s a really useful little snapshot of information. So, the graph is great, but seeing why under the common attributes is much more important for me to decide whether it’s somebody that would be good to connect with. ... I’ll have the common attributes higher up, and the rest of it as sort of additional information ... [because] I’m not sure how useful the graph is. Whether it really tells you much about somebody”. (P08)

Perhaps the preference for the list of common attributes over the likeness graph chart is due to the simplicity of the former in contrast to the complexity of the latter, which, although “catchy”, was unintelligible to some. “I like the idea of the percentages, [although I’m] not sure what percentages mean, to be honest. I would go straight to the common attributes and read that first and probably rely on that” (P04). And yet, it caught our attention that, despite its unintelligibility, the likeness graph greatly influenced participants’ trust in the outcomes.

“I love the graph. It makes it look scientific. It makes it look the opposite of folksy. It’s looking professional. It’s looking trustworthy. ... This is something that I can trust ... [because] I associate infographics with research [or] statistically accurate information. So, this immediately appeals to me”. (P06)

### 5.3. A balancing act

To receive relevant recommendations, whether people to connect with or self-care ideas, users are to disclose highly sensitive information, such as diagnoses, symptoms, and treatments. This puts users in the dilemma of preserving privacy or risking data misuse. The present theme explores participants’ concerns about this issue and their preferences for flexible privacy controls.

Participants objected to the prospect that any other user of the application could follow them. Namely, their main privacy concern was that the application, by default, did not require their consent for “any Tom, Dick, and Harry” —as said by P05— to become their followers and, by this means, “have full or even partial access” to their health data.

“This raises a whole different ball game for me because we’ve left, in my opinion, about 30 ft in the one jump. We’ve gone from basic knowledge to now discovering that an unknown number on the face of it has access to a lot of my private medical stuff. I would want to know who these people are. I don’t just want people who click on a follow button to know stuff about me”. (P05)

A distinction must be made here. Although participants were averse to having their profile openly public, they were willing to disclose personal health data for the peer recommender system to suggest whom to follow. In this regard, their responses somehow reflected a privacy calculus—or, in their own words, “a balancing act”—and showed that they were aware of the detrimental effect of data withholding on the quality of recommendations.

“To get the best peers, you gotta have people give an awful lot of information about themselves to start with. So, there’s a bit of a balance there. You need all the information out there to create [a] good search and a good peer group, but people may be reluctant to give that information. So, there’s a bit of a contradiction there, almost. And people will be possibly a little bit reticent to give too much information, but that will almost be to the detriment of the app because it would make finding peers a little bit more difficult”. (P01)

“It’s all gonna be down to the privacy settings people set up, isn’t it? But maybe that’s one of the risks; if you don’t share things like your gender or your location, then you’re gonna get [fewer] matches, and people ... aren’t gonna find you in the same way. And that’s just part of the balancing act you do. ... It’s just a balance that each individual’s gonna have to try and work out for themselves how much they want to connect with other people, so how much will they share”. (P08)

Once familiar with the control feature to approve who became their follower, participants stated that only then did the consent model—whereby it was up to them what data to share and to whom to share it—make sense. “I was quite hesitant about the privacy aspect of the app when I first started looking at this section, but now that I know what the controls are, I’m completely at ease with me determining who can see what” (P05).

And it was about the audience that participants had further considerations. In particular, they requested more flexibility to share information less uniformly so that they could create groups with which more would be shared. For example:

“I don’t know whether there’s an option where ... certain people can see certain information, [or] whether you can put people in groups. Maybe thinking purely because, you know, back in my teenage days, I might have shared some information with my dad, but he certainly wouldn’t have known I was smoking. ... So, whether you had the option to make some groups of people have more access to information than others”. (P08)

This request is a call for even finer-grained privacy controls. And yet, participants associated the level of sophistication of the control mechanisms already available to them with high mental demand.

“All the stuff we’ve looked at, where you are sharing your information, I think that was possibly a little bit complicated or would need a lot of clicking through, or you’d want to play with it a bit to be sure you weren’t sharing it with everybody else. That would take a little bit of getting used to”. (P01)

“To me, that’s slightly confusing. Let me say, . . . there are too many options. It’s confusing for someone; it’s too fine-tuned. Maybe it needs fewer options to start with”. (P06)

Finally, another privacy consideration was that, by default, the user profile should be restricted to the individual. Thus, only as they become more familiar with the privacy controls and the peer community will the individual share more information about themselves with the people of their choice.

“At first, joining the network or . . . getting the app, you probably wanna be fairly private and see how it works out, which is probably no different [from] go[ing] into a support group, and until you weigh up the people there, and you have a chat with them, you would be sort of slightly reticent to give out too much information. Once you’ve been there a while, and you get to know people and like people, you might be a little bit more inclined to open up with some more information. So, it’s a very similar process to that. You need to gain a bit of confidence”. (P01)

“I don’t know how it’s for the plan to be set up, but I always think with things like this, it’s better if they’re set up with the maximum security to start with, and then people build down from there. So, I would hope that [it] would be on automatically, and then I would be able to turn it off if I wanted to”. (P08)

#### 5.4. (Un)Awareness of the medical situation

In designing to facilitate learning self-care ideas from peers, we assumed that people were aware of their situation. For the sake of argument, by awareness of the medical situation, we mean knowing one’s diagnosis(es) and symptoms and their relation to one’s treatments. Nevertheless, our assumption does not hold up insofar as it is not uncommon for individuals not to know what their medicaments are for. Thus, the present theme intends to illustrate the (un)awareness that people with CVD have of their medical situation, especially from the clinicians’ point of view. This theme also refers to the possible implications of the medical situation’s unawareness.

First, clinicians linked the unawareness of the medical situation to the difficulty in distinguishing the actual cause of cardiovascular disease, considering that one single term often groups together a number of heart abnormalities.

“The patient has to say [for] themselves: I have coronary artery disease. So I think for some patients, it might be difficult. Coronary artery disease might be [because they] have had a myocardial infarction. . . . But also [if they] have only pain in the chest while exercising, that’s called stable angina, [and] that’s also coronary artery disease. So, I think it might be a bit difficult for patients to say for themselves what their condition is. I just wonder how patients know they have the correct info”. (C01)

During the session, C01 insisted on the correctness of the information as his primary concern. He maintained that the correctness would also be compromised by not knowing the purpose of treatments. In a context where comorbidities are common in people with CVD, C01 and C03, as shown below, pointed out that the individual often did not know what they were taking their medication for.

“People might have six or seven conditions, and it might be difficult for them to know . . . which medication is for which disease”. (C01)

“In my experience, a lot of patients don’t know why they’re taking all their medication. They don’t know which one is for blood clotting and which one is for elevated blood pressure. So, they just take all the pills and say, yes, [it has] something [to do] with my heart”. (C03)

Participants also echoed this difficulty in specifying what purpose the medication served. In this regard, some suggested that the application should tell them (e.g., “[If the application] explains to me what it’s used for, then that would be great. . . . If you put on the medicine, it tells you: . . . you are taking this for this” —P02), and another narrated that, were it not for asking them if she needed to take even more of the same medication, her healthcare providers would have over-prescribed it.

“I don’t want to have three different doctors all prescribing me the same medication. And it wasn’t till I said, do I really have to take more of them? . . . They realized that I was just taking [it] three times. I have all the medication that I don’t know who prescribed it for me. Somebody said, you need to take that, and people ask me why I’m taking it, and I genuinely don’t know. So, it would be somewhere I could collect that information and know why I am having this”. (P08)

Having explained the medical situation’s unawareness, we now list its possible implications, although not exhaustively. The first pertains, as already mentioned, to the correctness of the information. Here, C01 called for our design to involve clinicians in checking the information shared and, above all, to see this as an opportunity to raise the individual’s awareness of their situation.

“Maybe if you can come up with something that can be checked by a physician or [that] the patient can say, well, I’ll show this to my physician, and they can say if it’s correct. . . . It’s sort of like, why [did] you prescribe the medication? And is it [correct] the disease I filled in? . . . Otherwise, they [would be] walking around with incorrect information and then advising other patients with incorrect things. . . . So I see it as an opportunity [for] our patients to learn what they have and what medication they take for what disease”. (C01)

The second implication concerns treatment evaluations. Since physicians prescribe medicaments less for ailments than to prevent the worsening of heart disease, it will not be easy for people to assess the effectiveness of their therapies. Perhaps ignorance of this distinction in the medicament’s purpose would help explain people’s tendency to complain about side effects.

“[Let’s take] as an example the aspirin. Often, we [don’t] give medications for complaints but to prevent them from getting a myocardial infarction or worsening their heart disease. So, I think it might be pretty difficult for patients to say if it works or not. [If] a patient has had a myocardial infarction once, they will get aspirin lifelong”. (C01)

“I’m a bit struggling with the philosophical part of things. [On the one hand,] you don’t feel the benefits. I mean, who’s happy about not dying yesterday? We take it for granted. [On the other hand,] we do feel the disadvantages of statin. So, this discrepancy makes people on themselves have a tendency to blow up the disadvantages. . . . Patients, ideally, should speak our language. [For example,] I took two pills of Aspirin, so I’m happy I didn’t run into a ward with my cardiac disease. I didn’t die; I didn’t get infarction, [and] I didn’t get a stroke. So, that’s the discrepancy in patients’ communication”. (C02)

### 5.5. Keeping life as normal as possible

Earlier in this paper, we raised the question of what people with CVD want to learn from their peers about self-care. In the present theme, we seek to answer this question by reporting what matters participants were interested in and what drove their interest. We will also refer to clinicians' considerations and the extent to which our design was seen as conducive to gaining new insights into self-care.

To answer the question that motivates this theme, we have to start by saying that, in describing their considerations in choosing peers, we already anticipated that participants were seeking to fit their conditions into the life they wanted to lead. We now add that this quest seems to be a way of constructing a new normal (Genuis and Bronstein, 2017). At least, this is what excerpts such as the following show.

"It's despite the condition, despite the tablets, despite the defibrillator, I'm trying to make things as normal as possible. ... Even with the condition, one of the ways of approaching it, or maybe even the best way of approaching it, is to try and introduce a degree of normality. ... It's just the case of what you find gets you to that place. If you used to do a little bit of, I don't know, yoga or journal writing, ... carrying on that, with a bit of emphasis on the condition would be useful. But I probably don't ride as far or as fast as I used to on the bike. But I still ride, and it still makes me feel there's a degree of normality". (P01)

Therefore, this aspiration to keep life as normal as possible helps us elucidate what people with CVD want to learn about self-care from their peers, especially when the most useful suggestions for fulfilling their aspiration perhaps come from the fellow sufferers who are the most similar to them in terms of lifestyle.

"You have to find ways to fit [things] into your life in a different way. You know, I used to go swimming and do yoga three times a week, [and] I can't do that anymore. So, what can I do instead? And the only people who've been able to tell me that are other people who have rheumatoid arthritis [comorbid condition of the participant]". (P08)

"It would be quite nice to talk to somebody who has those same kinds of barriers, because they are barriers, massive barriers to what you can do and what you can't do. And I suppose kind of saying to them, what do you do? How do you get around that? How do you do anything differently? Someone might say, well, I do clay or something. How do you get around that? I think that's quite important, and you don't realize how much it impacts your life when you get it". (P10)

Certainly, not all participants' interest was confined to learning "small, practical changes". A few were enthusiastic about discovering therapies to treat their conditions better. Still, we believe that the interest in learning ideas about medication would be inversely proportional to the individual's perceived control over their medical situation. Thus, the individual would be interested in discovering medicines not out of curiosity but of necessity.

"There'll be other people who ... want to be able to go on there and say, 'oh God, I have these palpitations. I've tried Ramipril. I've tried this. Nothing is happening; nothing is working. Has anybody else got any ideas about what I can do?' And, at some point, I might do that. That's not something I would ever access unless I needed to. ... So, I would use it if I'd got something I was really worried about, and I wanted to kind of talk about it with people. But I wouldn't access it just as a matter of course, just to kind of see what's out there, see whether anybody's using anything different". (P10)

The lack of interest in this respect could also be explained by the participants' well-founded trust in medical professionals. Specifically, they were reluctant to consider therapies they could learn from their peers, as they claimed that their cardiologists knew how to treat their disease.

"I wouldn't be too confident in saying to my cardiologist stuff I saw online from this app or this chat group. I might ask him what he thinks; I don't know if it would be something I would say, have you tried this? Or have you heard about it? Or do you think we should be doing this? Normally because I've had pretty good advice from him for the last 15 years. He says, this is what we're doing, and I say, great, you're the expert; I'm just a patient. So, I don't know if I would create some odd conversations between me and the cardiologist". (P01)

As for the extent to which our design was seen as conducive to learning self-care ideas, participants underscored the fact that the design addressed the whole self and suggested ways to regain control over their lives.

"From sort of the mental health and emotional support standpoint, it's about how to still feel like you. You lose a lot of control, so I think having apps like this give[s] you some control back over your life. ... It does get [the] point where I'm no longer in control of anything in my life anymore. So, being able to find ways to get that back is huge". (P08)

"I think it's quite good that you could see what other people were doing and if it was helping them. It wasn't just focusing on the physical. It's focusing on the emotional and mental as well. So, how it was helping people mentally? If the activity was helping. If not, there were other activities that it was suggesting, like dancing, and walking and stretching. So, it was all fun and different things you could do to help yourself. So, it was quite good. That information would be helpful to me". (P09)

Additionally, participants were positive, as shown below, about the aggregate-level report of treatments since, on a single page, they could find out what their peers were doing in their situations, which, in turn, could help them in theirs.

"I think it's very great that you can see, okay, this [is] for swelling feet, and there's a prescription drug that you can ask your doctor about, and you can see how it helped everyone else. [Also,] what you can do to get your brain together, to get your mood swings right; [and] what type of exercises you can do. I think it's great because you can go into everything and check the people's comments and how it helped them and what they did, and what it did for them. So yeah, I think it's quite great". (P02)

However, a clinician stressed that it was necessary to point out that the information this aggregate-level report presented was not necessarily evidence-based and did not, in all cases, correspond to physicians' prescriptions.

"In this [app], there's input from peers, [for example, saying that] to treat high blood pressure, they take vitamin D. This might suggest that you don't need medication for blood pressure, that you can just take vitamin D, and everything is okay. Is all this information evidence-based? Or is there a notification that there's no evidence for it, that someone suggested that it's good to take the vitamin D? ... I think it's important that you show that it's not prescribed and that there's no evidence it's the right therapy to treat something like elevated blood pressure". (C03)

At this point, the feedback from participants and clinicians on the mechanism we devised to keep the latter in the loop is worth mentioning (see Fig. 3(c)). They both elaborated on the imperative need to validate with health professionals the appropriateness of any self-care idea before trying anything. In particular, clinicians stressed how important it was to warn people not to do too much on their own. Participants also echoed this warning in that self-care ideas from peers should not be seen as an alternative to medical advice but as something that would eventually supplement it.

“I think that’s a very important step because, for instance, not for every patient with heart disease, it’s good to go cycling. So, they cannot always estimate [for] themselves if it’s safe. So, I think that’s a very important step. Just saying, well, it might be interesting for you, but ask your physician first before doing something”. (C01)

“I do like that’s got this disclaimer about if you change the treatment, and you want to go on a different treatment, talk to your doctor. ... I wouldn’t want them [peers] to use an app and think that’s an alternative to medical advice because it’s not. It’s just an additional tool you can use to help yourself, I think. So, I thought that was quite helpful”. (P09)

## 6. Discussion

Here, we examine the main takeaways from the present research study and the implications for designing to facilitate locating peers and learning self-care ideas from them in online health communities. We limited ourselves to recruiting people with CVD and clinicians with experience treating this group of heart or blood vessel conditions. Still, the implications discussed below are arguably transferable to design for other communities.

### 6.1. From the preponderance of lifestyle to the little relevance of demographics: Making sense of considerations in locating peers

The present research study revealed the preponderance that people with CVD attach to lifestyle when locating and choosing peers. In contrast, our findings showed little relevance of demographics in this same regard. As expected, we found that the clinical profile was important, albeit with nuances in terms of its meaning for peer interaction.

Our findings seemingly contradict those of prior works. In the context of peer mentoring programs in online health communities, Hartzler et al. (2016a) report that mentees sought their mentors to be same-gender contemporaries. Fang and Zhu’s (2022) work adds further evidence of the relevance of demographics. Namely, theirs informs that support-seekers and support providers saw age as crucial for optimal matching due to generational matters.

A common denominator in Fang and Zhu (2022) and Hartzler et al. (2016a) is the predefined roles in peer interactions. In both of these works, it was clear what the roles were, and so were the expectations. That said, our findings regarding considerations that people with CVD have in locating and choosing peers are to be framed within a context of exploratory search, where the seeker is unclear about what they are looking for, let alone what they expect to achieve (Wildemuth and Freund, 2012). Hence, unlike mentor-mentee or seeker-provider relationships, we argue that roles are non-existent or, at best, ill-defined in exploratory peer search (Levonian, 2022).

Although the context of our research study informs how to interpret the findings and, incidentally, dissuades us from assuming that there is mixed evidence about the importance of demographics, it does not explain why participants felt that peers’ age and gender were of little relevance.

In this study, people with CVD rated the demographic profile as not at all important, as they were uncertain how heart or blood vessel conditions were related to age or gender. To illustrate, one participant argued that demographics were only relevant when it came to locating

menopausal women. It is worth mentioning here that comorbidities could have influenced participants’ ratings. For example, another participant discounted female peers since he thought diabetes could be sex-linked.

We now move on to discussing the findings on the clinical profile. Not surprisingly, there was participant consensus on the importance of diagnoses, symptoms, and treatments, as we tasked them with locating others in a health situation similar to their own as part of the prototype evaluation. Where we found nuance, though, was in what the clinical profile meant for peer interactions. Specifically, participants were reluctant to have everything in the community revolve around medical issues, as they might be distressed to learn how their situation could worsen from the lived experiences of peers. This allows us to draw a parallel with what Nunes et al. (2015) found about the duality of awareness-raising. On the one hand, it could enhance one’s understanding of illness and coping skills. On the other hand, it could have detrimental effects, such as feeling anxious or thinking that an adverse health event could happen to oneself, too.

We also found that participants sought perspectives on the adjustments they could make to fit their condition into the life they wanted to lead. Arguably, this quest helps explain lifestyle’s role in locating peers. More specifically, it appears that the more similar one is to their peers in terms of activity level and habits, the more helpful the perspectives they offer will be. Yet, preference for lifestyle in the context of peer support interventions is not unknown (see Levonian, 2022). Indeed, matching peers with similar lifestyles contributes to greater perceived usefulness of the support they provide to each other (see Hartzler and Pratt, 2011). To our knowledge, what was little known was the presumable role of lifestyle in locating peers.

**Design Implications.** We recommend matching peers by leveraging attributes that describe people’s lifestyles, such as their activity level on a typical day and smoking status. Given the variability in the value people place on characteristics when locating and choosing peers, our second recommendation is to allow the individual to adapt the matchmaking, or peer recommendations, to their needs and wishes, flexibility that other authors have already advocated (e.g., Fang and Zhu, 2022; Hartzler et al., 2016a).

### 6.2. Design for peer recommendations

Participants were enthusiastic about the design for peer recommendations proposed in this paper. In short, they emphasized that the design enabled them to narrow down the list of peers to a few like-minded people with little effort. Nevertheless, there is room for improvement in the presentation of recommendations, such that individual recommendations are intelligible and the whole set transparent.

Because the design asked them about the importance of their peers being like them in terms of demographics, lifestyle, and clinical profile, participants maintained that there was genuine interest in their preferences. These perspectives on exercising control in peer recommendations reinforce the recommender system literature in that user control and satisfaction move in tandem (He et al., 2016). Yet the fact that the recommender system provides control mechanisms could carry adverse effects: the more fine-grained the control, the higher the cognitive load (see Andjelkovic et al., 2016). Hence, how much control to provide to users without demanding a great deal of effort is a question that researchers and practitioners should address in designing interactive recommender systems.

In this study, engaging with the control mechanisms and thus expressing their notion of likeness was straightforward for participants. We believe this is due to grouping the various attributes —by which to match peers to each other— into three profiles and asking, using a Likert-type scale, the importance of each profile in locating peers. Certainly, our hypothesis should be further tested with the help of standard assessment instruments, such as the NASA-TLX (Task Load Index) (Hart and Staveland, 1988).



**Design Implications.** We recommend asking users to rate the importance of groups of attributes rather than individual characteristics when matching them to each other. This involves grouping attributes such as age and gender into demographics, diseases, symptoms, and treatments into clinical profiles, and activity level and smoking status into lifestyle. Furthermore, users should be allowed to set their preferences for each group of attributes using a Likert-type scale. Fig. 2(a) illustrates our design recommendations.

As for the presentation of outcomes or, interchangeably, recommendations, we found that the peer's primary condition on the list of recommendations was misleading in that if it bore no relation to the participant's illness(es), they discounted eventually connecting themselves to the recommended peer because there appeared to be nothing in common between the two. To top it all off, the perceived absence of commonality caused the impression that recommendations were randomly generated. Furthermore, the clinicians suggested that we could not rule out the possibility of individuals making potentially harmful inferences about their health from their peers' primary condition.

The next point we want to touch upon is the explainability of individual recommendations. The list of common attributes was the feature that best contributed to the understandability of each recommendation. In contrast, it caught our attention that, despite its unintelligibility, the likeness graph (the bar chart in Fig. 2(b)) appealed to participants and, more importantly, greatly influenced their trust toward individual recommendations. This finding further proves that people may prefer a visualization they do not comprehend (Reading Turchioe et al., 2020). Indeed, subjective preferences do not always correspond to objective comprehension of visualizations, but they seem driven by factors such as aesthetics (Reading Turchioe et al., 2020). In this study, one of the main reasons for endorsing the likeness graph was that it gave the design a scientific, professional, and trustworthy look and feel.

The (lack of) transparency of the whole set of recommendations also warrants our attention. Our findings showed that uncertainty about the sorting criteria affected participants' engagement with the recommendations.

**Design Implications.** Because the peer's primary condition arguably does more harm than good, we recommend eliminating it from the list of recommendations. Our subsequent recommendation concerns the explainability of individual recommendations. Specifically, we suggest making the list of common attributes more prominent and exploring the potential of visual analogies to explain how similar the individual and the recommended peer are, given that graph illiteracy is highly prevalent (see Reading Turchioe et al., 2020). Last, we recommend quantifying and showing, alongside the recommended peer's (user)name, age, and gender, the degree of matching between them and the individual, either numerically (e.g., from 1 to 10) or with a unidimensional scale from low to high, as this measure could help make the whole set of recommendations transparent.

To conclude, we address the individual's privacy. The participants' main concern in this regard was that any community member would become their follower, owing to the sensitivity of personal health data.

**Design Implications.** We suggest a default setting where users must approve all connection requests. This ensures that other community members cannot automatically follow a user and access their personal health data. However, a user's profile should still be able to appear in the peer recommendations provided to the community. In this regard, we recommend a toggle-like privacy control feature, enabled by default, that allows users to choose whether their profile is discoverable within the community.

### 6.3. Everyday self-care strategies

Our findings showed the aspiration of people with CVD to lead as normal a life as possible. In light of this, we argued that participants sought suggestions from their peers to realize their aspirations and that

the more similar they were to each other in lifestyle, the more helpful the suggestions would be.

Often, participants drew parallels between their non-illness normal and their breakdown of normal (Genuis and Bronstein, 2017). For example, how they used to exercise and the fact that they could no longer do it in the same way. Discontinuities in their daily life led participants to wonder what they could do instead or how to do it differently. In this context, patient-expertise sharing can help the sense-maker meet their information needs and thus construct a new normal after health-related life disruptions (Genuis and Bronstein, 2017; Hartzler and Pratt, 2011).

It is well known that sources of patient expertise concern, to a large extent, personal matters, such as family, work, and interpersonal relationships (Hartzler and Pratt, 2011). In this regard, participants highlighted that the design to facilitate learning self-care ideas from peers addressed the whole self and suggested ways to regain control over (everyday) life. Equally important was that the suggestions were presented on one single screen, making patients' aggregate expertise readily accessible.

In view of the above, we believe that design should attend to the everyday self-care strategies each member can contribute to the community. Recently, Kuosmanen et al. (2023) created a web repository of Parkinson's disease self-care techniques by leveraging the crowd's wisdom. Their work offers insights into how design can facilitate knowledge-acquisition processes in online peer support settings.

**Design Implications.** We propose a new entity, Everyday Self-Care Strategies, to encompass any methods, techniques, or practices that individuals within the community employ to manage personal health challenges in their daily lives. For example, community members could be asked about their approaches to staying physically active, maintaining emotional well-being, engaging in leisure activities, and nurturing and strengthening social connections. Kuosmanen et al.'s (2023) categorization of self-care techniques, which includes physical activity, well-being, leisure and hobbies, nutrition, and social interaction, can provide a framework for gathering and organizing community input on these everyday self-care strategies. Our subsequent recommendations pertain to the presentation of information. At the individual level, we recommend that strategies have the same prominence as diagnoses, symptoms, and treatments. At the community level, the aggregation of strategies that community members have contributed and evaluated, for example, based on their effectiveness, affordability, difficulty, and familiarity (Kuosmanen et al., 2023), could be presented through the typical user interface of streaming platforms, as shown in Fig. 3(a).

Symptoms and medications to treat them follow in our discussion. We found that interest in this regard seems contingent upon the individual's perceived control over their medical situation. More specifically, the individual would be interested in learning medication ideas from their peers not out of curiosity but out of necessity. In any case, participants were reluctant to consider therapeutic medical treatments that peers could suggest, as their cardiologists knew best how to treat their condition.

There would not be much to add in the sense that participants preferred clinician expertise over patient expertise when it came to medications were it not for some subtleties of meaning that caught our attention. We observed how participants wanted to behave as good patients who recognized the clinician's expert status. For example, one participant remarked that he abided by his cardiologist's instructions because the cardiologist was the expert, whereas he was just the patient. In this regard, Galasiński et al. (2023) describe how beliefs that patients should stay passive and let clinicians make decisions for them exacerbate the power imbalance in the patient-physician relationship.

Evidence-based medicine can be another source of epistemic injustice (Galasiński et al., 2023). This approach, rooted in positivism, prioritizes evidence gathered from quantitatively controlled trials in healthcare decision-making. However, without due attention to people's experiences, priorities, and preferences, it may risk overlooking knowledge that only the sufferer can contribute. To illustrate, one

clinician questioned the design's alleged failure to note that self-care recommendations (see Fig. 3(a)) were not necessarily evidence-based, nor did they correspond to medical prescriptions.

Finally, we found that the clinicians' main concern was the correctness of the information due to the individual's unawareness of their medical situation. Specifically, our findings showed that people with CVD do not always distinguish their condition's etiology or know what their medications are for, perhaps due to the complexities of their situation, such as comorbidities. In Huh and Pratt's (2014) work, clinicians refer to such a lack of context in the patient's history as misinformation.

**Design Implications.** We discourage making recommendations about medications that might help the individual cope with their situation. Our findings showed how uninterested participants were in this regard. Moreover, the richness of patient expertise lies in the knowledge of a more personal than clinical nature (Hartzler and Pratt, 2011). Even so, we recommend the mechanism we devised to keep clinicians in the loop, as shown in Fig. 3(c), consisting of a high-emphasis button—with a catchy text label such as “Can this help you?”—that triggers a dialog box inviting discussion with healthcare providers about the appropriateness of any self-care ideas through a discussion list.

## 7. Limitations

There is a duality in the fact that the prototype was low fidelity. While it could make participants feel less constrained in expressing criticism and suggesting changes, it could also limit the transferability of the research findings. First, the participants in our study were unfamiliar with low-fidelity prototypes, so assistance from the facilitator was necessary for the early activities of the prototype evaluation. This assistance decreased as participants moved on to later activities, and their interaction with the prototype became increasingly smooth.

Second, as we wanted the participant to reflect on their situation, we asked them to provide us with their health data so that we could personalize the prototype before the evaluation. Therefore, it remains to be seen what issues users might encounter when interacting with the prototype from scratch, for example, when inputting their demographic and lifestyle information, diagnosis(es), symptoms, treatments, and strategies. One challenge we know they might face in earlier phases is specifying what their medications are for.

The evaluation of the prototype warrants our attention, too. It should be expressly noted that the findings of the present research study come from a brief online evaluation. Alongside this is the source of the recommendations participants engaged with. In this regard, we acknowledge that the findings on peer recommendations could be influenced by our “Wizard of Oz” setup, wherein we searched PatientsLikeMe and served the results to participants.

We recruited participants based on diagnosis, sex, and age to cover a broad spectrum of perspectives. Nevertheless, this purposive sampling strategy has a number of limitations. Since participants self-reported having been diagnosed with coronary artery disease or heart failure, we cannot ascertain whether they met the eligibility criteria. In this regard, empirical evidence suggests that Prolific's participants score high on honesty tests (Peer et al., 2022). Moreover, we validated consistency by asking potentially eligible participants whether they had been diagnosed with CVD by a doctor at the beginning of the pre-evaluation survey. Although highly subjective, hearing them reflect on their situation while evaluating the prototype makes us believe that participants were familiar with CVD.

Other limitations pertain to the gender and ethnicity of participants. Specifically, none self-identified with a gender other than male or female, nor was there any ethnicity other than white. These limitations then speak of the lack of representation of minorities and ethnic diversity.

## 8. Conclusion

In this paper, we set out to investigate how we may design to facilitate locating peers and learning self-care ideas from them in online health communities. To this end, we built a prototype and evaluated it with people suffering from CVD and clinicians with experience treating this group of heart or blood vessel conditions. Our findings revealed the preponderance of the lifestyle profile in locating and choosing peers. The fact that participants sought how to fit their condition(s) into the life they wanted to lead may help elucidate the role of lifestyle. Specifically, we argued that the more similar individuals are to their peers in terms of habits and activity level, the more helpful the suggestions they receive will be. However, we noted that these findings should be understood in the context of exploratory peer search.

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## CRediT authorship contribution statement

**Jhon Adrián Cerón-Guzmán:** Writing – original draft, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Daniel Tetteroo:** Writing – review & editing, Supervision. **Jun Hu:** Writing – review & editing, Supervision. **Panos Markopoulos:** Writing – review & editing, Supervision, Project administration, Funding acquisition.

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Data availability

Data will be made available on request.

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