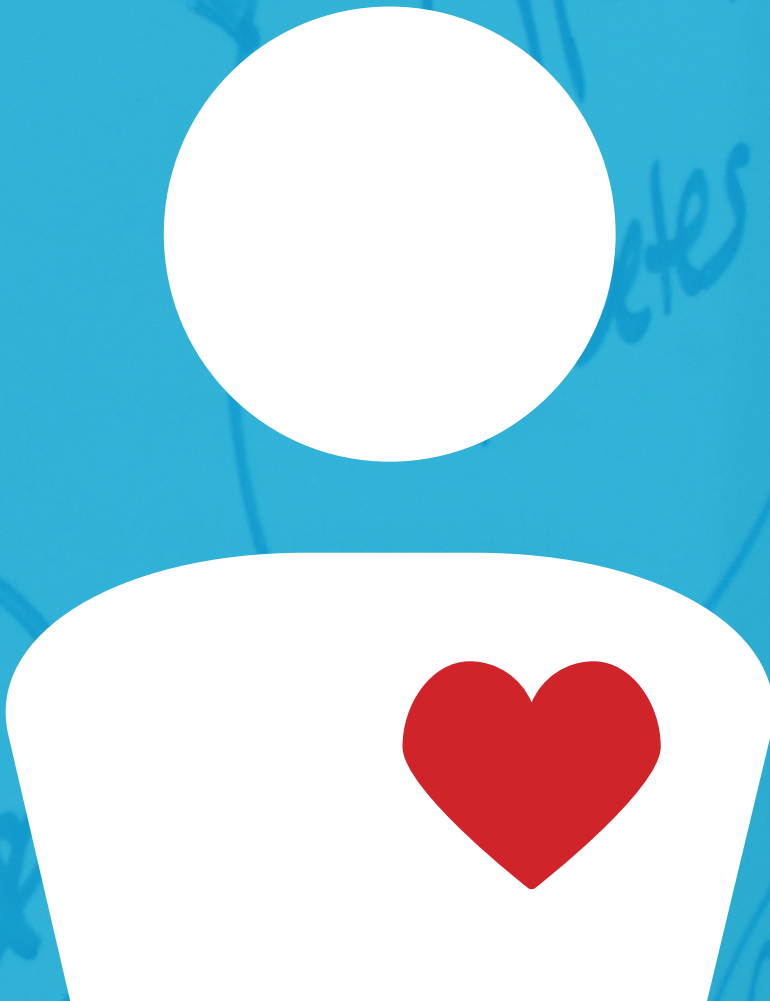


Design for Chronic Illness

EXPLORING SERVICE SYSTEMS & NEW TECHNOLOGIES
FOR PATIENTS WITH TYPE 2 DIABETES



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Design for Chronic Illness: Exploring Service Systems and New Technologies for Patients with Type 2 Diabetes

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ABSTRACT

My thesis project focuses on designing new services and technologies to assist with the daily management of type 2 diabetes. Through an ethnographic study, survey, and interviews, I identified that the patients who struggle most with management are those who lack social support. To combat the lack of social support after diagnosis, I propose an intervention directly after diagnosis in the form of a peer mentor service rooted within an online community for people with type 2 diabetes.

I have designed the general service framework for an online peer mentor community called CareMentors, along with the web site architecture, general interface and system touchpoints. A prototype was created in terms of visual artifacts and video sketches, and evaluated by 24 users through role-playing scenarios. The results of the evaluation suggest that mentor relationships are most beneficial to users when they are initially diagnosed or feel they are losing control. The CareMentors service must be vigilant with who becomes a mentor, as the users want background checks on mentors-in-training for safety purposes. Users also want to control their sense of anonymity within the community, but many are willing and excited to give back by becoming a mentor.

methods for
different people

type II
diabetes

denial

don't want to
change

Control

don't see

family helps

removes bad food

kids

gause

walk together

care + love

ignores disease

conceptions

INTRODUCTION 

The U.S. National Center for Health Statistics defines a chronic illness as an illness lasting at least 3 months and does not often “resolve spontaneously, and [is] rarely cured completely”¹. The 1998 U.S. National Medical Expenditure Panel Survey states, “the number of people with chronic illness in the U.S. alone is projected to reach 171 million by the year 2030”². At some point, nearly everyone will encounter a chronic illness either directly or through a family member or close acquaintance. It is estimated that 25.8 million people in the U.S. have diabetes, which is enough to fill 337 football stadiums. Worldwide, 150 million people have diabetes—18 times the population of New York City. This is expected to double by 2025. Of these numbers, 90-95% of these cases are type 2 diabetes. The Centers for Disease Control and Prevention call this an epidemic. In 2007, the U.S. spent \$174 billion dollars on diabetes treatment—that is enough to buy 743 jet airplanes. If a person can manage his type 2 diabetes well, he may not need medications and will encounter less or no complications³.

These people, along with their families, suffer directly the burden of managing their illness. They are constantly confronted with health decisions without a doctor’s guidance. According to University of Pittsburgh social and behavioral scientist Jacqueline Dunbar-Jacob, poor management of chronic illness is often a result of errors and lack of understanding around prescriptions, side effects, and daily management regimen. Patients and families become tired of carrying out the management regimen, disagree about the disease or treatment, lack clinical support and illness education, or simply are not aware of what to do or how to monitor the proper management behavior for the illness⁴.

1 Centers for Disease Control Prev. (CDC). (2003). *Chronic Diseases: The power to prevent, the call to control*. www.cdc.gov. Archived by WebCite at <http://webcitation.org/5jqlEPC9>.

2 Agency for Healthcare Research and Quality. (1998). *U.S. National Medical Expenditure Panel Survey*.

3 American Diabetes Association. (2011). *2011 National Diabetes Fact Sheet*. <http://www.diabetes.org/diabetes-basics/diabetes-statistics/>.

4 Coalition for the Advancement of Health Through Behavioral and Social Science Research (CAHT-BSSR). *Congress Briefed on Self Management of Chronic Illness Research*. <http://www.cossa.org/caht-bssr/selfmanagement.htm>.

There has been a movement towards collaborative care between patients and health care providers, but still, a large amount of care is left to the patient. In the best cases, health care providers offer patients self-management education, which includes general information, technical and problem-solving skills. However, the concept of collaboration has not been implemented effectively. As Dunbar-Jacob illustrates, management practices are often widely varied, and less than half of U.S. patients with a chronic illness receive appropriate support and health management instructions. Many patients are left to find and process information alone, without a firm grasp of the problem solving skills necessary to manage their illness. To supplement the information given in the clinical setting, patients now use the internet as a guide.

Many patients are turning to the Internet, specifically online support communities, for solutions. According to the 2007 Pew Internet and the American Life report on online health, 86% of adult Internet users with a chronic health condition have searched for health information online, and as a result, 40% of these users have then taken a health related action⁵. Patients are educating themselves on their illnesses and taking management steps through their own judgement. They are haphazardly fulfilling the needs that their doctors' are ignoring.

As a result, I chose to focus my thesis on the challenges of chronic illness lifestyle management outside of the doctor's office, with my case study being patients with type 2 diabetes. Through my design research, I explored the use of social communities for support after the diagnosis of type 2 diabetes. Using a survey, interviews, and directed storytelling, I looked at the general patient experience from diagnosis to long-term management. My user research led to the discovery that patients who struggled with management often lacked social support from their doctor, family or friends. My design solution shifted from creating a tool for behavior change, and instead focuses on creating an intervention of social support after diagnosis, with the goal that it will lead to better management in the long term.

5 Fox, S. (2009). *The social life of health information*. www.pewinternet.org/reports/2009/8-the-social-life-of-health-information.aspx.

LITERATURE ON LIFESTYLE MANAGEMENT

A review of significant literature provided guidance for my thesis project. Many of the readings came from the fields of psychology, anthropology and sociology focused on health care and chronic illness. I also explored literature around social media, new technologies, and health care innovation. What I found is that peer support is key for lifestyle management. Peer support allows for storytelling, which is incredibly important in coping with illness. Social communities are being used as a platform for these narratives. Sharing a personal story is linked with improved health and chronic illness control, in part because stories help break down denial through engagement and identification with the storyteller⁶.

According to a recent study, peer support, even through community health workers, has been shown to benefit health in many ways⁷. Specific to diabetes, these benefits include improved blood sugar control⁸. Peer support has four key components: assistance in daily management, social and emotional support, linkage to clinical care, and ongoing support extended over time.⁹ What is unique about peer support is that it functions to complement, supplement and extend formal primary care services—it does not replace the role of professional health care providers (SEE FIGURE 1).

Peer support can be a successful method to foster patient empowerment—helping patients discover and develop the capacity to be responsible for his or her own life. Empowerment theory recognizes that patients are the experts on their lives, and they are the primary decision-makers in control of their illness. Funnell and Anderson state, “Intervention strategies that enable patients to make decisions about goals, therapeutic options, and self-care behaviors and to assume responsibility for daily diabetes care are effective in helping patients care for themselves”¹⁰. My design solution aims to utilize peer support to foster patient empowerment in care and to create better management of diabetes.

6 Chen, P. (2011). When Patients Share Their Stories, Health May Improve. *New York Times*. http://www.nytimes.com/2011/02/10/health/views/10chen.html?_r=2.

7 Swider, S.M., Outcome effectiveness of community health workers: an integrative literature review. *Public Health Nursing*. 2002. 19: p. 11-20.

8 Joshu, C.E., et al., Integration of a promotora-led self-management program into a system of care. *The Diabetes Educator*. 2007. 33: p.158.

9 Heisler, M. (2006) Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success. *California Health Care Foundation*.

10 Funnell, M. M., Anderson, R. M. Empowerment and Self-Management of Diabetes. *Clinical Diabetes*. 2004 vol. 22 no. 3 123-127.

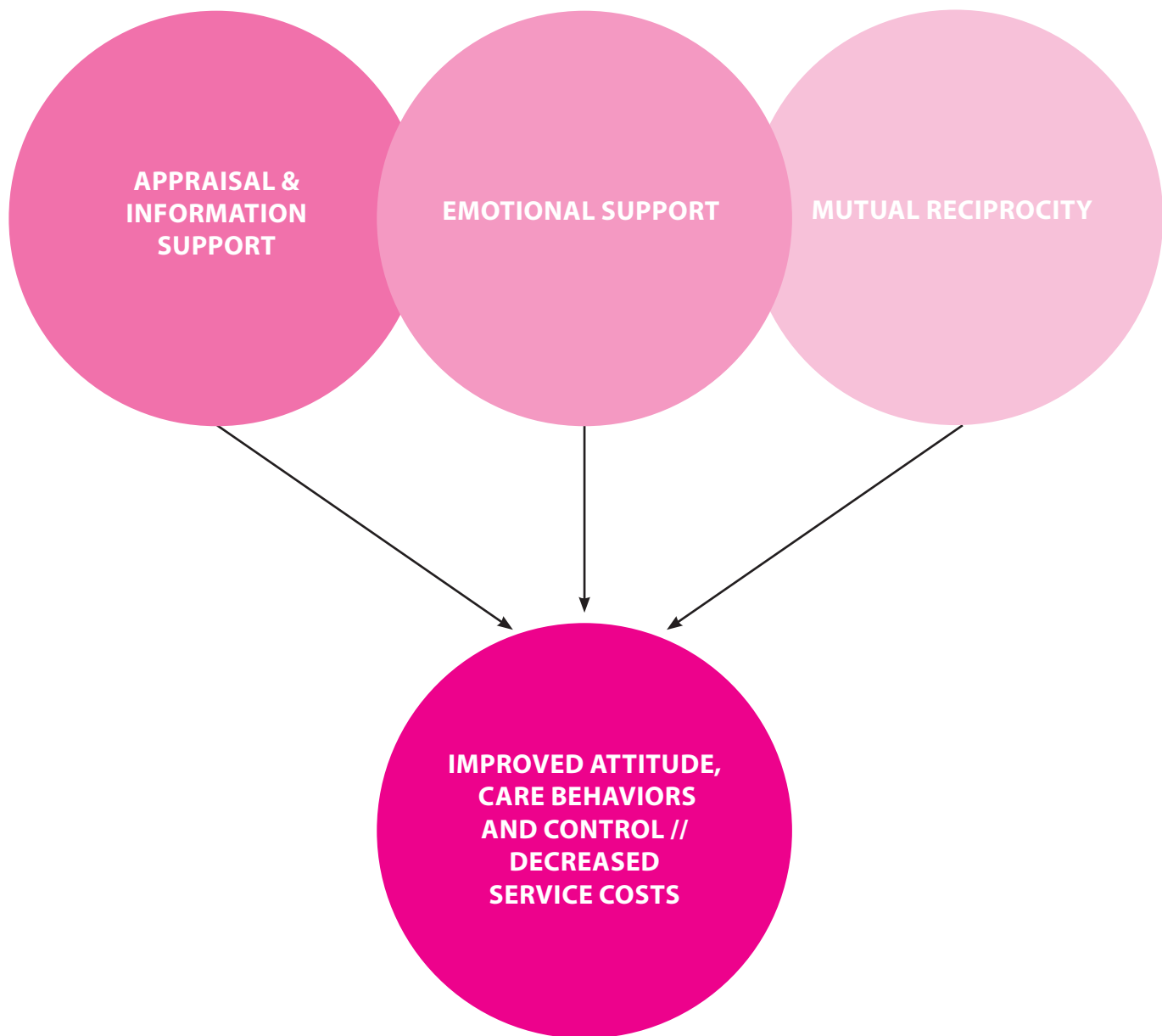


Figure 1 | Peer Support Model

RESEARCH 

DESIGN APPROACH

To explore and design for the management of type 2 diabetes, my design process focused on user research with patients, then synthesis of the data to locate patterns. Based on these patterns, a problem area emerged needing a designed solution. Concepts were quickly generated around the identified needs. These concepts were sketched out in the form of a scenario, and co-designed through participatory activities with the user. A prototype was then developed, and tested with the user.

USER RESEARCH

‘Think, Feel, Do’ is a theory focused on understanding how thoughts, emotions, behaviors, physical reactions and environments all work together to affect a person’s state of mind¹¹. In order to design a tool or a service for patients with type 2 diabetes, it was critical to develop an understanding of their day-to-day life. I looked for the subtleties in every user encounter through the following research activities:

Digital Observations of Online Communities
User & Expert Interviews with Directed Storytelling
Online Survey

STAKEHOLDER MAP

In order to understand the key players involved in my problem space, and to better see the system of care that surrounds a patient, I developed a stakeholder map (SEE FIGURE 2). Each person has an influence on the patient’s experience—the Doctors & Health Care System, Support Groups, and Family & Friends. Patients might not come in contact with everyone in the model, but the stakeholders will impact patient care and management success or failure.

11 Padesky CA, Mooney KA. (1990). Presenting the cognitive model to clients. *International Cognitive Therapy Newsletter*. 6. www.padesky.com/clinical_corner.htm.

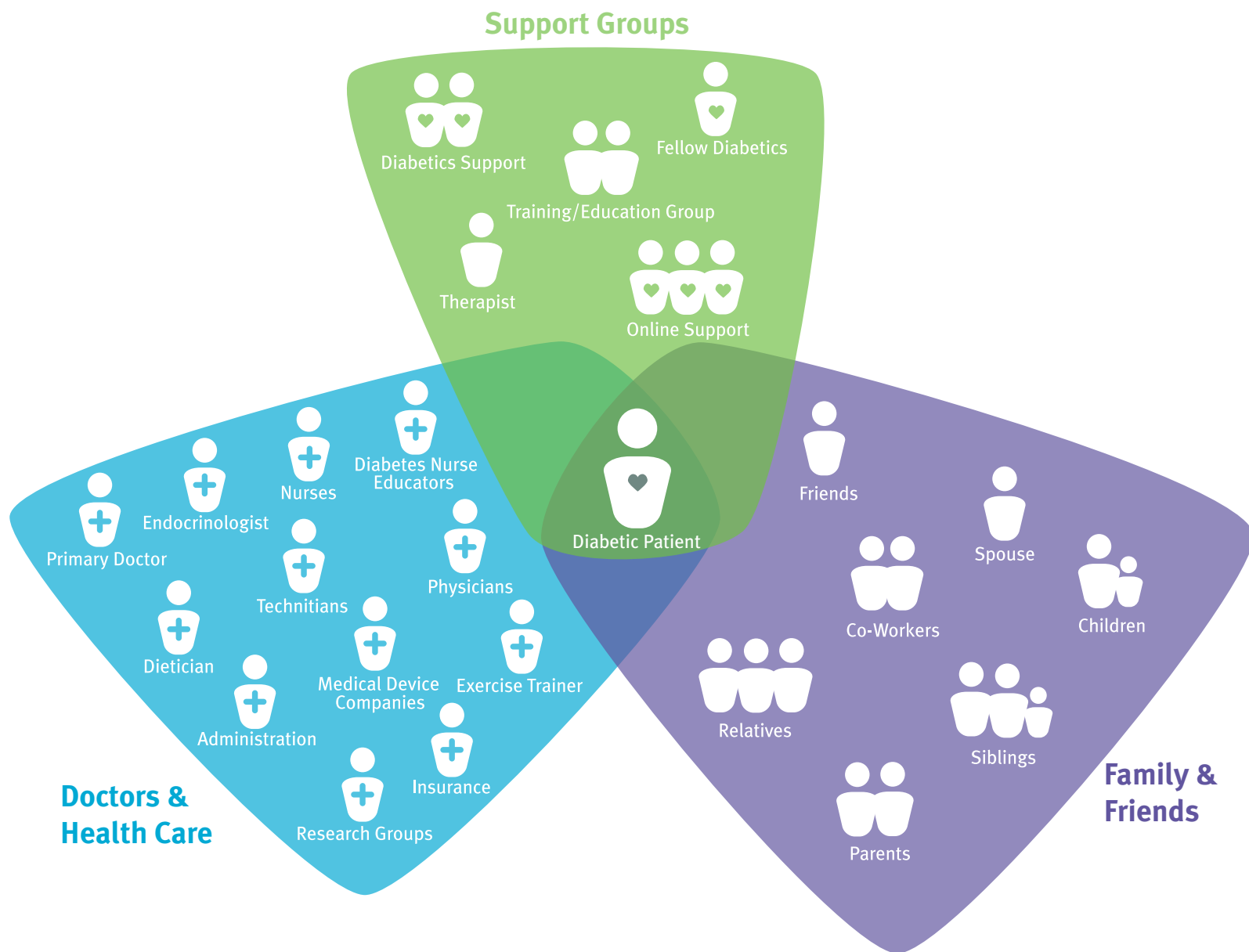


Figure 2 | Stakeholder Map

ETHNOGRAPHY OF ONLINE DIABETIC COMMUNITIES

Before I started interviewing patients, I began an ethnographic study of two online diabetic communities: *www.tudibabetes.com* and *www.diabeticconnect.com*. I performed digital observations, where I simply followed conversations and users on these web sites, observing what was being talked about, shared, and taking note of the relationships people were forming. I found that certain patients take on a 'leadership/peer mentor' role by welcoming new members, listening to their stories around diagnosis and coping, and sharing their own experience. There are a number of patients who dive into the community when they have a question, but then 'lurk' or remain inactive until they want to ask something again. Frequently patients discussed topics other than their diabetes, while at the same time, many patients felt the online community was the only place they could discuss their diabetes and be understood.

INTERVIEWS & SURVEY

The ethnographic study helped to gain a sense of why patients were using online social communities, and to highlight the most common struggles. By interviewing patients both face to face and via telephone, I was able to gather the more personal story of having type 2 diabetes. I also spoke to many patients who did not use online social communities. Professor Jennifer Mankoff's research team had 14 transcripts of interviews that had previously been performed. I thoroughly analyzed these before beginning my own interviews. Late in the semester, I helped to launch a survey with Professor Mankoff's team. The findings provided larger support for what was discovered in the interviews. Below are the interview and survey statistics, along with key insights and quotes (SEE FIGURE 3).

24 interviews, Range of age

14 females
10 males
2 doctors
1 nurse

57 Survey participants, Range of age

22 male
31 female
4 did not answer gender

To view interview questions, please turn to the Appendix, page 67.

Key Insights

- Patients use the internet (often right after diagnosis) as their largest source of information.
- Support is critical directly after diagnosis for healthy coping and developing a care strategy.
- Diabetes is very personal and patients see themselves as solely responsible for their care.
- Identity is questioned by patients; many struggle with blame and coping.
- Feeling knowledgeable, in control, and responsible leads to patient empowerment.
- Support from doctors, family members, and friends leads to better management.
- Family or doctors may have different views of illness than the patient. This clash in beliefs can cause many serious problems.

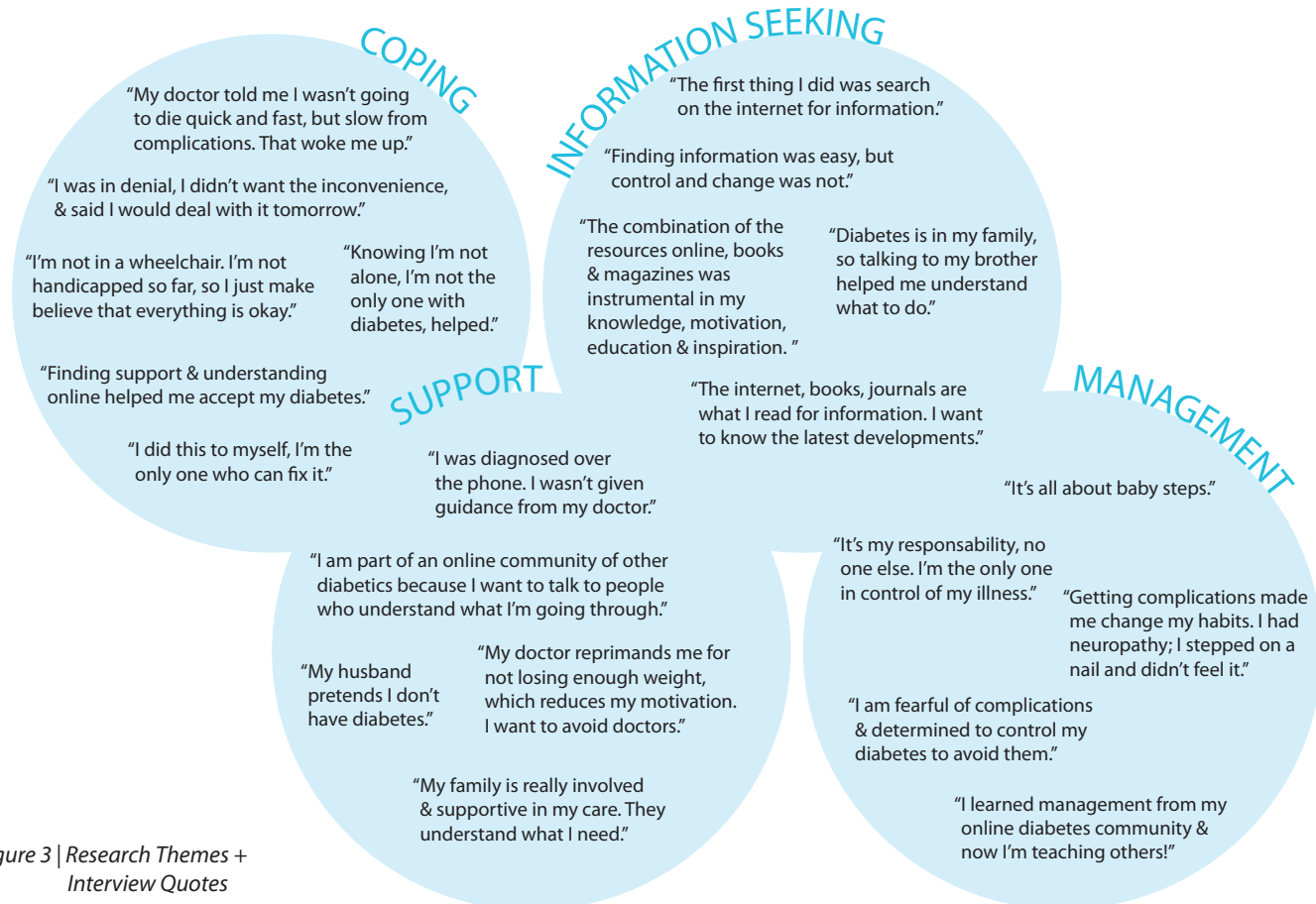


Figure 3 | Research Themes + Interview Quotes

SYNTHESIS 

RESEARCH SYNTHESIS

The digital observations, interviews and survey data regarding diabetes management was overwhelming. I was dealing with a complex system and I needed to map out my thinking, find the patterns within the system, and then order those patterns into a meaningful sequence (SEE FIGURE 4). From this diagram, I grouped patterns and categorized the insights. I bunched my insights into the needs and role of doctor, patient, or family and how they connected (SEE FIGURE 5 ON NEXT PAGE). Four major themes emerged, each with particular behavior patterns centered on coping, support, information seeking, and management.

The experience of diagnosis was a huge pain point for my users—some patients were diagnosed over the phone, and others had spouses who ignored their diagnosis. How doctors treat the situation has a huge influence on next steps for the patient. Whether the patients receive support after diagnosis impacts their ability to cope, which affects how they choose to manage their illness. Finding helpful and reliable information right after diagnosis sets the stage for how patients decide to change their habits and tackle their care. The users I interviewed (who either were still struggling with management, or who initially struggled and later got on a better track of care) all had one or more of the following issues: not gaining support from family/friends, not getting much time or care from doctors, not being guided towards diabetes education, not getting referrals to specialists, and not having support or guidance on how to deal with the diagnosis.



The general pattern was diagnosis, information seeking, education, then lifestyle changes. Yet not everyone makes those lifestyle changes. Some users talk about “taking control” and pushing forward with the desire to live well and change their lifestyle to “control diabetes.” Some struggle with this change, but they are determined and work towards it with small steps. Others deny the illness and ignore the condition, often until a complication arises and it scares them enough to make changes. Interviewees described this as a “light bulb suddenly turning on” or simply a moment that scared them into making the changes.

The moment of diagnosis kept coming up as either a successful guidance towards developing a care plan around diabetes, or a pain point that made the illness a struggle. My problem was reframed from dealing with general management to dealing with the moment of diagnosis as being what directs a patient’s next steps for care. If they can be led in the right direction after diagnosis, this would have significant benefit for coping and management in the long term.

NEW PROBLEM STATEMENT

What occurs during and directly after diagnosis of type 2 diabetes has a large impact on a patient’s well-being and disease management. If patients do not receive understanding and support from their doctor and/or social network, their steps toward care can be stunted. A key to healthy coping and management is social support: the physical and emotional comfort given to us by our family, friends, co-workers, and others, as well as knowing that we are part of a community of people who care for and value us. Unfortunately, social support is not always provided by doctors, family and friends. Providing social support after diagnosis helps the patient learn daily management skills, provides emotional support and motivation, and leads to overall improvement. With my thesis, I explored service systems and new technologies to design a social support intervention for patients directly after diagnosis.

Explanatory Models Shapes care/management

Doctor

- professional view of relationship (give biological-based advice in visit and care ends there v.s. follow-up support / continued help)

"tells what to do"
v.s.
"understanding help"

- does not see disease care and "lose weight"
v.s.
addresses all complex needs

Patient

- different view of disease (serious v.s. not serious)
- expects doctor support OR does not see doctor as caring resource (busy, not knowledgeable, influenced by \$)
- doesn't share w/ family for help (my body, my responsibility)
v.s.
relies on support

Family

- inaccurate / bias v. the illness v.s. ch
- limited knowledge v.s. ed
- helping in care v.s. "it's up to them" attitude
- doesn't know "how"

- Doc doesn't connect family about how they

PERSONAS

Based on the digital observations, interviews and survey, I developed 4 personas and the common paths they take after diagnosis (SEE FIGURE 6). People made certain choices in their next steps for care based on their level of support and their ability to cope with the diagnosis. By illustrating the current situation of these patients and mapping out their journey, I was able to see where breakdowns or problems were occurring for them. I would target Frank and Jason, the Late-Bloomer and the Reluctant patient, as these are the users closest to wavering and struggling with their diabetes. Achievers like Caitlin can easily use the design solution, and hopefully, the Shaunias who are in Denial can be steered towards support, acceptance, and better management.



Shauna was diagnosed over the phone, and her doctor takes little time to guide her. She has no social support, relies heavily on medication to manage her condition, and does not exercise.



SHAUNA | DENIAL

Healthy Food	♥
Exercise	♥
Social Support	
Medication Usage	🌱🌱🌱🌱



Even though Jason is reluctant to exercise or alter his eating habits, his wife cooks for a healthy diet, and her persistence helps him. He has recently joined a support group to talk about his struggles.



JASON | RELUCTANT

Healthy Food	♥♥
Exercise	♥♥
Social Support	♥♥♥
Medication Usage	🌱



Caitlin had a care team formed after diagnosis. Her husband walks daily with her, Caitlin's family helps her eat well, and she has an online community she speaks with weekly to swap tips and share stories.



CAITLIN | ACHIEVER

Healthy Food	♥♥♥♥
Exercise	♥♥♥
Social Support	♥♥♥♥
Medication Usage	



Frank relied on medication to manage his diabetes, and he continued with poor lifestyle habits until he had a stroke related to complications. He has contacted a diabetic support program and wants to change.



FRANK | LATE- BLOOMER

Healthy Food	♥♥
Exercise	♥
Social Support	♥♥
Medication Usage	🌱🌱

Figure 6 | Personas

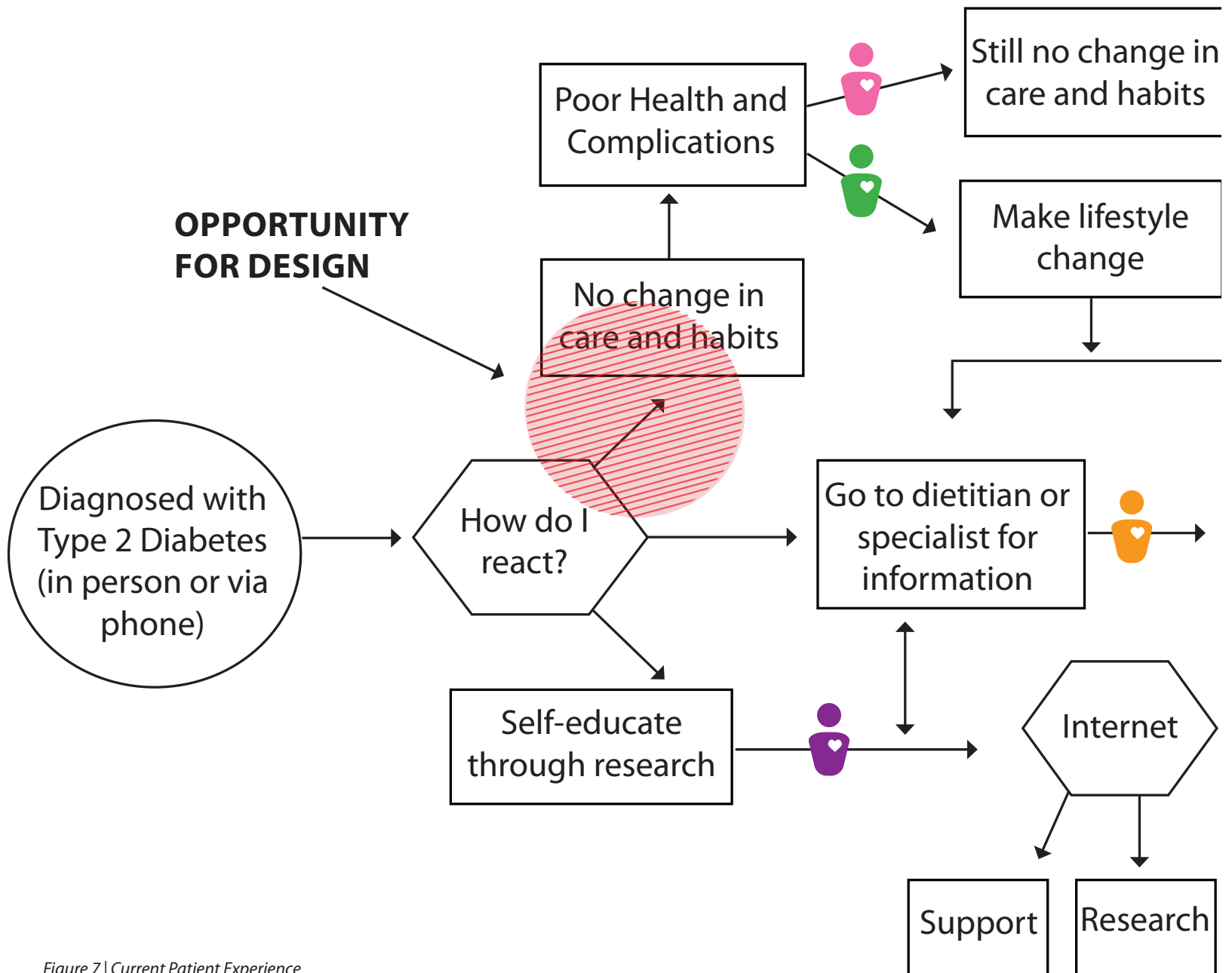
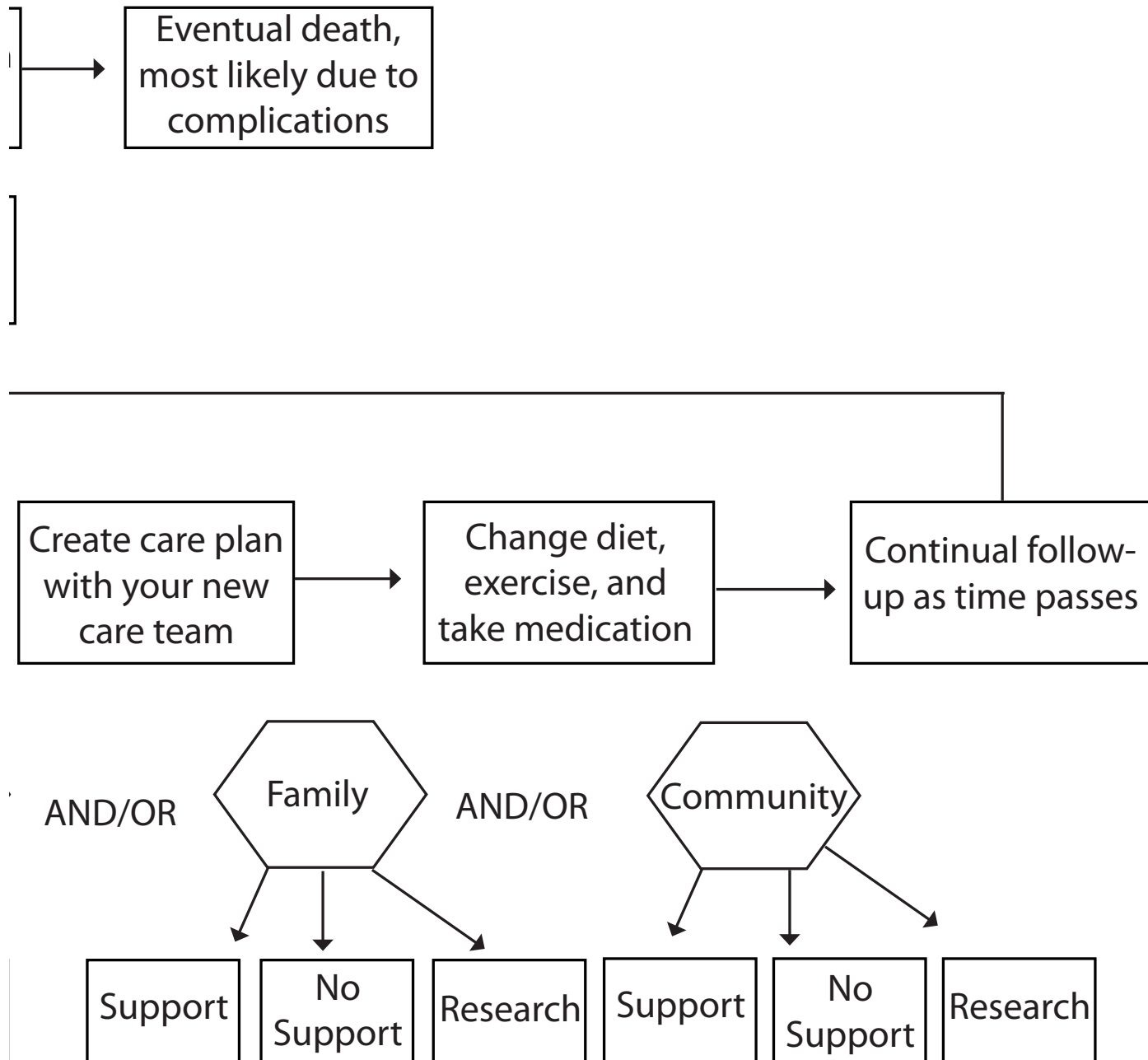


Figure 7 | Current Patient Experience



**PARTICIPATORY
DESIGN** 

DESIGN CONCEPTS

After the research and design synthesis phase, I began developing concepts based around the personas and research insights. I created a matrix (SEE FIGURE 8) focused on needs/ functions (social support, facilitative with caregivers, supports, interactive, education) and forms (environment, device, service, online, intervention, person, print). I used this matrix to generate the following concepts:

- Diabetes Peer Matching after diagnosis which would pair patients with other diabetics, like a “match maker” or “big brother” mentor service upon diagnosis. The match guides you through your experience.
- An interactive touch screen that could be placed in the waiting room of a doctor’s office, or examination room. A screen with four people- “healthy person, average person, diabetic, healthy diabetic” and the interface allows for a comparison of each condition. These screens could be a talking point for caregivers.
- When you type a health related search into Google, a search tool pops up that asks you “are you recently diagnosed, do you know someone diagnosed, or are you just browsing?” and depending on what you select, the search browser leads you on a learning journey.
- At the doctor’s office, after diagnosis, the patient chooses what is the most suitable “social care package” for them. In conjunction with their social support system, they also design their own care management system, choosing diabetic support tools that they think will help them.
- Conversation cards to prompt discussion between patients and doctor. Give a packet of cards that list cultural, gender, social diabetes struggles, and the patients pick cards that could apply to their situation. Each card has a list of issues/questions/discussion topics.
- “Recently Diagnosed” phone application with social support built in. Answers questions, links to social community for answers and discussions, provides goal tracking programs, gives the patient prompts to remind them about certain steps they need to take each day.
- Emergency phone line & application that links diabetes educators with patients.

Environment

device

mobile app.

Service (system)

online

intervention

per

Social

Facilitative

Supports

interactive

educational / teaching

"Recently diagnosed"
phone app. w/
social support
mobile

mentorship
service for
diagnosis w/
another diabetic
(service, person, social,
support, educate)
(similar to AEL?)

Real p
video
diabetic
video p
real t

video answer

Health avatar
attached to web
browser to guide
search, store
selected info., make
connections to
others online searching
same thing

Search tool that
categorizes and
leads you on a
"learning journey"
- detects on google
a health search

collage
on wall or
floor to bring
in attention
+ info

touch screen
in waiting
rooms

give an audio
tape/cd to listen to
on way home after
diagnosis
(pres work after big shock)

self-
educational
program online
w/ other diabetics
(social)
"so what now"
and ~~turns~~ into a
app like Diabetic Connect

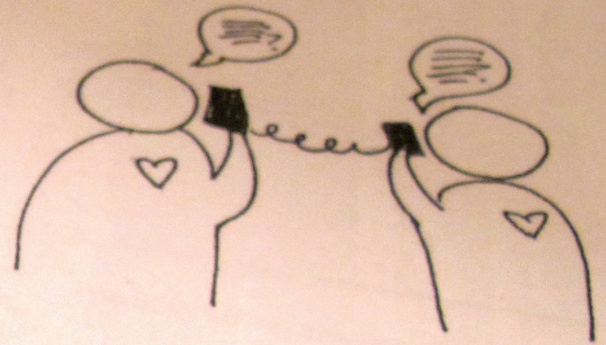
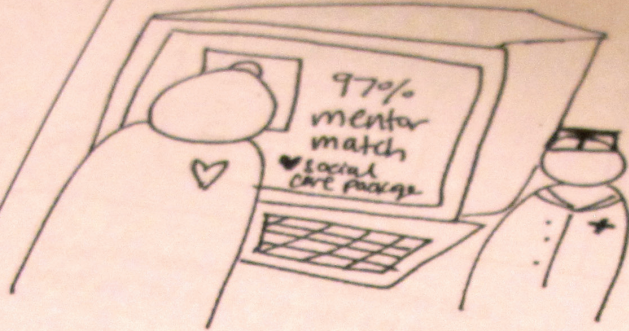
SPEED DATING SESSIONS

In order to validate my research insights and concept ideas, I held ‘speed dating’ sessions both in person and online. Speed dating is a method in which you sketch out brief scenarios of an idea and quickly “date” it with the user (SEE FIGURE 9). I sketched out scenarios for the above concepts, which are based on the research insights. The speed dating process began by asking a question related to the insight need, such as “do you ever wish, right after diagnosis, you had someone else in a similar situation to walk you through the learning process?” matched with sketches of how this might work as a concept, then asking “what is your initial reaction to this idea?,” “what do you find appealing or unappealing?” During the speed dating sessions, I asked about the level of interest, what was positive or negative, and if the concept would be useful. Below are the overall observations from the sessions:

- Participants respond positively to speaking with someone who has experienced diabetes.
- Participants want emotional support and understanding (not specific medical advice).
- Culture-specific mentors are good for issues such as food (both traditional cultural food and times of religious observation) and language barriers.
- Participants want their families to understand how best to help them.
- Participants want to share their stories and give back to their communities.
- Participants responded positively to community goal setting and mobile support.
- Emergency lines are a liability risk—they cannot replace proper care from a doctor.
- Participants want LOCAL support, but it must be safe.
- Participants want communication options for support matching.

By performing this activity, I was able to reaffirm the need for social support directly after diagnosis. I identified the ideas that were not resonating well with patients. As a result, I narrowed my design solution to a peer mentor matching service directly after diagnosis.

...wish, right after diagnosis, you
had someone else in a similar situation to
walk you through the learning process?



He or she inputs criteria for a mentor,
and system finds a match with
another person with type 2 diabetes.

The mentor answers questions as the
person learns how to manage his or
her diabetes.



COLLAGING ACTIVITIES

My next step was holding 4 participatory design sessions, along with continued speed dating. Participatory design is an approach that actively involves the users in the design process, with the aim to ensure the artifact designed will meet needs and is usable. Patients collaged what elements they would like to see addressed in a peer mentor service and in an online community while speaking aloud their thoughts (SEE FIGURE 10 & 11). They marked aspects of peer mentoring they would interact with along a time line from diagnosis. Below is the participatory design activity and resultant design insights.

Collaging activity based around peer mentoring and on a time line of diagnosis

- The program could be recommended at diagnosis, but then also reach out to the diabetic person after a little time has passed (maybe within first week).
- “I want the mentor relationship to form naturally. If it is a set match through a search only, with no options, then it could not be a good match. I need a combination of searching, along with allowing the relationship to start through serendipity.”
- Mentors need to go through training and have a background check for safety.
- Mentors cannot give medical advice. Each body has specific needs. The mentor program is providing emotional care, encouraging communication between the family, and guidance resources.
- “I want to give back as a mentor and help others to whom I relate.”



personalized

preparation

knowledge

inspiration

validation

resourceful

exercise

choice

change

easy

reflect



thorough

CAMPUS N

Collaging activity based around: What elements would you like to see in an online community? How would you like it to feel? How would you describe the experience?

- Recipe sharing (especially ethnic-specific food), local exercise buddies, discussion board that is easy to search, mentors and diabetes educators within the discussion.
- Flexibility to choose how to communicate with my peer mentor.
- “Each person is helping me in some way, sharing experiences, talking, answering questions. We are using teamwork to find answers!”
- The website should feel hopeful, cheerful, easy to use, and have good sense of humor.
- “My experience should be a discovery to learn new things about diabetes care and life in general.”
- “I want to trust in the people I am talking with and the information I am getting.”

laugh

learn

trust

discover

accessible

trustworthy

SHARE

answers



SOLUTION 

DESIGN SOLUTION

After my research and participatory design exploration, I created CareMentors, a peer mentor service rooted within a social community for people with type 2 diabetes (SEE FIGURE 12). After a user is diagnosed with type 2 diabetes, he or she is introduced to the service through brochures at the Doctor's office (SEE FIGURE 13 ON NEXT PAGE). Nurses then input the patient's contact information into the system. Within a week, CareMentors call the users to let them know they are not alone. The community is there to help. Users are matched with mentors who provide support and guidance concerning coping and learning about type 2 diabetes.

Once the user logs into the social community, he or she can search for mentors by location, age, ethnicity, gender and/or a specific mentor focus. They can form more natural relationships by first participating in discussion boards with mentors. Once a mentor is chosen, the user can select his preferred communication style, and they begin conversations once a week, while personalizing their shared "My Mentor & I" space. Once a user has increased management skills and health, they can enroll in training to become a CareMentor for others. CareMentors aims to help users cope, feel understood, in control, more likely to make healthy choices and actively seek education to foster better management of their illness.

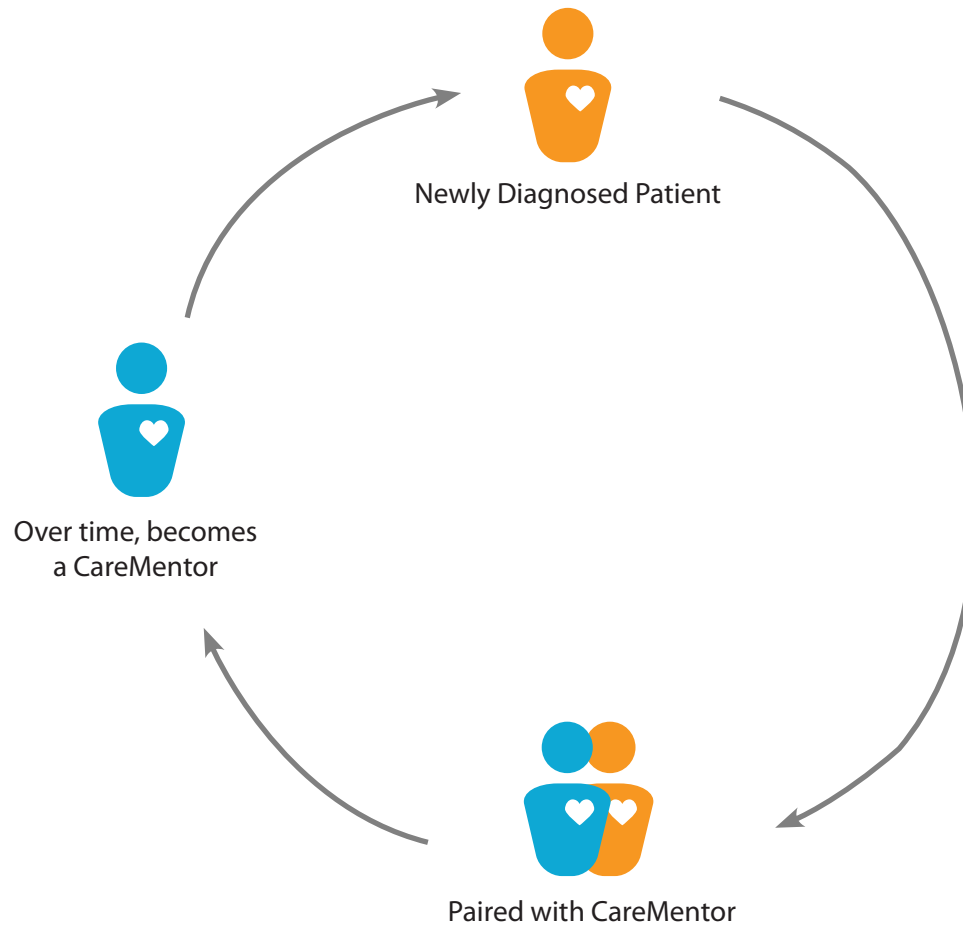
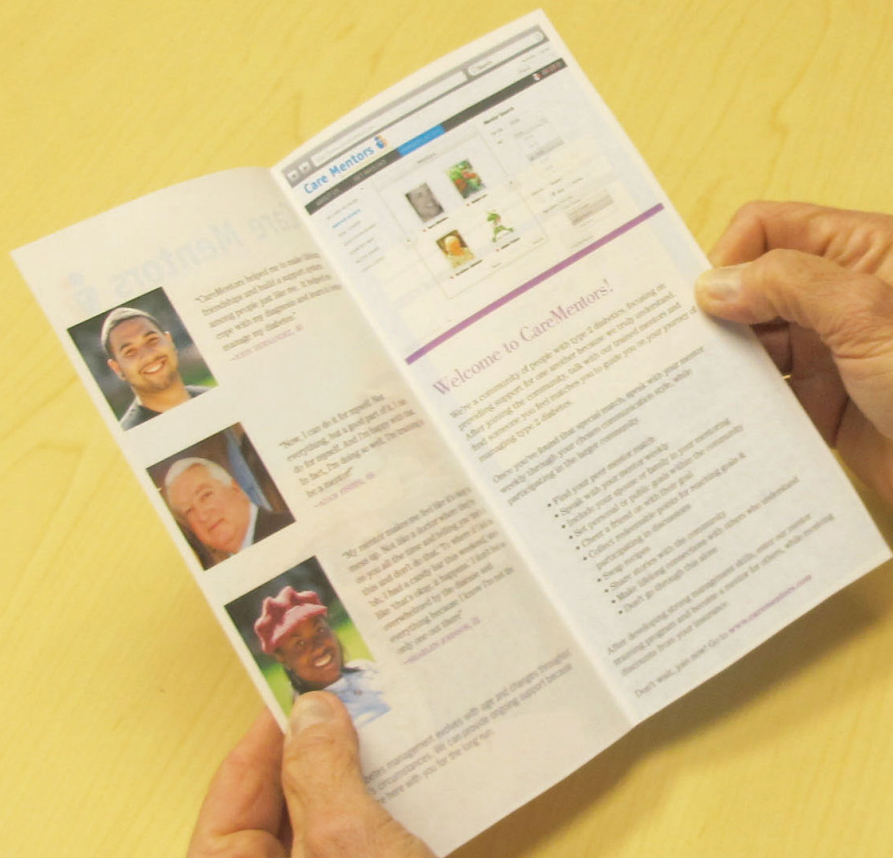


Figure 12 | CareMentors System

By using tools such as sketches, descriptive phrases, scenarios, diagrams, and models, I was able to move my idea from imagination into reality. Creating several rapid sketches focused on a narrative enabled me to imagine the experience and tell the story of someone using my design solution. From there, I was able to refine the concept “CareMentors” and map out the user experience journey (SEE FIGURE 14 ON NEXT PAGE). The process of modeling the experience allowed me to walk through each decision the patient might make, and where each particular choice might lead. Being able to visually see the flow allowed me to address each choice, tailoring my design to help the patient take the preferred track. To understand how CareMentors would actually work as a service and organization, the service blueprint model allowed me to address each layer of support, deciding what the structure would be for a system as intangible as a service (SEE FIGURE 15 ON PAGE 48).

Lastly, to tackle the complex design of the Care Mentors social community, building out the architecture of the web site permitted me to see which web pages were necessary, how they would collapse into one another, and how the user might navigate between the pages. As I modeled the structure, I was able to easily decide which pages to prototype and test with my user (SEE FIGURE 16 ON PAGE 49). The model continued to change as I tested and discovered new additions to the community, better pathways of navigation, and pages that were not useful.

To view screen shots of the UI, please turn to the Appendix, page 75.



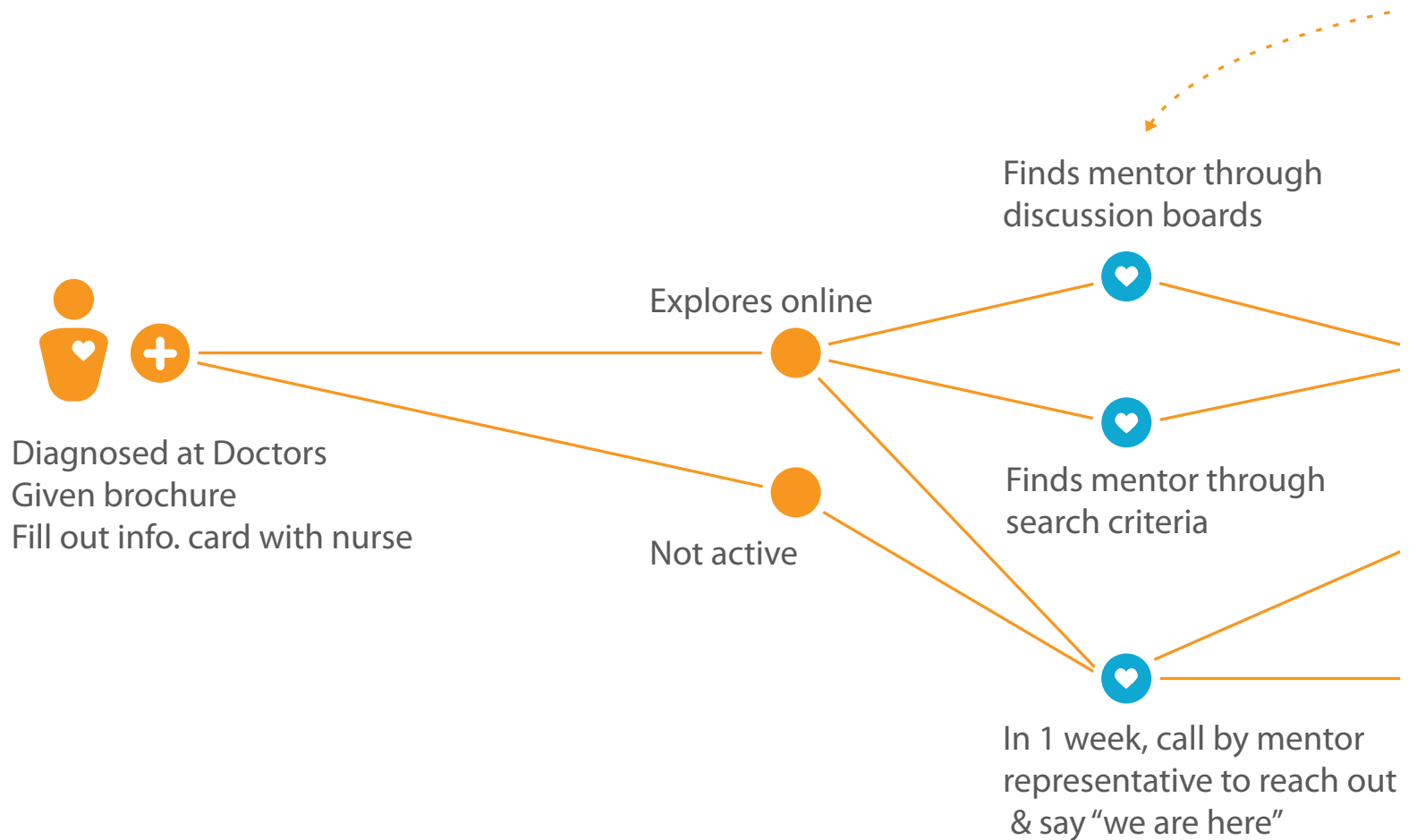
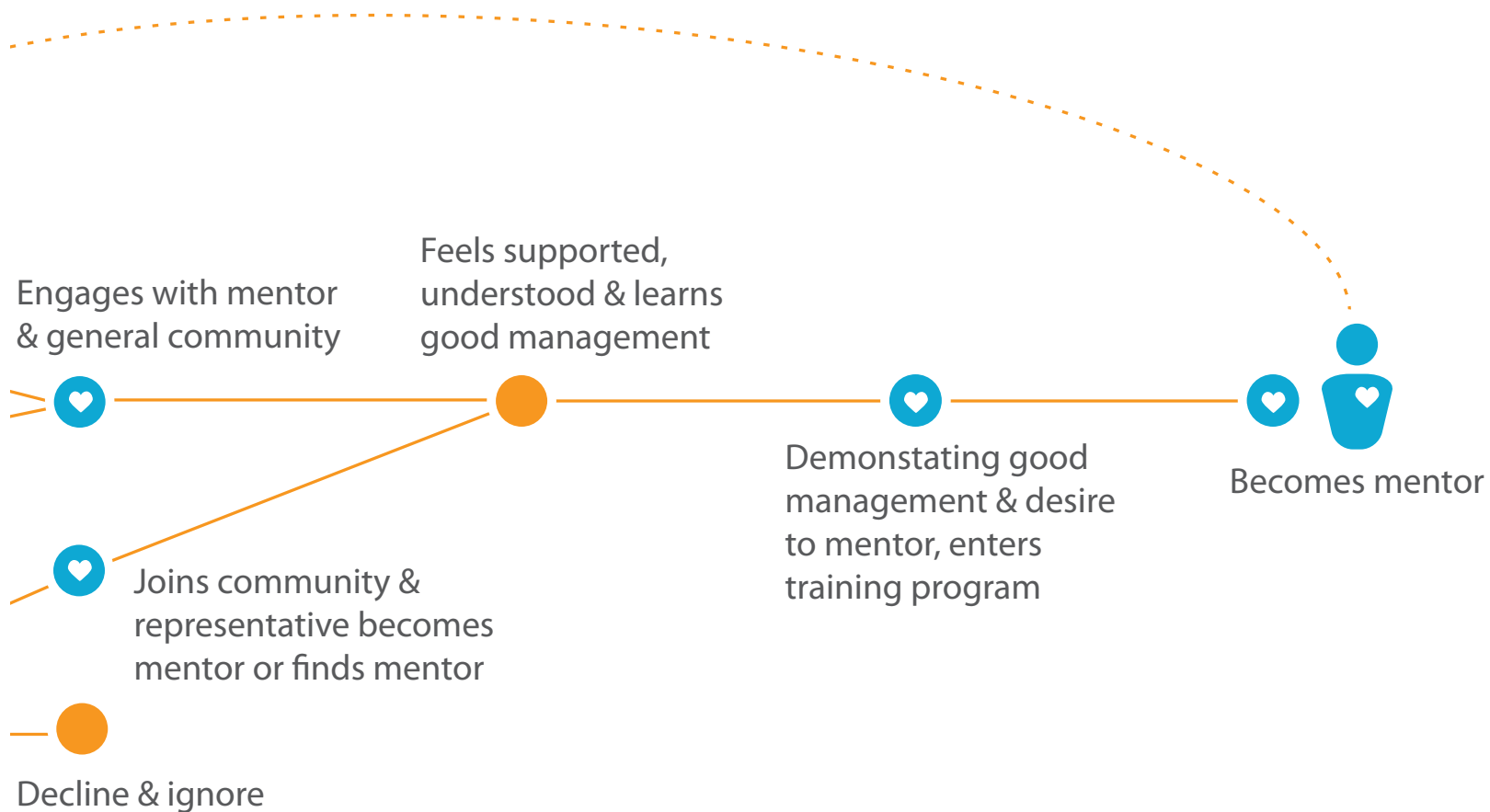


Figure 14 | CareMentors User Experience Journey



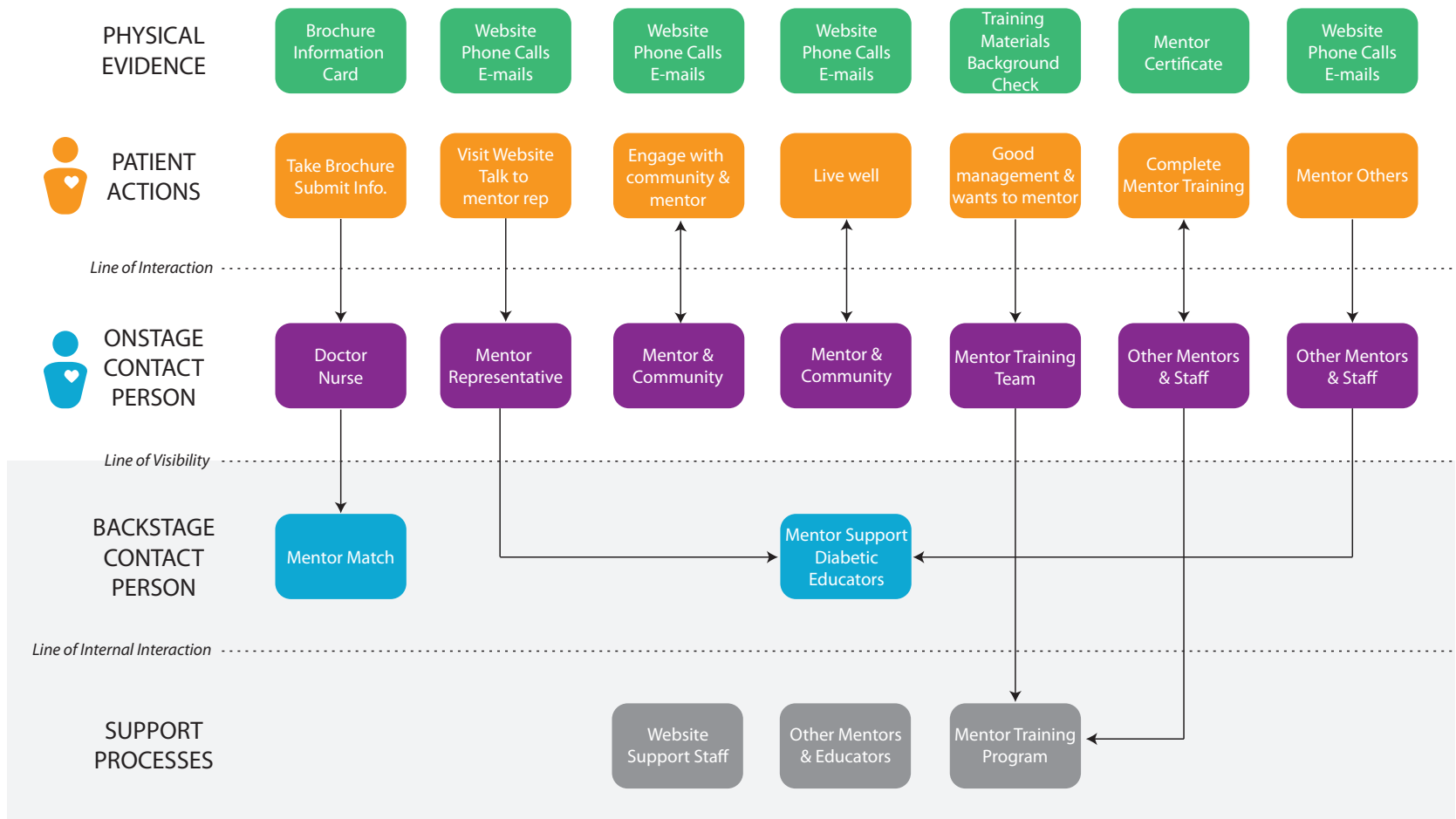


Figure 15 | Service Blueprint

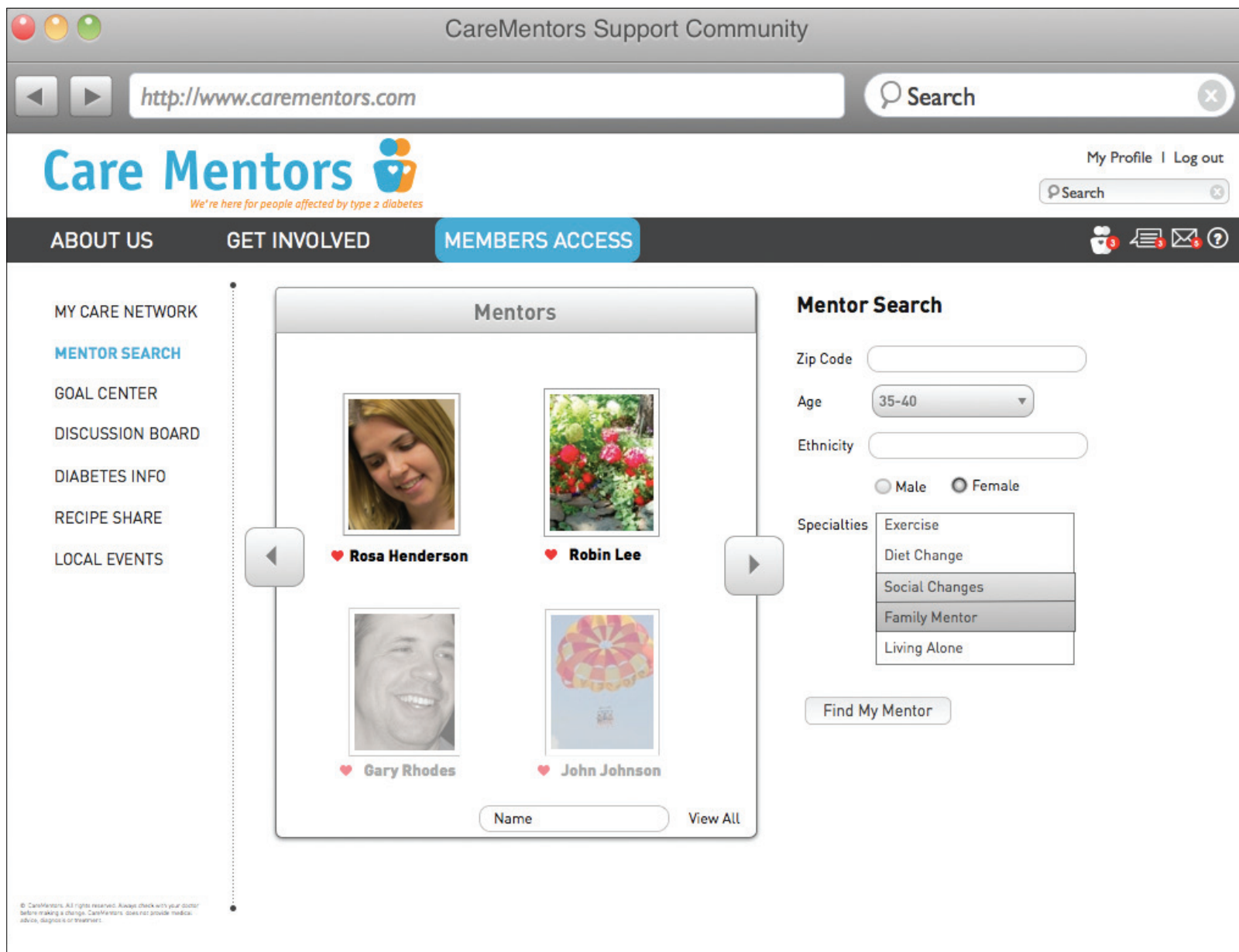


Figure 16 | Mentor Search Interface

USER SCENARIO

The following is the ideal situation of the CareMentors service.

Jenny hasn't been feeling well. Unsure of the cause, she books an appointment with her doctor.

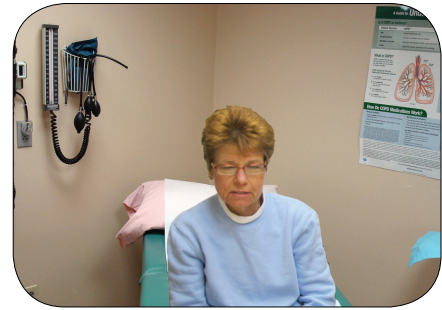
After running tests, Jenny learns she has type 2 diabetes. Her doctor explains the situation and recommends some educational programs, along with CareMentors, a peer mentor support program.

Jenny is given a brochure, and leaves her information for CareMentors to contact her. The news is tough. Jenny needs time to think over what to do next. She is upset, and doesn't know how to break the news to her family.

A week later, Jenny receives a phone call. It is CareMentors, and they want to know how she is doing and how they can help.

After talking about the program, Jenny goes online to check out the CareMentors community. She logs in and sets up a profile. Curious to find peer mentors who might be a good match for her, Jenny uses the Mentor Search feature to browse mentors. She narrows her search by location, age, ethnicity, gender, and a specific mentor focus on social changes and family mentoring.

Jenny wants the fit to be natural, and she's not sure how to know who will be right for her. She begins participating in the community discussion board, and finds herself in conversation with CareMentor Rosa Hernandez. She checks out Rosa's profile and requests Rosa to become her mentor. Jenny feels comfortable communicating weekly by phone.



Rosa accepts Jenny's mentor request, and the two begin filling their shared My Mentor page with conversations, stories, and photos of their lives.

Jenny decides to take advantage of the other community features. She and her family can add and search recipes by ethnicity and categories. They can create and search for local events focused around support, exercise, cooking, education or get together.

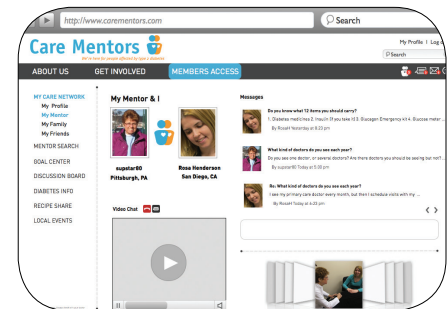
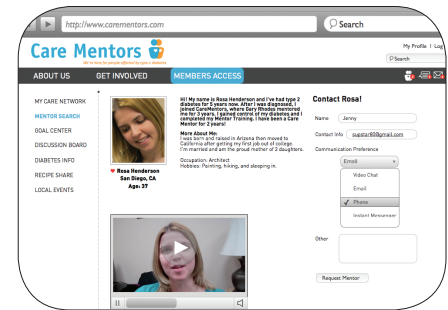
Rosa encourages Jenny to use the Goal Center, a place where Jenny can set goals for herself, view public community goals, or enter the monthly community health challenge. Jenny can set tasks and track her progress, and map it against other members.

Jenny can send her friends cheer on messages for encouragement. She sends a positive message to her friend Mary, who receives it on her CareMentors mobile application.

Jenny has been talking with Rosa over the phone every month. Her family has even participated in video calls to learn how they can best support Jenny. It's nice to have someone who has been through a similar experience.

7 months later, Jenny is in control of her diabetes, and is doing so well that Rosa recommends she become a CareMentor. Jenny decides to go for it.

After completing the CareMentors Training Program she receives her completion certificate. She can now give back to the community that has helped her take control of her life.



EVALUATION 

USER TESTING

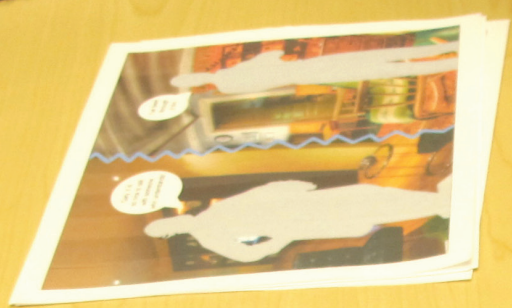
I tested my prototype in person with 4 patients, a diabetes pharmacist, and online with 24 patients from two online social diabetes communities (SEE FIGURE 17). It was a unique challenge to figure out how to build and evaluate my design solution since the peer mentor relationships are intangible and therefore cannot be easily generated. Even if I built a fully functional online community, unless I had it embedded with diabetes educators or trained mentors, I cannot test if my concept leads to better health and coping. To illustrate the success of peer mentor relationships, I found several studies which suggest that health and good management behavior can increase through peer mentors (SEE LITERATURE REVIEW). Instead of building the functioning web site, I instead focused the goals of my evaluation on the different methods of interaction for finding and retaining a mentor (mentor search v.s. natural discussion), motivation to become involved as a peer mentor, and what elements make the online community valuable to patients.

I ran my user testing sessions through role playing scenarios both in person and online (SEE FIGURE 18 ON NEXT PAGE). The initial in-person sessions used paper screens which I narrated, and the online survey used videos with audio. The user was introduced to the context: imagining they were just diagnosed, envisioning this is their current situation. When they reached the first touchpoint of the system, the brochure in the doctor's office, they were handed the brochure to examine and 'thinkaloud' their reaction. We then moved to the website. The user was given two different options for finding a mentor. After exploring various aspects of the website, the user was brought out of the interface and into the ending of the scenario. With a mentor recommendation and a visit to the doctor, the user has the option to enter into mentor training and become a CareMentor in the community, cycling back in the process.

The user then reflected on the process, the mentor program and online community. The users shared if they felt it aided with coping, gaining better understanding of diabetes, and whether it might help them to live healthier.

Printed materials for Care Mentors, including a "Care Mentors Support Community" brochure and a "Care Mentors" brochure. The brochures feature the Care Mentors logo and text about the program.

Handwritten pink sticky note with the text "Care Mentors" and a small drawing.



A printed screenshot of the Care Mentors website. The page features the Care Mentors logo, a navigation bar, and a list of mentors with their names, photos, and contact information. The text "Care Mentors Support Community" is visible at the top.



Through the user testing sessions, I verified that CareMentors is most beneficial to users when they are initially diagnosed or when they feel they are losing control. Users said “I would work with a mentor if I was just diagnosed or if I felt I was not on track with my care.” Once the patient feels stable, they may step back from the mentor relationship and only use the general online community for support.

If a health care provider or a friend recommended the CareMentors program, users would be more likely to join. Only 2 users said they would not want to use a mentor service. Users are willing and excited to give back to their community by becoming a mentor (13 users confirmed they would become a mentor if given the opportunity). Incentives such as insurance break or rewards also help to motivate participation. Users want to control and maintain a sense of anonymity in the community, and they want to be sure that CareMentors is vigilant with who becomes a mentor. They want background checks on mentors for safety, and to see more about the mentor on the Mentor Profile page.

Users tend to lean towards letting the mentor relationship develop naturally in discussions, but they find the mentor search to still be very important. It is useful when the user has a specific need or does not know where to start. Having the mentors express their personal selves on the Mentor Profile page is crucial to building trust with the user. The “My Mentor & I” page is also extremely valuable. This page is a log, a journal of the back and forth relationship and conversation. It is a place for users to express themselves and the mentor relationship. It should be fun, joyful, funny, personalized, expressive, relaxed, creative, and controlled by the user and mentor.

To view user testing questions, please turn to the Appendix, page 83.

CareMentors Support Community

http://www.carementors.com Search

Care Mentors

My Profile | Log out

ABOUT US GET INVOLVED MEMBERS ACCESS

MY CARE NETWORK

MENTOR SEARCH

GOAL CENTER

DISCUSSION BOARD

INFO CENTER

RECIPE SHARE

LOCAL EVENTS

Mentors

Gill Hernandez

Robin Lee

Kristine Johnson

Adam Fisher

Mentor Search

Name

Age

Ethnicity

☐ Male ☐ Female

MacBook Pro

CONCLUSION 

People with type 2 diabetes need a design that will foster agency within themselves. Over and over, I would hear, “diabetes is a very individual illness,” “diabetes is mine, I’m the only one who can control it.” No matter how many tools are put in place to push patients to change their behavior, they will not change it if they do not want to. With behavior change, patients have to take very small steps toward change, and it has to be of their own will. Many of my interviewees would describe a “light bulb moment in which I realized I needed to change or else I’d lose my leg or my sight or have a stroke” or even “my daughter was diagnosed with type 2 diabetes and I realized I had to change if I did not want her to have the same life I did.”

Peer support can be provided in many forms, but it will not reach the group who has not hit the light bulb moment. It can reach and help those who are very close to that moment (the Late-Bloomer persona), and people who struggle with control but are active in trying (the Reluctant persona). Designing for health care is very much about the subtle things. A designer needs to be very attuned to people and he or she needs to truly care.

The design solution presented in this thesis is not about the online interface, or the “features” in the community. It is about people—creating a connection with someone else who has gone through the process of having type 2 diabetes. It is about creating spaces for patients to share their story with another, and knowing they are not alone, especially when they feel they do not get support from those around them. The interface and the technology is simply a portal to explore various ways to interact, browse, and form the peer mentor relationship. Beginning to address the shock of diabetes, and hoping to ease it with the comfort of a peer, is in hopes of fostering agency to make change. And no system or service will make a patient change—it has to come from within him or herself. The patient’s peer will be there to help along the way. Sometimes, just knowing the support is there, even if the patient never uses it, is the needed comfort.

FUTURE STEPS

To further build on my thesis, the next steps could be to build a fully-functional prototype of the online community. Interface usability tests could be performed on the community and it could be redesigned based on these results. The Mentor Training Program needs to be structured, and a business model built to gain buy-in. A pilot study could be launched with a combination of trained mentors and diabetes educators in the online community. Management skills and level of health would be evaluated before using CareMentors, and several months after use to see if there is patient improvement. If the pilot study shows success, this could be used to develop support from health care providers, insurance agencies and corporations in terms of funding, marketing and general use.

APPENDIX 

Interview Questions

1. Can you tell me about how you were diagnosed?
2. Was that when you first noticed something was wrong?
3. What was your reaction to the diagnosis?
4. What did you first do after you were diagnosed?
5. How did you feel at that time?
6. What has been most useful to you in learning about diabetes?
Internet? Doctors? Family and friends?
7. How under control do you think your diabetes is?
8. What are some things that make it easier or harder for you to manage your diabetes?
9. Why do you think it started when it did?
10. What do you think is the best thing you can do to manage your diabetes?
11. What are the problems your diabetes has caused for you?
12. What do you fear most about your diabetes?
13. Can you tell me about your experience with any other doctors or specialists?
14. What did you worry about initially? (Money? Prognosis? Lifestyle changes? Family?)
15. Who did you go to for any kind of help with your diabetes?
16. Where did you look for information about diabetes?
18. Looking back on when you were diagnosed, what do you wish someone had explained to you?
19. What helped you cope?

Potential Follow Up Questions

20. How did your life change once you were diagnosed?
21. What was it like working with your doctor(s)?
22. What lifestyle changes did your doctors advise?
23. What lifestyle changes did you implement?
24. What was it like making these changes?
25. Can you tell me about a time(s) when you felt confused?
26. Can you tell me about a time(s) when you felt like you'd made progress, or felt a sense of triumph?
27. How does diabetes affect you on a daily basis?
28. What do you do to manage your diabetes?

29. How has your diet changed since you were diagnosed?
30. How have you decided which lifestyle changes to make in order to manage your diabetes?
31. How have you felt about these changes?
32. What has helped you make these changes?
33. What helps you stick to your treatment regimen?
34. What kind of information do you track or record about your diabetes? How?
35. Where do you get information about diabetes and how you can manage it? [Follow up probe: Do you use the Internet for this?]
36. When did you first go to the Internet for anything diabetes-related?
37. Can you tell me about the Internet sites you use?
38. Does anyone else ever go on the Internet for you for anything diabetes-related?
39. What do you do on these sites?
40. How has going online changed your experience with diabetes?
41. Can you tell me about something you have found useful online?
42. Can you tell me about any negative experiences you have had online?
43. What kind of information do you not have that you wish you had?
44. Whom have you told that you have diabetes?
45. Whom do you talk to about your diabetes?
46. Who helps you with your diabetes?
47. Does anyone help you manage your diabetes?
48. How do you like working with your doctors?
49. How have you felt letting your family in on your diabetes?
50. How have you felt letting your friends in on your diabetes?
51. How have you felt letting others in on your diabetes?
52. Do you know anyone with diabetes?

Demographics

Age

Gender

Marital status

Occupation

Education

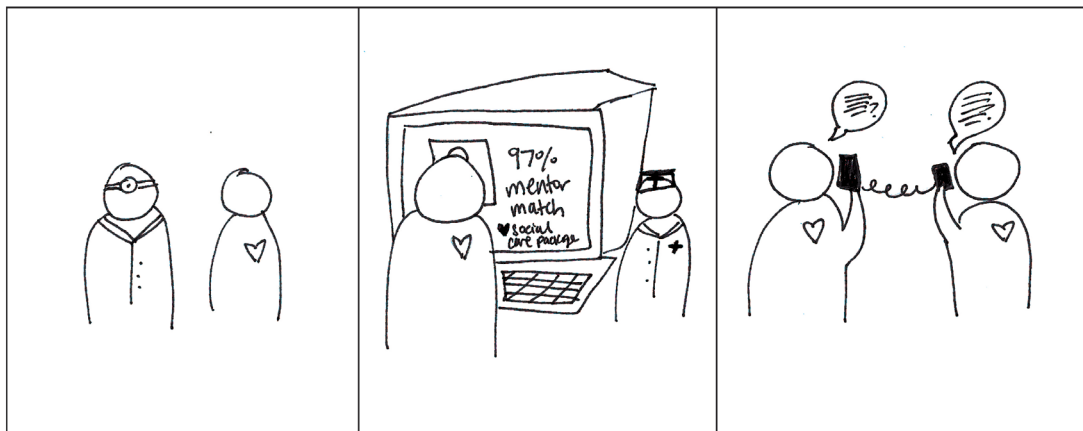
Speed Dating Scenarios + Questions

Users read through each scenario (see right) then answered the following questions:

1. What is your initial reaction to this idea?
 - a. Strongly Like
 - b. Like
 - c. No Opinion
 - d. Dislike
 - e. Strongly Dislike
2. What features of this idea are the most valuable or appealing to you?
3. What features do you find least appealing about this idea?
4. How interested would you be in using this service?
 - a. Very Interested
 - b. Somewhat Interested
 - c. Not Interested

Scenario 1

Do you ever wish, right after diagnosis, you had someone else in a similar situation to walk you through the learning process?



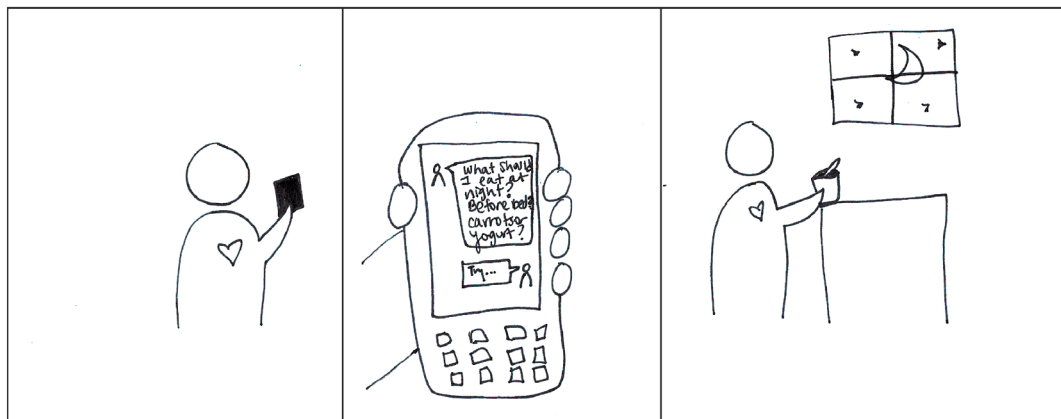
Person is diagnosed with type 2 diabetes. Doctor leaves, and nurse comes in to set up the person with a mentor.

He or she inputs criteria for a mentor, and system finds a match with another person with type 2 diabetes.

The mentor answers questions as the person learns how to manage his or her diabetes.

Scenario 2

Do you ever wish you had someone to help you with day to day decisions about your diabetes?



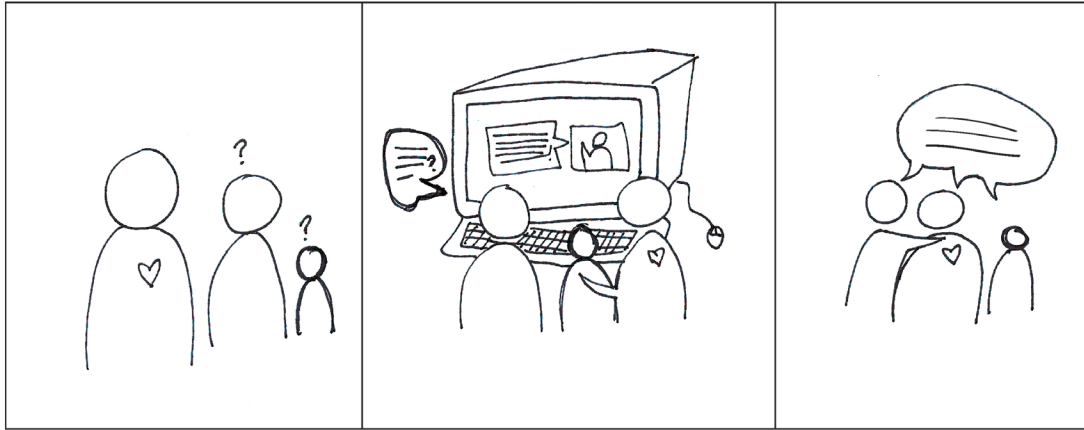
Person is not sure what to eat before going to bed to avoid hypoglycemia at night.

He or she sends out a question to a caregiver through a mobile device.

The question is answered quickly.

Scenario 3

Do you ever wish you had someone to help your spouse/family to understand what you are dealing with and how best to support you?



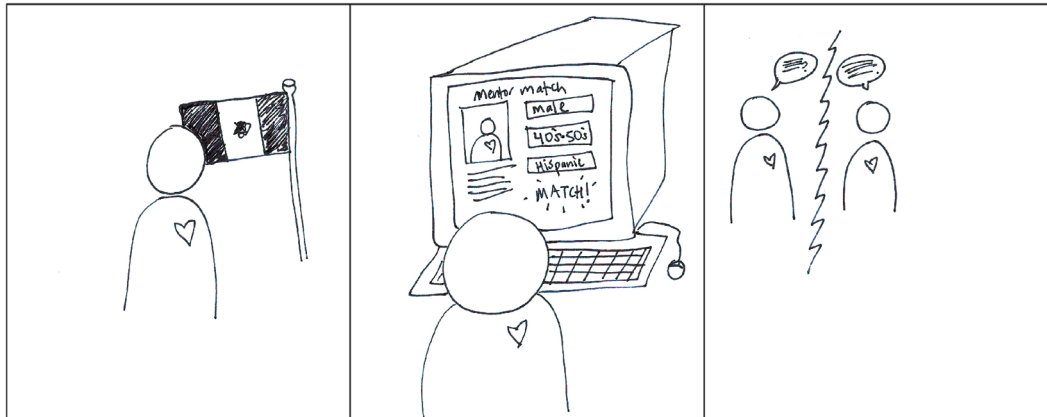
Family doesn't know how they can help their loved one with their type 2 diabetes.

Trained caregiver answers the families questions and provides helpful tips to be supportive.

Family is active in providing care for their loved one.

Scenario 4

Do you ever wish you had someone of a similar culture/background to talk with about type 2 diabetes?



Person wants to talk with someone of the same cultural background with type 2 diabetes.

Person is matched with another diabetic of the same background.

Both people share their experience and swap favorite traditional recipes.

Scenario 5

Do you ever wish you had an emergency line to have any questions answered?



Person is having an unexpected low and is not sure what to do.

He or she calls the emergency line, and is given proper medical advice.

He or she eats a snack and soon feels better.

Scenario 6

Do you ever wish you had an online community to find recipes, local exercise buddies, and to share a laugh while learning more about diabetes?

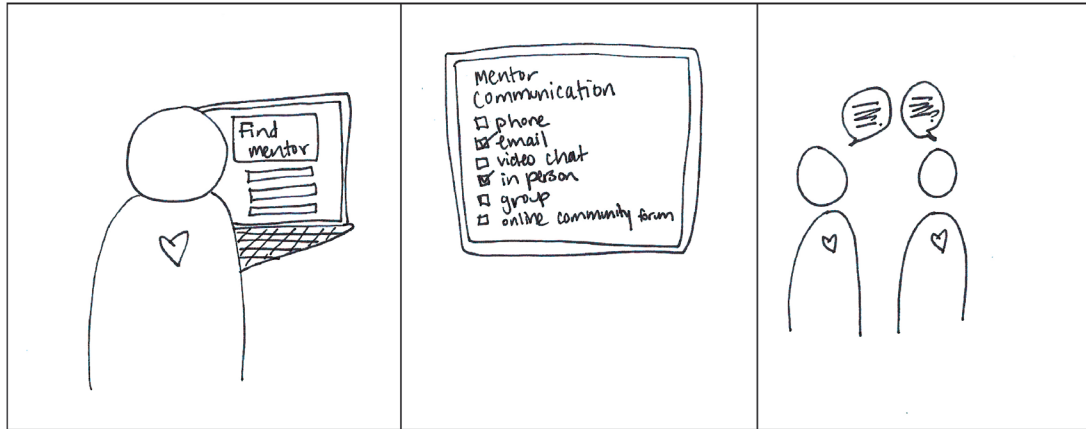


Person wants to find online diabetic community for information.

On the online diabetes community, he or she can share recipes, find local exercise buddies, set personal goals, enter a community challenge, and read a daily

Scenario 7

Do you ever wish you could have a diabetic mentor using your choice of communication?



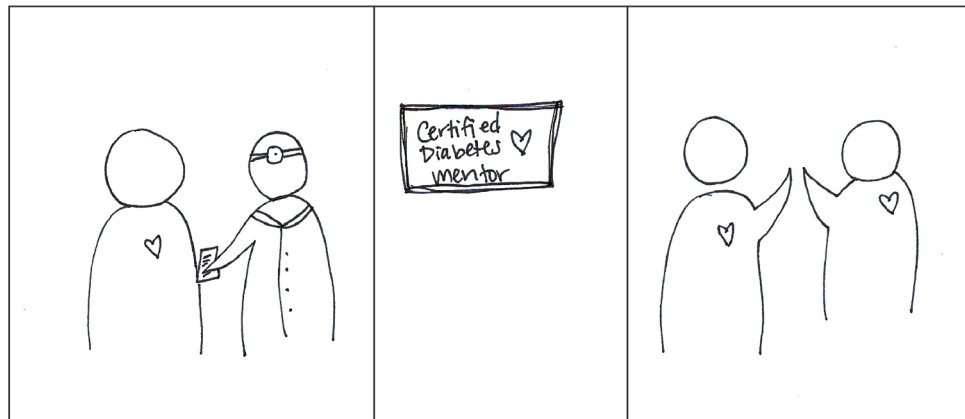
Once person has found a mentor, he or she can choose how to communication with mentor.

He or she selects e-mail and in-person communication for mentoring.

He or she meets with diabetic mentor twice a month in-person, and they e-mail outside of meeting.

Scenario 8

Do you ever wish you could be trained to be a mentor for other newly diagnosed diabetics?



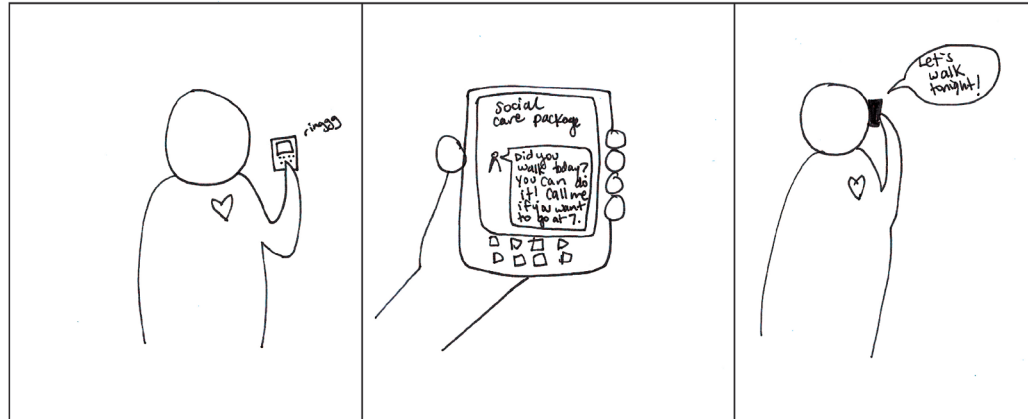
Person is asked if he or she wants to become a mentor to other people with type 2 diabetes.

He or she completes mentor training.

He or she begins mentoring other people with type 2 diabetes.

Scenario 9

Do you ever wish you had a tool to provide encouragement and social support?



Mobile device buzzes.

He or she is invited to go on a walk that evening with a friend from their social care network.

He or she feels encouraged and decides to join the walk.

Mentor Search

CareMentors Support Community

◀ ▶

http://www.carementors.com

🔍 Search

Care Mentors

We're here for people affected by type 2 diabetes

My Profile | Log out

🔍 Search

ABOUT USGET INVOLVEDMEMBERS ACCESS

MY CARE NETWORK

MENTOR SEARCH

GOAL CENTER

DISCUSSION BOARD

DIABETES INFO

RECIPE SHARE

LOCAL EVENTS

Mentors



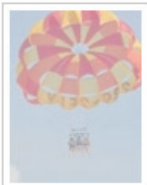
♥ Rosa Henderson



♥ Robin Lee



♥ Gary Rhodes



♥ John Johnson

Name

View All

Mentor Search

Zip Code

Age35-40

Ethnicity

Male

Female

Specialties

Exercise

Diet Change

Social Changes

Family Mentor

Living Alone

Find My Mentor

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MY CARE NETWORK

My Profile

My Mentor

My Family

My Friends

MENTOR SEARCH

GOAL CENTER

DISCUSSION BOARD

DIABETES INFO

RECIPE SHARE

LOCAL EVENTS

My Mentor & I

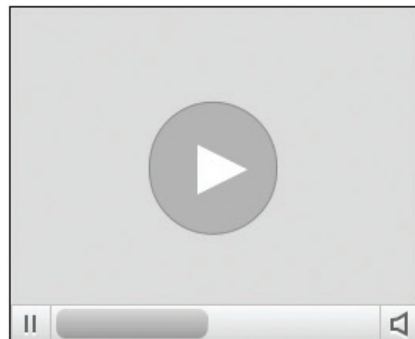


supstar80
Pittsburgh, PA



Rosa Henderson
San Diego, CA

Video Chat



Messages



Do you know what 12 items you should carry?

1. Diabetes medicines 2. Insulin (if you take it) 3. Glucagon Emergency kit 4. Glucose meter ...

By RosaH Yesterday at 8:23 pm



What kind of doctors do you see each year?

Do you see one doctor, or several doctors? Are there doctors you should be seeing but not? ...

By supstar80 Today at 5:00 pm



Re: What kind of doctors do you see each year?

I see my primary care doctor every month, but then I schedule visits with my ...

By RosaH Today at 6:23 pm



Mentor Profile

CareMentors Support Community

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LOCAL EVENTS



♥ Rosa Henderson

San Diego, CA

Age: 37

Hi! My name is Rosa Henderson and I've had type 2 diabetes for 5 years now. After I was diagnosed, I joined CareMentors, where Gary Rhodes mentored me for 3 years. I gained control of my diabetes and I completed my Mentor Training. I have been a Care Mentor for 2 years!

More About Me:

I was born and raised in Arizona then moved to California after getting my first job out of college. I'm married and am the proud mother of 2 daughters.

Occupation: Architect

Hobbies: Painting, hiking, and sleeping in.

Video player showing Rosa Henderson

Contact Rosa!

Name Jenny

Contact Info supstar80@gmail.com

Communication Preference

Email

Video Chat

Email

✓ Phone

Instant Messenger

Other

Request Mentor

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Recipe Share

CareMentors Support Community

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ABOUT USGET INVOLVEDMEMBERS ACCESS

3

3

3

?

MY CARE NETWORK

MENTOR SEARCH

GOAL CENTER

DISCUSSION BOARD

DIABETES INFO

RECIPE SHARE

LOCAL EVENTS

Beef Cuban Lunch

Add Recipe

Ethnic Recipes:

AfghanAfricanAlgerianAmericanAndaluciaArabArmenianAsian (multi-national)BaliBolivianBrazilianBritishCanadianCanary IslandsCaribbeanChileanChineseCreole & CajunCreteCubanCyprusCzechoslovakianDanishDominican RepublicDown UnderDutchEuropean, MiscellaneousFinnishFrenchGermany/AustriaGreeceHawaiianHispanic/LatinoHungarianIndianIndonesianIrishIsraeliItalianJapaneseKoreanLaosLebaneseMalaysianMediterraneanMexicanMiddle Eastern (Other)MoroccanPersianPeruvianPolishPortugueseRomanianRussianSardinianScottishSingaporeSlovenianSouth AmericanSpanish (Spain)SwedishSwissThaiTurkishUruguayanVietnam

Categories:

BeefPorkPoultrySeafoodBakedCheeseMushroomsChickenParmesanSaladsSkilletEggsSoupFishFruitVegetablesBreakfastLunchDinnerSnackDessertsSide DishDrinksVegetarianHoliday Recipe GuideLow CalorieWeight LossLow CarbLow FatLow CholesterolCarbs Under 45gCarbs under 10g

✕

Feature Recipe

Vegetarian Zucchini Salad



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Local Events

CareMentors Support Community

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http://www.carementors.com

Search

Care Mentors

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Search

ABOUT US

GET INVOLVED

MEMBERS ACCESS

👤 3

💬 3

✉ 3

?

MY CARE NETWORK

MENTOR SEARCH

GOAL CENTER

DISCUSSION BOARD

DIABETES INFO

RECIPE SHARE

LOCAL EVENTS

Find Events

Add Event

Find Local Events:

Zipcode

Support

Exercise

Cooking

Education

Get Together

Walking Club: Feb 8, 1PM

426 S Highland Ave, Pittsburgh

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79

Goal Setting

CareMentors Support Community

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ABOUT US

GET INVOLVED

MEMBERS ACCESS

MY CARE NETWORK

MENTOR SEARCH

GOAL CENTER

Set Goals

Cheer On!

Mobile Reminders

Daily Laugh

DISCUSSION BOARD

DIABETES INFO

RECIPE SHARE

LOCAL EVENTS

Goal

Progress

Date

☐

Exercise 30 minutes daily

Due March 5, 2011

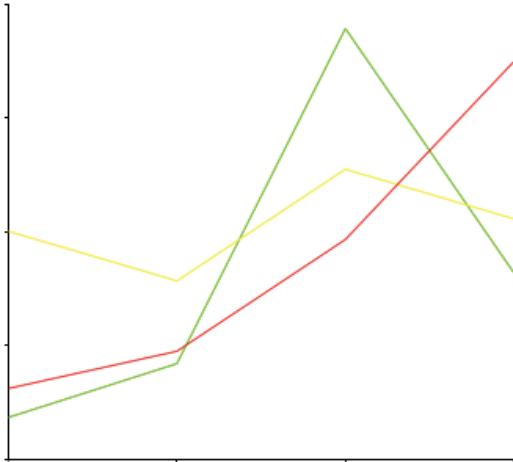
☐

Change breakfast foods

Due March 20, 2011

Edit

Map Progress



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Cheer On

CareMentors Support Community

◀ ▶

http://www.carementors.com

Search

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ABOUT US

GET INVOLVED

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👤 3

💬 3

✉ 3

?

MY CARE NETWORK

MENTOR SEARCH

GOAL CENTER

Set Goals

Cheer On!

Mobile Reminders

Daily Laugh

DISCUSSION BOARD

DIABETES INFO

RECIPE SHARE

LOCAL EVENTS



rdeer

Exercise 30 minutes daily

Cheer On!



janeZ

Change my breakfast for the next two months

✕

Device Mobile

Message

Way to go on nearly reaching your goal!
You're almost there! :D

Send

h week



joeab



anieski

Walk the dog every day

Cheer On!

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User Testing Questions

1. Year you were diagnosed with diabetes
2. Your age when you were diagnosed with diabetes
3. Would you say that seeking and receiving a diagnosis of diabetes was straightforward or complicated?
4. Would you say that you received social support after diagnosis?
5. Gender
6. Year of birth
7. Marital Status
8. Occupation
9. Education level (check highest level achieved to date)
10. Ethnicity
11. In what situations would you participate in the CareMentors program?
12. In what situations would you NOT want to participate in the CareMentors program?
13. The Brochure is:
 - a. Very Clear
 - b. Somewhat Clear
 - c. A Little Clear
 - d. Somewhat Unclear
 - e. Very Unclear
14. Please Explain.
15. Please describe what you DO NOT like about the mentor search feature.
16. Please describe what you DO like about the mentor search feature.
17. Would you be willing to find and participate in a mentor relationship?
18. Please explain why.
19. List three things you DON'T like about the web site.
20. List three things you DO like about the web site.
21. What features do you find valuable?
 - a. Recipe Share
 - b. Local Events
 - c. Goal Setting
 - d. Cheer On Messages
 - e. Discussion Board
 - f. Other

- 22. What features do you find to NOT be valuable?
 - a. Recipe Share
 - b. Local Events
 - c. Goal Setting
 - d. Cheer On Messages
 - e. Discussion Board
 - f. Other
- 23. How likely are you to participate in the CareMentors Training Program to later become a mentor yourself?
 - a. Very Likely
 - b. Somewhat Likely
 - c. Not Likely
- 24. Please explain why.
- 25. How interested would you be in using the CareMentors service and social community?
 - a. Very Interested
 - b. Somewhat Interested
 - c. Not Interested
- 26. Is there anything else you would like to tell us?

A thesis proposal submitted to the School of Design,
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