USING “DESIGN THINKING” TO CREATE PATIENT-CENTERED ELECTRONIC HEALTH RECORDS
PROJECT OVERVIEW

The Continuity-of-Care Document (CCD) is increasingly a critical tool providers are using to communicate information about a patient’s health status.

The California HealthCare Foundation partnered with design and innovation firm IDEO to create a patient-centered CCD that addresses the following design challenges:

- How might we engage patients in the continuity of their health care?
- How might we engage the electronic health record (EHR) vendor community in new models of collaboration?
CHCF: WHO WE ARE AND WHAT WE DO

Private, non-profit foundation, created when Blue Cross of California converted from non-profit to for-profit.

In operation since 1996, with offices in Oakland and Sacramento and staff of 52.

Approximately $40 million per year in projects and grants, primarily in four areas:
- Better Chronic Disease Care
- Innovations for the Underserved
- Market and Policy Monitor
- Health Reform and Public Programs Initiative
IDEO: WHO WE ARE AND WHAT WE DO

Human-centered design and innovation consultancy focused on understanding the interactions between people, products, services and environments.

Been around for over 30 years, currently in 11 countries, with a staff of 575 people from 34 nationalities. Have worked on over 5000 design and innovation projects across diverse industries.

Work in interdisciplinary teams such as interaction design, design research, software engineering, and behavioral economics.

Health and Wellness Practice accounts of one-third of annual revenue.
PROJECT GOALS

01 Introduce EHR vendors to design thinking and human-centered innovation.

02 Show how design thinking and human-centered innovation can be applied to the design and usability of the CCD.

03 Identify unmet patient needs that can serve as guiding principles for design.

04 Generate open-source, patient-centered CCD design concepts.

05 Identify collaboration models for the EHR vendor community.
WHAT IS DESIGN THINKING?

Design thinking is about accelerating innovation to create better solutions to the challenges facing business and society.

It starts with people – what we call human centered design – and applies the creative tools of design, like storytelling, prototyping, and experimentation to deliver new breakthrough innovations.
PROJECT PROCESS + TIMELINE

10/03 10/10 10/17 10/24 10/31 11/07 11/14

INSPIRATION & INSIGHT

SYNTHESIS & BRAINSTORMING

CONCEPT & DESIGN

REFINE & COMMUNICATE

Project Kickoff Summary of Insights & Design Principles EMR Vendor Workshop End of Phase Workshop
RESEARCH METHODS

Uncover patients’ unmet and latent needs

6 Patients + Caregivers 5 Physicians

“If I had asked my customers what they wanted, they would have said a faster horse.”
-Henry Ford
PATIENTS FEEL THEY ARE LEFT ON THEIR OWN TO FIGURE OUT THEIR NEXT STEPS.

“I don’t know how people can do it alone. I make sure he takes his meds. I fill and refill all the prescriptions. I manage all the insurance approvals. There’s so much to do just being the patient, let alone managing everything around being a patient.”

‘Veronica’ (59), caregiver

“The first time the surgeon tried to explain my treatment options, and how much each would reduce my chance of recurrence, we had no idea what she was talking about.”

‘Emily’ (54), cancer survivor

“The transition from the first, five-day hospital stay to home was challenging. They just say ‘ok go home.’ And we didn’t know what to do. It was all trial and error to figure it out.”

‘Bonny’ (40), mother of a child with type 1 diabetes

HOW MIGHT WE OPTIMIZE INTERACTIONS BETWEEN PATIENTS AND HEALTHCARE PROVIDERS?
PATIENTS WITH SERIOUS HEALTH ISSUES WORK AROUND THE SYSTEM TO GET THE BEST CARE.

“I butter them up because I know I’ll need them later. I kill them with kindness so I don’t feel bad if I need to call them at 3am on a Friday night. They are our lifeline and I want them to take my call.”

‘Veronica’ (59), caregiver

“We were very lucky. I had the cell phone numbers of all my doctors. I could bypass their practice coordinators and go straight to the docs whenever I needed to.”

‘Emily’ (54), cancer survivor

“New doctors are surprised and appreciate the well-organized documents I bring.”

‘Sandy’ (60), caregiver

HOW MIGHT WE GIVE PATIENTS PEACE OF MIND THAT THEY ARE RECEIVING THE BEST POSSIBLE CARE?
EPISODIC AND DISJOINTED CARE HIDES VALUABLE CONNECTIONS.

“After a five month medical investigation with allergists and pulmonologists and every other specialist, I wasn’t getting any better so my daughter just said, let’s go to the ER. She told them that I had chest pain and shortness of breath. I got a whole heart work up that I didn’t really need, but they did finally figure out my breathing problem.”

‘Terry’ (70), asthma patient

“How might we enable patients and physicians to see patterns and act on them?”

“No one could figure out why I had so much back pain. I couldn’t get out of bed. I had months of cortisone injections. But it was only when I went online to a breast cancer survivor support group that I learned there is a connection between my cancer drugs and joint deterioration. No one else saw the connection.”

‘Emily’ (54), cancer survivor

HOW MIGHT WE ENABLE PATIENTS AND PHYSICIANS TO SEE PATTERNS AND ACT ON THEM?
BOTH PATIENTS AND PHYSICIANS DOUBT THE RELIABILITY OF HEALTH DATA.

“I only trust clean, validated data….The Rx Order History is not the same as the Medication List. Just because I write an order doesn't mean the patient filled it, ever took it, or is still taking it. I need a different way of capturing what patients are actually doing.”

‘Dr. Wong,’ primary care physician

“My doctors are impressed with how thoroughly I’ve been tracking my husband’s medications. It helps them make better decisions for him.”

‘Veronica’ (59), caregiver

“Even I can’t trust what’s in my record. Take exercise. They’ll ask how often I do it. I’ll lie. They’ll write it down. We’ll move on.”

‘Emily’ (54), cancer survivor

HOW MIGHT WE HELP PATIENTS AND PHYSICIANS COLLECT, GROW, AND INTERPRET GOOD DATA?
PATIENT NEEDS

01 Represent what I truly care about.
02 Present information in a way I can relate to.
03 Help me cross-check my facts.
04 Help me close communication loops among my care team.
05 Set me up to have clarifying and guiding conversations.
06 Clearly lay out the next steps.
07 Show my trajectory over time.

PHYSICIAN NEEDS

01 Enable me to quickly spot clean and validated data.
02 Enable me to build strong rapport with new patients.
03 Allow me to communicate privately with other physicians.
04 Allow me to add additional information.
WORKSHOP COLLABORATION
INSIGHTS FROM THE WORKSHOP

01 “PATIENT-CENTERED CCD” IS AN OXYMORON.

Patient needs go well beyond what a CCD can offer. Designed for information exchange among physicians, the CCD standard isn’t well suited to meet patients’ many communication needs.

02 IT’S TIME FOR A PHR 2.0

The CCD is not a storage standard, but patients want a place to store their health data. They want to be able to connect their care team to their data, to access their data and protect it. Patients also generate quantified and qualitative data between visits to healthcare providers and they need a place to record it. All this data is currently scattered across various platforms, both digital and analog. In the absence of a more suitable standard we see a need to develop a new “storage standard” for patients.
The current convention for organizing a CCD is to separate data by “section” type and then within each section to list events in a table format in reverse chronological order.

The Timeline Meets Accordion Concept creates a visual connection between sections through the use of a timeline that also enables patients and physicians to view all the relevant dates for conditions, procedures, encounters/visits, medications “at a glance” on a fixed but consistent time scale. By clicking “into” each section, viewers gain more detail about each event, but always in the context of the overall time scale.

In this current implementation, the time scale is fixed. However, one can imagine adding the ability to scale time by zooming out by decades to account for someone’s whole lifespan or zooming in to a day or week view to see the details of someone who has had many issues in a short time period.
The Collage Concept creates a visual dashboard that represents each section as an individual box. Within the box, the most current information for that section presented is presented.

Viewers can “cycle” through the information in each section using the right and left arrows or click on the section to see the contents in their entirety.

This concept hints at the types of interactions that might be possible in the future, for example, enabling patients to track upcoming appointments or activities that they need to complete in order to optimize their health. In this example, the patient still needs to fill one of her prescriptions from her most recent physician visit.
During the workshop, teams explored a vision of the future in which the CCD and the whole Electronic Health Record was more dynamic and bi-directional in order to better meet the patient and healthcare provider needs uncovered in the design research.

We developed two scenarios a bit further.
FUTURE SCENARIOS

DYNAMIC CARE PLANS
Imagine if patients, caregivers, and healthcare providers could create dynamic care plans that served as an action plan for patients and as a way to generate mutually aligned appointment agendas for subsequent physician visits. This approach also supports real-time communication among care team members, real-time updates to the care plan, and tools to track outcomes.

PATTERNS and TRAJECTORIES
Imagine if we transform the EHR from a data-base to a knowledge-base by enabling patients and providers to see individual health patterns as well as collective, epidemiological patterns. These patterns would serve as the basis for recommendations to patients and healthcare providers about how to take meaningful action. The goal is to use all the data being collected by EHRs to help all stakeholders see patterns and catch negative outcomes early.
George has been struggling to manage the symptoms of Sarcoidosis for the past seven years. He and his wife Veronica work regularly with a primary care physician, a pulmonologist and a rheumatologist to manage the disease and the side effects of his meds. George has a monthly blood test to help set his medication levels. The lab results are distributed simultaneously to the whole care team, including the patient.
To get the most out of each appointment, George and Veronica use the Dynamic Care Plan system to help them generate a plan for their next appointment and to make sure that all the information is ready to review with their physician.

The system enables them to build their Appointment Agenda based on their current plan and it automatically creates an Appointment Checklist to help them prep all the information and all of their questions.
After each physician sees George, they keep each other up-to-date on their latest findings.

This ongoing communication enables George + Veronica to treat themselves to lunch with a clear afternoon ahead.
Terry, age 70, has struggled with chronic asthma for the past 30 years. His wife passed away three months ago, and he is showing signs of grief-induced depression. Angie, the medical assistant, takes Terry’s vitals, assesses the reason for today’s visit and enters the information into the EHR system.

The system enables Angie and Dr. Newbrook to see Terry “at a glance” as an individual and to see Terry compared to other patients like him. Dr. Newbrook reviews the information on his tablet and receives an alert about the trajectory of patients like Terry. The system makes recommendations about short term and long term interventions.
Dr. Newbrook performs an exam and creates a care plan with Terry to address his physical symptoms. Dr. Newman also introduces Terry to the “Virtual Pulse” tool. This tool enables Terry to quickly and easily track data that will help Terry and his care team make informed decisions about his health over time.

Terry has a hard week after his appointment. In spite of his enthusiasm and confidence in the exam room about the care plan developed with Dr. Newbrook, Terry is unable to follow through once he returns home alone. Though Terry is disappointed to see that Virtual Pulse is tracking his downward spiral and reflecting bad news, he is grateful that the system alerts a Care Team Manager who offers to call him.
DESIGN COLLABORATORS
“In order to transform the healthcare ecosystem, stakeholders will need to innovate to solve hard problems. As an industry that is requiring rapid transformation, we need more of this collaborative interaction to turn our thoughts into action.”

“This was a great experience and a very positive way to influence the improvement of EHRs.”

“In the past when talking about EHR usability, ONC has been vocal in asking - ‘Why can’t the industry take care of the usability problem itself?’” Well, this is a great example of the industry collaborating to take care of EHR usability.”
MORE INFORMATION

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