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## “Am I OK?” Using human centered design to empower rheumatoid arthritis patients through patient reported outcomes

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Authors' contributions

JY and GS conceived of the study, participated in its design and coordination, and contributed to the drafting and editing of the manuscript. DR scoped and led participant research, prototype design and testing, and drafted the manuscript. BB scoped and contributed to participant research, prototype design and testing, and editing of the manuscript. JL led recruitment and coordination of patient and provider participants, participated in participant research and prototyping, and contributed to drafting of the manuscript. LT participated in the design and coordination of the study and helped draft the manuscript. JG contributed to research and prototyping data synthesis and drafting of the manuscript. MM contributed to the participant research and helped draft the manuscript.

DECLARATIONS

Ethical approval and consent to participate

We obtained informed consent for all participants in this study. The UCSF institutional review board approved this study protocol. The IRB reference number is 15–18282.

Consent to publish

Not applicable

Availability of data and materials

The datasets generated and/or analyzed during the current study are not publicly available due to patient confidentiality but are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests

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## Abstract

**Objective**—Use of patient reported outcomes (PROs) in the routine care of rheumatoid arthritis (RA) has been shown to improve health outcomes, However, integration of PROs into the clinical visit is inconsistent. We aimed to develop a “dashboard” for RA patients to display relevant PRO measures for discussion during a routine RA clinical visit.

**Methods**—Patients (N=45) and providers (N=12) were recruited from rheumatology clinics at a university center and a safety net hospital. Using a human-centered design process involving patients, clinicians, designers, and health-IT experts, we performed interviews, clinic observations, and focus groups, which subsequently guided an iterative phase of prototype testing.

**Results**—RA patients and their providers shared the goals of assessing wellbeing and developing a personalized treatment plan. We found conflicting views of which data were most important for guiding decision-making and for answering the patient’s overarching question of “Am I OK?”

**Conclusion**—The final dashboard simplified the display of PRO data and correlated it longitudinally to the patient’s medication regimen. It also included laboratory values relevant for RA care.

**Practice Implications**—By presenting data graphically, the dashboard may provide a platform for patients and providers to communicate around PROs and shared goals.

**Trial registration:** Not applicable

## Keywords

Human-centered design; Patient reported outcomes; Rheumatoid Arthritis; Low-literacy; Shared decision-making; Dashboard

## 1. INTRODUCTION

Rheumatoid arthritis (RA) is the most common inflammatory arthritis affecting up to 1% of U.S. adults and causing significant disability, excess mortality and economic burden.<sup>1,2</sup> The disease is characterized by pain and swelling in the joints, fatigue, and profound joint stiffness. Over time, inflammation can cause joint deformities and impair physical functioning. RA is among the few chronic diseases that have an existing set of validated Patient Reported Outcomes (PROs, including disease activity and physical function) that show promise in improving outcomes when used as part of routine clinical care.<sup>3,4</sup> However, the routine assessment of PROs in patients with RA is inconsistent. Data from the American College of Rheumatology’s national patient registry (known as the Rheumatology Informatics System for Effectiveness or RISE) indicates that, among 49,205 patients with

RA, over a 1-year period, only 50.7% of patients had a disease activity score recorded in the EHR, and only 53.2% had a functional status score recorded.<sup>5</sup> Existing electronic health records (EHRs) are frequently unable to import or display PRO data and seldom incorporate these measures in a way that physicians and patients can easily interpret.<sup>6,7</sup>

Several institutions have built tools to share trajectories of pain and functional measures with providers or patients.<sup>6,8,9</sup> There are ongoing efforts in European countries to build digital tools for RA, including the Swedish Rheumatology Quality Register.<sup>10,11</sup> In these cases, time-trended data available for display during the clinical encounter helped to inform clinical decisions. For example, in the Geisinger health system, a specialized software system (Rheum-PACER™) has been used to collect information from patients, physicians, nurses and the electronic health record, and to aggregate this information into a scorecard to measure RA patient care gaps.<sup>6</sup> The system has resulted in impressive gains in quality of care as well as efficiency. Whereas these systems have for the most part focused on making relevant information for providers more easily accessible, patient-facing EHR-based dashboards have yet to be developed.

To fill this gap, we aimed to develop a patient-facing “PRO dashboard” for patients with RA using principles of human-centered design. The goal of this dashboard is to better incorporate PROs into the routine care of RA patients. Through interviews and focus groups with patients and the healthcare team, we studied which data elements should be included in such a dashboard and investigated how an electronic version of a PRO dashboard could be incorporated into clinical workflows in the future.

## 2. METHODS

### Overview.

We performed a qualitative study to develop a PRO dashboard for patients with RA. Our approach included principles of human-centered design, which aims to integrate the needs of people, the possibilities of technology, and the requirements for success, and is used widely in the development of health-IT tools.<sup>12,13,14</sup> The core tenets of human-centered design include the following sequential steps: empathize with all stakeholders; define the problem; conceptualize in an open-minded manner; prototype solutions; and test. We utilized a modified version of A/B testing with patients where they provided verbal feedback on prototypes ranging from rough sketches on paper to interactive mock-ups on a tablet computer. We chose this approach to A/B testing because we have found that simpler, paper-based prototypes often elicit more detailed feedback from individuals without much design or technology expertise than refined, digital versions. Our application of human-centered design was based on the framework of Grounded Theory, in which themes are identified during a series of focus groups and interviews. Additional interviews and focus groups were conducted until theme saturation was attained.<sup>15,16,17</sup>

Our project team was comprised of rheumatologists, clinical and social sciences researchers, designers, and technology specialists at the University of San Francisco (UCSF). Our human-centered design process included patients, providers, and staff at 2 clinics – the

UCSF outpatient Rheumatology clinic, a large academic rheumatology clinic, and at Zuckerberg San Francisco General (ZSFG), the city's safety net hospital.

**Patient recruitment:**

Patient recruitment: Participants were selected from both clinics by convenience sampling. For the interviews, we selected 3 days at each clinic when we knew RA patients would be seen. We recruited RA patients for interviews by calling patients in advance of their scheduled clinical visit and asking if they would be willing to stay for 30 minutes after their visit to talk about their experience with RA. For focus groups, patients were recruited by calling a convenience sample from a roster of all RA patients generated by the EHR. Once phone contact was established, patients were invited to a 2-hour session near their care location.

**Patient information:**

Patient characteristic information was obtained from the electronic health record, including age, sex, race, and insurance status.

**Dashboard development.**

We completed 3 phases of work.

**Interviews with stakeholders (phase I).**

Phase I included 8 in-person interviews, 8 clinic visit observations, and 5 provider interviews, lasting 30 minutes each. Our goal for these interviews was to understand the range of factors that influence patients' understanding of RA and which data elements they had previously considered as part of their decision-making process for medication or lifestyle changes. Patients were asked about their history with RA, how they manage their RA daily, how it affects their daily life, and how they make decisions about their treatments. After each clinic visit observation, we interviewed the providers to understand what supported or compromised their interactions and communication with their patients.

**Patient and provider focus groups (phase II).**

Phase II consisted of two patient focus groups and one provider focus group. The groups were structured around generative activities such as the creation of paper dashboard prototypes and role-playing. We recruited 14 patients and invited them to one of 2, 2-hour focus groups. Four providers were recruited from UCSF and ZSFG clinics for a separate focus group.

Both focus groups began with a comprehensive conversation about the insights and themes gathered in Phase 1. In the first patient focus group, we displayed several hand-drawn visual data sheets that included joint radiograph results, various PROs charted over time, and laboratory data [see Additional file 1]. Patients were instructed to share which data sheets resonated with them and why. Then they were asked to act out their ideal clinic visit in pairs, using their chosen data sheets, with one person playing the "doctor" and the other the "patient." All participants were asked to share what they liked and disliked about the

interaction. The goal of this activity was to give participants a chance to show what they hoped for from their clinic visits.

During the second patient focus group, patients completed an exercise to create their ideal dashboard prototype, including a selection of various health measures that they would prefer to see on a personal dashboard. They were prompted to choose a subset of measures that we provided or insert their own in order to create a dashboard that gave them a comprehensive view of their health and helped them make the decisions that were right for them [see Additional file 2]. Participants then discussed why they chose certain measures and used their dashboard prototype in an enactment of their ideal clinic visit.

Finally, we held a focus group with 4 providers where they completed the exercise of creating their own ideal dashboard prototype for use in clinical care [see Additional file 3]. We facilitated a discussion about selected data elements. Providers shared examples of how they currently use PRO data in their practice and how they would like to in the future.

### **Prototype and testing of PRO dashboard (phase III).**

Phase III incorporated the information from phases I and II into the design of a prototype PRO dashboard. We performed 3 rounds of testing at UCSF and ZSFG, where 6 iterations of a paper prototype were tested with 23 unique patients during real clinic visits [see Additional files 4–6]. Using a paper prototype allowed us to iterate frequently and rapidly based on feedback in the clinics. It also allowed us to work with patients with low health literacy or who were less comfortable with technology.

For each round of prototyping, we gathered each patient's health data from the EHR for their last 5 visits. We printed a personalized dashboard and gave the sheet to each patient immediately before their visit. After these visits we asked the patient, any accompanying friends or family members, the provider, and clinic staff if and how they used and understood the dashboard. We asked for feedback on the design and content. We applied what we learned and observed to design the next round of prototypes.

### **Data analysis.**

Recordings, notes, photographs, and prototypes generated from the interviews and focus groups were analyzed to establish a series of themes, insights, and hypotheses at the end of each phase. The analysis was conducted in five phases. First, the focus group audiotapes were transcribed verbatim. Second, all transcripts from the two focus group interviews were imported into ATLAS.ti (software for qualitative data analysis). Third, an initial list of codes was generated by drawing from key words and phrases in transcripts and field notes. Transcripts were then further coded using open coding manually by 1 author (JG), thus allowing for new codes to emerge that were not clear from the first round of focused coding. Next, the codes were discussed by 2 authors (JG, DR), and consensus was reached. Fourth, all interview codes were organized into categories by JG. Finally, the code categorization from the focus groups was reviewed by all authors in group meetings until consensus on the themes was reached.

We used this synthesized data to establish goals about the types of behavior, patient understanding, and in-clinic conversations that we would try to support through design and prototyping of the PRO dashboard.

### 3. RESULTS

Most participants were women, consistent with the epidemiology of RA, and 60% were non-white (Table 1). A total 12 physicians participated in the study, with mean years of practice of 20.7 (SD 10.7). The majority were attendings, with 1 fellow and 1 nurse practitioner; seven of them (58%) were female.

#### Insights from Phase 1: Defining the problem by interviewing stakeholders.

Themes, quotes, and actions from Phase I are shown in Table 2. Patients consistently highlighted the importance of a strong personal relationship with their provider to enhance confidence in their care and treatment, even when they had adverse disease progression that caused them pain or fear. Paired with a solid support system, understanding of their own health data was important to patients, but how and when they felt they needed that data varied widely, often moving beyond the clinic visit. The following insights helped us frame the context in which a PRO dashboard would function.

**1. Patients value a personal relationship with their provider.—**Patients consistently appreciated having a provider know details of their life that impact their overall wellbeing. This helped them feel confident in their joint decision-making process, trusting that their provider was acting in their best interest. In general, RA patients have frequent (4 times per year) visits with their rheumatology providers, and both providers and patients value the long-term relationships and frequent meetings that foster mutual understanding and empathy.

**2. Critical conversations and decision-making occur outside of the visit.—**While many patients shared that they rely heavily on their provider's guidance during the visit, they told us about how their ongoing self-education and their final decisions often happen outside of the visit. Patients reported consulting with family members as well as having to take into account opinions of their non-rheumatology providers or insurance policies and costs. Patients often had to act as their own advocate in these interactions.

**3. Patients' need for accessing their own health data is highly personal and varies throughout the course of their disease.—**Some patients with controlled RA spoke of only needing to see their health data in detail at the onset of their disease and at times of symptom flares because that is when treatment changes are needed. Others monitored their symptoms on their own constantly, no matter the state of their RA, largely because of a fear of medications doing harm to their bodies or in hopes of understanding any cause and effect of their lifestyle choices on their symptoms.

## Insights from Phase 2: Conceptualizing the information needs of patients and providers.

Themes, quotes, and actions from Phase II are shown in Table 3. Overall, we found that patients see their health holistically, viewing their disease within the context of tangible, long- and short-term, lifestyle goals. This was true across levels of health literacy. However, their fear of potential negative side effects from their RA medications often overshadows this holistic view, forcing them to focus primarily on “objective” health measures, such as their liver or kidney lab test results.

Providers largely share their patients’ holistic views but also understand the risk of untreated RA far outweighs any medication risk, so they do not see a need to prioritize a discussion of lab results during the visit. This mismatch seemed to set up a conflict during the clinic visit where patients come focused on answering the question of “Am I OK?” through their lab test values, while providers attempted to answer this question for their patients through a variety of data, including disease activity scores and other PROs.

**1. Patients view their health holistically.**—Patients tended to view their health as involving not just their diagnoses and medications, but their diet and lifestyle choices. They crave information about how lifestyle and diet affect their RA because of a noted lack of that type of information.

**2. Patients have long term goals or fears within which they couch their shorter-term decisions.**—Many patients had very tangible life experiences or visions that overpowered all other information that was presented to them. In some cases, they never expressed these goals and fears to their provider but still used them to guide their own lifestyle and treatment decisions.

**3. Existing clinic processes and patterns exacerbate patients’ fear of medications and establish conflicted understandings between patients and providers.**—Every patient in our focus groups included liver or kidney lab test results as one of their most important data measures to include in the dashboard prototype. However, none of the providers from our focus groups or interviews included these measures on their dashboard prototype or highlighted them to be a priority. Patients talked about their liver and kidney lab test results as the primary measure of if they were “OK” because the fear of side effects was so salient for them. Providers cited these lab results as important to measure, but not something to be prioritized in the visit above other measures, such as PROs.

One of the reasons behind these mismatched expectations seemed to be that lab tests are consistently performed concurrently with each clinic visit, and they represent a concrete measure upon which patients believe they can evaluate their health. Conversely, the PROs have been, until recently, inconsistently gathered, and patients have had little to no education about their significance and use. Therefore, patients do not fully understand the value or impact of PROs but understand their lab results as central, concrete, consistent ways of tracking their health at each visit. Additionally, providers report that they have not been trained in how to make PROs useful in the visit.



### Insights from Phase 3: Prototype solutions for the PRO dashboard.

Themes, quotes, and actions from Phase III are shown in Table 4. With a better understanding of the gaps between patient and provider information needs, and the ways existing processes contributed to these gaps, our prototyping phase focused on clarifying the most critical data elements. Overall, we learned that we could balance the data needs of patients and providers by including, but not emphasizing, lab test results.

**1. Patients want an immediate answer to, “Am I OK?”**—The PRO dashboard would not meet patients’ needs without clearly showing their lab test results, but the design needed to do so in a way that did not make lab results a focus for the visit. Placing lab tests on the dashboard as a simple number with coloring and icons showing if the lab value was within a healthy range sufficed in communicating to patients that their medications were not doing damage to their bodies. Placing it at the bottom of the page, smaller than the PROs, did not compromise this understanding and helped emphasize that lab values are not the primary focus of the visit.

**2. Information needs to be clearly focused on what is most essential.**—When there were too many measures on the page, both providers and patients did not know where to focus their attention. Initial prototype feedback confirmed that there were three types of information that were useful and important for patients and providers: lab results, PROs, and medication data. We determined that the most important PRO measures to highlight were disease activity scores and physical function measures, two of the most important measures providers use in making treatment decisions or changes. Adding simple iconography and brief definitions of terms to the design helped patients understand which information the measures represented. During testing, when patients did not understand a measure, most asked a provider or clinic staff to explain the PRO measures and received a verbal definition.

**3. “Normal” is relative.**—While there are “normal” ranges for all measures included in our prototypes, it was important for providers and patients to show progress over time to see when positive gains had been made for PROs. A longitudinal, line graph design with coloring to show the desirable range helped patients see their measures more as a process than as a moment in time.

**4. Each team member plays a unique role in implementing new tools and workflows.**—Unexpectedly, even clinic staff, including medical assistants, found the PRO dashboard useful. One medical assistant reported that he is often asked by patients, “How am I doing?” as he rooms them before their visit, and how that question almost always refers to their lab values. He explained how he might look up their lab results for them in the room and provide them with their numbers before the provider arrives. By handing them the prototype PRO dashboard paper before the visit, he met their need without having to be asked, and he saved the step of looking up that information.

## 4. DISCUSSION AND CONCLUSION

### 4.1 Discussion

Using an iterative, human-centered design process, we developed a graphically-enhanced PRO dashboard for patients with RA. Our goal for generation of the dashboard was to support a productive and informative conversation between the patient and provider, centered on PROs that were identified as high priority by both parties. During our development process, we found that RA patients and their providers shared the goals of assessing wellbeing and developing a personalized treatment plan. Patients placed a high value on the personal relationship and trust they develop with their providers. In addition, we found that persistently framing clinical visits as necessary due to a need for laboratory safety monitoring has resulted in patients focusing on lab results to know if “they’re OK.”

Our process for developing the PRO dashboard prototypes was unique **in several ways**. We incorporated principles of human-centered design into our dashboard development process. This process is important but often omitted from technology development, leading to low eventual uptake of tools.<sup>18</sup> The promise of human-centered design is that deep and meaningful involvement of end users in the development and testing of technology applications leads to a product that is more likely to meet their information needs. In this study, we observed and tested prototypes with all stakeholders and team members to uncover and utilize all existing knowledge, processes, and resources that may have otherwise gone unnoticed. Specifically, it was only through observations and interviews that we learned how patients view their clinic visits and lab testing with equal importance, and the role that the visit and testing structure played in establishing that mindset. Furthermore, our insight about ancillary members of the health care team – for example, the medical assistant who found the PRO dashboard to be very useful - highlights the utility of a human-centered approach.

We also found that patients have a strong desire to access and understand information about their own condition, but this information can be overwhelming, and needs to be provided “at the right time, in the right place.” To make the PRO dashboard accessible, we focused on two primary elements in the design. First, we limited the amount of information on the dashboard and presented it in a simple graphic. Second, we incorporated plain language and simple descriptions written in the first-person from the patient’s perspective. The main headers became “How I’m Doing,” “My Meds,” and “My Most Recent Labs,” using language patients used themselves to describe their health to us. Additional development work to make the dashboard customizable with, for example, links that can be clicked through to get more information, would be useful for addressing this issue.

Although our approach was patient-centered by design, it is interesting to note that there may be discordance between what patients desire to see on a PRO dashboard compared to which pieces of information are required to make treatment decisions. Indeed, prior work has shown that patients may be overconfident in their knowledge of medications and their side effects, and that there are social pressures for conformity and agreeableness which can affect patient choices.<sup>19,20</sup> Our findings are consistent with other studies showing that relationships and trust with physicians play a much more important role in decision making compared to medication knowledge.<sup>21</sup>

It is important to place our project in the context of prior work. Although the Rheum-PACER™ software developed in the Geisinger health system and the dashboard of the Swedish Rheumatology Quality Register collect many of the same data elements we identified in this study, these tools were not specifically designed to be patient-facing.<sup>6,8</sup> Other studies have reported on decision aids specifically around medication choices, including for patients with RA focused on low-literacy populations, but without an assessment of patient-reported outcomes such as physical function.<sup>22,23,24,25,26</sup> Although several tools to help with the treatment decision-making process in RA have been developed, our PRO dashboard tool is unique because it is focused on helping patients understand their disease outcomes in the context of medication use rather than guide a particular treatment decision.

This study has several limitations. First, participation of a different group of patients may have yielded different results. However, despite the selection of patients through convenience sampling, the distribution of patient characteristics across age, sex, race and insurance status is representative of the entire clinic. In addition, we reached thematic saturation during our interviews and focus groups, which increases the validity of our findings. Second, focus groups were conducted in English, so patients with limited English proficiency were necessarily excluded. Future work should expand development and testing efforts to additional populations, including patients with limited English proficiency or limited health numeracy. Third, the dashboard developed here incorporated PROs specific to our clinics (disease activity measured using CDAI and functional status measured using PROMIS); however, because our methods for developing the dashboard were agnostic to specific measurement instruments, other measures such as DAS, HAQ, or others can be readily substituted if such a dashboard is implemented, as we hope it will be, at facilities outside our own.

Future work will include applying the insights from this project to build an EHR-enabled version of the PRO dashboard. Our objective is for the PRO dashboard to exist within the EHR and for all of the data elements to be populated from the EHR automatically. A fully implemented PRO dashboard should be studied to evaluate its effects on clinical outcomes, quality of care, and patient satisfaction and engagement.

## 4.2 Conclusion

In summary, we used principles of human-centered design to develop a PRO-focused dashboard that supports a conversation about RA disease activity and treatment.

## 4.3 Practice implications

After being developed through hands-on use and testing in multiple clinic settings, the PRO dashboard and the principles behind its design, hold potential for use in multiple different types of clinics and conditions. This is especially true for those where chronic conditions are monitored and treated, where ongoing discussions about progress and options may not be fully supported in the existing visit structure, or where patients could benefit from being more informed and empowered.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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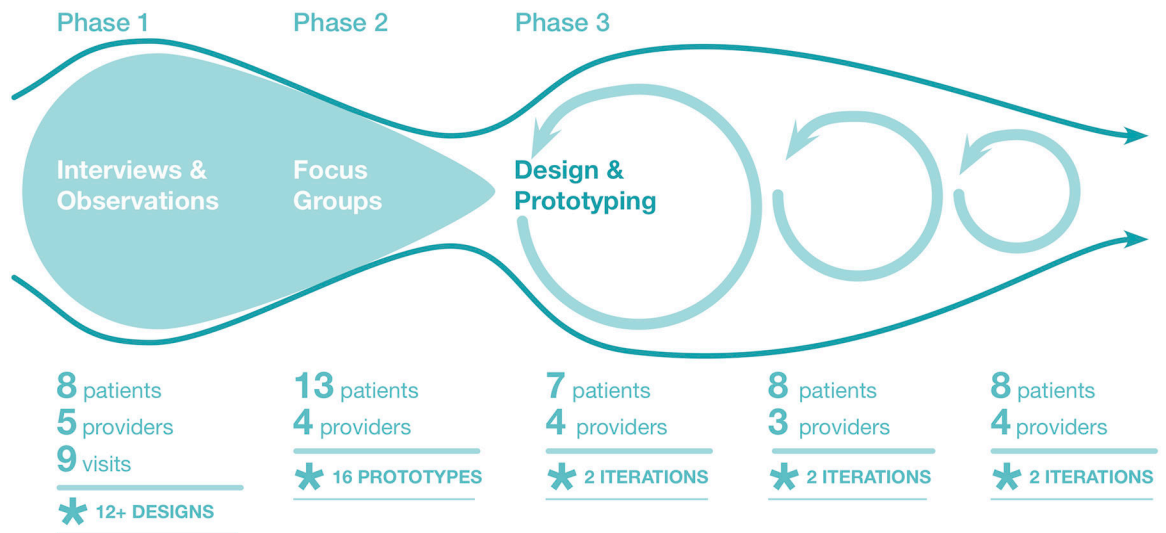
## LIST OF ABBREVIATIONS

<b>RA</b>	Rheumatoid Arthritis
<b>PRO</b>	Patient-reported Outcomes
<b>UCSF</b>	University of California, San Francisco
<b>ZSFG</b>	Zuckerberg San Francisco General
<b>EHR</b>	Electronic Health Record
<b>CDAI</b>	Clinical Disease Activity Index
<b>PROMIS</b>	Patient-Reported Outcomes Measurement Information System
<b>RISE</b>	Rheumatology Informatics System for Effectiveness
<b>PACER</b>	Patient Centric Electronic Redesign

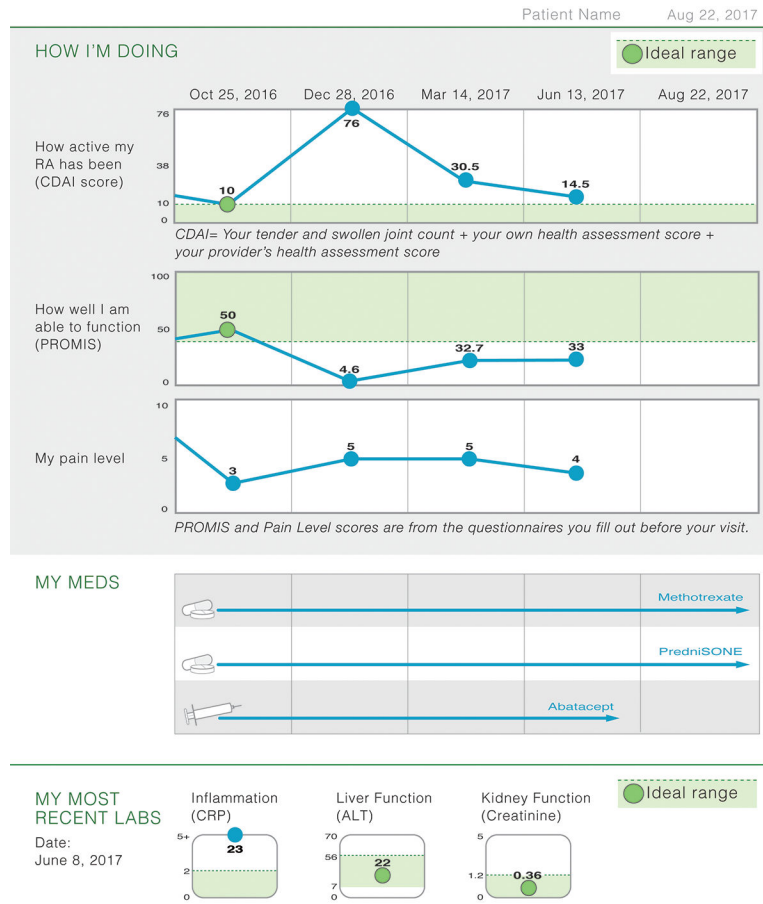
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**Fig. 1:** Three-phase human-centered design process used for this project



**Fig. 2:** Final prototype design developed through prototyping. Additional files #4-6 show previous versions.

**Table 1.**

Characteristics of participating patients.

Characteristics	All patient participants n=45	Semi-structured interviews n=8	Focus groups n=14	Clinic prototyping interviews n=23
<b>Age, mean ± SD</b>	59.7±11.2	56.5±10.1	56.0±12.2	63.1±10.3
<b>Female, n (%)</b>	34 (75.6)	7 (87.5)	10 (71.4)	17 (73.9)
<b>Race/ethnicity, n (%)</b>				
White	17 (37.8)	3 (37.5)	7 (50)	7 (30.4)
Hispanic	6 (13.3)	2 (25)	1 (7.1)	3 (13)
Africa America	8 (17.8)	2 (25)	3 (21.4)	3 (13)
Asian	8 (17.8)	1 (12.5)	1 (7.1)	6 (26.2)
Mixed/Other	6 (13.3)	0	2 (14.4)	4 (17.4)
<b>Insurance, n (%)</b>				
Private	13 (28.9)	2 (25)	6 (42.9)	5 (21.7)
Medicare	23 (51.1)	5 (62.5)	6 (42.9)	12 (52.2)
Medicaid	7 (15.6)	1 (12.5)	2 (14.2)	4 (17.4)
None	2 (4.4)	0	0	2 (8.7)
<b>Site, n (%)</b>				
UCSF	30 (66.7)	8 (100)	8 (57.1)	14 (60.9)
ZSFG	15 (33.3)	0	6 (42.9)	9 (39.1)



**Table 2:**

Themes, Quotes, and Actions from Phase I

Phase 1: Define the problem by interviewing stakeholders		
Insights	Quotes	Actions
Patients value a personal relationship with their provider.	<i>“This is like a family thing here. I have to be comfortable with my doctor. I have to have some kind of relationship. They have to know what you are about.” –Patient, ZSFG</i>	Support centering the visit on the patient’s priorities and needs, not just their numbers.
Critical conversations and decision-making occur outside of the visit.	<i>“My mother used to work in the medical field, so she is used to all the lingo and such...I have always included her in my decision making... We have both of us to reflect.” – Patient, UCSF</i>	Make dashboard available to patients outside of their visits to track information and communicate with family, friends, other providers.
	<i>“It would be nice to have a way of tracking symptoms if I wanted to...just symptom track a little bit online, so it’s there and the doctor can look at it.” –Patient, UCSF</i>	
Patients’ need for accessing their own health data is highly personal and varies throughout the course of their disease.	<i>“I don’t need to see this [data] now. I’m in remission, and I know how I feel.” –Patient, UCSF</i>	Show patient’s progress over time so that they can see and use data at any point in their care.
	<i>“I have a spreadsheet with all of my lab data. Every time I got to the doctor, I record my labs. I track everything.” – Patient, UCSF</i>	

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**Table 3:**

Themes, Quotes, and Actions from Phase II

Phase 2: Conceptualize the information needs of patients and providers		
Insights	Quotes	Actions
Patients view their health holistically.	<i>"In the morning I used to jump out of bed and say, 'I'm super woman, I can get going.' Now I'm like, 'Stop and stretch. Do a couple of bends.'"</i> –Patient, ZSFG	Design dashboard as a “snapshot” of how the patient is feeling over time to support a deeper conversation about their longer-term goals.
	<i>"For myself I had to do some changes in my diet to help me live with my RA. [I had to give up] certain things I really, really like."</i> –Patient, ZSFG	
Patients having long term goals or fears within which they couch their shorter-term decisions.	<i>"Spending time with my grandchildren where they can just come over and I'm not in so much pain. I want to do things with them."</i> –Patient, ZSFG	
	<i>"I also have a visual of my grandmother...She was bedridden, never left the house, and was totally deformed. I want to be able to maintain [my current health] forever."</i> –Patient, UCSF	
Existing clinic processes and patterns exacerbate patients' fear of medications and establish conflicted understandings between patients and providers.	<i>"My biggest question all of the time is the medicine and how will it damage my body over more time."</i> –Patient, ZSFG	Make lab values clear to provide reassurance, but not the focus.
	<i>"Lab results rarely show a problem. I don't need to focus on them unless they do."</i> –Provider, UCSF	

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**Table 4:**

Themes, Quotes, and Actions from Phase III

Phase 3: Prototype solutions for patient-facing dashboard		
Insights	Quotes	Actions
Patients need an immediate answer to, "Am I OK?"	<i>"He didn't talk about my lab tests. I worry about my liver...I don't know what's normal."</i> –Patient ZSFG	Make it immediately clear whether progress is being made and if patient is in "healthy" range
	<i>"I see I'm doing well. It's good to see that."</i> – Patient, UCSF	
Information needs to be clearly focused on what is most essential.	<i>"This is too much information for my patients to process."</i> –Provider, ZSFG	Narrow down data represented, move CDAI, PROMIS to top and enlarge to highlight
	<i>"I want to know the difference and what the numbers mean...I don't know what this stuff means. What level am I supposed to be at? What am I supposed to do and can I get it back to where I'm supposed to be?"</i> –Patient, UCSF	Demonstrate what each PRO value means with simple lay language, iconography.
	<i>"They want to talk that doctor's talk."</i> –Patient, ZSFG	
"Normal" is relative.	<i>"Looks like I'm better than I was before, so that's good."</i> –Patient, ZSFG	Show data over time to show change and improvements.
Each team member plays a unique and critical role in implementing new tools and workflows.	<i>"This was helpful. Patients always ask me how they're doing, and I have to look up their lab tests for them."</i> –Medical Assistant, UCSF	Address the needs of the entire clinic team and include them in the process when appropriate.

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